



HIFA Project on Communicating health research

Supported by TDR/WHO

Full compilation, #1-122

[hifa] A new HIFA project: Communicating health research to support evidence-informed policymaking

Sender: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

Date: Tue, 17 May 2022 08:05:33 +0000

From: Neil Pakenham-Walsh <neil.pakenham-walsh@ghi-net.org>

Read online: <https://www.hifa.org/news/new-hifa-project-communicating-health-research-support-evidence-informed-policymaking>

We are delighted to announce a new project sponsored by TDR, the Special Programme for Research and Training in Tropical Diseases at WHO.

The project - 'Communicating health research to support evidence-informed policymaking' - will support the HIFA community to explore methods and issues around communicating health research evidence to support evidence-informed policymaking.

This builds on past work by HIFA and TDR to support three previous discussions on the HIFA forums: 1. country-level policymaking, 2. implementation research, and 3. systematic reviews (see HIFA Evidence Informed Policy and Practice).

What we shall do

We now turn our attention to the information needs of policymakers and how these needs can be more effectively met. This project will look at how research is packaged and communicated, including for example the role of policy briefs as well as videos, social media and newsletter content.

HIFA will host a 4-week in-depth discussion on the HIFA forums from 27 June to 22 July 2022, supported by a working group of TDR staff and HIFA volunteers. There is currently funding for one thematic discussion, with potential for further work in the future.

Who can participate?

We invite anyone with an interest in health to join these discussions. This includes health professionals, community health workers, members of civil society, policy makers, and people working in the field of research communication.

How does it work?

HIFA members receive a daily compilation of messages from the previous 24 hours, sent by email to their personal inbox.

HIFA members contribute to the discussions by sending email to: hifa@hifaforums.org
All contributions are assessed and approved for distribution to HIFA's 20,000+ members worldwide Contributions are synthesised and offered to the wider research and policymaking community.

How to join?

If you are already a HIFA member, then you do not need to take action. The discussion will take place on the HIFA forum.

If you are not already a HIFA member, you can join here (free).

HIFA and TDR: Working together for a world where every policymaker has access to the information they need to protect the health of the people for whom they are responsible.

Read more: <https://www.hifa.org/projects/new-communicating-health-research-support-evidence-informed-policymaking>

Best wishes, Neil

Joint Coordinator, HIFA Communicating health research

<https://www.hifa.org/projects/new-communicating-health-research-support-evidence-informed-policymaking>

Let's build a future where every person has access to reliable healthcare information and is protected from misinformation - Join HIFA: www.hifa.org

HIFA profile: Neil Pakenham-Walsh is global coordinator of the HIFA global health movement (Healthcare Information For All - www.hifa.org), a global community with more than 20,000 members in 180 countries, interacting on six global forums in four languages in official relations with WHO. HIFA brings stakeholders together to accelerate progress towards universal access to reliable healthcare information. Twitter: @hifa_org neil@hifa.org

[hifa] A new HIFA project: Communicating health research to support evidence-informed policymaking (2)

Sender: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

Date: Tue, 17 May 2022 18:05:10 +0000

From: "Joseph Ana, Nigeria" <HIFA@hifaforums.org>

Dear Neil,

This is interesting and exciting: '

'HIFA and TDR: Working together for a world where every policymaker has access to the information they need to protect the health of the people for whom they are responsible.'

[<https://www.hifa.org/dgroups-rss/new-hifa-project-communicating-health-research-support-evidence-informed-policymaking>]

we look forward to the discussions.

Joseph Ana

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HIFA profile: Joseph Ana is the Lead Consultant and Trainer at the Africa Centre for Clinical Governance Research and Patient Safety in Calabar, Nigeria, established by HRI Global (former HRIWA). In 2015 he won the NMA Award of Excellence for establishing 12-Pillar Clinical Governance, Quality and Safety initiative in Nigeria. He has been the pioneer Chairman of the Nigerian Medical Association (NMA) National Committee on Clinical Governance and Research since 2012. He is also Chairman of the Quality & Performance subcommittee of the Technical Working Group for the implementation of the Nigeria Health Act. He is a pioneer Trustee-Director of the NMF (Nigerian Medical Forum) which took the BMJ to West Africa in 1995. He is particularly interested in strengthening health systems for quality and safety in LMICs. He has written Five books on the 12-Pillar Clinical Governance for LMICs, including a TOOLS for Implementation. He established the Department of Clinical Governance, Servicom & e-health in the Cross River State Ministry of Health, Nigeria in 2007. Website: www.hri-global.org. Joseph is a member of the HIFA Steering Group and the HIFA working group on Community Health Workers.

Website: www.hri-global.com Joseph is a member of the HIFA Steering Group and the HIFA working group on Community Health Workers.

<http://www.hifa.org/support/members/joseph-0>

<http://www.hifa.org/people/steering-group> Email: info@hri-global.org and jneana@yahoo.co.uk

[hifa] A new HIFA project: Communicating health research to support evidence-informed policymaking (3)

Sender: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

Date: Thu, 19 May 2022 13:05:39 +0000

From: Neil Pakenham-Walsh <neil.pakenham-walsh@ghi-net.org>

Dear HIFA colleagues,

We look forward to launch a new thematic discussion on HIFA on 27 June, supported by TDR at WHO.

Please retweet and invite your colleagues and contacts to join HIFA:

https://twitter.com/hifa_org/status/1527274784601653248

"We are thrilled to launch a new project with @TDRnews @WHO COMMUNICATING HEALTH RESEARCH for evidence-informed policymaking <http://bit.ly/3NjspNq> Join #HIFA #globalhealth forum <http://hifa.org/joinhifa> #healthinfo4all #healthresearch"

There are limited places for HIFA volunteers to help on the project working group. Contact me: neil@hifa.org

Best wishes, Neil

Joint Coordinator, HIFA Communicating health research
<https://www.hifa.org/projects/new-communicating-health-research-support-evidence-informed-policymaking>

Let's build a future where every person has access to reliable healthcare information and is protected from misinformation - Join HIFA: www.hifa.org

HIFA profile: Neil Pakenham-Walsh is global coordinator of the HIFA global health movement (Healthcare Information For All - www.hifa.org), a global community with more than 20,000 members in 180 countries, interacting on six global forums in four languages in official relations with WHO. HIFA brings stakeholders together to accelerate progress towards universal access to reliable healthcare information. Twitter: @hifa_org neil@hifa.org

[hifa] New HIFA discussion: Effective communication of health research to policymakers, 5 September to 7 October 2022

Sender: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

Date: Sun, 28 Aug 2022 08:08:38 +0000

From: Neil Pakenham-Walsh neil.pakenham-walsh@ghi-net.org

Join HIFA colleagues,

On 5 September we officially start a new thematic discussion on HIFA, supported by TDR, the Special Programme for Research and Training in Tropical Diseases at WHO: Effective communication of health research to policymakers. The discussion will continue through to 7 October 2022.

BACKGROUND What are the most impactful methods for researchers to communicate their research to policymakers so that the research is seen and applied? How can research be better packaged and communicated, including for example the role of policy briefs as well as academic journals, videos, social media, infographics, newsletters, use of video, and newsletter content? We shall consider the preferences of policymakers, and the role of researcher-policymaker communications at all stages of the research cycle. We shall also consider the role of intermediaries such as journal editors, communication professionals, publicists and journalists. We shall be inclusive in the different types of research we consider, including primary research (eg randomised controlled trials, observational studies, implementation research, operational research); secondary research (eg systematic reviews), and their geography (global, national, local); and tertiary research (where cumulative evidence is operationalised in, for example, the form of policy briefs and clinical guidelines). We are looking primarily from the perspective of researchers, whose motivation is typically to communicate their research effectively. At the same time, researchers need to know what policy-makers want and require, and they need to have an understanding of how their research fits in with the broader perspective of evidence-informed policy. **GUIDING QUESTIONS** The questions below are offered as a guide to the discussion. Please feel free to comment on any aspect of health research communication at any time. Email your comments to the forum here: hifa@hifaforums.org

1. What do we mean by Effective communication of health research to policymakers? How do we measure it?

2. What are the different approaches to communicating research (eg academic journals, policy briefs, interaction with policymakers, press releases, social media, infographics, use of video)? What is your experience with these approaches? What works and what doesn't?
3. What is the role of researchers in research communication, beyond publication of their paper? What is the role of other stakeholders (eg communication professionals, editors, media, public health professionals and critical thinkers)
4. What are the needs and preferences of policymakers?
5. What can be done to better support researchers in the communication of health research?

Please forward this message to your contacts and networks and encourage people to join by going to our website: www.hifa.org or direct to our Join page: www.hifa.org/join

The discussion will take place on HIFA (English), CHIFA (child health, English), HIFA-French, HIFA-Portuguese and HIFA-Spanish.

More info here: <https://www.hifa.org/projects/new-effective-communication-health-research-policymakers>

Contact: Neil Pakenham-Walsh, HIFA Global Coordinator: neil@hifa.org

[hifa] Communicating health research (5) Identifying barriers and facilitators of translating research evidence into clinical practice: A systematic review of reviews

Sender: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

Date: Tue, 05 Jul 2022 10:07:47 +0000

From: Neil Pakenham-Walsh neil.pakenham-walsh@ghi-net.org

This 'systematic review of reviews' finds that 'the translation of new evidence was limited predominantly by individual-level issues and less frequently by organisational factors. Inadequate knowledge and skills of individuals to conduct, organise, utilise and appraise research literature were the primary individual-level barriers. Limited access to research evidence and lack of equipment were the key organisational challenges.'

CITATION: Identifying barriers and facilitators of translating research evidence into clinical practice: A systematic review of reviews.

Abu-Odah H et al. Health Soc Care Community. 2022 Jul 1. doi: 10.1111/hsc.13898.

Translating research into clinical practice is a global priority because of its potential impact on health services delivery and outcomes. Despite the ever-increasing depth and breadth of health research, most areas across the globe seem to be slow to translate relevant research evidence into clinical practice. Thus, this review sought to synthesise existing literature to elucidate the barriers and facilitators to the translation of health research into clinical practice. A systematic review of reviews approach was utilised. Review studies were identified across PubMed, Scopus, Embase, CINAHL and Web of Science databases, from their inception to 15 March 2021. Searching was updated on 30 March 2022. All retrieved articles were screened by two authors; reviews meeting the inclusion criteria were retained. Based on the review type, two validated tools were employed to ascertain their quality: A Measurement

Tool to Assess Systematic Reviews-2 and International Narrative Systematic assessment. The framework synthesis method was adopted to guide the analysis and narrative synthesis of data from selected articles. Ten reviews met the inclusion criteria. The study revealed that the translation of new evidence was limited predominantly by individual-level issues and less frequently by organisational factors. Inadequate knowledge and skills of individuals to conduct, organise, utilise and appraise research literature were the primary individual-level barriers. Limited access to research evidence and lack of equipment were the key organisational challenges. To circumvent these barriers, it is critical to establish collaborations and partnerships between policy makers and health professionals at all levels and stages of the research process. The study concluded that recognising barriers and facilitators could help set key priorities that aid in translating and integrating research evidence into practice. Effective stakeholder collaboration and co-operation should improve the translation of research findings into clinical practice.

COMMENTS (NPW)

1. The authors start with the rather provocative premise that 'Healthcare professionals' lack of motivation, lack of continuous education, uncooperative and unsupportive organisational culture and the disintegration between knowledge producers and users are the key barriers to the translation of research into clinical practice.'
2. They note that 'Establishing collaborations and partnerships between policy makers and health professionals at all levels and stages of the research process were the main facilitators of the knowledge translation process'.
3. I have not had a chance to read through the whole text in depth, but it seems that the paper says hardly anything, if anything at all, on the role of researchers in research communication.

Neil Pakenham-Walsh, Global Coordinator HIFA, www.hifa.org neil@hifa.org
Working in official relations with WHO

[hifa] Communicating health research (6) Points to ponder for researchers in hitting the broader perspectives of evidence-informed policy

Sender: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

Date: Wed, 17 Aug 2022 08:08:18 +0000

From: "Khin Thet Wai, Myanmar" <khinthewaidmr@gmail.com>

'Points to ponder for researchers in hitting the broader perspectives of evidence-informed policy'

- My experience of involvement in three research studies that focused tropical diseases (multiple helminth infections, dengue and Japanese Encephalitis) [1-3] has generated the requirement for extended scope of evidence-informed health policy at the central level. Three themes are emanated for consideration of researchers: hierarchical health care infrastructure, multiple stakeholder networks and transdisciplinary model.

- The scope of evidence-informed policy in health sector depends on the best available research evidence to leverage the impact of the action plan by engaging the different levels of decision-makers (central level, local level) and collaborative partners.

- In the resource-constrained settings of lower and middle income countries (LMIC), researchers are able to promote the utilisation of policy-linked research findings through strengthening of scientifically sound and ethically competent research works from the outset. Besides, it is critical to choose the health priorities, the appropriate study context and collaborative approaches.

- The quality of deliverables as an input for evidence-informed policy depends on the capacity of researchers at every stage of research and the stringent assessment of funding agencies by filtering low quality proposals.

- The Special Programme for Research and Training in Tropical Diseases at the World Health Organization (WHO/TDR) funded implementation research (small grant) on multiple helminth infections in flooded rural areas in collaboration with Township Health Department highlighted the necessity of extended scope of evidence-informed health policy in form of rural development policy to mitigate the targeted health problem [1].

- The intervention study (implementation research) in controlling dengue vector breeding sites in peri-urban areas [2] funded by WHO/TDR and IDRC pointed out the involvement of multiple stakeholder networks (administrative authorities, education sector, municipal authorities for urban water supply and refuse disposal) apart from community members. Notably, the scope and impact of evidence-informed health policy needs to cover multiple sectors such as intensification of preventive guidelines in urban wards and schools to control dengue vector breeding sites and enhancing urban continuous water supply policy and regular refuse collection system and policy of municipal authorities.

- The operational research study on Japanese Encephalitis confined to secondary data from program records and a survey database of health service provider perceptions. This research was conducted through the Structured Operational Research and Training Initiative (SORT IT), a global partnership led by WHO/TDR. The training program, within which this paper was developed, was funded by the Department for International Development (DFID), London, UK. Salient findings that includes the necessity to take into account of pig vaccination to be carried out in collaboration with the veterinarian sector clearly outlines the encroachment of evidence-based health policy for one health intervention guidelines and policy.

References 1. Han, K. T., Wai, K. T., Aye, K. H. et.al (2019). Emerging neglected helminthiasis and determinants of multiple helminth infections in flood-prone township in Myanmar. *Tropical medicine and Health*, 47, 1. <https://doi.org/10.1186/s41182-018-0133-6>
2. Wai, K. T., Htun, P. T., Oo, T. et. al (2012). Community-centred eco-bio-social approach to control dengue vectors: an intervention study from Myanmar. *Pathogens and global health*, 106(8), 461468. <https://doi.org/10.1179/2047773212Y.0000000057>
3. Win, A.Y.N., Wai, K.T., Harries, A.D. et al. The burden of Japanese encephalitis, the catch-up vaccination campaign, and health service providers' perceptions in Myanmar: 2012–2017. *Trop Med Health* 48, 13 (2020)). <https://doi.org/10.1186/s41182-020-00200-3>

HIFA profile: Khin Thet Wai is a former Director at the Department of Medical Research, Myanmar. She is a medical doctor and holds the Master's degree in Public Health from Institute of Medicine, Yangon and has a second Master's degree conferred by the Institute for Population and Social Research, Mahidol University, Thailand. She is a dedicated public

health researcher specializing Epidemiology and Health Policy and Systems Research.
https://www.hifa.org/support/members/khin-thet_khinthewaidmr_AT_gmail.com

[hifa] Communicating health research (7) Role of local evidence in policy and practice

Sender: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

Date: Wed, 17 Aug 2022 13:08:24 +0000

From: Neil Pakenham-Walsh <neil.pakenham-walsh@ghi-net.org>

To: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

Role of Local Evidence in Transferring Evidence-Based Interventions to Low- and Middle-Income Country Settings: Application to Global Cancer Prevention and Control.

(with thanks to Irina Ibraghimova and LRC Network)

'What local, contextual evidence is needed when transferring and adapting an intervention or strategy to a specific LMIC setting?' This paper aims to answer this question with regards to cancer prevention and control. Citation, abstract and a comment from me below.

CITATION: JCO Glob Oncol. 2022 Aug;8:e2200054. doi: 10.1200/GO.22.00054. Role of Local Evidence in Transferring Evidence-Based Interventions to Low- and Middle-Income Country Settings: Application to Global Cancer Prevention and Control. Parascandola M(1), Neta G(2), Salloum RG(3), Shelley D(4), Rositch AF(5).

PURPOSE: Although the global burden of cancer falls increasingly on low- and middle-income countries (LMICs), much of the evidence for cancer prevention and control comes from high-income countries and may not be directly applicable to LMIC settings. In this paper, we focus on the following question: When the majority of the evidence supporting an evidence-based intervention or implementation strategy comes from high-income countries, what local, contextual evidence is needed when transferring and adapting an intervention or strategy to a specific LMIC setting? **METHODS:** We draw on an existing framework (the Population, Intervention, Environment, Transfer-T process model) for assessing transferability of interventions between distinct settings and apply the model to two case studies as learning examples involving implementation of tobacco use treatment guidelines and self sampling for human papillomavirus DNA in cervical cancer screening. **RESULTS:** These two case studies illustrate how researchers, policymakers, practitioners, and consumers may approach the need for local evidence from different perspectives and with different priorities. As uses and expectations around local evidence may be different for different groups, aligning these priorities through multistakeholder engagement in which all parties participate in defining the questions and cocreating the solutions is critical, along with promoting standardized reporting of contextual factors. **CONCLUSION:** Local, contextual evidence can be important for both researchers and practitioners, and its absence may hinder translation of research and implementation efforts across different settings. However, it is essential for researchers, practitioners, and other stakeholders to be able to clearly articulate the type of data needed and why it is important. In particular, where resources are limited, evidence generation should be prioritized to address real needs and gaps in knowledge.

COMMENT (NPW): In the full text, the authors 'offer some additional tools and best practices for researchers to consider', drawing on the broader literature and their own

experience: '1. Engage stakeholders: Whole system stakeholders should be involved from the start in identifying priorities, framing research questions and participating in study design decisions to both build commitment and to ensure that relevant data needs are addressed. Stakeholder groups should include implementers as well as policymakers. 2. Apply conceptual frameworks: Conceptual frameworks and theories, such as the Consolidated Framework for Implementation Research... 3. Use hybrid study designs when feasible: Study designs should consider and include process, context, and outcome measures aligned with stakeholder priorities... 4. Promote standardized context reporting: Publications often lack information about context. Standardized reporting of the context in which an intervention was tested would allow for greater understanding of the role of local factors and transferability... 5. Embed capacity building: To account for local context in the design, conduct, and interpretation of research studies, it is essential to have participation of skilled local researchers...'

I invite comments on any of the above.

Also, it seems to me that the challenge of systematically merging global with local evidence is huge and highly complex. Do you have practical experience of such synthesis? What are the most promising approaches?

Best wishes, Neil

Neil Pakenham-Walsh, Global Coordinator HIFA, www.hifa.org neil@hifa.org Working in official relations with WHO

[hifa] Communicating health research (8) Engaging users of health research

Date: Fri, 19 Aug 2022 09:08:15 +0000

From: "Ellos Lodzeni, Malawi" <HIFA@hifaforums.org>

Any Research which has to be relevant must involve and engage the users through their Associations or organizations. This will ensure that all relevant factors have been taken into account and there is acceptance and cooperation from the users. User co-creation is very critical. Any deviation will produce sub standard results. Users are experts in their own right due to personal experiences.

Ellos Lodzeni Policy, Governance and Partnership Advisor-Patient and community welfare Foundation of Malawi-PAWEM IAPO Board member BettereHealth Advisory Board member

HIFA profile: Ellos Lodzeni is patron and trustee at the Patient and Community Welfare Foundation in Malawi. Professional interests: Health governance and patient safety advocate. lodzene AT yahoo.co.uk

[hifa] Communicating health research (8) Role of local evidence in policy and practice (2)

Sender: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

Date: Sat, 20 Aug 2022 13:08:48 +0000
From: "Oluwatosin Caleb Adeyemi, Nigeria" unltd51@gmail.com

Hi Neil,

I have some experience with this in Contraceptive Programming led by youth. In about six years of research and policy work targeted at improving youth access to contraceptives, stakeholders and youth identified that integrating contraceptive access with usual care was most effective where youth-friendliness was instituted. However, programme after programme attempted to implement a 'Youth-friendly clinic' separated from standard care. IYAAP in Nigeria continues to provide this evidence to INGOs, but most funders appear to be set on implementing evidence from HICs to LMICs. You can follow our work and literature publications on the PRB website- <https://www.prb.org/projects/empowering-evidence-driven-advocacy/>

Adeyemi, O.C., Lecturer, Department of Clinical Pharmacy and Biopharmacy, Faculty of Pharmacy, University of Lagos Nigeria

HIFA Profile: Oluwatosin Caleb Adeyemi is an Academic Lecturer at the Faculty of Pharmacy, University of Lagos in Nigeria. Professional interests: Drug Information Centre, Outcomes research, Antibiotics stewardship. Email: unltd51 AT gmail.com

[hifa] Communicating health research (9) Introducing new HIFA thematic discussion: Effective communication of health research to policymakers

Sender: HIFA - Healthcare Information For All <HIFA@hifaforums.org>
Date: Thu, 01 Sep 2022 14:09:57 +0000
From: Neil Pakenham-Walsh <neil.pakenham-walsh@ghi-net.org>

Welcome to those who have joined HIFA in the past few days. I'd like to introduce you all to our new HIFA thematic discussion, Effective communication of health research to policymakers, supported by TDR, the Special Programme for Research and Training in Tropical Diseases at WHO. The discussion starts officially on 5 September and runs for five weeks.

