Confidence in Communicating about Research

Talking about the quality and reliability of evidence

Speakers

Moderator - Tracey Brown, OBE, Director, Sense about Science

Richard Horton, OBE, FRCPCH, FMedSci

Professor Quarraisha Abdool Karim, PhD

Director, Centre for the AIDS Programme of Research in South Africa (CAPRISA)

Dr. Alejandra Paniagua-Avila, MD DrPH MPH

Postdoctoral Fellow, Columbia University



Researcher Academy





Talking about the quality and reliability of evidence

Tracey Brown, OBE





Resources

- Where to find additional resources researcheracademy.elsevier.com
- · What's coming up in the webinar series:
 - Webinar 2: Communicating what research is and isn't
 - Webinar 3: Dealing with the rough and tumble of communicating in practice





Topics covered in today's session

- Good practice in communicating findings
- Communicating the status of findings
- Reducing scope for hype and misrepresentation





Good practice in reporting findings

Researchers are increasingly worried that there isn't a common understanding of research practices and principles in society on which they can draw.

Confidence in research: researchers in the spotlight revealed high levels of concern among researchers internationally, particularly early career researchers, about engaging with discussions about research amid policy debates, polarisation and competing information claims.

- Less than a third of researchers interviewed were confident in communicating about research findings with policymakers (26%) or journalists (28%), and even fewer on social media (18%). This was most pronounced among ECRs.
- And yet... half of those interviewed (51%) feel a responsibility to engage in debate online, with nearly a quarter (23%) seeing publicly countering misinformation as one of their primary roles in society.
- Over half (54%) identified communications training as the most useful form of support.







About the speakers



Richard Horton is the Editor-in-Chief of *The Lancet*. He graduated in physiology and medicine from the University of Birmingham in 1986 and joined *The Lancet* in 1990, becoming North American Editor in 1993. Horton has chaired global health commissions and cochaired the UN's Expert Review Group on Women's and Children's Health. He has received numerous awards, including the Friendship Award from China (2015) and the WHO Director-General's Health Leaders Award (2019). He is a Foreign Associate of the US Institute of Medicine and advocates for planetary health. Horton authored *The COVID-19 Catastrophe* (2020), with a second edition released in 2021, and was awarded an OBE in 2023 for services to health and medical journalism.



Prof. Quarraisha Abdool Karim, PhD, is an infectious disease epidemiologist and Associate Scientific Director of CAPRISA. She is also Pro-Vice-Chancellor for African Health at the University of KwaZulu-Natal and a Professor at Columbia University. Karim has led groundbreaking research in HIV prevention, HIV-TB co-infection, and the impact of COVID-19 on HIV. She serves as President of TWAS and UNAIDS Special Ambassador for Adolescents and HIV, contributing to global health initiatives. With over 300 publications, she has trained 600+ Southern African scientists and received over 30 global honors, including the Lasker-Bloomberg Public Service Award and the L'Oréal-UNESCO Women in Science Award.



Dr. Alejandra Paniagua-Avila, Guatemala – Postdoctoral Fellow, Columbia University (USA); President and Co-founder, Asociación para la Salud Mental Saqirsán. Alejandra Paniagua-Avila is a Guatemalan medical doctor and early career scientist dedicated to advancing access to recovery-oriented mental health services for all. She has a particular interest in addressing the health and social needs. Dr. Avila is a 2025 OWSD-Elsevier Foundation Award winner, recognized for her outstanding contributions to inclusive health.





Talking about the quality and reliability of evidence

Dr. Alejandra Paniagua-Avila, MD DrPH MPH

Postdoctoral Fellow, Columbia University





Talking about the quality and reliability of evidence

Richard Horton, OBE, FRCPCH, FMedSci

Editor-in-Chief, The Lance





CONFIDENCE IN COMMUNICATING ABOUT RESEARCH

Talking about the quality and reliability of evidence



Richard Horton

The Lancet

IF ONLY IT WERE SO SIMPLE...

THE LANCET

www.thelancet.com

The Lancet Commission on dementia



"Effective dementia prevention, intervention, and care could transform the future for society and vastly improve living and dying for individuals with dementia and their families. Acting now on what we already know can make this difference happen."

