The Henry G. Friesen
INTERNATIONAL PRIZE
in Health Research

LE PRIX INTERNATIONAL
de la Recherche en Santé Henry G. Friesen

2015 Friesen International Prize Program

Institutional Visit University of Alberta

"*Trust in Science*"

Featuring Sir Paul Nurse

Director & Chief Executive, The Francis Crick Institute, London (UK)

Proceedings of a Policy Roundtable

May 5, 2016

GenomeCanada

Alberta Innovates Health Solutions

UNIVERSITY OF ALBERTA
FACULTY OF MEDICINE & DENTISTRY

Li Ka Shing Institute of Virology

FCIHR/AIRSC

UNIVERSITY OF ALBERTA
CANCER RESEARCH INSTITUTE
OF NORTHERN ALBERTA (CRINA)

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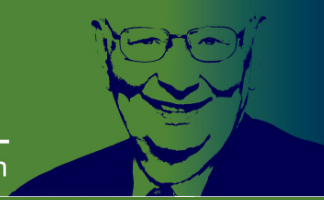

Preamble by Dr. Aubie Angel:

The Henry G. Friesen International Prize in Health Research is awarded in recognition of the distinguished leadership, vision and innovative contributions of Dr. Henry G. Friesen. The prize supports an annual Public Forum and address to the Canadian Academy of Health Sciences (CAHS), often in Ottawa, but other centres as well. Through the partnership of CBC Radio One Ideas, the lecturer is interviewed for broadcast to reach a national audience. Over the past decade a variety of activities have been added including institutional visits and high level roundtables on major health research topics. The Roundtable reported here on "Trust in Science" exemplifies our effort to increase discourse on policies that enhance science literacy. Please Visit http://www.fcihr.ca/prize/ for more information and a history of the Henry G. Friesen International Prize. Our thanks to Dr. Richard Fedorak, Dean of the Faculty of Dentistry & Medicine, for hosting this event.

Welcoming Remarks:

Dr.Stephanie Yanow, PhD
Associate Professor in Global Health, School of Public Health, University of Alberta

Welcome everyone. Thank you to the audience for joining us today and thank you to Dr. Angel from Friends of CIHR for hosting this event. My name is Stephanie Yanow and I am an Associate Professor in the School of Public Health. I will be your moderator today. I will first introduce our panelists, professors from the University of Alberta, who will share their perspectives on the topic of "Trust in Science".

Biographies :

Lorne Tyrrell, OC, AOE, MD, PhD, FRCP, FRSC
Director, Li Ka Shing Institute of Virology, University of Alberta

D.Lorne Tyrrell is a Distinguished University Professor at the University of Alberta. He is the Founding Director of the Li Ka Shing Institute of Virology and has focused his research since 1986 on viral hepatitis which has resulted in the licensing of the first oral antiviral agent to treat chronic hepatitis B infection – lamivudine – in 1998. He has also been involved in the establishment of a biotech company—KMT Hepatech Inc. based on the first non-primate animal model for HCV. He is the Chair of the Gairdner Foundation Board.

Dr. Joel Dacks, PhD
Associate Professor
Department of Cell Biology,
University of Alberta,

Dr. Joel Dacks is an Associate Professor in the Department of Cell Biology. He is also an adjunct to the Division of Community Engagement in the Faculty of Medicine, Scientific Associate of the Natural History Museum, and a fellow of the Linnean Society of London. His work using genomics and informatics to explore the evolution and diversity of the eukaryotic membrane-trafficking machinery has led to the discovery of protein complexes and transport pathways in human cells and to understanding of the fundamental evolutionary mechanisms for increased cellular complexity.