What are the most impactful methods for researchers to communicate their research to policymakers so that the research is seen and applied? How can research be better packaged and communicated, including for example the role of policy briefs as well as academic journals, videos, social media, infographics, newsletters, use of video, and newsletter content?

In this discussion we are looking primarily from the perspective of researchers, whose motivation is typically to communicate their research effectively. At the same time, researchers need to know what policy-makers want and require, and they need to have an understanding of how their research fits in with the broader perspective of evidence-informed policy.

The HIFA working group on research communication [<https://www.hifa.org/projects/new-effective-communication-health-research-policymakers>] offers five questions to guide the

discussion. We shall look at each question in turn, week by week. We invite you to comment on any of the questions at any time, and indeed you are welcome to contribute on any aspect of research communication. The five questions are:

1. What do we mean by 'Effective communication of health research to policymakers?' How do we measure it? 2. What are the different approaches to communicating research (eg academic journals, policy briefs, interaction with policymakers, press releases, social media, infographics, use of video)? What is your experience with these approaches? What works and what doesn't? 3. What is the role of researchers in research communication, beyond publication of their paper? What is the role of other stakeholders (eg communication professionals, editors, media, public health professionals and critical thinkers) 4. What are the needs and preferences of policymakers? 5. What can be done to better support researchers in the communication of health research?

In my next message I'll write a few words to introduce question 1.

As usual, this discussion will take place here on the HIFA forum alongside any spontaneous discussions that may occur.

To send a message to HIFA forum, simply send email to hifa@hifaforums.org and your message will be approved and distributed to all our members.

Here is a reminder of How to use the HIFA forums: <https://www.hifa.org/forums/how-use-hifa-forums>

Do you speak French, Portuguese or Spanish? You may like to also join our HIFA forums in these languages: Join HIFA-French: <http://www.hifa.org/join/rejoignez-hifa-francais> Join HIFA-Portuguese: <http://www.hifa.org/join/junte-se-ao-hifa-portuguese> Join HIFA-Spanish: <http://www.hifa.org/join/unase-hifa-espanol>

Best wishes, Neil

Joint Coordinator, HIFA Communicating health research <https://www.hifa.org/projects/new-effective-communication-health-research-policymakers>

Let's build a future where every person has access to reliable healthcare information and is protected from misinformation - Join HIFA: www.hifa.org

HIFA profile: Neil Pakenham-Walsh is coordinator of the HIFA global health movement (Healthcare Information For All - www.hifa.org), a global community with more than 20,000 members in 180 countries, interacting on six global forums in four languages in collaboration with WHO. HIFA brings stakeholders together to accelerate progress towards universal access to reliable healthcare information. Twitter: @hifa_org neil@hifa.org

[hifa] Communicating health research (10) Q1. What do we mean by Effective communication of health research to policymakers? How do we measure it?

Date: Fri, 02 Sep 2022 13:09:12 +0000

From: Neil Pakenham-Walsh <neil.pakenham-walsh@ghi-net.org>

Welcome to our thematic discussion on Effective communication of health research to policymakers, supported by TDR.

Question 1 of our discussion is: "What do we mean by Effective communication of health research to policymakers? How do we measure it?"

I'll offer a few reflections based on the meetings of the HIFA working group for this project.

The first thing to note is that there is no absolute definition of 'effective', 'communication', 'health research' or 'policymakers'. So we are not seeking an absolute definition of 'Effective communication of health research to policymakers'.

Instead we want to start with this question so that we all develop a collective understanding of the scope and purpose of this discussion.

The HIFA working group offers the following points for discussion and exploration:

1. The main aim of this discussion is to identify the most impactful methods for researchers to communicate their research to policymakers. For example, how can research be better packaged and communicated, including for example the role of policy briefs as well as academic journals, videos, social media, infographics, newsletters, use of video, and newsletter content?
2. We are looking primarily from the perspective of researchers. From their point of view, this means that their research is considered by policymakers where appropriate. This implies that it is visible, accessible, clear and readily understandable, that it is seen by policymakers as relevant and reliable, and that it is in a format that meets the perceived needs of policymakers.
3. 'Health research', for the purposes of this discussion, is inclusive. We invite you to discuss the communication of primary research (eg randomised controlled trials, observational studies, implementation research, operational research), secondary research (eg systematic reviews), and tertiary research (where cumulative evidence is operationalised in, for example, the form of policy briefs and clinical guidelines). We also invite you to consider research at all levels: global, national, local.
4. The term 'policymakers' includes not only those who make health Policy decisions (big "P") at national or subnational levels, but also those who make policy decisions (little "p") in programme implementation.
5. The question 'How do we measure it?' invites us to assess the effectiveness of different methods of communication. What indicators can we use to measure the effectiveness of communication?

Research communication is a highly complex issue that is integrated in a wider sphere of policymaking, where many factors influence politicians other than evidence and the way evidence is communicated. I'm sure we'll touch on these issues but as we proceed I invite you to keep a focus on what researchers can do to increase their impact.

Looking forward to discuss any of the above with you further. Please send your comments to: hifa@hifaforums.org

Best wishes, Neil

Joint Coordinator, HIFA Communicating health research <https://www.hifa.org/projects/new-effective-communication-health-research-policymakers>

Let's build a future where every person has access to reliable healthcare information and is protected from misinformation - Join HIFA: www.hifa.org

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**[hifa] Communicating health research (11) Q1. What do we mean by
~Effective communication of health research to
policymakers? How do we measure it? (1)**

Sender: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

Date: Sun, 04 Sep 2022 07:09:03 +0000

From: "Chris Zielinski, UK" <chris@chriszielinski.com>

Thanks for introducing this topic, Neil. This is to offer an opinion on an indirect way of communicating health research to policy makers which is often underestimated or ignored.

On one hand we have researchers and on the other policy makers: Researchers have been academically prepared and trained by experience and example to write up their work according to a standard format known to everybody. The research is then submitted to a journal for publication, where it is usually reviewed by another researcher or academic, and then - if it clears all the hurdles - published in what is typically a low-circulation journal only read by other academics and researchers working in the field. Citations in later publications give it some continued life. If the author is lucky, the paper will be collected up into a systematic review, or form part of a policy paper extracted from a collection of papers published on a particular topic. Policy makers (in the expanded definition adopted here) range from complete politicians who may have no scientific background or academic competence, to subject specialists who are themselves former researchers and academics. Most policy makers lie between these two extremes. In most countries, the former instruct the latter - health policy is usually set at senior levels, typically (but not always) in a ministry of health. It is nice to imagine that health policy makers spend their Sundays reading academic biomedical journals - or even the policy briefs laboriously prepared for them by intermediaries - nice, but completely unlikely. Instead, they kick on the TV, grab the newspaper, listen to a podcast or read a tweet. To them, whatever health issue is making the headlines is clearly the most important one, especially in democratic societies where no elected official wants angry or disappointed voters. Only after consuming the evening news do they reluctantly begin to peruse their policy briefs.

So if new health research is to be taken up by policy makers, there needs to be a strong and conscious effort for the research community to interact with the media. Let's remember that the aim is not just R2P - research to policy but R2P2P - research to policy, and then from policy to practice. (The latter is actually the point of the whole exercise.) The application of policy implies creating community understanding and awareness, and this will never come purely from research published in academic journals. We need joint efforts, collaborations and partnerships between research and media. HIFA could consider what mechanisms are possible for such interaction, and advocate for establishing them.

Chris Zielinski chris@chriszielinski.com Blogs: <http://ziggytheblue.wordpress.com> and <http://ziggytheblue.tumblr.com> Research publications: <http://www.researchgate.net>

HIFA profile: Chris Zielinski: As a Visiting Fellow in the Centre for Global Health, Chris leads the Partnerships in Health Information (Phi) programme at the University of Winchester. Formerly an NGO, Phi supports knowledge development and brokers healthcare information exchanges of all kinds. Chris has held senior positions in publishing and knowledge management with WHO in Brazzaville, Geneva, Cairo and New Delhi, with FAO in Rome, ILO in Geneva, and UNIDO in Vienna. Chris also spent three years in London as Chief Executive of the Authors Licensing and Collecting Society. He was the founder of the ExtraMED project (Third World biomedical journals on CD-ROM), and managed the Gates Foundation-supported Health Information Resource Centres project. He served on WHO's Ethical Review Committee, and was an originator of the African Health Observatory. Chris has been a director of the World Association of Medical Editors, UK Copyright Licensing Agency, Educational Recording Agency, and International Association of Audiovisual Writers and Directors. He has served on the boards of several NGOs and ethics groupings (information and computer ethics and bioethics). UK-based, he is also building houses in Zambia. Email- [chris AT chriszielinski.com](mailto:chris@chriszielinski.com) His publications are at www.ResearchGate.net and <https://winchester.academia.edu/ChrisZielinski/> and his blogs are <http://ziggytheblue.wordpress.com> and <https://www.tumblr.com/blog/ziggytheblue>

[hifa] Communicating health research (12) Q1. What do we mean by ~effective communication? (3) Q2. What are the different approaches to communicating research?

Date: Mon, 05 Sep 2022 06:09:30 +0000

From: "Joseph Ana, Nigeria" <HIFA@hifaforums.org>

To: HIFA - Healthcare Information For All <HIFA@hifaforums.org>,

I join Chris [<https://www.hifa.org/dgroups-rss/communicating-health-research-11-q1-what-do-we-mean-%CB%9Ceffective-communication-health>] to thank Neil for his introduction to this discussion [<https://www.hifa.org/dgroups-rss/communicating-health-research-10-q1-what-do-we-mean-%CB%9Ceffective-communication-health>]. I also align with the content of Chris's contribution. But it is important to note that the traditional pathway of research to publication and then policy and maybe practice has been undergoing an evolution since about 1990 / 1991 when the internet became available to the civilian world. Since then, every level of the pathway has been impacted by the evolution (some say revolution) in research and publication.

Today, researchers can pre-print their work before or whilst they submit their manuscript to a journal of choice, thereby side-stepping traditional peer review scrutiny. The result is that before the peer reviewed and 'approved' research report is published, policy makers already have seen and / or read the unscrutinised version. Therefore, increasingly, policy is informed by the un-peer reviewed pre print and implementation already on the way before the 'approved' peer reviewed version is published. Retractions have been known to happen, too late before harm has happened in some instances. It can also have serious consequences for all the stakeholders (end user / community, implementer, policy makers, researcher, etc), as was frequently the case when the covid-19 pandemic was at its peak in 2020, for example the mis-information and dis-information about the pandemic, including the correct treatment, the vaccines and in some instances there are doubters who question whether there is a pandemic at all, even with all the incredible level of mortality and socio-economic damage, everywhere. This relatively 'new' world of research to publication to policy makers and practice needs to take account of the effects of such unregulated open access.

One other influencer or confounder of the current research to publishing to policy to practice pathway is the blog!. In the beginning, about 1994, again with the availability of the internet, what has now more or less settled with the title, 'Blog' had several monikers: 'online diary', 'personal web page', 'web blog', etc, with the common denominator, that they represent personal opinion which is not peer reviewed. The initiated (researcher, author, journals, subject experts, etc) know that blogs are personal opinion, without peer review but the uninitiated politician-policy maker does not know that. Today, blogging in addition to being largely for fun, is increasingly being used to 'report' some research finding or observations, by-passing the tradition peer review scrutiny, just like the pre-print.

So, in creating necessary links and cooperation for communicating research to inform policy makers, HIFA can highlight and educate policy makers to be aware of these new methods by which some researchers by-pass traditional peer scrutiny, which may impact negatively on implementation of policy derived from them, when eventually the approved peer reviewed research result is published. Preprints and Blogs apart from the labels, need to carry some Alert sign, especially for the uninitiated politician-policy maker, so that they and other readers including initiated policy makers and the media know that these are the personal opinion of the researcher. And that the report may change after peer review and therefore should not be the basis for making Policy. The same awareness should be applied if secondary (systematic review, meta analysis) or tertiary level (guidelines and policy briefs) researches reports are being used / prepared: that is, information from pre prints and blogs, should be marked as such, so that users should know that the information may change later.

Joseph Ana

Prof Joseph Ana Lead Senior Fellow/ medicalconsultant. Center for Clinical Governance Research & Patient Safety (ACCGR&PS) P: +234 (0) 8063600642 E: info@hri-global.org 8 Amaku Street, State Housing & 20 Eta Agbor Road, Calabar, Nigeria. www.hri-global.org

HIFA profile: Joseph Ana is the Lead Consultant and Trainer at the Africa Centre for Clinical Governance Research and Patient Safety in Calabar, Nigeria, established by HRI Global (former HRIWA). In 2015 he won the NMA Award of Excellence for establishing 12-Pillar Clinical Governance, Quality and Safety initiative in Nigeria. He has been the pioneer Chairman of the Nigerian Medical Association (NMA) National Committee on Clinical Governance and Research since 2012. He is also Chairman of the Quality & Performance

subcommittee of the Technical Working Group for the implementation of the Nigeria Health Act. He is a pioneer Trustee-Director of the NMF (Nigerian Medical Forum) which took the BMJ to West Africa in 1995. He is particularly interested in strengthening health systems for quality and safety in LMICs. He has written Five books on the 12-Pillar Clinical Governance for LMICs, including a TOOLS for Implementation. He established the Department of Clinical Governance, Servicom & e-health in the Cross River State Ministry of Health, Nigeria in 2007. Website: www.hri-global.org. Joseph is a member of the HIFA Steering Group and the HIFA working group on Community Health Workers. Website: www.hri-global.com Joseph is a member of the HIFA Steering Group and the HIFA working group on Community Health Workers. <http://www.hifa.org/support/members/joseph-0> <http://www.hifa.org/people/steering-group> Email: info@hri-global.org and [jneana AT yahoo.co.uk](mailto:jneana@yahoo.co.uk)

[hifa] Communicating health research (13) Q2. What are the different approaches to communicating research? (2) Academic journals

Sender: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

Date: Mon, 05 Sep 2022 06:09:46 +0000

From: "Irina Ibraghimova, Croatia" <ibra@zadar.net>

Dear all,

I would like to share some thoughts as an editor of a journal that 'is oriented to serve those at the policy and governance levels within government, healthcare systems or healthcare organizations'.

- In our author guidelines we advise the authors besides 'Research implications' also to identify 'Practical implications' and 'Social implications' and include those sub-headings in the structured abstract of an article. - We also recommend to add a 'plain language summary'.
- Each journal issue provides a review of included articles, which concludes what healthcare practitioners, educators, and managers can learn from that issue and apply to their own areas of practice. Those reviews are in open access. - As an editor I am constantly working to attract authors and peer-reviewers not only from academia, but from other sectors as well.

I have also found recently specific recommendations for authors how to make their research known to policy-makers. Such guides look to me promising if they are country- and subject-specific.

Helpful hints for sharing research with people in policy (the UK)

<https://www.emeraldgrouppublishing.com/opinion-and-blog/helpful-hints-sharing-research-people-policy>

Connecting research with policy: Guide to writing for policy-makers (Australia, National Environmental Science Program) <https://www.nespthreatenedspecies.edu.au/publications-and-tools/connecting-research-with-policy-guide-to-writing-for-policy-makers>

Research Engagement with Policy Makers: a practical guide to writing policy briefs (the UK, NIHR Policy Research Unit in Behavioural Science) <https://osf.io/m25qp>

Irina Ibragimova, PhD Co-editor, International Journal for Health Governance
<https://www.emeraldgroupublishing.com/journal/ijhg>

Call for papers: Special Issue 'Models of Digital Health Governance: Best Practices, Lessons Learned, and Future Priorities' <https://www.emeraldgroupublishing.com/calls-for-papers/models-digital-health-governance-best-practices-lessons-learned-and-future> HIFA profile: Irina Ibragimova is an independent consultant with a PhD. in library sciences and more than 20 years' international experience in ICT for health projects. She now serves as a Co-editor for the International Journal of Health Governance (Emerald Publishing). Professional interests: Information and health literacy, evidence-based practice, science communication and medical journals editing. <http://www.healthconnect-intl.org/> She is a HIFA country representative for Croatia: <https://www.hifa.org/support/members/irina>

[hifa] Communicating health research (14) Q2. What are the different approaches to communicating research? (3) Social media

Sender: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

Date: Mon, 05 Sep 2022 07:09:06 +0000

From: "Richard Fitton, UK" <richardpeterfitton7@gmail.com>

Researchers may also need to consider communicating with "influencers" as the UN did using the South Korea K-pop group BTS last year General Assembly. BTS at UN General Assembly BTS ENCYCLOPEEDIA <<https://btsencyclopedia.com/bts-at-un-general-assembly/#:~:text=September%202021%2C%20was%20a%20big%20day%20where,Diplomatic%20passport%20provides%20facilitate%20the%20holder%20international%20travel.>>>

K-pop - Wikipedia <<https://en.wikipedia.org/wiki/K-pop>>

---- Influencers: The Modern Entrepreneur | National Geographic Society [note from moderator NPW: the text below is reproduced from the website]

<https://education.nationalgeographic.org/resource/influencers-modern-entrepreneur>

Influencers: The Modern Entrepreneur

“Though there are some key differences between them, today’s social media influencers have much in common with traditional entrepreneurs when it comes to driving the economy.

“Social Media Influencer

“Some social media influencers use their platform to earn money by partnering with companies to advertise services or products, like lipsticks, to their followers. Like traditional entrepreneurs, they jump-start new businesses.

"Social media influencers are individuals who utilize social media platforms to build their own personal brand or influence their followers to act (including buying products, supporting a brand, or vacationing in a certain location). They can share anything from clothes and beauty products to make-at-home slime with their followers. While it might seem like frivolous fun, some influencers are making significant amounts of money from their connection to their fans, making them the modern entrepreneur. While not every social media

influencer is an entrepreneur, the ones who have started their own businesses from the brand they created online have much in common with traditional entrepreneurs when it comes to driving the economy.

"Are Influencers Entrepreneurs?"

Entrepreneurs are people who organize, manage, and take on the risks of a business. They often start a new business in response to a perceived need for a good or service. An influencer, on the other hand, is someone who has the power to affect or change people and their behavior through social media - often to get them to buy something. Influencers who start their own business certainly fall under the first part of the definition of entrepreneur, as they are managing their business and taking on risk. But are they fulfilling a need? Many say yes: companies can target highly specific groups of people through employing an influencer - groups that might be missed by traditional advertising. And because influencers form a more personal relationship with their followers, the followers are seemingly more likely to buy what the influencer suggests.

"Getting Started"

One area where entrepreneurs and influencers differ the most is in their processes of starting a business. Nearly all traditional businesses have startup costs, which go toward buying materials to create goods, equipment to manufacture items or provide a service, or office space. But entrepreneurs do not always have to put their own savings into a business. They can get venture capital, or money to start or grow a business, from outside investors, often in exchange for part ownership of the company. Influencers, on the other hand, have fewer startup costs, though it can vary by the influencer's specialty. Beauty and fashion influencers may have to get new clothes, buy the latest makeup, and hire a professional photographer to start out, but others only need their social media accounts and a smartphone. Additionally, many of the costs that apply to starting a business do not apply to influencers, like renting office space, as many work from home. ----

HIFA profile: Richard Fitton is a retired family doctor - GP, British Medical Association. Professional interests: Health literacy, patient partnership of trust and implementation of healthcare with professionals, family and public involvement in the prevention of modern lifestyle diseases, patients using access to professional records to overcome confidentiality barriers to care, patients as part of the policing of the use of their patient data. Email address: richardpeterfitton7 AT gmail.com

[hifa] Communicating health research (15) Q4. What are the needs and preferences of policymakers? (1) What can we learn from the COVID-19 pandemic?

Date: Mon, 05 Sep 2022 10:09:49 +0000

From: "Wilber Sabiiti, UK" <HIFA@hifaforums.org>

Dear Neil

Is there anything that we can learn from COVID-19 response? The response was generally led by politicians (non-scientists in general) at national level with support from scientists in the form of advisory committees. Did the politicians do a good job in communicating the

messages to the public? Did the scientists do a good job in communicating evidence to the political leaders? Were there some good communication practices that we could borrow a leaf from? COVID-19 makes a perfect example because it set a scenario where there was hunger for evidence to support policy decisions almost daily.

COVID-19 pandemic, particularly between March 2020 and March 2021 is a perfect example of a scenario in which policy makers and decision makers expressed hunger and readiness to receive research evidence to inform their course of action. Consequently, the channels of communication between researchers (scientists) and policy makers were established and open 24-7 for evidence to stream in and get used as quickly as possible. We often heard politicians, say, 'we are following science for every decision taken'. There was a direct line of communication between scientists (national scientific advisory committees) and policy makers and often media played the 3rd partly role of informing the public of decisions taken. The advisory committees served as research evidence translators before passing it on to policy makers for action. One take home from this is that readiness to receive information by the recipient (policy maker) from the communicator (researcher) is a critical for effective communication. COVID-19 was a unique situation, a public health emergency of a disease with little known about and inevitably instilled fear in everyone including policy makers, and perhaps that's why we saw the hunger for evidence. How then do researchers maintain such a direct channel of communication in non-emergency periods? Will it be the art of communicating the information from their research? Will it be identifying and placing information in spaces where policy makers are more likely to interact with it? Will it be communicating in the first instance why their research is worth the policymaker's attention in order to get their attention? It seems humans are more likely to pay attention to a message if they believe there is something valuable to them. By answering these questions, we may produce one of the effective ways to communicate health research to policy- and decision-makers.

Best regards Wilber

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HIFA profile: Wilber Sabiiti is Principal Research fellow in Medicine at the Division of Infection and Global Health, School of Medicine, University of St Andrews, Scotland.
<https://www.hifa.org/support/members/wilber>

**[hifa] Communicating health research (16) Q1. What do we mean by
~Effective communication of health research? (4) Systematic
review of communication strategies**

Sender: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

Date: Tue, 06 Sep 2022 08:09:25 +0000

From: Neil Pakenham-Walsh <neil.pakenham-walsh@ghi-net.org>

We have noted that 'the main aim of this discussion is to identify the most impactful methods for researchers to communicate their research to policymakers. How can research be better

packaged and communicated, including for example the role of policy briefs as well as academic journals, videos, social media, infographics, newsletters, use of video, and newsletter content?'