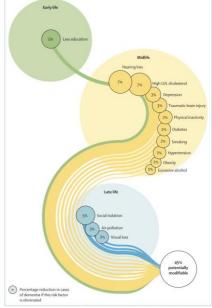


Figure 9: Population attributable fraction of potentially modifiable risk factors for dementia

Fourteen lifestyle changes that could stop dementia revealed

30 per cent higher risk

Eleanor Hayward Health Editor

Nearly half of all dementia cases could be prevented if people adopted healthier lifestyles and lowered their cholesterol, a major study has revealed. The review by the Lancet Commis-

sion has unveiled 14 controllable risk factors, including obesity and too much alcohol, that are behind hundreds of thousands of cases in the UK.

It reveals for the first time that having high cholesterol - which affects six in ten British adults - increases the risk of getting dementia by 30 per cent, and is responsible for 7 per cent of all cases. Experts said middle-aged adults

could ward off dementia by taking statins or doing exercise to lower "bad" LDL cholesterol. The paper was written list of 12 known risk factors including by 27 global experts, led by University College London. It identified two new factors that contribute to dementia - treatable risk factors are responsible for high cholesterol and untreated vision 45 per cent of dementia cases, or loss in old age. These were added to a 440,000 of Britain's estimated 982,000 called for radical public health policies

Major factors that increase risk

Loneliness Social isolation in later life increases dementia risk by 60 per cent Hearing loss Sufferers are 40 per cent more likely to succumb:

hearing aids can help Vision loss Sight loss in old age increases the risk by 50 per cent High cholesterol High toyols of "bad" LDL cholesterol means a

depression, smoking and loneliness.

Between them, these 14 modifiable or

Depression Doubles the risk; responsible for 3 ner cent of cases Head injuries Traumatic brain injury increases the risk by 70 per cent Physical inactivity Increases dementia risk by 20 per cent

Air pollution increases risk by 10 per cent Smoking Increases the Poor education risk by 30 per cent Using your brain from Diabetes increases the an early age increases risk by 70 per cent "cognitive reserve"

> cases, with hearing loss and high cholesterol the two biggest preventable causes. The authors said their findings demonstrate that dementia does not simply "hit people in a random way", and

High blood pressure

Increases the risk by

30 per cent higher risk

21 units a week ups the

Alcohol More than

risk by 20 per cent

Obesity Linked to

such as smoking bans and restrictions on junk food - finding this would reducing dementia-related costs to the NHS and social care.

Professor Gill Livingston, the lead author from UCL, urged people to "give yourself a chance" through lifestyle changes, adding "There's a lot of things think that's a remarkable bonus that we didn't know about."

The commission made 13 recommendations, including encouraging hearing aid use and treating high cholesterol from the age of 40. Samantha Benham-Hermetz, from

Alzheimer's Research UK, called for "cost-effective public health measures" such as blood pressure checks, adding-"The new government must seize this win-win opportunity - extending healthy life expectancy, while putting public funds to better use."

Almost half of dementia cases could be staved off. study finds

Andrew Gregory

Almost half of all dementia cases worldwide could be prevented entirely or delayed, a landmark study has found, as experts named 14 risk

hugely increase the chances of not developing dementia or pushing back its onset. It's also important to stress that while we now have stronger evidence that longer exposure to risk has a greater effect ... it's never too early or too late to take action."

People at all stages of life, from children to the elderly, could still take steps to reduce their risk of developing the disease - which has no cure - or at least fend it off until later in life, added Livingston, of University College London.

The report adds two new risk factors that are associated with 9% of all dementia cases. About 7% of cases are linked to high low-density lipoprotein (LDL) or "bad" cholesterol in midlife from about the age of 40 years, while 2% of cases are linked to untreated vision loss in later life.

These two new risk factors are in addition to 12 previously identified by the Lancet commission in 2020

Statins and specs: Two new ways to cut risk of dementia

screening and treatment for vision and hearing loss.



Quarter in UK believe Covid was a hoax, poll on conspiracy theories finds

"An important book for an era of weaponized information."

—George Musser, contributing editor, Scientific American and Nautilus

THE MISINFORMATION AGE



How False Beliefs Spread

CAILIN O'CONNOR AND JAMES OWEN WEATHERALL

HOW DO YOU MINIMISE THE RISK OF YOUR RESEARCH BEING MISUNDERSTOOD?

THREE QUESTIONS THREE CAUTIONS ONE PLEA

THREE QUESTIONS

What was the evidence before you completed your study?