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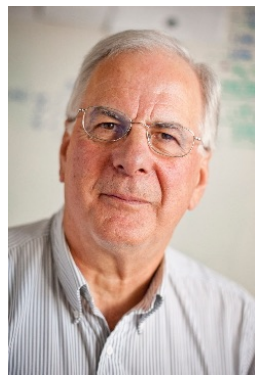
Dr. Sandra T. Davidge, PhD
Professor, Depts. of Ob/Gyn and Physiology

Dr. Sandy Davidge is the Director of the Women and Children's Health Research Institute (WCHRI) and a Professor in the Departments of Obstetrics & Gynecology and Physiology at the University of Alberta. Her research program encompasses studying vascular function as it relates to 1) complications in pregnancy (preeclampsia and maternal aging) and 2) developmental origins of adult cardiovascular diseases.



Brian D. Sykes, FRS, FRSC
Distinguished University Professor, Department of Biochemistry, University of Alberta

Dr. Brian Sykes is Distinguished University Professor in the Department of Biochemistry at the University of Alberta. His research is in the area of biophysical studies of protein structure and function, especially the use of high-resolution nuclear magnetic resonance spectroscopy to study protein structure, dynamics and biomolecular interactions. His research is focused on cardiovascular function and disease through elucidation of the molecular mechanism of the thin filament based regulation of contraction in cardiac muscle.

Dr. Tania Bubela, BSc (Hons), PhD, JD
Professor School of Public Health
University of Alberta

Dr. Bubela is Professor and Associate Dean Research in the School of Public Health. She has a PhD in biology from the University of Sydney Australia and a law degree from the University of Alberta. Her research focuses on the legal and ethical challenges for the translation of new health technologies from the laboratory to the clinic for the benefit of patients. She has provided advice on precision medicine, stem cell research and gene therapy to policy makers, industry and patient organisations.

Dr. Jack H. Jhamandas, MD, PhD, FRCPC, FCAHS
Distinguished University Professor, Department of Medicine, University of Alberta

Jack Jhamandas is currently Distinguished University Professor in the Division of Neurology, Department of Medicine at the University of Alberta. Dr. Jhamandas is a practicing Neurologist and Neuroscientist whose research program focuses on studying misfolded proteins in Alzheimer's disease. He is currently Vice President Research for the Association of Faculties of Medicine of Canada.

Introduction of Sir Paul Nurse By Dr. Stephanie Yanow

Professor Sir Paul Nurse, PRS, PhD, Director and Chief Executive, The Francis Crick Institute London, U.K.

It is now my great pleasure to introduce Paul Nurse. Paul is currently the Director of the new Francis Crick Institute in London, past President of the Royal Society, past President of Rockefeller University in New York and past Director of Cancer Research UK. He

has had an illustrious scientific career, culminating with the Nobel Prize in Physiology or Medicine, which he received in 2001 for his pioneering work on the genetic basis of cell division. But as we begin this discussion on trust in science, I would like to focus my introduction on another aspect of Paul's career, and that is his role as a mentor. And I speak from my own personal experiences as Paul's former PhD student.

I have heard Paul advocate that part of building trust in science is for senior scientists to mentor trainees in the values that underscore the pursuit of truth. I would like to share with you an experience that I had during my PhD that exemplifies this.

The focus of my PhD was to try and understand the way in which DNA replicates, or is copied, within each new cell. I wanted to know where along the double helix of DNA does it first melt and separate to start this process. We developed a few different hypotheses about how this might happen in yeast cells and one approach that we used was to look at the DNA directly under an electron microscope while it was in the process of replicating. And we saw the most amazing thing - we saw the DNA replicating exactly as predicted by one of our hypotheses. I was ecstatic, and started writing the paper immediately.

But Paul always insisted that before we submit a paper, we should ask our colleagues for feedback. So we shared these data with a colleague who had expertise in electron microscopy. When he saw our photos of the DNA, he was troubled and recommended we test one more control, just to be sure. Now this was a negative control, which means that we expected to see nothing, but instead we saw the exact same thing as before, meaning that the DNA we saw previously wasn't actually replicating, it was just tangled up in a knot. To use the most dreaded word in my vocabulary…it was 'an artifact'.