An initial thought from me is that (almost) all research should at least be available in a peer-reviewed journal, and the paper should ideally be freely accessible to all. ('Tertiary research' is an exception, as this is typically defined in terms of policy briefs and clinical guidelines. Even then, tertiary research should (almost) always be peer-reviewed, and indeed the process for WHO guidelines, for example, is more rigorous than standard peer review.)

As Chris Zielinski has said, policymakers are not likely to 'spend their Sundays reading academic biomedical journals' [<https://www.hifa.org/dgroups-rss/communicating-health-research-11-q1-what-do-we-mean-%CB%9Ceffective-communication-health>] The question then becomes: how can the findings of a paper be made more accessible, and more useful, to policymakers? A more digestible format is the policy brief. Chris suspects policymakers are not likely to read these either. So do some of us take it for granted that policy briefs have an impact?

Two members of our HIFA Communicating health research group - Rob Terry (TDR/WHO) and Tanja Kuchenmuller (Evidence to Policy and Impact/WHO) published a paper on this subject at the end of last year:

CITATION: Assessing the impact of knowledge communication and dissemination strategies targeted at health policy-makers and managers: an overview of systematic reviews. Evelina Chapman et al. Health Research Policy and Systems volume 19, Article number: 140 (2021) <https://health-policy-systems.biomedcentral.com/articles/10.1186/s12961-021-00780-4>

They concluded: 'There is limited evidence regarding the effectiveness of interventions targeting health managers and policy-makers, as well as the mechanisms required for achieving impact.'

ABSTRACT Background: The use of research evidence as an input for health decision-making is a need for most health systems. There are a number of approaches for promoting evidence use at different levels of the health system, but knowledge of their effectiveness is still scarce. The objective of this overview was to evaluate the effectiveness of knowledge communication and dissemination interventions, strategies or approaches targeting policy-makers and health managers.

Methods: This overview of systematic reviews used systematic review methods and was conducted according to a predefined and published protocol. A comprehensive electronic search of 13 databases and a manual search in four websites were conducted. Both published and unpublished reviews in English, Spanish or Portuguese were included. A narrative synthesis was undertaken, and effectiveness statements were developed, informed by the evidence identified.

Results: We included 27 systematic reviews. Three studies included only a communication strategy, while eight only included dissemination strategies, and the remaining 16 included both. None of the selected reviews provided 'sufficient evidence' for any of the strategies, while four provided some evidence for three communication and four dissemination strategies. Regarding communication strategies, the use of tailored and targeted messages

seemed to successfully lead to changes in the decision-making practices of the target audience. Regarding dissemination strategies, interventions that aimed at improving only the reach of evidence did not have an impact on its use in decisions, while interventions aimed at enhancing users' ability to use and apply evidence had a positive effect on decision-making processes. Multifaceted dissemination strategies also demonstrated the potential for changing knowledge about evidence but not its implementation in decision-making.

Conclusions: There is limited evidence regarding the effectiveness of interventions targeting health managers and policy-makers, as well as the mechanisms required for achieving impact. More studies are needed that are informed by theoretical frameworks or specific tools and using robust methods, standardized outcome measures and clear descriptions of the interventions. We found that passive communication increased access to evidence but had no effect on uptake. Some evidence indicated that the use of targeted messages, knowledge-brokering and user training was effective in promoting evidence use by managers and policy-makers.

The paper raises lots of interesting points and questions and I invite you to comment. Email hifa@hifaforums.org

Neil Pakenham-Walsh, Global Coordinator HIFA, www.hifa.org neil@hifa.org Working in official relations with WHO

[hifa] Communicating health research (17) Check out these resources around communicating effectively with policy makers

Date: Tue, 06 Sep 2022 10:09:01 +0000

From: "Chikezie Nwankwor, Nigeria" <chikezie.nwankwor@unn.edu.ng>

https://www.bennettinstitute.cam.ac.uk/publications/effective_communications/ [1]

<https://www.frontiersin.org/articles/10.3389/frma.2021.654191/full> [2]

HIFA profile: Chikezie Nwankwor is a Lecturer at the University of Nigeria, Enugu Campus, in Nigeria. Professional interests: Networking & Mentoring. Email address: chikezie.nwankwor@unn.edu.ng

[*Note from NPW, moderator: Thank you Chikezie. For the benefit of those who may not have immediate web access, here are brief extracts:

[1] Communications: How to communicate effectively to policy makers How to communicate effectively to policy makers - A guide for Academics

Introduction: The difficulty of communicating complex knowledge to policy makers has generated a substantial literature. Ironically despite this wealth of literature the evidence on what works in communicating scientific findings is mixed[1] although there is a growing consensus that the starting point should always be your audience(s). This may seem obvious but understanding how policy makers' process evidence and the context in which they operate is key [2]. Policy makers often have too much information to digest so will use heuristics to filter information and make decisions quickly. So ask yourself how can I help policy makers process what it is I want to say? What should my communication strategy be? What format

should I communicate in and when should I communicate? Finding the right time to communicate can also effect whether you have a receptive audience or not...

Increase your visibility...

The way you present or frame your evidence can have a fundamental effect on how it is understood and whether it's taken up by policy makers... Using stories or tailoring your message can help with framing your evidence...

[2] Bringing Policymakers to Science Through Communication: A Perspective From Latin America

This perspective article aims at providing some recommendations to build bridges between science and decision-making parties through communication, by exploring how Latin American diplomats and policymakers engage with scientific knowledge...]

[hifa] Communicating health research (18) Systematic review of communication strategies (2) Policy briefs

Sender: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

Date: Tue, 06 Sep 2022 14:09:50 +0000

From: "Joseph Ana, Nigeria" <HIFA@hifaforums.org>

Neil, wrote, 'The question then becomes: how can the findings of a paper be made more accessible, and more useful, to policymakers?' [<https://www.hifa.org/dgroups-rss/communicating-health-research-16-q1-what-do-we-mean-%CB%9Ceffective-communication-health>]

The answer lies in recognizing significant characteristics of a policy brief as one tool aimed to increase the possibility of transferring research to policy and then practice. By nature, policy briefs are different from academic reports. They are meant to be presented to usually, a non academic chief executive / policy maker to aid policy making that is based on evidence, informal, brief, clear and engaging in a positive tone. To be effective and persuasive, it should not be dominated by technical and specialist jargons. The chief executive should not have to browse google to search for meaning of terminologies in the brief.

Policy briefs are generally valued by policy-makers, so long as they meet the criteria listed above. In addition, the writer /author of the brief must bear the policy maker and his needs in mind. It should easy to read because decision-making is already a complex process, with other conflicting interests, ideas and values in the mix, to take account of. Furthermore, prior established credibility of the writer/author and the research source are equally important. In our experience, a policy brief should not be more than three pages which the often busy chief executive can spend between thirty minutes to one hour to read, leisurely, understand, and act on.

Joseph Ana.

Prof Joseph Ana Lead Senior Fellow/ medical consultant. Center for Clinical Governance Research & Patient Safety (ACCGR&PS) P: +234 (0) 8063600642 E: info@hri-global.org 8 Amaku Street, State Housing & 20 Eta Agbor Road, Calabar, Nigeria. www.hri-global.org

HIFA profile: Joseph Ana is the Lead Consultant and Trainer at the Africa Centre for Clinical Governance Research and Patient Safety in Calabar, Nigeria, established by HRI Global (former HRIWA). In 2015 he won the NMA Award of Excellence for establishing 12-Pillar Clinical Governance, Quality and Safety initiative in Nigeria. He has been the pioneer Chairman of the Nigerian Medical Association (NMA) National Committee on Clinical Governance and Research since 2012. He is also Chairman of the Quality & Performance subcommittee of the Technical Working Group for the implementation of the Nigeria Health Act. He is a pioneer Trustee-Director of the NMF (Nigerian Medical Forum) which took the BMJ to West Africa in 1995. He is particularly interested in strengthening health systems for quality and safety in LMICs. He has written Five books on the 12-Pillar Clinical Governance for LMICs, including a TOOLS for Implementation. He established the Department of Clinical Governance, Servicom & e-health in the Cross River State Ministry of Health, Nigeria in 2007. Website: www.hri-global.org. Joseph is a member of the HIFA Steering Group and the HIFA working group on Community Health Workers. Website: www.hri-global.com Joseph is a member of the HIFA Steering Group and the HIFA working group on Community Health Workers. <http://www.hifa.org/support/members/joseph-0> <http://www.hifa.org/people/steering-group> Email: info AT [hri-global.org](mailto:info@hri-global.org) and jneana AT [yahoo.co.uk](mailto:jneana@yahoo.co.uk)

[hifa] Communicating health research (19) Open access and research communication

Date: Tue, 06 Sep 2022 14:09:42 +0000

From: Neil Pakenham-Walsh <neil.pakenham-walsh@ghi-net.org>

Many of us would argue that open access is a critical aspect of effective communication of health research to policymakers. It promotes transparency and trust, and it allows the policymaker (and those who write policy briefs or use other methods to inform the policymaker) to interrogate the full text.

PLOS, and their flagship journal PLOS Medicine, is one of the pioneers of open access publishing. Here, PLOS leaders discuss their 'values-driven vision for change in the scholarly community': [Read online with links to blogs: bit.ly/3QeCs7G]

--- What drives us? Using a values-driven approach to initiate bold change in science communication A selection of our senior leaders discuss the importance of values in Open Science and how practicing these values generates positive impacts within the research community and society as a whole. Emily Chenette George Vousden PLOS ONE Editor-in-Chief Emily Chenette and Deputy Editor-in-Chief George Vousden discuss their roles, the history of the journal, and the creation of our new Inclusivity in Global Research policy. Ensuring fair opportunities for all authors Marcel LaFlamme PLOS Open Research Manager, Marcel LaFlamme discusses the importance of Open Science and being curious and collaborative in our approach to building solutions. Exploring the possibilities of Open Science Roheena Anand Executive Director, Global Publishing Development, Roheena Anand, discusses PLOS' aims to ensure representation and inclusion of local research communities in developing a fair and equitable open research future. Collaborating globally to build trust in science Emily Chenette Chief Publishing Officer Niamh O'Connor discusses her role in building strong teams and working together to achieve a strong vision for PLOS. Working together to lead science communication forward Sara Rouhi Sara Rouhi, Director of Strategic Partnerships, discusses her vision for inclusivity in scholarly publishing, reducing

the barriers for more authors to publish open access. Changing the landscape to make Open Access more affordable --

Best wishes, Neil

Joint Coordinator, HIFA Communicating health research <https://www.hifa.org/projects/new-effective-communication-health-research-policymakers>

Neil Pakenham-Walsh, Global Coordinator HIFA, www.hifa.org neil@hifa.org Working in official relations with WHO

[hifa] Communicating health research (20) Academic journals (2)

Nature

Sender: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

Date: Wed, 07 Sep 2022 06:09:37 +0000

From: "David Cawthorpe, Canada" <cawthord@ucalgary.ca>

Dear Neil,

All great points [<https://www.hifa.org/dgroups-rss/communicating-health-research-16-q1-what-do-we-mean-%CB%9Ceffective-communication-health>]. May I draw your attention to the following article about Nature.

The Fall of 'Nature' A once-respected journal has announced that it will be subordinating science to ideology. <https://quillette.com/2022/08/28/the-fall-of-nature/>

Best regards, David

HIFA profile: David Cawthorpe is Adjunct Assistant Professor at the University of Calgary, Canada. His professional interests include: Human Development, Developmental Psychopathology, and Delivery of low bandwidth medical education curriculum. cawthord@ucalgary.ca

[hifa] Communicating health research (21) Academic journals (3)

Miscommunication

Date: Wed, 07 Sep 2022 06:09:35 +0000

From: "David Cawthorpe, Canada" <cawthord@ucalgary.ca>

Here is a cross-posting from EVIDENCE-BASED MEDICINE that brings forward a raft of relevant issues. [*see note below]

Great contribution Irina. [<https://www.hifa.org/dgroups-rss/communicating-health-research-13-q2-what-are-different-approaches-communicating-research>]

to reiterate another set of domains containing more sinister violations below:

Faked Beta-Amyloid Data. What Does It Mean? <https://www.science.org/content/blog-post/faked-beta-amyloid-data-what-does-it-mean>

OR

One of the oldest (pharma) games in the book (Bait and Switch):

The serotonin theory of depression: a systematic umbrella review of the evidence: The main areas of serotonin research provide no consistent evidence of there being an association between serotonin and depression, and no support for the hypothesis that depression is caused by lowered serotonin activity or concentrations. (The difference between rat brain slice and human therapeutic effects.) <https://pubmed.ncbi.nlm.nih.gov/35854107/>

Purdue Pharma and the Sackler family, which owns it, have reached a new deal to settle lawsuits that accused them of fueling the opioid addiction epidemic with aggressive sales and marketing of OxyContin and other painkilling drugs:

<https://www.webmd.com/a-to-z-guides/news/20220304/sackler-family-purdue-pharma-settlement>

Closing ranks around Doctors Debate Transvaginal Mesh Risks (Dr. Zipper's invention): https://www.govinfo.gov/content/pkg/USCOURTS-utd-2_20-cv-00109/pdf/USCOURTS-utd-2_20-cv-00109-0.pdf

<https://www.drugwatch.com/news/2014/05/29/doctors-debate-transvaginal-mesh-risks/>

<https://www.drugwatch.com/transvaginal-mesh/lawsuits/>

And OOPS! The updated view of the NEJM after many publications:

<https://www.jwatch.org/fw114661/2018/10/11/vaginal-mesh-controversy-examined>

LANCET: [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(18\)32480-2/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(18)32480-2/fulltext)

Best!

HIFA profile: David Cawthorpe is Adjunct Assistant Professor at the University of Calgary, Canada. His professional interests include: Human Development, Developmental Psychopathology, and Delivery of low bandwidth medical education curriculum. cawthord AT ucalgary.ca

[*Note from NPW, moderator: Thanks David. I have chosen the term Miscommunication to introduce this new subthread, and hope that this covers the examples you give.]

[hifa] Communicating health research (22) Q1. What do we mean by Effective communication of health research? (5) How do we measure it?

Date: Wed, 07 Sep 2022 08:09:51 +0000

From: Neil Pakenham-Walsh <neil.pakenham-walsh@ghi-net.org>

Dear HIFA colleagues,

For the purposes of our discussion, the HIFA working group on Effective research communication proposes the following definition:

"Effective communication: From a researcher point of view, this means that their research is considered by policymakers where appropriate. This implies that it is visible, accessible, clear and readily understandable, that it is seen by policymakers as relevant and reliable, and that it is in a format that meets the perceived needs of policymakers."

It can be argued there are various levels of effective communication to policymakers (PMs):
1. PM is aware of the research (whether directly or indirectly)
2. PM understands the key findings of the research
3. PM has confidence in the research
4. PM includes the research as part of their decision making process
5. There is a demonstrable link (direct or indirect) between the research and subsequent policy
6. The policy is implemented and has an impact on health outcomes.

Any of the above may be facilitated/affected by several types of actor: advisers, policy brief writers, media, journalists, civil society organisations, not to mention the original researchers themselves.

Note that the above is a representation from the perspective of a researcher who wants to communicate *their* research.

A definition of 'effective communication' from a public health perspective would arguably be different. For example, many of us would say that optimal policymaking should not be based on which research team is the most effective communicator. By definition, this promotes biased policymaking. We would argue that effective communication is that which supports evidence-informed policymaking, which WHO describes as ensuring that 'the best available research evidence is used to inform decision-making... characterized by systematic and transparent access to and appraisal of evidence as an input into the policy-making process.'
<https://www.euro.who.int/en/data-and-evidence/evidence-informed-policy-making/evidence-informed-policy-making>

That said, our discussion is looking primarily from a researcher perspective, noting that much relevant research does not even come to the attention of policymakers or their advisers, let alone be considered systematically (or otherwise) in policymaking.

This leads us to the question: How might we *measure* the effectiveness of health research communication? I look forward to your comments.

Best wishes, Neil

Joint Coordinator, HIFA Communicating health research <https://www.hifa.org/projects/new-effective-communication-health-research-policymakers>

Let's build a future where every person has access to reliable healthcare information and is protected from misinformation - Join HIFA: www.hifa.org

HIFA profile: Neil Pakenham-Walsh is coordinator of the HIFA global health movement (Healthcare Information For All - www.hifa.org), a global community with more than 20,000 members in 180 countries, interacting on six global forums in four languages in collaboration with WHO. HIFA brings stakeholders together to accelerate progress towards universal access to reliable healthcare information. HIFA is administered by Global Healthcare Information Network, a UK based non-profit in official relations with the World Health Organization. Twitter: @hifa_org neil@hifa.org

[hifa] Communicating health research (23) Q1. What do we mean by Effective communication of health research? (6)

Date: Wed, 07 Sep 2022 14:09:24 +0000

From: "Chris Zielinski, UK" <chris@chriszielinski.com>

Thanks for pushing this discussion forward, Neil.

I think the definition you provide needs unpacking a bit: "Effective communication: From a researcher point of view, this means that their research is considered by policymakers where appropriate. This implies that it is visible, accessible, clear and readily understandable, that it is seen by policymakers as relevant and reliable, and that it is in a format that meets the perceived needs of policymakers."

This seems to suggest that the only purpose for communicating research is to be "considered appropriate" by policymakers. But this is far from the whole story. Health research is carried out in distinctly different institution and under a range of circumstances and conditions.

For example, the research carried out by academics in a university setting needs to convince the academic hierarchy that it is/was worth doing - you won't get your PhD without that trusted communication tool, the thesis, and you won't get tenure or Professorship without a strong publications (= effective communications) record.

Equally, research funded by a government or other source will need to communicate effectively with the funding source - not necessarily at the policymaking level. So the funder's priorities come into play. In the UK, research funded by the National Institute of Health and Care Research (NIHR) is often funded so as to improve the educational establishment itself - to set up or strengthen new research capabilities and units, to train staff, etc. - which is not exactly policymaking.

Commercially funded health research usually has product-related goals. As in the other examples above, policymaking and policymakers don't enter into it.

So the definition of "effective communication" for health researchers proposed seems too narrow. A more accurate definition could be something like, "From a researcher point of view, this means that their research is considered as appropriate by the relevant target audiences, including funders, academic authorities and policymakers, among others. In all cases, research communications should be visible, accessible, clear and readily understandable. Effective research communications for policymakers should be in a format that meets their perceived needs, and should be seen as relevant and reliable."

Chris Zielinski chris@chriszielinski.com Blogs: <http://ziggytheblue.wordpress.com> and <http://ziggytheblue.tumblr.com> Research publications: <http://www.researchgate.net>

HIFA profile: Chris Zielinski: As a Visiting Fellow and Lecturer at the Centre for Global Health, University of Winchester, Chris leads the Partnerships in Health Information (Phi) programme, which supports knowledge development and brokers healthcare information exchanges of all kinds. He is the elected Vice President (and President-in-Waiting) of the World Association of Medical Editors. Chris has held senior positions in publishing and knowledge management with WHO in Brazzaville, Geneva, Cairo and New Delhi, with FAO in Rome, ILO in Geneva, and UNIDO in Vienna. He served on WHO's Ethical Review Committee, and was an originator of the African Health Observatory. He also spent three years in London as Chief Executive of the Authors Licensing and Collecting Society. Chris has been a director of the UK Copyright Licensing Agency, Educational Recording Agency, and International Association of Audiovisual Writers and Directors. He has served on the boards of several NGOs and ethics groupings (information and computer ethics and bioethics). [chris AT chriszielinski.com](mailto:chris@chriszielinski.com). His publications are at <https://www.researchgate.net/profile/Chris-Zielinski> and <https://winchester.academia.edu/ChrisZielinski/> and his blogs are <http://ziggytheblue.wordpress.com> and <https://www.tumblr.com/blog/ziggytheblue>

[hifa] Communicating health research (24) Q1. What do we mean by Effective communication of health research? (7) How do we measure it? (2)

Date: Thu, 08 Sep 2022 15:09:31 +0000

From: Neil Pakenham-Walsh <neil.pakenham-walsh@ghi-net.org>

Dear HIFA colleagues,

In my last message I asked: How might we *measure* the effectiveness of health research communication?

To help answer this question, I looked at the paper by two members of the HIFA Communicating health research group (Rob Terry (TDR/WHO) and Tanja Kuchenmuller (Evidence to Policy and Impact/WHO)):

CITATION: Assessing the impact of knowledge communication and dissemination strategies targeted at health policy-makers and managers: an overview of systematic reviews. Evelina Chapman et al. Health Research Policy and Systems volume 19, Article number: 140 (2021) <https://health-policy-systems.biomedcentral.com/articles/10.1186/s12961-021-00780-4>

The main conclusion was: 'There is limited evidence regarding the effectiveness of interventions targeting health managers and policy-makers, as well as the mechanisms required for achieving impact.'

How did the studies measure 'effectiveness'?

Below are extracts from the full text that (partially) address this question, and a comment from me:

-- We included outcomes related to the effectiveness of communication and dissemination strategies targeted at managers or policy-makers...

Our primary outcomes were use or uptake of research results, decision-making, adherence to research knowledge (i.e. change in knowledge/awareness) and behavioural change...

Thirteen studies assessed the use or uptake of research results, 14 studies assessed decision-making or changing behaviours, six studies assessed intention to use or apply evidence, 14 studies assessed change in knowledge, and five studies assessed changes in awareness...

Secondary outcomes were those related to understanding, perception and persuasiveness. We considered only objective understanding and not self-reported understanding. Perception referred to how effective an intervention was perceived to be. Persuasiveness considered how likely participants were to make a hypothetical decision in favour of an intervention...