What is the added value of your study?

What is your interpretation in the light of the totality of available evidence?

prevent chikungunya virus infection or disease. To ensure a thorough understanding of the available evidence, we conducted an extensive literature review. The following database sources were searched for relevant studies: PubMed, Scopus, Web of Science, and Clinical Trials.gov. Additionally, we reviewed

Research in context Evidence before this study

We included studies that focused on vaccine candidates for published in peer-reviewed journals; and trials involving participants aged 12 years and older. Studies were excluded if

Before we undertook this trial, there were no licensed vaccines to

the rationale for our study, which aimed to address the unmet

IXCHIO, a live-attenuated vaccine delivered as a single dose after

June, 2024, and the European Medicines Agency in July, 2024 for

the prevention of chikungunya virus disease in individuals aged

18 years and older who are at increased risk of exposure. Since

February, 2024, the US Advisory Committee on Immunization

18 years and older travelling to countries or territories with

children younger than 12 years.

Practices recommends chikungunya vaccination for people aged

ongoing chikungunya outbreaks, as well as for laboratory workers with potential exposure to the virus. Before we undertook this trial, no marketed chikungunya virus vaccine was available for

need for an effective and licensed vaccine. Since our study.

Administration (FDA) in November, 2023, Health Canada in

reconstitution, was approved by the US Food and Drug

they: were not published in English or if translation was not virus: or were not relevant to vaccine development or immunisation strategies for chikungunya virus. Search terms used included combinations of the following keywords "chikungunya virus", "vaccine", "vaccine candidates", "clinical trials", "immunization", "vaccine development", and

"chikungunya disease prevention". The search was conducted using studies published from Jan 19, 2000, to Sept 17, 2021. Studies published before this period were excluded due to the rapid advances in vaccine research in the past two decades. We included all studies regardless of geographical location, given

the global impact of chikungunya. Based on this review, we concluded that although several vaccine candidates had entered clinical trials, there were no licensed vaccines at the time to prevent chikungunya virus infection or disease. This informed

reference lists from recent reviews, meta-analyses, and primary

research articles on chikungunya virus and vaccine development. chikungunya virus, including preclinical and clinical trials; studies available: focused on non-vaccine interventions for chikungunva adults (NCT05072080), and older adults (NCT05349617). Results from the present trial of adolescents and adults aged

Two pivotal phase 3 trials in individuals aged 12 years and older

have been completed with Bayarian Nordic's Vimkunya vaccine.

with positive safety and immunogenicity results in adolescents.

Added value of this study

12-64 years show that Vimkunya (previously chikungunya virus virus-like particle vaccine) induced a seroresponse, considered the presumptive seroprotective antibody response, in 97-8% of individuals at day 22 after vaccination, and in 96-8% of individuals at day 15 after vaccination, and persisted with a seroresponse rate of 85-5% at day 183. Vimkunya showed a favourable safety profile in all age strata; most adverse events were self-limiting and grade 1 or 2 in severity. The chikungunya virus virus-like particle component of the vaccine contains proteins from the chikungunya virus Senegal west African strain 37997. The proposed mechanism of action of Vimkunya is to induce antibodies against the chikungunya virus

capsid (C), and envelope (E1, E2) proteins contained in the vaccine, resulting in neutralisation of live chikungunya virus. Implications of all the available evidence Vimkunya elicits a high seroresponse rate at protective levels of chikungunya virus neutralising antibodies within 2 weeks after vaccination, which is beneficial to individuals receiving immunisation before travel, and displays a favourable safety

profile. Compared with IXCHIO, Vimkunya is offered as a singledose, prefilled syringe for easy administration and increased dosing accuracy, with the indication including adolescents aged 12 years and older. Virus-like particle vaccines are non-replicating. have been widely used for over 30 years, and generally are not contraindicated for use in immunocompromised populations and pregnant women. Vimkunya offers a robust immunogenic option

for a range of travellers due to its virus-like particle platform. The

FDA approved Vimkunya (chikungunya vaccine, recombinant) for injection on Feb 14, 2025, making it the first virus-like particle single-dose chikungunya vaccine in the USA for people aged 12 years and older. On Feb 28, 2025, the European Commission granted marketing authorisation in Europe for Vimkunya for active immunisation for the prevention of disease caused by chikungunya virus in individuals aged 12 years and older.