So I was devastated and I still recall that day as the worst day of my entire scientific career. I phoned Paul to tell him, in tears. He was very kind and reassuring, but he also reminded me that this was an important part of the scientific process of getting closer to the truth. And it was thanks to the way Paul values the views of his fellow scientists that we had not yet published this work, as it would have been incorrect and others would undoubtedly fail to repeat it. One of the pillars of good science is that anyone should be able to reproduce your work.

From Paul I learned an enormous amount about how to work as a scientist and how to think as a scientist, but most importantly, he taught me about the tremendous responsibility of being a scientist. Now, as I often face the pressures related to funding, publications, promotion, and so on, I am reminded of the principles that Paul instilled in me, that we should never risk compromising the truth. These are the greatest gifts that a young scientist can receive from a mentor and for that, Paul, I thank you and welcome you to the University of Alberta.

Professor Sir Paul Nurse, PRS, PhD,
Director and Chief Executive, The Francis Crick Institute London U.K.

EXCERPT – PAUL NURSE:

Nurse: It is a real pleasure to be here. I believe that "trust" is a major issue in Science, for two reasons. First, why should we have "trust" in Science? I think that is important and we need to discuss that. Second is, how should "trust" in Science be built for the common people? We need common people to make sure that scientists can be trusted. So I think that what surrounds this whole trust issue is the kind of relationship that exists between Science and Society. This depends on society, which brings the right balance. And the right values underpin this trust. In a democracy, this is backed by good governments. A democracy that can cope with the difficult decisions involved in Science is quite central to a healthy democracy.

How can we build this "trust" in Science? First, we have to start with our scientists. We need to be transparent to them, to each other and to the public. Our scientific papers – they have to be accurate descriptions of the data, how they were discovered, and the methodologies that we used. Another issue is that data need to be available. A good example is access to genome sequences and this is worth some debate because this is important to the molecular understanding of life and the basis of biomedicine. There is a pressing need to make these data available. But how can we ensure that this information is appropriately protected, but also make these data publicly available to scientists, doctors, healthcare providers, and public agencies?

We know that certain trials are not made publicly available and yet those data are important. We have to find ways to solve that. Otherwise, the public loses trust, as they think things are being hidden from them. And they are right – things are being hidden from them. This actually also applies to other medical interventions and natural medicine.

Now, in addition, to earn and keep trust, we scientists need to be transparent about our work. Now just because an experiment is funded commercially does not mean that it shouldn't be trusted, which is another thing that is often criticized. Some say that it can't be trusted and we need to get over that problem as well. And we also see that in non-

governmental agencies; there can be biases that distort science, keeping in mind that NGOs may rely on higher orders of individuals irrespective of the public. Other examples are environmental organizations, which oppose the use of certain technologies – even when those technologies are aimed at producing crops around the world. Such NGOs need to ask themselves boldly if they are being influenced by ideology. Or perhaps even worse, they may be concerned about financial support.

My view is that universities, such as the one we are sitting in, are operated by governmental funding agencies that are crucial in maintaining a proper scientific research endeavor because they can carry out research that is generally freer than emerging ideological interests. We have to have good universities that are run well, and allow for proper scrutiny of scientific data and scientific knowledge. To build "trust" in Science, scientists need to be honest. They need to be skeptical, particularly about their own ideas and their own hypotheses. What may happen is that you could be skeptical about everyone else, except your own self. These qualities are put into question when scientists are under pressure to generate particular results or to support particular theories. But over time, this gets even more pressurized when more demands are in place to come up with results within a given amount of time. And these pressures, if not properly modulated, lead to a distortion in Science and ultimately defy trust in Science. How do we counter it? I think when we discuss this, we look at all sorts of different issues. What we should actually be focusing on is having at the very root, a scientific culture in the scientific workplace. I guess the hypothesis is that Science is a high calling for the pursuit of "truth". Now similar questions may emerge when dealing with the media or public pressures and this is a good example too of people having to produce a certain outcome. And that is achieved under a lot of pressure.