Understanding was assessed by nine studies, perception by seven studies and persuasiveness by three studies, and cost was reported by a single study as a research gap...

Additionally, the included studies assessed outcome measures that were not included in our protocol. These included learning (six studies), attitudes/beliefs (four studies), skills or competencies (three studies), discussion regarding the evidence (two studies), health outcomes (two studies), engagement (two studies), policy changes (one study), value of research evidence (one study), scaling-up of intervention (one study), acceptability (one study), research culture (one study), intention to act (one study), sustainability of evidence-informed policy-making (EIPM) (one study), research coproduction (one study) and credibility (one study). --

COMMENT (NPW): The implication is that there are many possible outcomes to consider, and many possible approaches to measurement. As we have discussed previously, there are many aspects to the term 'effectiveness', and the definition of 'effectiveness' will vary from one perspective to another, and from one context to another. Are we able to identify a numerical indicator of 'effectiveness' that can be applied to research communication? It would seem perhaps not. I look forward to hear what Rob and Tanja and others have to say on this topic. Meanwhile I am reminded about a well-known and highly controversial measure - the journal impact factor - which is based on citations.

If there is no single numerical indicator of effectiveness of research communication, the implication is that each instance of communication needs to be assessed on a case by case basis, on the basis of whether the communication achieved the desired objective(s).

Meanwhile we can continue to explore the wider questions that frame our discussion:

1. What do we mean by 'Effective communication of health research to policymakers?' How do we measure it?
2. What are the different approaches to communicating research (eg academic journals, policy briefs, interaction with policymakers, press releases, social media, infographics, use of video)? What is your experience with these approaches? What works and what doesn't?
3. What is the role of researchers in research communication, beyond publication of their paper? What is the role of other stakeholders (eg communication professionals, editors, media, public health professionals and critical thinkers)
4. What are the

needs and preferences of policymakers? 5. What can be done to better support researchers in the communication of health research?

Please do share your experience and thoughts on any of the above, by email to:
hifa@hifaforums.org

Best wishes, Neil

Joint Coordinator, HIFA Communicating health research <https://www.hifa.org/projects/new-effective-communication-health-research-policymakers>

Neil Pakenham-Walsh, Global Coordinator HIFA, www.hifa.org neil@hifa.org Working in official relations with WHO

[hifa] Communicating health research (25) Q1. What do we mean by Effective communication of health research? (8) PAHO/WHO Policy on Research for Health

Sender: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

Date: Fri, 09 Sep 2022 06:09:20 +0000

From: "Jackeline Alger, Honduras" <jackelinealger@gmail.com>

Regarding question 1 on "What do we mean by "Effective communication of health research to policymakers? How do we measure it?", I want to comment on what is considered by the PAHO/WHO Policy on Research for Health.

The Policy on Research for Health document is available at:
<https://iris.paho.org/handle/10665.2/54411?locale-attribute=es>

The Policy is based on principles that guide the achievement of its goals and objectives including the principle related to Communication and Accessibility which means communicating to the public effectively and in a timely and pertinent manner the research activities and allowing free and unrestricted access to the research that PAHO/WHO supports and also urging that other agencies and allies that fund or conduct research do the same. It is explained that to achieve the objectives, the Secretariat of the Pan American Sanitary Bureau, Member States and partners must work together to benefit from science, technology, innovation and broader knowledge. It also notes that the implementation of the Policy will result in a number of tangible benefits for countries, including improved production, use and communication of reliable, relevant and timely information and evidence.

The Policy has six objectives, one each for the aspects of Quality, Governance, Human Resources, Partnerships, Standards, and Impact. In terms of impact, the Policy declares: 'Information and communications technologies can be used to give visibility to Regional research and to disseminate and promote the use of knowledge to improve health, equity, and development. Researchers, policy makers, health practitioners, and the public require timely and equitable access to research evidence. Strategies to bolster understanding of the essential links between research, policy, and action need to be developed, implemented, and evaluated.'

Since 2009, when the Policy on Research for Health was published, it has been promoted that member countries can integrate the policy and adapt it to local and national health research needs. As we can see, the Policy provides a broad framework on communication to policy makers and other actors.

Best regards Jackeline

HIFA-Spanish Moderator

HIFA profile: Jackeline Alger, MD, PhD, is a parasitologist associated to the Department of Clinical Laboratory of the University Hospital; Executive Director of the Antonio Vidal Institute for Infectious Diseases and Parasitology; Tegucigalpa, Honduras. HIFA Country Representative of the Year for the years 2015 and 2018. Email jackelinealger AT gmail.com

Why did I join HIFA? <https://www.youtube.com/watch?v=2NZ-U5Wv9FU>

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Join HIFA-Spanish: <http://www.hifa.org/join/unase-hifa-espanol>

[hifa] Communicating health research (26) Alcohol Warning Labels Need Updates to Reflect Harms: NEJM

Date: Fri, 09 Sep 2022 07:09:25 +0000

From: Neil Pakenham-Walsh <neil.pakenham-walsh@ghi-net.org>

This article in Medscape raises interesting points and questions about communicating health research. In this case there is overwhelming evidence that alcohol causes multiple adverse effects on physical and mental health, but this evidence has not yet translated into policy and practice. Below are extracts, and comments from me.

Forwarded from Medscape. Read in full:

https://www.medscape.com/viewarticle/980022?src=mkm_ret_220908_mscpmrk_trdalrtuk03_int&uac=438458DX&impID=4617848&faf=1

-- Alcohol Warning Labels Need Updates to Reflect Harms: NEJM Roxanne Nelson, RN, BSN

August 31, 2022

Warning labels on alcoholic products need to be updated to spell out details of potential harm in order to make them more effective, say two US researchers.

The current labeling, which has not changed for 30 years, focuses on risks during pregnancy and with operating machinery and includes a vague statement that alcohol "may cause health problems."

This is "so understated that it borders on being misleading," the two researchers argue.

The science related to the use of alcohol has moved on, and there is now firm evidence of harm. Alcohol has been classified by the International Agency for Research on Cancer (IARC) as a group 1 carcinogen and has been linked to an increased risk of many types of cancer. Drinking alcohol has also been linked to a wide range of other diseases, from liver disease to pancreatitis to some types of heart disease, the authors note.

Yet the general public is mostly unaware of the most serious health risks that are associated with alcohol consumption, they point out.

"We believe Americans deserve the opportunity to make well-informed decisions about their alcohol consumption," say Anna H. Grummon, PhD, MSPH, of the Harvard T. H. Chan School of Public Health, Boston, Massachusetts, and Marissa G. Hall, PhD, MSPH, of the University of North Carolina at Chapel Hill...

However, as previously reported by Medscape Medical News, pressure from the alcohol industry led to changes in the Yukon project, and while a general health warning remains, the label about increased cancer risk was removed.

The alcohol industry has tried to suppress efforts to educate the public, and this has created problems in conveying health information to consumers, the authors note. The industry spends more than \$1 billion each year to market its products in the United States. --

COMMENTS (NPW): 1. When considering 'effective communication of health research', we need to be thinking not only about the impact of a single study, but also on how research findings combine with existing research evidence. 2. In the case of policymaking to update alcohol warning labels, as with most policies, the decision is typically taken by a collective of policymakers. That said, a senior policymaker (such as the president or health minister of a country) can champion the cause. 3. Whether single or multiple, policymakers need compelling evidence, both to direct them to their favoured policy, and to persuade others of the merits of that policy. 4. Different policymakers will have different motivations. While a health minister may favour to update alcohol warning labels to decrease consumption, the president may be more interested to increase consumption, perhaps to generate more tax revenue. The Japanese government for example is actively *encouraging* young people to drink more alcohol: <https://www.bbc.co.uk/news/world-asia-62585809> 5. There is a human-rights dimension to this discussion. As HIFA has demonstrated in our white paper with the New York Law School, governments have a legal obligation under international human rights law to ensure that their citizens have access to reliable healthcare information. This implies that governments have a legal obligation to update alcohol warnings so that citizens are better informed.

With the above in mind, and considering the question of alcohol warning labels (or any other health policy), we can reflect on the five questions that guide our discussion: 1. What do we mean by 'Effective communication of health research to policymakers?' How do we measure it? 2. What are the different approaches to communicating research (eg academic journals, policy briefs, interaction with policymakers, press releases, social media, infographics, use of video)? What is your experience with these approaches? What works and what doesn't? 3. What is the role of researchers in research communication, beyond publication of their paper? What is the role of other stakeholders (eg communication professionals, editors, media,

public health professionals and critical thinkers) 4. What are the needs and preferences of policymakers? 5. What can be done to better support researchers in the communication of health research?

Neil Pakenham-Walsh, Global Coordinator HIFA, www.hifa.org neil@hifa.org Working in official relations with WHO

Subject: [hifa] Communicating health research (27) Review of Week 1
From: Neil Pakenham-Walsh <neil.pakenham-walsh@ghi-net.org>
To: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

Dear all on HIFA Communicating health research working group,

Many thanks to you all for your messages in week 1 of our 5-week in-depth discussion, supported by TDR, the Special Programme for Research and Training in Tropical Diseases at WHO.

I have prepared a short edit of the discussion so far:

https://www.hifa.org/sites/default/files/publications_pdf/Communicating_health_research_%201-26_short_edit.pdf

You will see that we have already touched on a wide range of relevant topics such as definitions, grades of impact, academic journals, preprints, open access, policy briefs, evidence-informed policymaking, role of the media, global and local evidence...

You can review all messages in full here: <https://www.hifa.org/rss-feeds/17>

As always, the email address for the forum is: hifa@hifaforums.org

As an aide-memoire our guiding questions are: 1. What do we mean by 'Effective communication of health research to policymakers?' How do we measure it? 2. What are the different approaches to communicating research (eg academic journals, policy briefs, interaction with policymakers, press releases, social media, infographics, use of video)? What is your experience with these approaches? What works and what doesn't? 3. What is the role of researchers in research communication, beyond publication of their paper? What is the role of other stakeholders (eg communication professionals, editors, media, public health professionals and critical thinkers) 4. What are the needs and preferences of policymakers? 5. What can be done to better support researchers in the communication of health research?

If you are unclear about how to contribute, let me know and I'll be happy to guide you.

Many thanks, Neil

Neil Pakenham-Walsh, Global Coordinator HIFA, www.hifa.org neil@hifa.org Working in official relations with WHO

Subject: [hifa] Communicating health research (28) Q2. What are the different

approaches to communicating research? (4)

From: Neil Pakenham-Walsh <neil.pakenham-walsh@ghi-net.org>

To: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

Welcome to week 2 of our discussion on Communicating health research, with thanks to TDR for their support.

This week I invite you to comment on Question 2: What are the different approaches to communicating research?

What is your experience of communicating research to policymakers?

Which approaches have you used? (eg academic journals, policy briefs, interaction with policymakers, press releases, social media, television, radio...)

Can you share one example of successful communication to policymakers? What approach worked for you? How did you know it was successful?

Can you share an example of failed communication to policymakers? Perhaps an example where the relevant policymakers remained unaware of your research? Or an example where they ignored it or failed to use it in policy and implementation?

We have already had a few contributions on this topic:

1. Journal editor Irina Ibraghimova (Croatia) points to the importance for researchers to include Practical implications in their papers. 2. NPW suggests (almost) all research should at least be available in a peer-reviewed journal, and argues that open access is a critical aspect of effective communication of health research to policymakers. 3. Joseph Ana (Nigeria) discusses pre-prints and blogs, and notes how they can sidestep the peer review process 4. Joseph Ana (Nigeria) notes that 'Policy briefs are generally valued by policy-makers, although a systematic review by Rob Terry, Tanja Kuchenmuller et al fails to find much evidence of impact. 5. Richard Fitton (UK) suggests researchers may also need to consider communicating with "influencers" as the UN did using the South Korea K-pop group BTS last year General Assembly. 6. Chris Zielinski (UK) notes the importance for researchers to communicate not only with policymakers but also academia and funders, and notes the need to engage with the media. 7. Ellos Lodzeni (Malawi) emphasises that researchers should 'involve and engage the users through their Associations or organizations'. 8. Wilber Sabiiti (UK) asks: Is there anything that we can learn from COVID-19 response? Here there was a 'hunger for evidence to support policy decisions almost daily'... 'There was a direct line of communication between scientists (national scientific advisory committees) and policy makers and often media played the 3rd partly role of informing the public of decisions taken.' 9. Chris Zielinski (UK) notes 'It is nice to imagine that health policy makers spend their Sundays reading academic biomedical journals - or even the policy briefs laboriously prepared for them by intermediaries - nice, but completely unlikely. Instead, they kick on the TV, grab the newspaper, listen to a podcast or read a tweet.'

Looking forward to hear your thoughts and experience. Please send to the HIFA forum: hifa@hifaforums.org

Many thanks, Neil

Joint Coordinator, HIFA Communicating health research <https://www.hifa.org/projects/new-effective-communication-health-research-policy-makers>

Neil Pakenham-Walsh, Global Coordinator HIFA, www.hifa.org neil@hifa.org Global Healthcare Information Network: Working in official relations with WHO

Subject: [hifa] Communicating health research (29) Q2. What are the different approaches to communicating research? (5) Engaging policymakers in knowledge synthesis

From: Neil Pakenham-Walsh <neil.pakenham-walsh@ghi-net.org>

To: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

Previous research has shown that engagement of policymakers in the research process increases the policy-relevance of research questions and promotes uptake and implementation. This 2018 paper looks at engagement in secondary research (knowledge synthesis).

Although the paper does not make the point, I would propose that engagement of policymakers in secondary research is even more important than engagement in primary research. This is because secondary research, when done rigorously, uniquely promotes evidence-informed policymaking and is therefore more likely than primary research to have robust conclusions for implementation in policy and practice.

As we have discussed previously on HIFA, it is also critical that policymakers and their advisers understand what evidence-informed policymaking actually means, ie that it is based on all available evidence (rather than the results of a single study). Furthermore, interpretation is complicated by the fact that much secondary research is overrepresented by research in high-income countries rather than LMICs. Therefore, LMICs have the added burden of synthesising global and local research, an important topic that is not addressed in the study below.

I look forward to your comments.

CITATION: Engaging policy-makers, health system managers, and policy analysts in the knowledge synthesis process: a scoping review Andrea C. Tricco et al. Implementation Science volume 13, Article number: 31 (2018)
<https://implementationscience.biomedcentral.com/articles/10.1186/s13012-018-0717-x>

ABSTRACT Background: It is unclear how to engage a wide range of knowledge users in research. We aimed to map the evidence on engaging knowledge users with an emphasis on policy-makers, health system managers, and policy analysts in the knowledge synthesis process through a scoping review.

Methods: We used the Joanna Briggs Institute guidance for scoping reviews. Nine electronic databases (e.g., MEDLINE), two grey literature sources (e.g., OpenSIGLE), and reference lists of relevant systematic reviews were searched from 1996 to August 2016. We included any type of study describing strategies, barriers and facilitators, or assessing the impact of

engaging policy-makers, health system managers, and policy analysts in the knowledge synthesis process. Screening and data abstraction were conducted by two reviewers independently with a third reviewer resolving discrepancies. Frequency and thematic analyses were conducted.

Results: After screening 8395 titles and abstracts followed by 394 full-texts, 84 unique documents and 7 companion reports fulfilled our eligibility criteria. All 84 documents were published in the last 10 years, and half were prepared in North America. The most common type of knowledge synthesis with knowledge user engagement was a systematic review (36%). The knowledge synthesis most commonly addressed an issue at the level of national healthcare system (48%) and focused on health services delivery (17%) in high-income countries (86%).

Policy-makers were the most common (64%) knowledge users, followed by healthcare professionals (49%) and government agencies as well as patients and caregivers (34%). Knowledge users were engaged in conceptualization and design (49%), literature search and data collection (52%), data synthesis and interpretation (71%), and knowledge dissemination and application (44%). Knowledge users were most commonly engaged as key informants through meetings and workshops as well as surveys, focus groups, and interviews either in-person or by telephone and emails. Knowledge user content expertise/awareness was a common facilitator (18%), while lack of time or opportunity to participate was a common barrier (12%).

Conclusions: Knowledge users were most commonly engaged during the data synthesis and interpretation phases of the knowledge synthesis conduct. Researchers should document and evaluate knowledge user engagement in knowledge synthesis.

EXTRACTS 'An estimated 85% of investment in health and biomedical research is wasted every year due to redundancies, failure to establish priorities based on needs of stakeholders (particularly end-users of knowledge), poorly designed research methods, and incomplete reporting of study results, leading to billions of dollars lost globally'

'There are numerous perceived benefits to engaging policy-makers, policy analysts, and health system managers in knowledge synthesis. Examples include more comprehensive literature searches, improved rigor of knowledge synthesis findings, greater clarity of results [59] as well as greater relevance, uptake, and usefulness of results. However, the results of our scoping review suggest that very little research has been conducted in this area.'

Best wishes, Neil

Joint Coordinator, HIFA Communicating health research <https://www.hifa.org/projects/new-effective-communication-health-research-policymakers>

Neil Pakenham-Walsh, Global Coordinator HIFA, www.hifa.org neil@hifa.org Working in official relations with WHO

Subject: [hifa] Communicating health research (30) Introduction: Ben Angoa, Solomon Islands

From: "Ben Angoa, Solomon Islands" <sippaeseaorma@gmail.com>

To: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

Hi

My Name is Ben Angoa, the Executive Director of Solomon Island Planned Parenthood Association (SIPPA).

I'm interested in Understanding effective communication of health research to policymakers; Using different approach to communicate research.

Thanks Ben

HIFA profile: Ben Angoa is Manager of the Solomon Island Planned Parenthood Association, Solomon Islands. Professional interests: Understanding effective communication of health research to policymakers; Using different approach to communicate research. Email: sippaeseaorma@gmail.com

Subject: [hifa] Communicating health research (31) Introduction: Ben Angoa, Solomon Islands (2) Communicating research on sensitive issues
From: Neil Pakenham-Walsh <neil.pakenham-walsh@ghi-net.org>
To: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

Dear Ben,

Thank you for your self-introduction and welcome to HIFA!

I would be very interested to learn about your experience of communicating health research to policymakers, particularly about contraception and abortion, and especially in Solomon Islands where there are profound legal restrictions on abortion. How can evidence be made available to, and understood by, policymakers in situations where the evidence does not fit with their 'world view' or with the current legal situation?

(Note to Ben: If you prefer not to say anything for whatever reason, please do not feel obliged to do so. In this case I open this important question for other HIFA members to explore.)

I note that 'a cross-sectional study of 1441 women in the Solomon Islands reported that one in six pregnant women (16.95) did not know any modern contraceptive methods'
<https://reproductive-health-journal.biomedcentral.com/articles/10.1186/s12978-021-01122-x>

Also, a paper published in July 2022 looks at health worker perceptions in the Solomon Islands, and 'affirms health workers as a key resource in addressing the unmet need for contraception in Guadalcanal, Solomon Islands, and calls for programme and policy solutions informed by their perspectives. The two main priorities they emphasised to help tackle the persistent problem of unmet need for contraception are an increase in their capability to provide contraceptive implants, and an increase in community education to boost acceptance of family planning care from women and their families'.
<https://pacifichealthdialog.nz/index.php/phd/article/view/133>

Research communication is complicated by Solomon Islands' legal status on abortion. From Wikipedia: 'Abortion in the Solomon Islands is only legal if the abortion will save the mother's life. In Solomon Islands, if an abortion is performed on a woman for any other reason, the violator is subject to a life sentence in prison. A woman who performs a self-induced abortion may also be imprisoned for life.'

https://en.wikipedia.org/wiki/Abortion_in_the_Solomon_Islands

Best wishes, Neil

Joint Coordinator, HIFA Communicating health research <https://www.hifa.org/projects/new-effective-communication-health-research-policymakers>

HIFA profile: Neil Pakenham-Walsh, Global Coordinator HIFA, www.hifa.org neil@hifa.org
Working in official relations with WHO

Subject: [hifa] Communicating health research (32) Responses to Q1, Q2, Q3, Q4, and Q5

From: "David R. Walugembe, Canada" <dwalugembe@gmail.com>

To: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

Hello Moderator, I am hopeful that this will find you well. Please receive [below] a copy of my input on the discussion of effective health communication. Regards David

HIFA profile: David R. Walugembe (PhD) is a graduate of Health Information Science from the University of Western Ontario and currently a Postdoctoral Research Fellow at the University of British Columbia, Canada. Professional interests: Implementation science; Health policy implementation; Knowledge translation and research utilization; Maternal and child health; Sustainability; Stakeholder engagement. [dwalugembe AT gmail.com](mailto:dwalugembe@gmail.com)

1. What do we mean by Effective communication of health research to policymakers? How do we measure it?

Effective communication of health research to policy makers – would mean when policy makers (intended recipient) of the intended messages get/ access them, give feedback (expected and unexpected- critical) or take appropriate actions on such messages. This is informed by the assumption that communication is only complete when the intended recipients decode the encoded messages. Therefore, when policy makers receive communication from researchers and provide feedback, request for more information/facts/evidence, enact policies or implement programs and or interventions, informed by the content of the research communication, then that may constitute effective communication of health research. However, there are still exist gaps in how to measure effective communication of health research. This is partly due to differences in interpretation of what constitutes effective communication of health research. Maybe applying frameworks that provide a priori indicators of effectiveness could enhance efforts in this direction.

2. What are the different approaches to communicating research (eg academic journals, policy briefs, interaction with policymakers, press releases, social media, infographics, use of video)? What is your experience with these approaches? What works and what doesn't?