THREE CAUTIONS

1. Transparency is your friend

Methods Informed consent

Results Competing interests

Reporting guidelines Role of funding source

IRB approval Contributions



Did you use an Al assistant?

THREE CAUTIONS

2. Peer review is not a panacea

Peer review is about the acceptability of your paper, not its validity

Peer review is a negotiation between author and editor about the scope of the claims made in your paper

THREE CAUTIONS

3. Humility is a strength

Embrace uncertainty

Explain your work's limitations

ONE PLEA

Protect research integrity

Say no to fabrication Say no to falsification Say no to plagiarism



"The greater the circle of light, the greater the boundary of darkness by which it is surrounded."

Sir Humphry Davy

THANK YOU!

Talking about the quality and reliability of evidence

Professor Quarraisha Abdool Karim, PhD

Associate Scientific Director, Centre for the AIDS Programme of Research in South Africa (CAPRISA)







Communicating Science with Policy makers and the Public

Confidence in Communicating about Research: Talking about the quality and reliability of evidence Elsevier - Sense About Science webinar, 24 April 2025

Quarraisha Abdool Karim

John C Martin Chair in Global Health: CAPRISA Associate Scientific Director: CAPRISA Professor in Clinical Epidemiology: Columbia University Pro Vice-Chancellor: University of KwaZulu-Natal President: The World Academy of Sciences UNAIDS Special Ambassador for Adolescents and HIV





















Living in most exciting era in Science

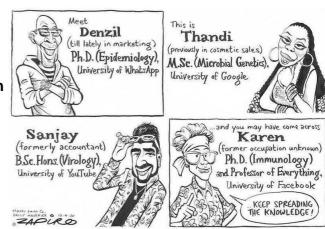
- Knowledge that improves lives and leaves no one behind
- More than publish or present findings at conferences
- Research that makes an impact
- Informing policy and practice
- Not all research can inform policy and practice

Scientists - Policy Makers, Politicians & Public

- Key Element of Interaction = Trust
- Trust dwindling for many reasons
- Rampant unchecked disinformation pervading social media
- Practitioners and communicators of science
- Communicate effectively with all stakeholders on an ongoing basis
- Build an:
 - Understanding of science
 - Scientific process
 - Value of Science

Social media has enhanced Disinformation

- Dangers of instant social media experts
- Dangers of personal opinion, speculation & misinformation masquerading as facts
- Dangers of deliberate spread of dis-information to undermine vaccination
- Dangers of "bots" used to amplify disinformation



How <u>not</u> to convey information to Policymakers or the Public

1. Don't hype the findings



NFECTIOUS DISEASES

Science: New antibody studies boost hope for an HIV cure

Pioneering trials discover potential strategy to keep the virus in check after stopping antiretroviral treatment



The FRESH Study Tests New HIV Remission Strategy in South African Women

March 12, 2025

Thumbi Ndung'u emphasized that the study's focus on women in South Africa is significant, as women are often underrepresented in clinical trials. This is the first HIV cure trial in Africa, and it's crucial to involve women because they are disproportionately affected by HIV." he noted.





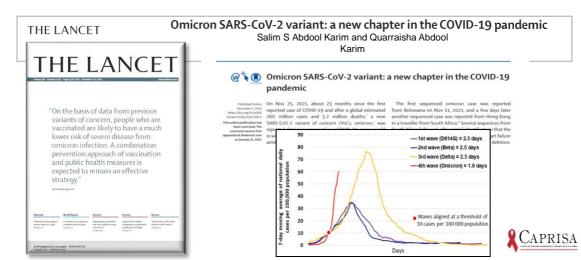
SA scientists release promising HIV cure trial results

outh African scientists have released the findings of the first HIV cure trial in Africa with promising results showing viral suppression in 20% of women who stopped taking antiretroviral therapy (ART) after



2. Be clear about uncertainty

2021: First epidemiological analysis of omicron – showed its higher transmissibility within a week



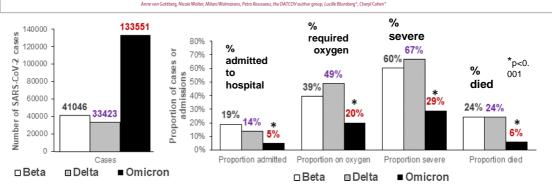
Shortly thereafter: Is Omicron more severe? NO!