We need to be aware, however, among all these contexts, that Science does proceed through trial-and-error. We do come to incorrect conclusions. This is half of what we do. And as a result, scientific knowledge evolves and may be tentative upon the coming age of research. We shouldn't just be criticized about that. Science advances by constant tentative steps that eliminate unsatisfactory ideas and hypotheses. And research sometimes comes from incorrect conclusions. In fact, we can't help but really advance in Science if we do not pursue bold ideas that can be tested, rejected and corrected. We can make faster progress in finding the motivation to avoid vague generalities – that we will "always be right" and "I will never vary my performance". The reason I say this is, to be narrow is a bad thing.

Now ensuring "Trust in Science" is not just a question of how Science is debatable. It's also a matter of how Society views Science. And that can be shaped certainly by how scientists interact with society and how science interacts with society. First of all, let's look at schools. Science education is obviously crucial. We need to note that Science is a difficult subject. We need teachers of high quality, who can communicate well and who can

describe how Science is done and how to generate knowledge. We need to stress the importance of reliable data. People need to understand trial-and-error and that Science needs knowledge. It can be seen as a process in which Science is done in order to find a viable way to generate good knowledge about the world that is built on reliable data and re-testing. If, however, and unfortunately this is not so uncommon, if Science is taught as just a “sandwich of facts”, without teaching about the processes that gave rise to those facts, why should people trust Science? Or pursue Science? Everyone in school should understand the difference between Astronomy and Astrology. I bet half the students have that trouble. If we just make assertions about Astrology, about what gave rise to these assertions, then how can we expect to believe in the topic in a reliable way? Once society is exposed to Science through mass media, radio, television, other sources, it is quite frequent that Science is criticized. I have to say that we have to sort out how this could best work with mass media. Science journalism has done quite a good job in explaining scientists’ work. Very good reports though end up matched with misleading headlines and this is what everyone ends up remembering because a copy editor wants to make something really sexy and you end up completely misleading people about what is going on. Journalists can be a bit overly enthusiastic about what they think is just around the corner or over the horizon. And of course, most of this never actually happens.

Another issue in the media is the misplaced sense of a balanced view, which distorts Science. We have in the UK now, a “Science Media Centre”, which puts journalists in contact with media-friendly scientists and this is an area where the problem comes up. Journalists can get more value in what is actually going on with a countering point of view. I sometimes think the media might be coming up with a countering point of view for its entertainment value. To have “Trust in Science”, it is important to have the scientists engaged in the public sphere. Not all scientists want to talk to the public.

We need to identify areas of interest or concern in society and we can do that at an early stage and then engage the public on what is being done and to ensure that the conflict is revealed. Some may say that scientists seem like “witch doctors” in a tribe. When they say that, they fail to see the useful knowledge for the public. They make it appear as though the public does not understand at all what we scientists are doing. So there is a combination of unreliable information. How do we deal with that? Public engagements, listening to people’s concerns, explaining what Science means. And that’s the way we have earned trust. And if we do not do these things, “Trust in Science” will be diminished among society. Now unfortunately, there are some exquisite threats to scientists who undermine public trust. One problem, which I get agitated about, is politicians and columnists who distort Science with their own ideological agenda. They displace Science that is based on rationality and their preconceived ideas are based more on ideology, or perhaps religion, where opinion, rhetoric, and tradition fall much more into the picture and this is where we need to talk about Science and the manner in which it should not be discussed. These individuals could be influenced by lobbyists, who do not properly respect how Sci-

ence is done, as they cherry-pick data, they distort arguments, mis-quote and personally attack the work they do not like. I say that because I have been subject to all that in time throughout my life. How can they pretend to be scientists when they are actually lobbyists of ideological views? And there are certain areas of Science that are very prone to such misrepresentation. The list includes GMOs, as I've already said, vaccination is another one, climate change particularly. Similar problems arise when certain fundamentalists with religious beliefs distort Science to support certain opinions that they have. We have to recognize, however, that Science is Revolutionary. It can lead to very unsettling conclusions, which can attack traditional beliefs. And that, understandably, leads to opposition. We have to be very careful. We have to go back in history – when Earth was discovered to not be at the centre of the universe. This moved man to being part of the overall tree of life, from special creation. That was a big deal and continues to be a big deal amongst some. Now, there are those that distort Science in lots of ways due to devalued trust in Science and they deny that there is benefit in Science. At least initially, we need to engage constructively with such individuals in claiming why Science should be taken seriously. However, I have a bitter view about "serial offenders". Those who continue to distort Science repeatedly need to be countered most robustly. If not, they will continue to undermine the whole scientific endeavor.