As rightly discussed, there are several approaches to communicating research including academic journals, policy briefs, interactions with policy makers, press releases, social media, infographics, and use of videos among others. To this list we can add book chapters, blogs, newspaper articles, websites, factsheets, drama skits, music pieces (edutainment), policy dialogues, townhall meetings, television and radio talk shows, conferences, workshops and meetings among others. I have had the unique opportunity of using several of these approaches while supporting eight health systems- related research coalitions in sub-Saharan Africa to engage their diverse stakeholders in knowledge translation. A brief comment about these approaches is that none works successfully independent of others! One needs a combination of these approaches to communicate effectively. They are also context specific- the success of some approaches varies from one context to the other. Additionally, the characteristics of the intended recipients of the health research communication (policy makers) including their capacity to read, interpret and assess/evaluate research communication, their power, influence and interest in relation to the research communication may all affect the approaches used to communicate. Additionally, the quality of the research communication (findings), their timing, public sentiments about the subject matter they relate to, may also influence which approaches may be successful in communicating research findings. For example, communicating research findings that may contradict government policies and programs via mass media during an election season may be interpreted as opposition to the government in power and may attract sanctions from policy makers while similar efforts may be welcomed as constructive input once the policy makers have successfully assumed their elective positions! Likewise, findings that address issues of concern to certain populations may be effectively communicated by mobilizing and engaging such communities pragmatically through activities or platforms that they are familiar and resonate with. For example, edutainment strategies such as sports, music, dance and drama may be effective ways in communicating key health messages to policy makers dealing with youths and communities that may not be able to read and write but can interpret and or use such messages.

3. What is the role of researchers in research communication, beyond publication of their paper? What is the role of other stakeholders (eg communication professionals, editors, media, public health professionals and critical thinkers)

Researchers in research communication may be equated to strategic planners or project managers. Basically, they play the role of conceiving the idea/project, thinking through its aims and objectives, target audiences, methods and approaches to conduct the research and to communicate the messages/research findings. Courtesy of this strategic role, researchers play the role of identifying which additional stakeholders and skills they need on the team to help them accomplish the aims and objectives of communicating their research findings. As strategic planners/project managers, researchers have a role to network and engage the identified stakeholders to bridge the identified gaps and provide sufficient clear guidance on what they would wish other stakeholders to support them with. It would also be critical for researchers to evaluate the effectiveness and impact of their research communication efforts beyond the metrics of citations, likes, and maybe academic promotions! How researchers evaluate the effectiveness and impact of their research communication efforts still remains a challenge that may require further research.

Other stakeholders guided by the strategic planner/project manager (researcher) may and should fill the identified gaps using their expertise, experience and skills. For example, communication professionals may come on board to help the researchers to package complex/ scientific/ discipline specific research findings in more accessible/non-technical and jargon-free language. They may and should help researchers in identifying the most appropriate formats and medium through which to communicate the research findings as well as render advice on how to segment various audiences. Editors may on the other hand help in ensuring that the content of the research communication is error-free, meets the standards of the medium through which it is being communicated including television, radio, journal, newspaper and books among others. The role of the media would be to promote the research findings and encourage public engagement with such findings. They should however go beyond and collect feedback on public perception of such findings as well as work with researchers to assess the effect and impact of their content! In addition to using the content/findings to advance practice and improve knowledge, public health researchers and critical thinkers may help in providing constructive criticisms and or conducting further research to address the identified challenges and gaps.

4. What are the needs and preferences of policymakers?

The needs and preferences of policymakers may vary from one context to another and are dependent on several factors. These may include their capacity, power, influence, interest, resources, ideas and institutions. Policymakers with all these variables at their disposal may need and prefer advice/evidence that can empower them to do better and deliver on their mandates. However, those that operate in constrained systems may not be receptive to ideas/evidence that puts more strain on their resources, challenges their approaches or threatens their survival in power. Additionally, policy makers in systems with empowered electorate and democratic systems that encourage accountability, would need feedback from the electorate on how best they can deliver services while those operating in alternative systems may not create empowering ambiances for such input.

5. What can be done to better support researchers in the communication of health research?

Researchers in communication of health research may be helped by bringing to their awareness the various 'strategic planner/project manager' roles that they need to play beyond generating journal articles/scientific publications. As strategic planners and or project managers, they have various roles to play to enhance the utility and uptake of their research findings by their target audiences who in most cases are policy makers! They also need to be supported to appreciate the contextual realities and dynamics across various contexts and how these affect their efforts. Most importantly, researchers in communication of health research need support in cultivating meaningful partnerships with other stakeholders to enhance uptake and utility of their research findings.

Subject: [hifa] Communicating health research (33) Health Systems in Action:
launch of new Insights from 14 countries, organised by the WHO Regional
Office for Europe and the European Observatory on Health Systems and Policies
From: "Richard Fitton, UK" <richardpeterfitton7@gmail.com>
To: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

[*see note from HIFA moderator NPW below]

12/09/2022 Tel Aviv Health Systems in Action: launch of new Insights from 14 countries, organised by the WHO Regional Office for Europe and the European Observatory on Health Systems and Policies

I joined this webinar. Each country had produced a collaborative and comparative understanding of its health system that could be understood in 30 minutes. The 'Health Systems in Action' can be seen at The 12/09/2022 WHO/European Observatory on health systems and policies 'Health Systems in Action (HSSIA)'

Issues covered included health illiteracy about antimicrobial resistance, shortage of family doctors and nurses, high costs of medicines, integrating management of NCDs and control of its risk factors into Primary Care, delivering equal services, content and quality in rural and urban settings.

A common theme was the inadequacy of data collection to advance quality of care and advance quality agendas by helping the analysis of requirements and one country mentioned the need to do a full assessment of its IT systems.

'The Health System in Action (HSiA) Insights are a set of short summaries that capture what is happening in non-EU Member States; highlight progress and challenges country by country; and provide context for the WHO/Europe's European Programme of Work and its Roadmaps for Health and Wellbeing.'

'They aim to support decision-makers with quick, easily accessible and concise evidence to help countries spot the key issues and how their country measures up over time and against their peers.'

'The new HSIA Insights will be launched during WHO's 72nd Regional Committee for Europe in Tel Aviv, Israel. The launch introduced 14 country Insights as a tool for ministries as they strengthen their health systems and as a baseline for future comparisons. The insights are shown through the eyes of four Member States (Israel, Georgia, Montenegro and Tajikistan) and are designed to show how concise health systems evidence gives a 'helicopter' view of issues; facilitates debate with other ministries; and builds an understanding of what works and of the lessons in other countries.

'The insights show case Regional Office and countries' efforts on antimicrobial resistance (AMR).

OPENING Hans Kluge, WHO Regional Director for Europe to open Nachman Ash, Ministry of Health of Israel: Israeli Insight launch Moderator: Gundo Weiler, WHO/Europe

OVERVIEW AND Antimicrobial resistance AMR - Suszy Lessof, European Observatory on Health Systems and Policies: How Insights support policy-makers and Nino Berdzuli, WHO/Europe: Antimicrobial resistance

COUNTRY EXPERIENCES AND RESPONSES were presented by Tamar Gabunia, First Deputy-minister, Ministry of Internally Displaced Persons from Occupied Territory, Labour, Health and Social Affairs (MoIDPLHSA) of Georgia, Vladimir Obradovic, State secretary,

Ministry of Health of Montenegro Rano Rakhimova, Head of the Department of International Relations of the Ministry of Health, Tajikistan and were introduced by the respective Head of WHO Country Office

The discussion was moderated by Josep Figueras, European Observatory on Health Systems and Policies and closed by Gundo Weiler, WHO/Europe

*Country Insights to be launched at

<https://eurohealthobservatory.who.int/publications/health-systems-in-action-insights>: are Albania, Armenia, Bosnia and Herzegovina, Georgia, Israel, Kazakhstan, Kyrgyzstan, Montenegro, North Macedonia, Republic of Moldova, Serbia, Tajikistan, Türkiye, Uzbekistan.

The Health Systems in Action insights series supports Member States in the WHO European Region that are not in the European Union.

The Insights for each country are intended to: • provide core information and data on health systems succinctly and accessibly; • outline the country health system context in which WHO Europe's Programme of Work (EPW) is set; • flag key concerns, progress and challenges health system by health system; and • build a baseline for comparisons, so that member states can see how their health systems develop over time and in relation to other countries.

The pilot series is co-produced by the WHO Regional Office for Europe and the European Observatory on Health Systems and Policies. It draws on the knowledge and understanding of the WHO Country Offices and of the Division of Country Health Policies and Systems (CPS), the Barcelona Office for Health System Strengthening and other WHO/Europe technical programmes; as well as the Health in Transition series and the work of the European Observatory on Health Systems and Policies. The Insights follow a common template that provides detailed guidance and allows comparison across countries.

HIFA profile: Richard Fitton is a retired family doctor - GP. Professional interests: Health literacy, patient partnership of trust and implementation of healthcare with professionals, family and public involvement in the prevention of modern lifestyle diseases, patients using access to professional records to overcome confidentiality barriers to care, patients as part of the policing of the use of their patient data Email address: richardpeterfitton7 AT gmail.com

Subject: [hifa] Communicating health research (34) Health Systems in Action: launch of new Insights from 14 countries (2) WHO provides an enabling framework for synthesis and sharing of research
From: Neil Pakenham-Walsh <neil.pakenham-walsh@ghi-net.org>
To: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

Thank you Richard for sharing your observations on this and previous webinars. I encourage others to do likewise, and we are especially interested to hear your personal reflections.

Reading the notes on this webinar, it seems there are a number of drivers here to successful research communication. First, it is relevant that WHO provides an enabling framework for synthesis and sharing of research at country level, through this new programme of Country Insights. The Insights provide a template which makes it both easier for countries to contribute, and provides for consistency and rigour. Those who are responsible for developing each Insight (policymakers at ministry of health? public health professionals?) will need to tap into their public health and research academic community for the relevant evidence, thereby creating a "pull" effect on research evidence. Furthermore it might be expected that this pull effect would favour secondary research and research from multiple studies rather than single primary studies, which might be expected to promote evidence-informed policy rather than policy driven by single studies. There are implications for communicators of primary and secondary research.

Perhaps it is more important to provide frameworks and incentives for policymakers to collect and share evidence (pull) rather than to focus on the ability of researchers to make their research visible? Indeed the two can be complementary.

Best wishes, Neil

Joint Coordinator, HIFA Communicating health research <https://www.hifa.org/projects/new-effective-communication-health-research-policymakers>

Neil Pakenham-Walsh, Global Coordinator HIFA, www.hifa.org neil@hifa.org Working in official relations with WHO

Subject: [hifa] Communicating health research (35) Q1. What do we mean by Effective communication of health research? (9) How do we measure it? (3)
From: "Samuel Sieber, Switzerland" <HIFA@hifaforums.org>
To: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

Hi everyone

Joining the current discussion on communication health research (apologies for my late entry!), here are five quick thoughts on what effective communication of health research to policymakers entails and how it can be measured (Q1).

(Please note: below thoughts reflect my own views and experience. They are meant as inputs for discussion and revision.)

1) Effective communication of health research implies a measurable change in policy or practice.

When discussing communication strategies with researchers, policy makers, or programme implementers, I often find there is no common understanding of what exactly we are looking to achieve and with whom. Yet, a shared vision of change and tangible objectives are fundamental to any successful communication strategy, and should precede summarizing evidence, selecting dissemination tools, and crafting messages. Communication is as

effective as the change it is trying to facilitate, and said change rarely unfolds in a linear way (see below).

2) To be effective AND efficient, communicating health research best aims at policy AND at practice.

Whether a piece of evidence points at the misuse of a potentially live saving drug, an innovative vaccination strategy, or the power of community engagement: the first and obvious take is usually to try and “inform” policy in a very traditional sense, for instance, a change in legislation, guidelines, or standard procedures. This builds on an all too simplistic perception of (top-down) power! In practice (pun intended!), most policies are only as good as their practical implementation. That’s why efficient communication of health research ideally aims at both the political decision-makers and those that implement said policy: doctors and healthcare workers, patients and people with lived experience, civil society and non-state actors, among others.

3) Measuring effective communication consequently should look at communication outcomes rather than outputs.

Neither the number nor the format of communication products determine communication success. An informal pitch to a decision-maker may have greater effect than a widely disseminated policy brief, and not every report merits a full-fledged social media strategy. Measuring communication must go beyond outputs (the communication products) and beyond activities (sharing/dissemination). A good communication strategy comes with a built-in outcome mapping, which allows both to get everyone on the same page on what impact may look like, and to monitor progress regularly.

4) Even with the best of strategies, effective communication also remains a game of opportunity, network, and politics.

Effective communication only gains traction when messages reach and resonate in the right networks, and when there is room and time for change. It’s able to recognize windows of opportunity (a sudden interest in a topic from a high-level politician, an invite to publish an op-ed in a magazine, a retweet from a major multilateral agency, etc.), and it builds on formats and communication products that can quickly be adapted, combined and recycled (combining an evidence brief with a patient interview, or using parts of a training video for public health campaign, etc.)

5) Effective communication of health research must remain true to the evidence.

Health research is often complex and highly technical. The very limited time and attention of decision-makers as much as the short formats of public communication formats often call for drastic synthesis of research results and for more actionable recommendations.

Communication professionals have much to offer in this translational process, but they also run the risk of oversimplifying or misinterpreting the original evidence. Effective communication of health research, however, can only be simplified to the point it remains true to the actual evidence. It should neither exaggerate, distort, unnecessarily dramatize nor accuse (unless there is irrefutable evidence to do so). Evidence-to-communication translation should therefore be a collaborative process of conceptualizing and editing between evidence

producers, brokers, and decision-makers (i.e., researchers, communicators, and policy-makers). ---

Best regards, Sam

Samuel Sieber PhD Knowledge Translation & Communication Specialist siebers@who.int
Twitter: @samsieber LinkedIn: samuelsieber

HIFA profile: Samuel Sieber is a Knowledge Translation and Communication Specialist, Global Coordination Mechanism on NCDs, Global NCD Platform, Deputy Director General's Office, WHO, Geneva, Switzerland. He is a member of the HIFA working group on Communicating health research. [https://www.hifa.org/support/members/samuel siebers AT who.int](https://www.hifa.org/support/members/samuel%20siebers%20AT%20who.int)

Subject: [hifa] Communicating health research (36) Q2. What are the different approaches? (6) Engaging stakeholders before and after research
From: "Khin Thet Wai, Myanmar" <khinthewaidmr@gmail.com>
To: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

Dear Sir,

Kindly consider my attached message [below] which I have prepared as a reflection concerning Q2 for the HIFA Communicating Health Research Working Group.

Thanking you in advance,

Yours sincerely,

Khin Thet Wai Member, HIFA Communicating Health Research Working Group

HIFA profile: Khin Thet Wai is a former Director at the Department of Medical Research, Myanmar. She is a medical doctor and holds the Master's degree in Public Health from Institute of Medicine, Yangon and has a second Master's degree conferred by the Institute for Population and Social Research, Mahidol University, Thailand. She is a dedicated public health researcher specializing Epidemiology and Health Policy and Systems Research. [https://www.hifa.org/support/members/khin-thet khinthewaidmr AT gmail.com](https://www.hifa.org/support/members/khin-thet%20khinthewaidmr%20AT%20gmail.com)

Q2. What are the different approaches to communicating research (eg academic journals, policy briefs, interaction with policymakers, press releases, social media, infographics, use of video)? What is your experience with these approaches? What works and what doesn't?

Communicating medical and health related research: before and/or after?

1. Before the initiation of the research projects

Advocacy to stakeholders This is the case that we have engaged prior to the initiation of the community-centered operational/implementation research projects to control dengue, malaria,

and vaccine preventable diseases in resource constrained settings. Our strategic approach in terms of advocacy meetings through the influential stakeholder groups paves the way to transparency, trust-building, and community consent. Communicating the favorable risks and benefits ratio of intended research through advocacy makes the recruitment plan in community surveys and service provider surveys at ease.

Press release through public media Publicity through the widely circulated daily newspapers requires for new community experiments to allay anxiety, doubts, and misperceptions. There was a good example of one special event in 2018 in commemoration of ASEAN Dengue Day held in a school compound in the provincial context of Thailand. Collaborating research teams from low and middle-income countries in Asia participated in this event to attract community attention to the release of sterile *Aedes* mosquitoes as an innovative pilot research project led by Mahidol Scientists. [Source: The Nation, Volume 41; 18 June 2018, Thailand]

2. The aftermath of the research projects

Dissemination meetings We have conducted the dissemination of research results at different levels (local/subnational, national and global levels) to ensure the uptake of research results to improve the training manuals for service providers in malaria elimination and service delivery guidelines for disease control and surveillance activities of childhood vaccine preventable diseases such as measles.

Policy briefs For health emergencies preparedness and management, a policy brief entitled: "Measles outbreaks among hard to reach populations as a health crisis: implications for cost-effective vaccine delivery strategies in Myanmar" has been developed and disseminated. It was successfully presented as a poster for the wider scientific community at the Global Health Security Conference, 2019 in Sydney, Australia. Three policy recommendations were developed; (1) school entry check of vaccination status against measles and referring the unimmunized children to health facility, (2) urban immunization project, and (3) recruitment of volunteers in rural areas to improve MCV coverage in migratory population in Myanmar.

Scientific publications Dengue outbreaks at smaller towns and rural sites led the necessity to strengthen advocacy and coordinated movements of healthcare providers and concerned stakeholders elucidated in a peer reviewed Journal. Other scientific publications put emphasis on controlling malaria among mobile migrants, challenges in training healthcare providers for malaria elimination and controlling measles outbreaks to achieve the elimination goal through preventive vaccination.

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and measles vaccination coverage in Myanmar from 2014 to 2018. Trop Med Health 48, 4 2020. <https://doi.org/10.1186/s41182-020-0191-4>

Subject: [hifa] Communicating health research (37) Responses to Q1, Q2, and Q3
From: "Ama Fenny, Ghana" <HIFA@hifaforums.org>
To: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

These are my answers to the first three.

1. What do we mean by Effective communication of health research to policymakers? How do we measure it?

In my opinion this refers to making research products more accessible to policymakers by packaging it in a way that makes it easier for them to understand and also find useful. It must address specific problems and be linked to existing government policies. How much of the evidence is used for formulating policies could be used as a measure of effective communication.

2. What are the different approaches to communicating research (eg academic journals, policy briefs, interaction with policymakers, press releases, social media, infographics, use of video)? What is your experience with these approaches? What works and what doesn't?

There are a variety of ways to present the same information and from my experience, lengthy reports and academic journals are hardly used by policymakers. Rather, briefs, press releases and infographics catch their attention. Sometimes as a researcher, you are often asked what the key message is from all the study results and what is your call for action. This can be hard if your study has several objectives but I would limit the key messages to at most three per study.

3. What is the role of researchers in research communication, beyond publication of their paper? What is the role of other stakeholders (eg communication professionals, editors, media, public health professionals and critical thinkers)

The researchers work does not end with the publication of their paper as is often the case. It is important for the results to be given more visibility. Many times, researchers are not fully equipped with the skills to communicate findings using other approaches. This is where other communication professionals are needed to bridge this gap. The role of the media in disseminating research findings should not be overlooked especially when findings are relevant for policymakers. But the media should be given the right information and key concepts explained to them properly. Otherwise they may put their own spin on the results and distort the findings. There should guidelines for engaging the media and transparency throughout the process.

Ama Pokuaa Fenny ISSER, University of Ghana

HIFA profile: Ama Pokuaa Fenny is a Senior Research Fellow with the Institute of Statistical, Social and Economics Research (ISSER) at the University of Ghana. She is a health economist whose research focuses on the evaluation of health and development programs in low- and middle-income country settings. In these settings, she studies the role

of health financing strategies in offering social protection to vulnerable groups, targeted health system strategies to improve health seeking behavior and costing and cost-effectiveness methods that address efficiency of health programmes. Her current research focuses on the evaluation of child and adolescent health interventions and the integration of governmental policies into service delivery systems in Africa. At ISSER, Dr. Fenny provides leadership and oversight to projects involving research, project implementation, technical assistance and policy advocacy across a range of subjects. She is a member of the HIFA working group on Communicating health research.

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[*Note from NPW, moderator: For reminder of the five questions and background:
<https://www.hifa.org/projects/new-effective-communication-health-research-policymakers>]

Subject: [hifa] Communicating health research (38) Q3. Role of researchers (1)
Q4. Needs and preferences of policymakers (3) Q5. Support for researchers (2)
From: "Khin Thet Wai, Myanmar" <khinthewaidmr@gmail.com>
To: HIFA - Healthcare Information...snip... Pakenham-Walsh <neil@hifa.org>
Cc: "TERRY, Robert Fraser" <terryr@who.int>

Dear Sir,

Kindly allow me to share my experience and knowledge [below] to HIFA Forum concerning the role of researchers in research communication, needs and preferences of policymakers and support for researchers in communicating health research.

Thank you and regards,

Khin Thet Wai Working Group Member HIFA-TDR project

HIFA profile: Khin Thet Wai is a former Director at the Department of Medical Research, Myanmar. She is a medical doctor and holds the Master's degree in Public Health from Institute of Medicine, Yangon and has a second Master's degree conferred by the Institute for Population and Social Research, Mahidol University, Thailand. She is a dedicated public health researcher specializing Epidemiology and Health Policy and Systems Research.
https://www.hifa.org/support/members/khin-thet_khinthewaidmr AT gmail.com

Q3. What is the role of researchers in research communication, beyond the publication of their paper? What is the role of other stakeholders (eg communication professionals, editors, media, public health professionals and critical thinkers)

It is of utmost importance to create the enabling environment for research communication beyond scientific publications. Researchers need to engage with regulatory authorities, policymakers and program implementers, academia, media personnel, and other influential stakeholders for future research directions to gather more evidence. The attempts to communicate reliable evidence to attract funding agencies for subsequent primary and secondary research are not uncommon. Multiple platforms and multiple channels are desirable in championing the relevant issues among public health professionals and also among academia to address further advancement of new knowledge gained. When it comes to unprecedented pandemics such as COVID-19, proven evidence of therapeutic and preventive

interventions stimulates the pharmaceutical industries for mass production. Moreover, communicating research evidence beyond published articles to regulatory authorities brings about specific actions such as emergency use authorization, expansion of authorization, and withdrawal of previously authorized therapeutic products. Researchers could convince policymakers to operationalise the cumulative evidence by simply phrasing policy briefs, plain language summaries, and new/modified/updated clinical guidelines. This reflects the role of tertiary research in handling the portfolio of research evidence beyond publications. On the other side of the coin, researchers' endurance is critical when facing with challenges of knowledge translation and transfer for complex issues.