THE LANCET

Clinical severity of COVID-19 in patients admitted to hospital during the omicron wave in South Africa: a retrospective observational study

Waasila Jassat, Salim S Abdool Karim, Caroline Mudara, Richard Welch, Lovelyn Ozougwu, Michelle J Groome, Nevashan Govender,

Preprints with THE LANCET



"Severe" defined as respiratory distress, oxygen, mechanical ventilation, high care / ICU care or death

6 weeks later in 2022: Does omicron escape vaccine

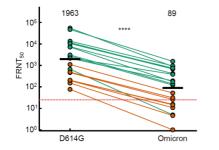
Abs? Yes, Pfizer vaccine Abs ↓ neutralisation

nature

Omicron extensively but incompletely escapes Pfizer BNT162b2 neutralization

Sandile Cele¹³, Laurelle Jackson¹, David S. Khoury³, Khadija Khani¹³, Thandeka Moyo-Gwete⁴⁵, Hourilyah Tegally⁵⁷, James Emmanuel San⁶, Deborah Cromer³, Cathrine Scheepers⁴³, Daniel G. Amoako⁵⁷, Farina Karini²⁷, Mallory Bernstein³, Gila Lustig⁶, Dereseree Archary⁶⁸, Muneerah Smith⁵⁹, Yashica Ganga⁷, Zesuliwe Jule¹, Kaja Reedoy⁷, Shi-Hsia Hwa⁷, Jennifer Glandhari⁶, Jonathan M. Blackburn⁶⁸, Bernadett I. Gosnelli¹³, Salim S. Abdool Karini¹³, Willem Hanekom¹³, NGS-SA⁷, COMMIT-KZN Team⁷,





- Pfizer vaccinee sera had a <u>+</u>40-fold lower neutralization of Omicron versus D614G
- Mild breakthrough infections are occurring and increasing in SA's 4th wave
- Implications for clinical efficacy of vaccines for mild & severe infections unclear...



How <u>not</u> to convey information to Policymakers or the Public

- 1. Don't hype the findings avoid over-reach
- 2. Be clear about uncertainty Don't be matter of fact
- 3. Focus on what is known don't speculate on findings



Three issues for consideration when providing advice to Policymakers (or the Public)

- Conveying information not opinion
- Conveying uncertainty meaningfully
- Conveying evidence not speculation or conjecture



1. Conveying Information vs Opinion

- Looking for unvarnished truth that enables weighing options and make decisions
- Do not promote your preferred position or push your agenda
- Advisor agnostic to the final decision = Trust 'no skin in the game'
- Challenge formulated views based on available data vs conveying evidence in a neutral manner



2. Conveying uncertainty meaningfully

- Explain relationships in data
- Build a story summarizing large amounts of data (some conflicting)
- Convey uncertainty and quality when providing evidence



3. Conveying the evidence – not speculation or conjecture

- Policy makers often want information that is simply not available
- Be careful to help policy makers appreciate that the future is not known
- Need to fully appreciate challenges in predicting what may happen based on trends, extrapolation or modelling



Conclusion: Timing and Certainty

- Policy makers seek advice on decisions that need to be made within a short timeframe
- · Advice cannot wait for new studies to be done
- Timing issue available evidence not exactly what is being sought
- Critical questions requiring advice little data; poor quality data or studies still underway
- Cannot wait for higher levels of certainty decision made with available limited data
- Underscore guidance based on best available evidence at time; if new data becomes available share and provide updates
- Scientists provide advice to policy makers decision of policy maker considers more than scientific considerations (factor in: feasibility, cost, public expectations, demands of multiple constituencies served)



Talking about the quality and reliability of evidence

Question and Answer session

Please pop your questions in the Q&A section





Upcoming webinars

Webinar 2: Communicating what research is and isn't

Topics will include:

- · Discussing uncertainty in science
- Evaluating the relevance and reliability of evidence
- The impact of AI on communicating the reliability of research

Webinar 3: Dealing with the 'rough and tumble' of communicating in practice

Topics will include:

- How to prepare research information for media and policy audiences
- Where to find tips and advice
- How to handle unfounded criticism and harassment





Thank you.

Build your confidence in communicating about research with our free training on:

researcheracademy.elsevier.com