Another threat comes from what I call, "Science Elite Contraries". These are scientists on the fringe, or scientists who develop an interest in other areas and they take up rather extreme positions and I think they do so because they need attention for having taken up such extreme positions. And they get all sorts of attention on the telly. We should be skeptical about Science, but these people also need to be skeptical about their own ideas and their own opinions. We need to take notice of the consensus view of science. That sounds so boring. In the end of all this, Science does prevail. But a lack of trust in Science does slow progress down. Society should respect Science and with strong democratic traditions, feel at ease from any threats. People throughout the world need to recognize the value of Science and how it can contribute to our civilization, to the world, to the quality of our lives, and to improve the lot. We need to bring attention to the full benefit to mankind. I strongly believe that to build trust in Science and scientists, we need to educate our citizens to believe in Science and that is why "trust" is such an important issue.

We do need to lead by example. This is really critical. You lead by good training. But getting people to do things isn't really good training; it doesn't really work that way. We need training with constant exposure to good practice at the coal face of the laboratories. The key to institutional advancement is that you have an open debate about issues. This is so that things cannot get swept under the carpet. For example, we get advice from experts in areas where we are not experts. Having an open environment for discussion of subjects and ideas – that should clear up these issues. There are a variety of things – culture.

One thing about Science is that you can tell it through stories. And even journalists have asked me to re-write some of my scientific papers. The second thing that was said about Science and emotion is that we have to understand that scientists are human beings – they are also emotional. You should see how a group of researchers talk about this sort of thing. I'm not saying that it's a good thing; I'm just saying that it's something you have to recognize. We are emotional too. It's a human activity. We are human beings. We do have to try, but we're not robots.

Dr. Lorne Tyrrell, OC, AOE, MD, PhD, FRCP, FRSC
Director, Li Ka Shing Institute of Virology, University of Alberta

Thank you very much, Paul. That scientists maintain the public trust is an exceedingly important issue. We are at a time when we are seeing amazing advances in science. But this is also a time when many of the advances produced by science are being questioned by the public. I will use the example of CRISPR/Cas9 and the ability to edit genes. We may not have an adequate regulatory policy in place to deal with the rapid advances in gene editing. Science discoveries are often ahead of legal and ethical issues and this challenges the public trust. So it is important that, as we develop new technologies, we inform and consult with the public about ethical and legal issues well in advance of the application of these new technologies. This will enable the public to understand that these issues are also of concern to scientists and we value their input.

Scientists must spend more time communicating the implications of their work in a balanced way. Communication is critically important to maintaining public trust. We know there is a need for scientists to bring science discoveries to the public which is providing the support for their research. But scientists reporting new discoveries need to educate the public about the potential timeline so they can have a realistic understanding of both what may result from the discovery, and when. Too often, discoveries are announced without adequate context about when they may actually reach the public. An example would be monoclonal antibodies that were developed in the late 1970s. The development of monoclonal antibodies has had tremendous impact in diagnostics and therapeutics. However, the time from discovery of the technology to the benefits has been two or three decades. The reasons for long lag periods from discovery to benefit are something that scientists can help the public understand and thus garner their trust.

I see and care for patients with AIDS. Many of these patients arrive with a great deal of information, often from their inquiries on the internet. However, it is part of the role of the physician (and other health professionals) to help the patient interpret the reliability of this information. Approximately 70% of patients going to the doctor today have already googled their condition on the internet, but they have no idea what information is reliable and what is not. It is something we need to do – help the public to know what can be trusted and how to deal with this overwhelming and often contradictory information.