Q4. What are the needs and preferences of policymakers?

Needless to say, researchers' commitment towards seeking solutions by primary and/or secondary research to address priority health problems and to empower communities should match with the preferences of policymakers. Considerable understanding of the needs and concerns of policymakers from the outset should be in place by taking into account of the annual reports, keynote addresses, recent health regulations and acts, donor evaluation reports, meeting minutes etc. Mostly, policymakers might prefer research recommendations leading to short term solutions with visible outcomes to gain public confidence and quick win. By and large, rapid surveys and mixed methods approaches might fulfil the needs of policymakers for quick decisions and resource allocation for implementing effective strategies. However, safeguarding the quality of research in terms of scientific integrity and ethical soundness is of paramount importance.

Q5. What can be done to better support researchers in the communication of health research?

Capacity building for knowledge management and developing policy briefs in terms of short courses, training workshops and introducing mentoring process will effectively support researchers to communicate health research successfully to policymakers. Their communication skills require further improvement in this connection. On the other hand, training/advocating policy makers and program implementers in knowledge translation and utilization of research findings might be helpful for researchers to overcome the existing barriers.

Subject: [hifa] Communicating health research (39) Q3. Role of researchers (2)

Sender: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

Date: Fri, 16 Sep 2022 10:09:28 +0000

From: Neil Pakenham-Walsh <neil.pakenham-walsh@ghi-net.org>

Dear HIFA colleagues,

Thank you all for your contributions to date. As an aide-memoire, here are the five guiding questions:

1. What do we mean by 'Effective communication of health research to policymakers?' How do we measure it?
2. What are the different approaches to communicating research (eg academic journals, policy briefs, interaction with policymakers, press releases, social media, infographics, use of video)? What is your experience with these approaches? What works and what doesn't?
3. What is the role of researchers in research communication, beyond

publication of their paper? What is the role of other stakeholders (eg communication professionals, editors, media, public health professionals and critical thinkers) 4. What are the needs and preferences of policymakers? 5. What can be done to better support researchers in the communication of health research?

We are especially keen to hear examples from your own experience as a researcher, policymaker or any other perspective.

You can review all messages here:

And you can contribute by sending an email here: hifa@hifaforums.org

Note: The above questions are for guidance only. Please feel free to comment on any aspect of health research communication. *We are especially keen to hear examples from your own experience as a researcher, policymaker or any other perspective.* For example, as a researcher, do you feel that your work has been considered in policymaking? Has it had an impact on policy and practice?

On this last point, a few people have suggested the aim is to change policy and practice. I'm not sure about this. 'Pushing' the findings of primary research to change policy and practice is not always the best way forward. There may be times when a primary study is, on its own, sufficient and compelling, but I suspect more often policy and practice should be based on research synthesis. Powerful communication of primary research direct to policymakers has the potential to distort rather than inform policy. What do you think?

Best wishes, Neil

Joint Coordinator, HIFA Communicating health research <https://www.hifa.org/projects/new-effective-communication-health-research-policymakers>

HIFA profile: Neil Pakenham-Walsh, Global Coordinator HIFA, www.hifa.org neil@hifa.org
Working in official relations with WHO

Subject: [hifa] Communicating health research (40) Q2. What are the different approaches? (7) Engaging stakeholders before and after research (2)
From: Neil Pakenham-Walsh <neil.pakenham-walsh@ghi-net.org>
To: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

The message below is forwarded from our sister forum CHIFA (global child health and rights). This is a great example of lived experience of research communication.

Communicating health research From "Martin Ndinakie Yakum, Cameroon"
<martinyakum@gmail.com> To CHIFA - Child Health and Rights
<CHIFA@hifaforums.org>

Dear all,

I think it is a bit difficult to give a standard definition to effective communication.

I want to share my experience in communicating research findings effectively. I believe that effective communication of research findings is a process starting from the research planning to the final results dissemination. I had a great experience in research findings communication when I was working with M.A.SANTE in Cameroon on the sustainable cholera surveillance research project. I can say that the communication with decision makers was effective because the findings of the research was used to revise national cholera contingency plan, organize OCV vaccination campaigns in cholera hotspots, and to integrate environmental cholera surveillance into the national surveillance system.

The success of this particular case could be attributed to multiple factors but essentially the following:

1. Policymakers were engaged at the planning stage of the study. The researcher's research question sometimes is not exactly the same question the policy makers are seeking answers. Therefore, engaging the health authorities, policy makers and other stake holders in the planning stage of the research would enable us (researchers) to know and integrate their concerns and questions on the subject matter. This early engagement stage does not only help to integrate their point of view but equally create some sort of expectations and anxiousness in them.
2. I was designated by our team to represent the project team at the national surveillance meeting in the MoH (held every week). This was a very good opportunity for the health authorities to remain in touch with the research team, keep everyone updated on the study progress.
3. Results dissemination seminars were organized 2 times per year, which was participated by policymakers, technical departments of the MoH, research team, and other partners. In this meeting, points discussed included research progress, key study findings, and recommendations. Sometimes recommendation to include certain aspects in the study, which would lead to amendment of the protocol.
4. Because the study team was constantly in contact with the health authorities, the team was always invited by the MoH anytime a seminar was organized on cholera or emergency response. For instance, the revision of national cholera contingency plan. These were opportunity for the team to give contributions and advocate for the findings of this study to be included in the national guidelines when applicable.

In summary, effective communication of research findings with policymakers is a continues process done in a participatory approach. This approach gives the chance to every stakeholder to express their needs in terms of research question and to formulate the recommendation from the study together. Just to share this experience because I think it might be useful.

Martin N. Yakum Epidemiologist martinyakum@gmail.com WhatsApp/Cell:
+237676489573

CHIFA profile: Yakum Martin Ndinakie is an Epidemiologist at M.A.SANTE in Cameroon. Professional interests: Health research in general and infectious diseases of poverty in particular. martinyakum AT gmail.com

Join CHIFA (child health and rights): <http://www.hifa.org/joinchifa>

Subject: [hifa] Communicating health research (41) Q1. What do we mean by Effective communication of health research? (10)
From: "Jacklyne Ashubwe, Kenya" <jashubwe@live.com>
To: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

Hi everyone,

I would like to share some thoughts on Q1: what is effective communication of health research to policy makers and how do we measure it?

1. I think to be effective there needs to be a clear roadmap for the communication which details the inputs, processes, and expected outcomes (both intended and potentially unintended). These (inputs, processes and outcomes) may be considered useful measurement points of effectiveness because doing the right thing, in a right way, is likely to produce the desired results

2. At the inputs level we can think about the key messages (content), which need to be aligned to the issues that are pertinent to the policy makers, in format that they find easy to interact with and provide clear recommendations in what actions need to be taken to bring about the desired change. It would also be useful to ensure that the message is accurate and reliable to ensure that it fosters sustained reliance on evidence to inform decision making by the policy makers in the long term.

3. The processes may include considerations such as the identification of the correct stakeholders/ audience for the specific message, timing of the communication, frequency of communication (will there be need for follow-up communication to reinforce/ clarify the issues), nature of forum/ setting for the communication etc.

4. The outcomes may include the consideration of the evidence alongside the other factors to be considered in the decision-making; an indication of intent to initiate a behavior change; interest from the decision makers to know more about the subject and what other evidence there is on the subject, etc.

These are just my personal reflections from my experience.

Kind regards, Jacklyne Ashubwe-Jalemba

HIFA profile: Jacklyne Ashubwe-Jalemba is a medical doctor and health systems researcher based in Nairobi, Kenya. She is a member of the HIFA project on Communicating health research, supported by TDR <https://www.hifa.org/projects/new-communicating-health-research-support-evidence-informed-policymaking>
<https://www.hifa.org/support/members/jacklyne> Email: jashubwe AT live.com

Subject: [hifa] Communicating health research (42) Webinar: Building Trust in Science Communication
From: "Khin Thet Wai, Myanmar" <khinthewaidmr@gmail.com>

To: HIFA - Healthcare Information...snip... neil.pakenham-walsh@ghi-net.org>

Dear Sir,

May I forward the announcement of special online event related to research communication.

Thank you and Regards,

Khin Thet Wai

HIFA profile: Khin Thet Wai is a former Director at the Department of Medical Research, Myanmar. She is a medical doctor and holds the Master's degree in Public Health from Institute of Medicine, Yangon and has a second Master's degree conferred by the Institute for Population and Social Research, Mahidol University, Thailand. She is a dedicated public health researcher specializing Epidemiology and Health Policy and Systems Research. <https://www.hifa.org/support/members/khin-thet> khinthetwaidmr AT gmail.com

From PLOS <community@e.plos.org> Date Mon, 12 Sep 2022, 22:07 Subject You're invited! Building Trust in Science Communication – a special online event!

Join speakers from Retraction Watch, Science Media Center, and PLOS View this email in your browser

<<https://view.e.plos.org/?qs=184f3c9a17ae3dce18e45cfb9006c67978406a06818792d8d97b4a5f50cab4e4cde59a5671b7842897c963c1610667f8cb2035b345993bb1a3758f5c5ad9af05cf3871555b280562296d7f579384b2c4>> - How do we know when scientific research is reliable? - What is the role of journalists in communicating new discoveries? - How should we handle suspected misconduct?

This Peer Review Week, explore issues at the intersection of peer review, science, and the media with a panel of experts from Retraction Watch, Science Media Center, and PLOS.

Thursday September 22nd 5pm CET | 4pm BST | 11am EST | 8am PT Register Now
<<https://click.e.plos.org/?qs=af7f48e63b250722020f7cf42dd3b97193b84558ccf37322a91e846deaf7cd55e126b795ba80f092aa59f0d1fdce730f11cf1d6c2d75a59a>>

About the webinar

Building Trust in Science Communication: the role of journals and journalists, pre- and post-publication

In celebration of Peer Review Week 2022, join a panel of experts in science journalism and editorial ethics to explore issues related to peer review, research integrity, and the public's understanding of—and trust in—science. We'll explore issues including:

- Interpreting research for the public in a way that balances accessibility with the mutability and nuance inherent in discovery - Communicating about the scientific editorial and peer review process itself - What happens when concerns arise after an article is published

With panelists: Ivan Oransky, Retraction Watch Fiona Fox, Science Media Center, UK
Renee Hoch, PLOS Publication Ethics Team

Hosted and moderated by Beth Baker, Sr. Media Relations Manager at PLOS

Subject: [hifa] Communicating health research (43) Q1. What do we mean by Effective communication of health research? (11) How do we measure it? (4)
From: "Khin Thet Wai, Myanmar" <khinthewaidmr@gmail.com>
To: HIFA - Healthcare Information...snip...
Neil Pakenham-Walsh <neil@hifa.org>

Please allow me to share my ideas concerning "Effective communication of health research to policymakers".

Effective communication of health research to policymakers implies the reach of clear, concise, credible, feasible, and understandable investigator-proposed solutions/research recommendations in different forms in combination in a timely manner through multiple communication channels and multiple platforms during dissemination. Apparently, it is not a far cry from reality.

Apart from the dissemination efforts targeting policymakers at various levels after completion of research, enablers of effective communication of health research should also include initial advocacy about the research project to policymakers and other stakeholders. This will facilitate to attain more than tangible and intangible benefits.

I would like to propose indicators to measure the effectiveness inclusive of: awareness, interest, understanding, gaining trust towards research evidence, degree of meeting the expectations/needs/preferences, able to integrate with political and other commitments, timely application and visibility of potential health impact. These process and outcome indicators can be measured by ranking as low, medium and high. Frankly speaking in resource constrained settings compared to affluent societies, impact in terms of regulations, changing implementation guidelines in public health and clinical dimensions and societal changes will take time depending on donors and other support.

Regards, Khin Thet Wai

HIFA profile: Khin Thet Wai is a former Director at the Department of Medical Research, Myanmar. She is a medical doctor and holds the Master's degree in Public Health from Institute of Medicine, Yangon and has a second Master's degree conferred by the Institute for Population and Social Research, Mahidol University, Thailand. She is a dedicated public health researcher specializing Epidemiology and Health Policy and Systems Research. <https://www.hifa.org/support/members/khin-thet> khinthewaidmr AT gmail.com

Subject: [hifa] Communicating health research (44) UN: 'We are not asking scientists to tell us what to do. We are asking scientists to show us the options'

From: "Richard Fitton, UK" <richardpeterfitton7@gmail.com>
To: HIFA - Healthcare Information For All <HIFA@hifaforums.org>
Cc: UN World Data Forum <dataforum@un.org>

INTERVIEW: New General Assembly President will seek every opportunity to build trust || UN News <https://news.un.org/en/interview/2022/09/1126781?utm_source=UN+News+-+Newsletter&utm_campaign=92f9ed91e3-EMAIL_CAMPAIGN_2022_09_17_12_46&utm_medium=email&utm_term=0_fdbf1af606-92f9ed91e3-107387858>

The new Assembly President also told UN News that the theme for the body's 77th session, would be 'solutions through solidarity sustainability and science', aiming specifically to enhance the role of science in the UN body's decision shaping.

'Member States are struggling with declining trust [and] division. Our task is to find solutions based on evidence; solid evidence that can help us move forward. Science can provide science-based evidence, Mr. KÅ‘rÅ‘si said, stressing; 'We are not asking scientists to tell us what to do. We are asking scientists to show us the options and to show us what might be the consequences of our actions or inaction. Science should be invited as a 'supporter', but ultimate political decision making remains with the Member States.

A global EHR solution seems to fit the bill for an objective that every one can aim for?

R

Digital health (who.int) <https://www.who.int/health-topics/digital-health/#tab=tab_1>

HIFA profile: Richard Fitton is a retired family doctor - GP. Professional interests: Health literacy, patient partnership of trust and implementation of healthcare with professionals, family and public involvement in the prevention of modern lifestyle diseases, patients using access to professional records to overcome confidentiality barriers to care, patients as part of the policing of the use of their patient data Email address: richardpeterfitton7 AT gmail.com

Subject: [hifa] Communicating health research (45) Q3. Role of researchers (3)
From: Neil Pakenham-Walsh <neil.pakenham-walsh@ghi-net.org>
To: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

Dear all,

Thank you for your contributions to the discussion so far. - Review messages here: <https://www.hifa.org/rss-feeds/17> - More info here: <https://www.hifa.org/projects/new-effective-communication-health-research-policymakers> - Send your thoughts by email here: hifa@hifaforums.org

We now enter week 3 of our discussion and our guiding question is:

Q3. What is the role of researchers in research communication, beyond publication of their paper? What is the role of other stakeholders (eg communication professionals, editors, media, public health professionals and critical thinkers)

On this topic we have already had some relevant comments:

David R. Walugembe (Canada): 'As strategic planners/project managers, researchers have a role to network and engage the identified stakeholders to bridge the identified gaps and provide sufficient clear guidance on what they would wish other stakeholders to support them with.'

Ama Fenny (Ghana): 'The researchers work does not end with the publication of their paper as is often the case. It is important for the results to be given more visibility...'

Khin Thet Wai (Myanmar): 'It is of utmost importance to create the enabling environment for research communication beyond scientific publications. Researchers need to engage with regulatory authorities, policymakers and program implementers, academia, media personnel, and other influential stakeholders...'

There seems to be consensus that researchers should have a role in research communication, and that this role should be strengthened.

What do you think?

Best wishes, Neil

Joint Coordinator, HIFA Communicating health research <https://www.hifa.org/projects/new-effective-communication-health-research-policymakers>

Let's build a future where every person has access to reliable healthcare information and is protected from misinformation - Join HIFA: www.hifa.org

HIFA profile: Neil Pakenham-Walsh is coordinator of the HIFA global health movement (Healthcare Information For All - www.hifa.org), a global community with more than 20,000 members in 180 countries, interacting on six global forums in four languages in collaboration with WHO. HIFA brings stakeholders together to accelerate progress towards universal access to reliable healthcare information. HIFA is administered by Global Healthcare Information Network, a UK based non-profit in official relations with the World Health Organization. Twitter: @hifa_org neil@hifa.org

Subject: [hifa] Communicating health research (46) Q1. What do we mean by Effective communication of health research? (12) How do we measure it? (5)
From: Neil Pakenham-Walsh <neil.pakenham-walsh@ghi-net.org>
To: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

The central question in our discussion is: What are the most impactful methods for researchers to communicate their research to policymakers so that the research is seen and applied?

With this in mind, I would like to ask all researchers (and others) on HIFA:

Have you ever published a paper? Did it make a difference to policy or practice? Or was it ignored?

Please let us know your experience!

Meanwhile, I was interested to see that Google Scholar publishes 'most influential papers' each year. It bases this on citations - easy enough to measure, but does the number of citations correlate with whether or not the research is seen and applied in policy and practice? I suspect there is a weak correlation. The most cited medical paper of 2021, however, has indeed been referenced also in almost 100 policy documents to date.

-- Google Scholar reveals its most influential papers for 2021 Read in full:
<https://www.nature.com/nature-index/news-blog/google-scholar-reveals-most-influential-papers-research-citations-twenty-twenty-one>

'Early clinical observations of COVID-19 and its mortality risk factors among the most cited output, while a five-year-old AI paper continues to command attention.

'COVID-19-related papers have eclipsed artificial intelligence research in the annual listing of the most highly-cited publications in the Google Scholar database. The most highly cited COVID-19 paper, published in The Lancet in early 2020, has garnered more than 30,000 citations to date (see below for paper summary)...

'Published in February 2020, this is one of the earliest papers to describe the clinical characteristics of COVID-19. It was authored by researchers in China and doctors working in hospitals in Wuhan, the city where COVID-19 was first detected in late 2019...

'The final sentences of the paper call for robust and rapid testing, because of the likelihood of the disease spreading out of control...

'The paper has been referenced or cited in almost 100 policy documents to date, including several released by the World Health Organization on topics such as mask-wearing and clinical care of patients with severe symptoms...' --

Best wishes, Neil

Joint Coordinator, HIFA Communicating health research <https://www.hifa.org/projects/new-effective-communication-health-research-policymakers>

Let's build a future where every person has access to reliable healthcare information and is protected from misinformation - Join HIFA: www.hifa.org

HIFA profile: Neil Pakenham-Walsh is coordinator of the HIFA global health movement (Healthcare Information For All - www.hifa.org), a global community with more than

20,000 members in 180 countries, interacting on six global forums in four languages in collaboration with WHO. HIFA brings stakeholders together to accelerate progress towards universal access to reliable healthcare information. HIFA is administered by Global Healthcare Information Network, a UK based non-profit in official relations with the World Health Organization. Twitter: @hifa_org neil@hifa.org

Subject: [hifa] Communicating health research (47) Q3. Role of researchers (4)
From: "Meena Cherian, Switzerland" <cherianm15@gmail.com>
To: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

Dear Neil,

In response to the Q3: What is the role of researchers in research communication, beyond publication of their paper? What is the role of other stakeholders (eg communication professionals, editors, media, public health professionals and critical thinkers)

Researchers will have to expand their role beyond 'academic goals' by involving themselves in communicating their research to community level.

Raising awareness on the burden of disease and solutions at the grassroots level is a catalyst for socio-behavioural change and policies.

Very often, important research are published and cited in high impact factor journals, however there is a delay in communication to the public particularly in layperson's language.

Therefore, collaborations between health information forums and media, schools, public/community centres would not only enhance updated scientific information but would also generate evidence-based decision-making for proposing policy agenda in a timely manner.

Best wishes meena

Dr Meena Nathan Cherian, MBBS, MD (Anaesthesia) Former WHO Lead Emergency and Essential Surgical Care Program, Geneva, Switzerland. Director, Global Health New Challenges:online courses, Geneva Foundation for Medical Education & Research (GFMER), Switzerland. www.gfmer.ch/surgery/cancer.htm Senior Advisor, Global Action, International Society of Geriatric Oncology (SIOG), Switzerland. SIOG Secretariat - SIOG Adjunct Prof. The Chinese University of Hong Kong, Shenzhen, HK China. <https://med.cuhk.edu.cn/en/teacher/371> WHO-HIFA Working Group on Essential Health Services and COVID-19; mHEALTH-INNOVATE. www.hifa.org Geneva, Switzerland. +41 763837253(m); cherianm15@gmail.com

HIFA profile: Meena Cherian is Director, Emergency & Surgical Care program, Geneva Foundation of Medical Education and Research, Geneva, Switzerland. She is a member of the HIFA working group on Essential Health Services and COVID-19. <https://www.hifa.org/support/members/meena> <https://www.hifa.org/projects/essential-health-services-and-covid-19> www.gfmer.ch cherianm15 AT gmail.com

Subject: [hifa] Communicating health research (48) Q3. Role of researchers (5)

How can researchers make their research more visible?

From: Neil Pakenham-Walsh <neil.pakenham-walsh@ghi-net.org>

To: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

1. Meena Cherian (Switzerland): 'Researchers will have to expand their role beyond 'academic goals' by involving themselves in communicating their research to community level.' 2. David R. Walugembe (Canada): 'As strategic planners/project managers, researchers have a role to network and engage the identified stakeholders to bridge the identified gaps' 3. Khin Thet Wai (Myanmar): 'Researchers need to engage with regulatory authorities, policymakers and program implementers, academia, media personnel, and other influential stakeholders...'

There is growing consensus in our discussion that researchers should take a stronger and wider role in research communication.

Clearly, if a researcher's objective is to make their research more visible, then they will want to use whatever means at their disposal for this objective.

I invite discussion: How can researchers make their research more visible?

Here are some initial thoughts, some perhaps obvious, some already mentioned:

1. Align the research with policymakers' priorities 2. Engage with policymakers before, during and after the research 3. Publish the research in a high-impact journal 4. Provide a summary of the research in the appropriate format and language(s) 5. Prepare and implement a dissemination strategy 6. Present the research at conferences and press meetings, as appropriate...

Would you like to add or comment on the above?

A representative of the research team (usually the 'corresponding author') needs to be available at all times after publication for other academics and other stakeholders to contact for comment, questions and clarifications. From my experience, it is hit-and-miss (more often miss) whether a corresponding author responds in practice. Occasionally we have corresponding authors join the HIFA forum to engage in discussion on the implications of their research.

What about the role of other stakeholders, eg communication professionals, editors, media, public health professionals and critical thinkers?

With communication professionals, perhaps the research team itself includes a communication professional, or at least someone who has built skills and expertise in this area. In some research institutions, perhaps there is a dedicated communications and media department whose role is specifically to increase the visibility of research. Have you any experience of working as (or with) a media or communication professional? It would be great to hear from you: hifa@hifaforums.org

We would also like to hear from you if you are an editor, a public health professional, or a 'critical thinker'.

Best wishes, Neil

Subject: [hifa] Communicating health research (49) Q1. What do we mean by Effective communication of health research? (13)
From: "Neil Pakenham-Walsh, UK" <neil.pakenham-walsh@ghi-net.org>
To: HIFA - Healthcare Information For All <HIFA@hifaforums.org>
Cc: terryr@who.int ...snip...
siebers@who.int

Dear Sam and all,

Thank you for your 'five quick thoughts on what effective communication of health research to policymakers entails and how it can be measured (Q1)'. <https://www.hifa.org/dgroups-rss/communicating-health-research-35-q1-what-do-we-mean-effective-communication-health>

As you say, these were intended as 'inputs for discussion and revision'.

To keep this message short, I'm just going to look at the first:

"1) Effective communication of health research implies a measurable change in policy or practice."

I think 'effective communication of health research' does not necessarily imply a measurable change in policy or practice. It depends on whose perspective one is talking about, and how one defines the term 'effective'.

From the perspective of a primary researcher, I suspect that many (not all) would want to see a change in policy or practice that had resulted from their research, at least in part. And if that change is shown to lead to improved health outcomes, so much the better.

But not all health research recommends a change in policy or practice, and often such recommendations are not specific. Some research may even recommend current policy to stay as it is.

So perhaps the term 'effective communication' should focus more on getting the attention and consideration of policymakers (and their advisers) rather than what they choose to do with it?

You continue: "When discussing communication strategies with researchers, policy makers, or programme implementers, I often find there is no common understanding of what exactly we are looking to achieve and with whom. Yet, a shared vision of change and tangible objectives are fundamental to any successful communication strategy, and should precede summarizing evidence, selecting dissemination tools, and crafting messages. Communication is as effective as the change it is trying to facilitate, and said change rarely unfolds in a linear way (see below)."

Here I am on the same page. The definition of 'effectiveness' depends on what the objectives are for the communication. And if there is no common understanding of objective, and a plan to achieve it, then communication is more likely to fail.

I would be very interested to hear any examples of a communication strategy for a piece of research. What were the objectives for the communication? What did you do? What were the results? Were any lessons learned that could be shared with others.

Best wishes, Neil

Subject: [hifa] Communicating health research (50) Q2. What are the different approaches? (8)

From: "Joseph Ana, Nigeria" <HIFA@hifaforums.org>

To: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

Neil thank you for sharing the question: 'The central question in our discussion is: What are the most impactful methods for researchers to communicate their research to policymakers so that the research is seen and applied?'

On seeing the shocking findings of the failing Health system in Cross River State, Nigeria in 2004, from the comprehensive situation analysis conducted by the State Ministry of Health (SMOH), especially the findings that previous policies did not seem to factor in measures to address the social determinants of health: such as poverty, ignorance and superstition that exacerbated existing heavy disease burden. It was decided that whatever plan we designed had to draw-in and engage other sectors of the state government, hence the first state health plan was anchored on a Health in All Policies Policy (HiAPP) approach, which gave birth to the 12-Pillar Clinical Governance Programme. We (the SMOH) engaged all of government in health, in particular, the ministries of Finance, Education, Water resources, Power and Electricity, Works and Roads, Lands and Housing, Information and Public Enlightenment, and Governor's Office had representation the Management Committee of the Centre for Clinical Governance Research and Training (the Think Tank). We also engaged every donor / development partner working in the State and outside it. In addition, there was a patient representative in the Committee. The interaction with and participation of these non medical representatives provided a rich resource pool for feeling the pulse of the users of the health system, from which some research questions were even generated. The HiAPP made it easier for research results to be shared across government and the public much more easily.

Some of the outputs from HiAPP, led Cross River State to lead other states in ground breaking policies, including i) that only Cross River State bought into the National Health Insurance Scheme in 2006 to deal with the challenge of out of pocket payment for health care services driving families into poverty and making millions delay access to care and leading to more complications, cost of care and poorer prognosis; ii) passing the Legislation on mandatory wearing of car seat belts and helmets for motor cyclists, which led to a dramatic fall in morbidity and mortality from Road Traffic Accidents; iii) overcoming the population's resistance to the ABC (abstinence, Be faithful, Condom) message for HIV Control, which led to unprecedented 50% drop in HIV seroprevalence in three years (from 12% to 6.1%). The message here is that involving non medical people and the wider population at the pre-research [pre-research] and concept level aids later communication of the results from research, which also aids evidence informed policy making and implementation.

Joseph Ana.

Prof Joseph Ana Lead Senior Fellow/ medicalconsultant. Center for Clinical Governance Research & Patient Safety (ACCGR&PS) P: +234 (0) 8063600642 E: info@hri-global.org 8 Amaku Street, State Housing & 20 Eta Agbor Road, Calabar, Nigeria. www.hri-global.org

Subject: [hifa] Communicating health research (51) Q2. What are the different approaches? (9)

From: Neil Pakenham-Walsh <neil.pakenham-walsh@ghi-net.org>

To: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

Joseph, thank you. You said: "from the comprehensive situation analysis conducted by the State Ministry of Health (SMOH)... only Cross River State bought into the National Health Insurance Scheme in 2006 to deal with the challenge of out of pocket payment for health care services driving families into poverty... passing the Legislation on mandatory wearing of car seat belts and helmets for motor cyclists, which led to a dramatic fall in morbidity and mortality from Road Traffic Accidents... overcoming the population's resistance to the ABC (abstinence, Be faithful, Condom) message for HIV Control... involving non medical people and the wider population... aids evidence informed policy making and implementation"

In the context of our discussion on research communication, what I am understanding here is that evidence-informed policy leading to improved outcomes has less to do with the effectiveness of communication of individual researchers, and more to do with the mindset of policymakers. Policymakers in Cross River State, including yourself as High Commissioner, recognised the need for evidence-informed policymaking. The situation analysis looked at all the available evidence on a range of issues and developed policy on that basis.

Looking at the role of researchers, it is important that they work together to promote evidence-informed policymaking. The question then becomes: What is the role of researchers (and other stakeholders) in promoting evidence-informed policymaking and what is their role in countering policymaking that ignores the evidence? For the latter, I am reminded of the role of academics in countering the heads of state of the USA and Brazil during the COVID-19 pandemic.

Best wishes, Neil

Subject: [hifa] Communicating health research (52) Q2. What are the different approaches? (10)

From: "Joseph Ana, Nigeria" <HIFA@hifaforums.org>

To: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

Thank you Neil.

At least in the environment and context where my experience comes from, it will be more difficult for a sole researcher to get his/her result put into policy, because of all the other

extraneous factors that come into play when public policy is being made. Not least is the 'carrying along' factor.

Therefore engaging as wide as possible many people especially those in the policy making corridors is crucial. Yes, the research findings should be valid and useable but engagement as early as in the pre-research Stage is very important. Other advantages of early engagement are that everyone has a sense of ownership in the policy and the outcomes and it makes scale up more likely and easier.

Joseph Ana

Subject: [hifa] Communicating health research (53) Q2. What are the different approaches? (11)

From: Neil Pakenham-Walsh <neil.pakenham-walsh@ghi-net.org>

To: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

Dear Joseph,

"it will be more difficult for a sole researcher to get his/her result put into policy"

Indeed, do we have any researchers on HIFA whose work has led to a change in policy. whether Policy (with a big P, as in national/subnational policy) or policy with a small p (eg project/programme implementation)?

What were the key ingredients to make this happen in terms of research communication? What was the role of your research team? What was the role of your institution?

The above questions apply especially where the research team is fully convinced they have robust findings and recommendations that they believe should be implemented.

Perhaps more often the research team recognises that their results are just part of a bigger picture and their objective is not to change policy but to help inform policy. The best approach available to paint this bigger picture is the systematic review. So one definition of 'effective research communication' is that the study is included in a subsequent systematic review.

In addition to contributing to a systematic review, local/national researchers have a unique role to study relevant factors in their country, so that policymakers and their advisers can synthesise global evidence (typically systematic review) with local evidence. Or perhaps there are occasions when the local evidence is so compelling that the global evidence becomes secondary? And there may be situations where decision making relies entirely on local evidence.

We look forward to learn from your experience. The outputs of this discussion will help inform future efforts in research communication.

Please send your thoughts to: hifa@hifaforums.org

Best wishes, Neil

Subject: [hifa] Communicating health research (54) Q2. What are the different approaches? (12)

From: "Ama Fenny, Ghana" <HIFA@hifaforums.org>

To: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

Dear Team,

In answer to this thread, I agree that the job of communicating research output to the relevant stakeholders takes more than the effort of one person. What has worked for us in one of my past projects was the involvement of all stakeholders - government, CSOs, NGOs, queen mothers and chiefs etc right from the inception to the end of the project. When the final results were released, we did an abridged version and shared this with all the people who were part of the process. As we engaged on different platforms - workshops, national forums etc, we were eventually called to present the findings to the Vice president of Ghana. We still published several papers and book chapters but what made the impact was making the information less technical and more accessible to those who needed it the most - policymakers.

Ama Pokuaa Fenny, PhD Institute of Statistical, Social and Economic Research (ISSER) University of Ghana, Legon, Ghana Tel: +233 261563405 Skype: afenny Twitter: @ama_fenny Profile: <http://isser.ug.edu.gh/people/dr-ama-pokuaa-fenny> Blogs: <https://r4d.org/blog/how-covid-19-affected-vaccine-procurement-processes-in-ghana/> <http://southernvoice.org/ensuring-equitable-vaccine-access-in-africa-and-the-role-of-regional-partnerships/>

HIFA profile: Ama Pokuaa Fenny is a Senior Research Fellow with the Institute of Statistical, Social and Economics Research (ISSER) at the University of Ghana. She is a health economist whose research focuses on the evaluation of health and development programs in low- and middle-income country settings. In these settings, she studies the role of health financing strategies in offering social protection to vulnerable groups, targeted health system strategies to improve health seeking behavior and costing and cost-effectiveness methods that address efficiency of health programmes. Her current research focuses on the evaluation of child and adolescent health interventions and the integration of governmental policies into service delivery systems in Africa. At ISSER, Dr. Fenny provides leadership and oversight to projects involving research, project implementation, technical assistance and policy advocacy across a range of subjects. She is a member of the HIFA working group on Communicating health research.

<https://www.hifa.org/support/members/ama> amafenny AT yahoo.co.uk

Subject: [hifa] Communicating health research (55) Q2. What are the different approaches? (13)

From: Neil Pakenham-Walsh <neil.pakenham-walsh@ghi-net.org>

To: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

Dear Ama,

Thank you for your description of how you involved stakeholders in your research. You mentioned that "what made the impact was making the information less technical and more accessible to those who needed it the most - policymakers". Can you say a bit more about this? Was there anything in particular which seemed to have a great impact on policymakers? Was it perhaps the plain-English summaries, or perhaps the delivery of powerful speeches at face-to-face events?

It would be wonderful to hear from you and others what made an impact. If I think back to previous conferences and meetings, sometimes a personal story was even more compelling than a stark statistic. I have heard policymakers speak movingly about how they witnessed a death or someone suffering, and I even remember one policymaker who said something like "I resolved there and then to make this my priority in office". My own experience of witnessing 35 years ago an unnecessary child death in Peru due to lack of basic knowledge on how to treat diarrhoea (the parents had believed they should withhold fluids, thereby unknowingly precipitating her death) was the seed for my lifelong commitment to improve the availability and use of reliable healthcare information.

Do you or others have examples of different approaches to research communication you can share?

Best wishes, Neil

Subject: [hifa] Communicating health research (56) Q2. What are the different approaches? (14)

From: "Mark Storey, USA" <mstorey@igc.org>

To: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

Dear colleagues,

I think this topic is of real significance, but I wonder to what extent the lessons learned from past experience are sufficiently generalizable. Setting aside the question of whether the research conclusively points toward a necessary change (which is another very significant and interesting topic), I think approaches will vary based on a number of complex factors including:

1. What is the operational level of the change you are seeking?

Who has the authority to implement the change? Is the intervention or change something that can be implemented by individual practitioners (e.g., physicians, public health officials), or does it require a policy approval or decision within an organization (e.g., a hospital, clinic, or agency), or is it something that needs to be agreed upon or enacted at the association or government level?

2. What are the political and personality factors among the individuals and organizations that have the authority to approve the change or not?

This is going to vary everywhere, but I think lessons can be drawn from experiences in which people have overcome obstacles among different personality/obstacle types (e.g., individuals who will only act if they see something in it for themselves, individuals with a vested interest in keeping the status quo, individuals who are just set in their ways and don't want to be bothered).

3. Who are you?

Are you an insider/part of the system and what is your institutional relationship to the authorities you are trying to influence? Or are you an outsider (from a foreign-financed NGO or an independent entity) and what is your reputation, what kinds of leverage/incentives do you have available?

There are a wide range of approaches that might be appropriate depending on the answers to the questions above, and it would be useful to develop a toolkit (describing the different types of interventions) together with a number of brief case studies providing examples of different approaches used at many of the different operational levels and local settings in which changes have successfully (or even unsuccessfully) been promoted.

In my own past experience, which focused on promoting the use of evidence-based clinical guidelines at the institutional hospital or clinic level, our approach was to (a) identify and promote individual champions within the institution and (b) learn about existing quality review processes and try to find ways to engage within them to promote change. But if we had been doing something at the city, regional, or national level our approach of course would have been quite different.

P.S. It's been more than a decade since I've engaged with HIFA because my career took me in other directions for a while, but I've stayed on the HIFA mailing lists because it's a cause I've always felt passionate about. I'm excited to be back and firmly rooted in global public health, and I look forward to engaging with all of you more proactively again!

Mark Storey mstorey@igc.org Senior Research Associate, Department of Epidemiology, Milken School of Public Health, George Washington University Managing Director, HealthConnect International, <http://healthconnect-intl.org/> MPH Program, Milken Institute School of Public Health, George Washington University

HIFA profile: Mark Storey has designed, implemented, and evaluated ICT for health programs for over fourteen years. As the former Director of ICT Programs at the American International Health Alliance, he created the Learning Resource Center project, which established ICT capacity at over 160 health organizations in Eurasia and Africa, and the EurasiaHealth Knowledge Network, an online clearinghouse and virtual community supporting health professionals in the Eurasia region. He has directly provided consulting support for health ministries in Albania, Eritrea, Kyrgyzstan, and Turkmenistan. He specializes in program design and management, evaluation and assessment, information architecture, and sustainability training.

[*Note from NPW, moderator: Thank you Mark for this thoughtful contribution, and welcome back! For your HIFA profile I have borrowed the text from <http://healthconnect-intl.org/team.html> as this is more uptodate than the one we have.]

Subject: [SPAM][hifa] Communicating health research (56) Incremental policy change (1) Adoption of patient access to medical records
From: "Richard Fitton, UK" <richardpeterfitton7@gmail.com>
To: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

30 years of research, design and implementation seems almost irrelevant to when considering the pace at which covid was responded to but the principles are the same, perhaps requiring design, development, ethically approved experiment, then technical, public, government, media, regulatory and professional acceptance and buy in.

I have been well supported by 5 out of six MPs and am in correspondence with and in attendance at the surgery of my local MP on two digital health issues.

I reckon iterates [it takes] 12 to 18 months to successfully help an MP to "understand" your case and about another two or three to get the all party committees to understand.

It was through the House of Commons and then Health Minister Alan Johnson that we helped persuade the MOH, Liam Donaldson, to write to the DG of the WHO asking the WHO to include patient access to records in the WHO ec directive.

Microsoft came to our practice as and before they launched their Healthvault. Healthvault was what was needed to allow patients to process their own health using their own records. As one IT project lead said of our mission in 2001 "you are so far down the road that no one can see you."

We wrote a report for the house of lords and Richmond Group of Charities on the political, regulatory, clinical, media, research and public engagement history of patient access to records in 2018.

I have pasted an edited version which is probably too long [*] but it shows the interdependence of all of the above agencies.

I can share the complete report with anyone who is interested.

Digital versus paper data

The General Practice records in the United Kingdom were traditionally paper-based and importantly retained cradle to grave. One very commonly encountered way of organising a patient's entire medical record was to place it in a buff-coloured, stiff card, 5 by 7 inch wallet known as a Lloyd-George Envelope. The records were linked to a national register of British citizens held by Somerset House and managed at Exeter.

*From cradle to grave and after? *

Each record was lifelong, beginning at the birth of each patient or of their registration with Somerset House or with the health insurance scheme. All correspondence and events (including birth, maternity, contraception, vaccinations, infancy, breast and bowel and cervix screening, disease, death and dying) relating to the patient's health care under the health

insurance and later to their NHS care were to be copied to the record in paper hard copy making it a life long record of the patient's medical and preventative history.

At that time most practices only recorded incident by incident notes with no summary and in handwriting and mnemonics that could not be interpreted except by the author.

The senior partner at West Gorton Medical Centre 1 1984 explained Richard - patients in the inner city have less choices and enjoy immediate gratification over deferred gratification
How to address these issues? Could the patient accessed record with results, text and documents become a source of education for the patient?

Over the next twenty years the press - particularly the editor of The Glossop Chronicle were immensely helpful in supporting the different approach to health.

November 1992 Dr Fitton applied to North Derbyshire Family Health service Authority take over a single handed practice in Hadfield, Glossop to utilise patients, information and building to improve health and to allow patients to have copies of and to access their records

October 1995 A paper was written with the patients on 'A patient-centred medical centre' a radical rethink about patient care:

Could an interoperable personal health record controlled by the patient and as such not subject to the Data Protection Act help communication?

[...]

HIFA profile: Richard Fitton is a retired family doctor - GP. Professional interests: Health literacy, patient partnership of trust and implementation of healthcare with professionals, family and public involvement in the prevention of modern lifestyle diseases, patients using access to professional records to overcome confidentiality barriers to care, patients as part of the policing of the use of their patient data Email address: richardpeterfitton7 AT gmail.com

[*Thanks Richard, yes I have redacted this for length - All: please contact Richard to obtain full copy]

Subject: [hifa] Communicating health research (58) Responses to Q1, Q2, Q3, Q4 and Q5

From: "Hajime Takeuchi, Japan" <takechanespid@gmail.com>

To: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

I reply to the questions.

1. What do we mean by 'Effective communication of health research to policymakers?' How do we measure it?

If the products derived from health research and released to the public lead to better health of people, such research products will be adopted as the medical basis for policy formulation,

and the interests of the people affected by the policy should be given top priority in the Diet [*1 see note below] that the discussion will take place.

The measurement is the number or percentage of health research products used as medical grounds for policymaking. And the actual policy decisions and the extent to which policy is based on research products. It is also important for an evaluation to be verified by a third-party organisation from an impartial standpoint.

2. What are the different approaches to communicating research (eg academic journals, policy briefs, interaction with policymakers, press releases, social media, infographics, use of video)? What is your experience with these approaches? What works and what doesn't?

Policymakers possibly make policy proposals based on research results during Diet deliberations. Alternatively, to create public opinion that policymakers have no choice but to reflect health research in policy, we will hold study sessions with the media in the Diet members' office building. Another option is to gather the petitions for the necessary policies and submit them to representatives of Diet members or the Minister of Health, Labor and Welfare. In reality, however, such policy-making proposals are often ignored, and the mass media do not even attempt to report on them. On the other hand, when the wind as the possibility of the proposal is realised blows, the mass media pick up the proposal as news, and policymakers may react sensitively to that wind.

3. What is the role of researchers in research communication, beyond publication of their paper? What is the role of other stakeholders (eg communication professionals, editors, media, public health professionals and critical thinkers)

Research results should be returned to society and should never be researched for research [*2]. To that end, it is essential to design what the research is for what and for whom, what hypotheses exist, and what we want to clarify. As long as it is health research, we should make some new proposals for current health policy. It is crucial to conduct research from the standpoint of the socially vulnerable, aim for a better society, and stand on the side of those in difficulty to raise their voices and reflect it in the policy.

4. What are the needs and preferences of policymakers?

I think it depends on the position of the politician. Still, in the case of Japan, the government has been in a conservative place for a long time after WW2, and some private appropriations can not be said to be democratic. These interpretations to realise policies are convenient for the government but are twisted.

5. What can be done to better support researchers in the communication of health research?

I think that solidarity with international society is important. In the Japanese medical community, there is a strong tendency to evaluate cutting-edge technologies such as iPS cells and genetic research and clinical medicine such as emergency medicine.

Human resources development related to public health is not emphasised, the domestic sociological society is small, and the pediatric community has not yet formed an appropriate recognition of the field of social paediatrics.

In such a situation, the Japanese medical community needs to incorporate the perspective of medicine as a social science that understands health problems in society. I think bringing in a wind of information from international organisations is essential.

Hajime

A dream you dream alone is only a dream. A dream you dream together is reality.