For the last 15 years, I have been eating nothing but margarine. Now I'm told that I should eat butter! As Professor Nurse said, much of science is based on the best knowledge at the time, but that can change with new knowledge. Science is an evolving process; knowing the facts, knowing how science works, recognizing the problems, and knowing the path to solutions. Unfortunately, scientists often overstate the importance of their science. Granting agencies have an important influence on how scientists portray their research. Today, we see many CIHR grants with a small paragraph at the end of the application explaining how the applicant's work will have major translational benefits — often a stretch - but the pressure to translate is present. We need to support discovery science and, when it can be translated, we should capitalize on that opportunity.

The contrast between the public opinion and scientists' opinion is often dramatic. The best example may be around genetically modified organisms (GMOs). The difference between scientists' and the public's trust in GMOs is almost 50%; more than 80% of scientists trust GMOs but only 30% of the public share this trust. This reflects the ingrained distrust in bringing science to the public, especially if there is a profit involved.

The last example I will use is about naturopaths and homeopaths. Why, in society, do we allow licensing of people with minimal or no academic credentials to deliver therapies with absolutely no proven health benefits? This can lead to tragedy, as we have seen in Lethbridge, Alberta as an example, where a family completely believed what they were hearing from a "doctor" of naturopathy who was treating their child with meningitis. Similarly, the increased public antipathy to vaccination resulting from a thoroughly discredited study on autism has resulted in significant negative public health consequences. When I was starting in Infectious Diseases in Alberta, we saw about 200 to 250 patients under the age of 2 with meningitis each year. Now, with haemophilus influenza type B vaccination, we have virtually eliminated this disease with only about 1 case per year, usually in an infant or young child where the family opposed vaccination.

We, as scientists, must speak out more strongly to dispel the myths about scientific issues such as vaccination, and help restore and maintain public trust in science that has dramatically improved health, but recently has had an increasing element of lack of trust in certain segments of society. It is a clear example that the "public" is not homogenous, but is made up of a broad band of people with differing opinions and trust, making our efforts to ensure people benefit from science ever more challenging, but also more essential.

Dr. Sandra T. Davidge, PhD,
Professor, Depts. of Ob/Gyn and Physiology, University of Alberta

It's hard to not repeat everything that was already said, but for my approach, I am going to talk about the tools that I have, one as a scientist and one as the Director of the Women and Children's Health Research Institute. I love Stephanie's stories. I'm going to start there. I think that it is very important for Mentors in the laboratory to lead by example. It is important that Faculty and their students are working at the highest level of integrity and supported by the system. But there is a lot of pressure to publish; including pressure on graduate students and postdoctoral fellows. I believe that our system is broken, when it comes to publishing negative results. It is important that we share negative results as a scientific community. I believe that we need a system to have a repository for negative results. Sometimes in other countries students are required to publish before they can graduate. This is too much pressure that could affect scientific integrity. Our institutions and scientific community need to create an environment of the highest integrity in order to maintain trust in this high pressure system.

As the Director of the Women and Children's Health Research Institute, I have the privilege of working with the public now. I work with staff and the Boards of two hospital Foundations and it is important to have trust. There is the power of research. But it is important to explain that there is a lengthy timeline for research and also emphasize the importance of Discovery Research. It is also important to translate this knowledge. I work with Foundations who support their respective hospitals and by supporting a research institute they are ultimately supporting the best possible health care. As Scientists, we can help in translating that research. Now because of building relationships, the Foundations (not just the scientists) are communicating the benefits of research to the community and I think that is very powerful; plus this provides an additional mechanism for scientists to engage with the community. We all have our communities. We need to continue to highlight the importance of Science within our own communities.

Brian D. Sykes, FRS, FRSC
Distinguished University Professor, Department of Biochemistry,
University of Alberta

We have had the pleasure of listening to Paul this afternoon, and I agree with virtually everything he and the other panelists have said. I would like to focus on what I think has happened to science over the last 50 years since I started my career as a young Assistant Professor of Chemistry at Harvard University. At that time academic excellence was the most important criteria, one published largely in society journals in one's field so that it was properly reviewed, and industrial applications were frowned upon. My comments are summarized in 3 points.

Point 1: the demise of science started with the creation of the "impact factor", so that administrators can judge academics without really understanding the value of their research. Now we all rush to have our work published in the high impact, 'sexy' journals. The standard joke in my lab is: just because it is published in Science or Nature does not necessarily make it wrong. In 2012 Amgen tried to repeat 53 papers deemed to be 'landmark' studies, and could only confirm 6 of these. An editor of the New England Journal of Medicine has stated that it is "No longer possible to believe much of clinical research published" There is too much of a rush to get research out to the wide audience.

Point 2: The demise of science has been brought upon us by the credo of Translational Research. This has lead to scientists overselling their research. In 1971, Nixon and NIH began the Fight on Cancer hoping for a solution in 5 years. Well, we didn't solve Cancer. Now $250 million, 300 scientists and 40 labs are a part of Sean Parker's revolutionary project to 'solve' cancer. Now I know we have made significant advances in the treatment of Cancer, but to promise a cure is to not understand the nature of this complex set of diseases. If we solved diseases at the rate that we highlight them on the U of A website, there would be no diseases left. Here, I think one thing we need to do is to hire public relations staff who have some expertise in science.

Point 3: (which I take from a talk presented at the U of A a decade ago by Harold Schachman (Berkeley)) is that we need to be aware of 'self aggrandizement. Many times we may present our results a little too uncritically, and ourselves a little too unbashfully. In essence, don't fool yourself.

Dr. Joel Dacks, PhD,
Associate Professor Department of Cell Biology University of Alberta,

Question: What should health scientists do to ensure we have and keep the public trust?There are obviously many answers to this question, perhaps foremost being for we scientists to BE trustworthy and produce robust, informative science.

However, in terms of connecting with an open-minded public, who are simply not trained as scientists, we need to better communicate our findings, and particularly our rationale, so that the public is empowered to make informed judgments when they are inundated with the information and opinions so easily available on the internet and other sources. I think that we need to better explain how scientific information is gathered and how scientists come to conclusions, focusing on the scientific process, mindset and vocabulary.

We need to talk about why something that is observed repeatedly, many times and by different people, is more reliable than one off personal experience. We can better convey that that science works in cycles of proposing an idea, testing that idea and modifying it, often revealing even more questions. It is an ever on-going process. There can be confidence at each stage, but that the goal isn't to get a "final answer" or absolute truth. And it needs to be conveyed that for a scientist uncertainty is not a statement of weakness, but often highlights an area of opportunity. For example, for a scientist the statement that "there is debate regarding the theory of evolution" does NOT mean that there is doubt about the basic premise of natural selection. It does NOT mean that there is doubt that life evolves by natural processes, which are within our capacity to understand! It DOES mean that evolution is so much more than just a single "fact". Instead, because the basic premise is supported by vast amounts of data, the theory of evolution encompasses a large number of questions in an exciting field of investigation where the areas of uncertainty are being debated and pursued using a well-honed set of intellectual tools and field-tested suite of approaches.

It is exceptionally important that these processes, mindsets and vocabulary are communicated, through outreach by the scientific community. There are absolutely better ways for us to do that, including working with our partners in this endeavor. These may be members of communities where public trust is endangered. It is most certainly teachers at the primary and secondary school level. I would also argue that full-time professional science

communicators, well-trained in the skills of both science and communications could play more of a role in conveying accurate information in a format that the public feels that they can trust.

I think all of this means that to have and keep the public trust we need to both generate trustworthy information and recognize its communication as an integral part of the scientific endeavor.

UAlberta May 5, 2016

Roundtable: Trust in Science

Dr. Tania Bubela, BSc (Hons), PhD, JD
Professor School of Public Health University of Alberta

I'm going to be pragmatic and say that just because we can communicate doesn't mean that we know how to communicate and that communication is becoming more and more complex. It is getting harder and harder to get the message out, and to have the message heard. So what do I mean?

First, one visualization of science communication is that, if only we could pour in more information/facts, then members of the public would see the world the way that scientists see it. But in fact, that is not the case. People come with different perceptions of the world, and there are other voices out there that have much greater influence among the lay public, leaders and peer groups. Second, I have great sympathy for high school teachers, competing with the teenage brain, Twitter and other methods of communication, just trying to get the message across. This littering and fragmentation of the communication environment is raising increasing challenges. We cannot partner with science journalists just to get the message out. In fact, there are hardly any science journalists left. They are the first "death" in the newsroom - what gets cut when the media cuts most of its journalist staff. We are now seeing new voices in social media, and it is simply getting harder to be heard amongst this cacophony of stories. (audio time: 1:00:03). So, when we do find voices that are willing to play, they are often rattled and not trained as science journalists. This leads to 2 things that Sir Paul did point out: one of them being the key framing devise for journalists - controversy, and the other being cheerleading because journalists are too lazy to go out and find a contrary view. So this is manifested in a cycle of scientists telling the story, which generates a press release from the university, which is then published pretty much verbatim into the media. And the challenge, in my part, is that I do

a lot of work with patients and patients' organizations where they feel this tension between (1) being blocked from getting the treatments that they feel they need when the media told them that there is "a cure", and (2) having their safety protected by a very strong regulatory body in bringing these treatments to market. There is tension when individuals trust regulators (for example, listeria outbreaks), but at the same time, the patients are blocked from getting access to all of this great Science. This tension gives rise to "medical tourism" in areas of the world where there are lower regulatory standards, where there are clinics that would give therapies not available in countries like Canada. So this brings me full circle back to the real importance of regulation. I think that the law is, under certain contexts, playing "catch-up". What we need are adaptive regulatory regimes that can respond to changes in Science. You cannot come down with very hard models. Canada needs nimble models and tools available to respond to advances in Science. And I will leave it there.

Jack H. Jhamandas, MD, PhD, FRCPC, FCAHS
Distinguished University Professor, Department of Medicine,
University of Alberta

Dr. Jack Jhamandas: Sir Paul Nurse, members of the Round table, colleagues, ladies and gentlemen. It is a privilege to participate in this panel discussion on 'What should Health Sciences Scientists do to ensure we have and keep the public trust?'. This is a broad and complex topic with many facets to it, different perspectives and probably no shortage of opinions. I would like to spend a couple of minutes and provide my perspective as a Neurologist and Neuroscientist on one aspect of this topic which relates to the interface between Science, the practice of Medicine and trust. I think most people would agree that the practice of Medicine with a few exceptions has its foundations firmly rooted in evidence based science. An important challenge that physicians face in providing care, be it recommending a test or a particular therapeutic intervention, is to engender a sense of confidence and trust on the part of the patient that the proposed

course of action is rational and founded on evidence-based science. Communication is thus a key element in earning and keeping this trust in an enduring manner. Rupture of this trust through miscommunication, lack of professionalism or a myriad of other factors can have potentially dire consequences. Let me illustrate this point by alluding to a recent tragic case in Alberta, that Dr. Tyrrell referred to in his remarks, where parents of a two year old child with meningitis treated the toddler with herbal remedies for two weeks and only sought medical attention when it was too late. The child tragically succumbed to bacterial meningitis.

It is difficult to be certain why the parents opted to trust the alternative forms of treatment that are unproven (for the treatment of meningitis) rather than seek timely medical help through a doctor or hospital. It seems, however that somewhere along the line, communication between the parents and the medical profession was broken. As such there was no means to convey and convince the parents that evidence based science would have provided a rational alternative and likely served as a successful treatment for their child. Public trust in science occurs through many portals but engendering and keeping this trust requires thoughtful and compassionate communication particularly from health scientists and professionals as the stakes can be occasionally high - life or death.

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