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Prof. Hajime Takeuchi, MD (Paediatrician) School of Social Welfare Graduate School of Social Welfare BUKKYO University 96, Kitahananobo-cho, Murasakino, Kita-ku, Kyoto 603-8301, Japan TEL +81-75-366-5595 (dial-in) E-mail: takechanespid@gmail.com

HIFA Profile: Hajime Takeuchi is a professor at the Bukkyo University in Japan. Professional interests: child health, child poverty, child wellbeing. takechanespid@gmail.com He is a CHIFA Country Representative for Japan and a member of the CHIFA Steering Group (child health and rights) <http://www.hifa.org/support/members/hajime> takechanespid AT gmail.com

[*Note from NPW, moderator: 1. 'The National Diet is Japan's bicameral parliament. It is composed of a lower house, called the House of Representatives, and an upper house, the House of Councillors' https://en.wikipedia.org/wiki/National_Diet] 2. Hajime, please can you explain "should never be researched for research"?

Subject: [hifa] Communicating health research (59) Q2. What are the different approaches? (15)

From: Neil Pakenham-Walsh <neil.pakenham-walsh@ghi-net.org>

To: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

[On behalf of Ama Fenny]

Thanks Neil for the question. [<https://www.hifa.org/dgroups-rss/communicating-health-research-55-q2-what-are-different-approaches-13>] It was in simple English and also stating the key messages clearly. It involved 3 basic steps, stating the facts (results), stating the implications (effect on individuals, families, businesses and economy) and finally the call to action (advocating for policy change to curb productivity loss).

Different news agencies captured it in their own style, an example in the link below: [https://www.isser.ug.edu.gh/policy-comment/ghana-lost-189m-2016-economic-costs-violence-against-women-%E2%80%93-isser#:~:text=A%20study%20by%20the%20Institute,women%20and%20girls%20\(VAWG\).](https://www.isser.ug.edu.gh/policy-comment/ghana-lost-189m-2016-economic-costs-violence-against-women-%E2%80%93-isser#:~:text=A%20study%20by%20the%20Institute,women%20and%20girls%20(VAWG).)

Thanks, Ama

Subject: [hifa] Communicating health research (60) Q1. What do we mean by Effective communication of health research? (14)

From: "Samuel Sieber, Switzerland" <HIFA@hifaforums.org>

To: HIFA - Healthcare Information...snip... neil.pakenham-walsh@ghi-net.org>

Dear Neil, dear all

Thanks for picking up on some of my thoughts from last week, you raise some interesting discussion points. [<https://www.hifa.org/dgroups-rss/communicating-health-research-49-q1-what-do-we-mean-effective-communication-health>]

-- "Not all health research recommends a change in policy or practice, and often such recommendations are not specific. Some research may even recommend current policy to stay as it is."

-> This is very true and important to remember. I would argue, however, that no change in policy or practice is also a recommendation worth communicating, with the desired outcome of maintaining and strengthening an existing policy or practice. -> Unspecific recommendations, on the other hand, are in my experience a major challenge in knowledge translation and research communication. In any given study or review, recommendations are necessarily bound to the actual evidence. This often makes them very general, and does not allow to take political context, implementation considerations etc. sufficiently into account. Making research recommendations actionable often requires reflecting and enriching them with additional sources of "evidence", such as programme data, evaluations and direct interaction with policy-makers, implementers, and people with lived experience. In my view, this is the core supporting function of knowledge translation. And I would very much second the importance involving key stakeholders from the beginning of any research process.

"So perhaps the term 'effective communication' should focus more on getting the attention and consideration of policymakers (and their advisers) rather than what they choose to do with it?"

There usually is a wealth of information, opinions and factors influencing any decision-making process. We observed this during the COVID-19 pandemic, when a fast changing and sometimes contradictory body of evidence posed a real challenge to policy-makers and advisory bodies. And there is always the additional risk of decision-makers being unable to correctly interpret and translate findings. I would therefore argue that "getting attention and consideration of policymakers (and their advisers)" is not enough to define effective communication. And I would strongly advocate for a definition that also appeals to a researchers' responsibility to seriously consider and promote policy and practice implications and evidence translation of any piece of evidence. --

I'll try to follow-up shortly with a few practical steps and communication tools I have seen work well in research communication for policy and practice change. Very much enjoy reading the practical examples shared on this forum.

Best regards,

Sam

HIFA profile: Samuel Sieber is a Knowledge Translation and Communication Specialist, Global Coordination Mechanism on NCDs, Global NCD Platform, Deputy Director General's

Office, WHO, Geneva, Switzerland. He is a member of the HIFA working group on Communicating health research. [https://www.hifa.org/support/members/samuel_siebers AT who.int](https://www.hifa.org/support/members/samuel_siebers_AT_who.int)

Subject: [hifa] Communicating health research (61) Q1. What do we mean by Effective communication of health research? (15)
From: Neil Pakenham-Walsh <neil.pakenham-walsh@ghi-net.org>
To: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

Dear Sam and all,

"I would argue, however, that no change in policy or practice is also a recommendation worth communicating, with the desired outcome of maintaining and strengthening an existing policy or practice."

Yes, absolutely I agree 'change' or 'no change' are important to communicate. My point was in response to your original statement that 'Effective communication of health research implies a measurable change in policy or practice'. I wanted to point out that effective research communication can and does take place without a change in policy or practice.

It is arguably more appropriate to say something like 'Effective communication of health research implies that the key messages of the research have been integrated in the development of policy and practice'. This integration can be indirect. Typically, a single primary research study will not result in a change in policy or practice. However, it can be said to be effectively communicated if, for example, it has been included in a research synthesis (eg systematic review).

"Unspecific recommendations, on the other hand, are in my experience a major challenge in knowledge translation and research communication. In any given study or review, recommendations are necessarily bound to the actual evidence. This often makes them very general, and does not allow to take political context, implementation considerations etc. sufficiently into account."

Yes, I agree. In my day-to-day reading of global health research, I suspect that most of the recommendations I see are really quite non-specific. This is fine if it accurately reflects the actual research (it makes no sense to make recommendations specific for the sake of it, without the evidence for that specificity). The research then becomes one part of a jigsaw of pieces of evidence that, ideally, are interpreted for specific countries or contexts. It would be interesting to hear more from HIFA members about the challenges of global and local synthesis.

"Making research recommendations actionable often requires reflecting and enriching them with additional sources of "evidence", such as programme data, evaluations and direct interaction with policy-makers, implementers, and people with lived experience. In my view, this is the core supporting function of knowledge translation."

Yes, again it would be good to hear from HIFA members about their experience with this.

"I would therefore argue that "getting attention and consideration of policymakers (and their advisers)" is not enough to define effective communication."

I look forward to hear more on this. I think research communication is indeed more about the sharing of knowledge than persuading policymakers to make a particular decision. Researchers can undertake the latter, but I would call it advocacy.

"And I would strongly advocate for a definition that also appeals to a researchers' responsibility to seriously consider and promote policy and practice implications and evidence translation of any piece of evidence."

Yes indeed. As we started out the planning of this discussion we considered the researcher's perspective, the policymaker's perspective and the public health (and civil society) perspective. We acknowledged there is sometimes a tension, even a contradiction, between these perspectives. If a researcher is primarily motivate by getting *their* recommendations into policy and practice, this can lead to bias and negative health outcomes. I am reminded of the 'effective communication' of Andrew Wakefield and the MMR vaccine.

"I'll try to follow-up shortly with a few practical steps and communication tools I have seen work well in research communication for policy and practice change. Very much enjoy reading the practical examples shared on this forum."

Brilliant, thanks Sam.

Best wishes, Neil

Subject: [hifa] Communicating health research (62) Responses to Q1, Q2, Q3, Q4 and Q5 (2) Adoption of patient access to medical records (2)
From: "Richard Fitton, UK" <richardpeterfitton7@gmail.com>
To: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

"In reality, however, such policy-making proposals are often ignored, and the mass media do not even attempt to report on them. On the other hand, when the wind as the possibility of the proposal is realised blows, the mass media pick up the proposal as news, and policymakers may react sensitively to that wind." [Hajime Takeuchi, Japan: <https://www.hifa.org/dgroups-rss/communicating-health-research-58-responses-q1-q2-q3-q4-and-q5>]

Hajime's comments "when the wind of the possibility of the proposal blows the mass media pick up the proposal as news, and policy makers may react sensitively to that wind" has rung through during our 30 year professional struggle to release doctor's grip on their medical notes.

The first wind was the murder of over 200 patients by a family doctor who covered his tracks by altering his medical records to cover his tracks about false diagnoses of causes of death. The second has been the covid19 pandemic.

The first wind forced the attention of the medical regulatory body, press and government, the second has done so too. Patient access to records is an objective of Europe, the G7 countries, China and, I am sure, of many other countries but we started to implement the change in the early 1990's.

Richard

HIFA profile: Richard Fitton is a retired family doctor - GP. Professional interests: Health literacy, patient partnership of trust and implementation of healthcare with professionals, family and public involvement in the prevention of modern lifestyle diseases, patients using access to professional records to overcome confidentiality barriers to care, patients as part of the policing of the use of their patient data Email address: richardpeterfitton7 AT gmail.com

Subject: [hifa] Communicating health research (63) Getting research findings into policy and practice
From: Neil Pakenham-Walsh <neil.pakenham-walsh@ghi-net.org>
To: HIFA - Healthcare Information For All <HIFA@hifaforums.org>

One perspective on 'effective research communication' is that it has an impact on policy and practice.

A related but different perspective is that effective research communication simply contributes to the collective evidence that may be used to inform policy and practice - it does not need to have a direct impact.

With respect to direct impact of single primary research studies, can anyone give examples where this has been realised? I suspect it is most common when the research is looking at specific implementation issues at the local level? This may impact especially on policy decisions with a 'little p' (eg programmes and projects) but perhaps there are also examples of impact on Policies with a 'big P' (national and subnational policy).

Where single studies impact on policy, what are the key communication approaches that have been successful? Policy briefs, face-to-face meetings, media?

Perhaps more often policy is not driven by a single primary study, but by synthesis of all available evidence (eg systematic review).

Even then, such synthesis may be based on research in contexts that are very different to the national context. Recommendations may, as Sam Sieber says, be 'very general, and do not allow to take political context, implementation considerations etc. sufficiently into account'. National/local analysis and further research may be required to contextualise the recommendations.

Another point is that we have tended to talk of research communication as a linear process from the researcher to the policymaker. And yet the comments in this discussion clearly show that it is a lot more complex than this. Another perspective is to start from the policymaker, who in reality will be seeking multiple inputs, only some of which are directly research-related. Seldom is there a simple researcher-to-policymaker dynamic.

Perhaps the term 'effective communication' could apply less to the push of a single research study, and more to the factors that encourage and enable policymakers to consider all the relevant evidence? This implies more collaboration and less competition, more focus on improving health outcomes and less on getting the next funding award.

I look forward to your comments.

Best wishes, Neil

Communicating health research (64) Q1. What do we mean by Effective communication? (16) Q2. What are the different approaches? (16)

24 September, 2022

Our UK patient access to records pioneers would agree with you that "Making research recommendations actionable often requires reflecting and enriching them with... direct interaction with policy-makers, implementers, and people with lived experience. In my view, this is the core supporting function of knowledge translation." [Sam Sieber, Switzerland: <https://www.hifa.org/dgroups-rss/communicating-health-research-60-q1-wha...>]

In 2007, once pioneers of patient access to records had gained the attention of the press, government, patients, the public, regulatory body, professional organizations, IT companies and medical indemnity organizations, the pioneers set up a Record Access Collaborative (RAC) and advised the very helpful and supportive medical profession's regulatory body - the General Medical Council (GMC) to undertake wide consultations with many bodies throughout the UK (Organizations who replied are shown below to show the breadth of the survey and engagement,). This consultation was fortunately supported by a strong secretariat and GMC President.

If it is any help as an example here is the list of organizations that actually gave evidence in response to requests from the GMC secretariat: The number of replies suggests considerable buy-in from civic/patient and professional bodies. The survey also acted as a communication of intent which in itself achieved one of the objectives of communication of the results of research and of the eventual functionality of the guidance.

CIVIC/PATIENT ORGANIZATIONS: Action for Blind People, Addison's self help group, Arrhythmia Alliance, Atrial Fibrillation Association, Behcet's syndrome Society, Diabetes UK, Gorlin Syndrome Group, Herpes Virus Association, HPTH (hypoparathyroidism) UK, Insulin Dependent diabetes Trust, Migraine Action, Mind, Pelvic Pain Support Network, Rotherham General Hospital Foundation Trust Patient panel, Royal National Institute of Blind People, Skin Care Campaign, Syncope Trust and Reflex Anoxic Seizures, Terrence Higgins Trust, Torbay Inflammatory Bowel Disease Panel, Tuberosus Sclerosis Association, Which? magazine.

PROFESSIONAL: Allied Health Professionals Federation, Breast Cancer Care, British Dietetic Association, British Medical Association, Cancer Research

UK, Clinical Leads, Community Practitioners' and Health Visitors' Association/Unite, Department of Health, Faculty of Dental Surgery, Royal College of Surgeons of England, General Medical Council, Joint GP IT Committee, Medical Defence Union, Medical Protection Society, National Clinical Reference Panel, National Information Governance Board, Nursing and Midwifery Council, Information Commissioner's Office, Public Health Nurse, Royal College of General Practitioners, Royal College of Nursing, Royal College of Obstetrics and Gynaecology, Royal College of Paediatrics and Child Health, Royal College of Physicians, Royal Pharmaceutical Society of Great Britain, The British Society for Rheumatology,

Richard

HIFA profile: Richard Fitton is a retired family doctor - GP. Professional interests: Health literacy, patient partnership of trust and implementation of healthcare with professionals, family and public involvement in the prevention of modern lifestyle diseases, patients using access to professional records to overcome confidentiality barriers to care, patients as part of the policing of the use of their patient data. Email address: richardpeterfitton7 AT gmail.com

Source link:

<https://hifaforums.org/ /0XhE2e90>

24 September, 2022

Dear Richard,

Thank you for your comments. This highlights the role of collaboration and advocacy in driving policy change.

Revisiting the central question for our discussion - What are the most impactful methods for researchers to communicate their research to policymakers so that the research is seen and applied? - it seems that we can now look at this from at least three angles:

1. Direct communication of a single study from researcher (or research team) to policymakers
2. Communication of a single study through engaging multiple stakeholders
3. Collaboration with other research teams and other stakeholders to pool research evidence and drive advocacy.

I think there are multiple examples of #3 - indeed perhaps this is the most common approach and effective in practice?

However, the spirit of our original question was "How can a researcher (or research team) communicate their single study to policymakers with more impact?". Can anyone describe a single piece of research that they have done (or know about) and how this was communicated (or not) to policymakers?

How often is there a direct line between a single piece of primary research and policymakers?

Best wishes, Neil

Joint Coordinator, HIFA Communicating health research <https://www.hifa.org/projects/new-effective-communication-health-research...>

Let's build a future where every person has access to reliable healthcare information and is protected from misinformation - Join HIFA: www.hifa.org

HIFA profile: Neil Pakenham-Walsh is coordinator of the HIFA global health movement (Healthcare Information For All - www.hifa.org), a global community with more than 20,000 members in 180 countries, interacting on six global forums in four languages in collaboration with WHO. HIFA brings stakeholders together to accelerate progress towards universal access to reliable healthcare information. HIFA is administered by Global Healthcare Information Network, a UK based non-profit in official relations with the World Health Organization. Twitter: @hifa_org neil AT hifa.org

Source link:

https://hifaforums.org/_/vavy7k4r

Global health in practice: investing amidst pandemics, denial of evidence, and neo-dependency

24 September, 2022

Anadach Group cordially invites you to participate in the upcoming Author Discussion:

GLOBAL HEALTH IN PRACTICE: INVESTING AMIDST PANDEMICS, DENIAL OF EVIDENCE, AND NEO-DEPENDENCY

Wednesday, September 28, 2022, 9:00am EST/1pm UTC

The COVID-19 pandemic has highlighted the world's vulnerabilities to health and economic ruin from disease outbreaks. The pandemic has also revealed fundamental weaknesses and contradictions in global health. During this conversation, Dr. Olusoji Adeyi will discuss the roots of these weaknesses and contradictions; how geo-politics, power dynamics, knowledge gaps, racism, and corruption affect global health; and why foreign aid for health

is due for a radical overhaul. Drawing on his 30 years of experience, Dr. Adeyi will outline his recommendations for a brighter future for global health.

We hope you will join us for a discussion on Dr Soji Adeyi's book, which seems even more relevant given the potential new epidemics on the horizon. It is a riveting perspective on global health, looking at global health players, donors and African Governments.

Guest Speakers

Dr. Olusoji Adeyi; President, Resilient Health Systems and former Director of the Health, Nutrition and Population Global Practice at the World Bank.

Panelists

Dr. Frannie Leautier; Partner, Executive Vice-Chair at SouthBridge Group and CEO of South-Bridge Investment.

Moderator

Dr. Segun Dawodu, CEO, PMREHAB Pain and Sport Medicine.

Discussant

Ms. Zouera Youssoufou, Managing Director, CEO Aliko Dangote Foundation

If you are interested in joining us for this stimulating provocative conversation, please register at

<https://us02web.zoom.us/meeting/register/tZUvdu-gqjIuGtNyVcrQgTycz6KgT2o...>

We look forward to engaging with you. Pls share with friends and colleagues. Thank you.

HIFA profile: Egbe Osifo-Dawodu is a Partner of Anadach Group. www.anadach.com http://twitter.com/anadach_eosifodawodu AT anadach.com

WHO: Heads of State commit to Noncommunicable Disease Global Compact to save 50 million lives by 2030 (2)

24 September, 2022

Neil, you write "Knowledge is not a panacea, but it is a prerequisite."

Najeeb was leading a conversation that suggested that the difference between information, understanding and knowledge was that knowledge is an internal framework of experience and understanding that directs choices which experience, culture and personality affect as much or more than information? [*see note below]"awareness or familiarity gained by experience of a fact or situation: Knowledge-Wikipedia <https://en.wikipedia.org/wiki/Knowledge>

HIFA profile: Richard Fitton is a retired family doctor - GP. Professional interests: Health literacy, patient partnership of trust and implementation of healthcare with professionals,

family and public involvement in the prevention of modern lifestyle diseases, patients using access to professional records to overcome confidentiality barriers to care, patients as part of the policing of the use of their patient data

Email address: richardpeterfitton7 AT gmail.com

[*Note from NPW, moderator: Thanks Richard. I think the Wikipedia definition of information is helpful here: 'Information is an abstract concept that refers to that which has the power to inform. At the most fundamental level information pertains to the interpretation of that which may be sensed...' <https://en.wikipedia.org/wiki/Information>]

Communicating health research (64) Q1. What do we mean by Effective communication? (16) Q2. What are the different approaches? (16)

24 September, 2022

Our UK patient access to records pioneers would agree with you that "Making research recommendations actionable often requires reflecting and enriching them with... direct interaction with policy-makers, implementers, and people with lived experience. In my view, this is the core supporting function of knowledge translation." [Sam Sieber, Switzerland: <https://www.hifa.org/dgroups-rss/communicating-health-research-60-q1-wha...>]

In 2007, once pioneers of patient access to records had gained the attention of the press, government, patients, the public, regulatory body, professional organizations, IT companies and medical indemnity organizations, the pioneers set up a Record Access Collaborative (RAC) and advised the very helpful and supportive medical profession's regulatory body - the General Medical Council (GMC) to undertake wide consultations with many bodies throughout the UK (Organizations who replied are shown below to show the breadth of the survey and engagement,). This consultation was fortunately supported by a strong secretariat and GMC President.

If it is any help as an example here is the list of organizations that actually gave evidence in response to requests from the GMC secretariat: The number of replies suggests considerable buy-in from civic/patient and professional bodies. The survey also acted as a communication of intent which in itself achieved one of the objectives of communication of the results of research and of the eventual functionality of the guidance.

CIVIC/PATIENT ORGANIZATIONS: Action for Blind People, Addison's self help group, Arrhythmia Alliance, Atrial Fibrillation Association, Behcet's syndrome Society, Diabetes UK, Gorlin Syndrome Group, Herpes Virus Association, HPTH (hypoparathyroidism) UK, Insulin Dependent diabetes Trust, Migraine Action, Mind, Pelvic Pain Support Network, Rotherham General Hospital Foundation Trust Patient panel, Royal National Institute of Blind People, Skin Care Campaign, Syncope Trust and Reflex Anoxic Seizures, Terrence Higgins Trust, Torbay Inflammatory Bowel Disease Panel, Tuberos Sclerosis Association, Which? magazine.

PROFESSIONAL: Allied Health Professionals Federation, Breast Cancer Care, British Dietetic Association, British Medical Association, Cancer Research

UK, Clinical Leads, Community Practitioners' and Health Visitors' Association/Unite, Department of Health, Faculty of Dental Surgery, Royal College of Surgeons of England, General Medical Council, Joint GP IT Committee, Medical Defence Union, Medical Protection Society, National Clinical Reference Panel, National Information Governance Board, Nursing and Midwifery Council, Information Commissioner's Office, Public Health Nurse, Royal College of General Practitioners, Royal College of Nursing, Royal College of Obstetrics and Gynaecology, Royal College of Paediatrics and Child Health, Royal College of Physicians, Royal Pharmaceutical Society of Great Britain, The British Society for Rheumatology,

Richard

HIFA profile: Richard Fitton is a retired family doctor - GP. Professional interests: Health literacy, patient partnership of trust and implementation of healthcare with professionals, family and public involvement in the prevention of modern lifestyle diseases, patients using access to professional records to overcome confidentiality barriers to care, patients as part of the policing of the use of their patient data. Email address: richardpeterfitton7 AT gmail.com

Communicating health research (65) Q1. What do we mean by Effective communication? (17) Q2. What are the different approaches? (17)

24 September, 2022

Dear Richard,

Thank you for your comments. This highlights the role of collaboration and advocacy in driving policy change.

Revisiting the central question for our discussion - What are the most impactful methods for researchers to communicate their research to policymakers so that the research is seen and applied? - it seems that we can now look at this from at least three angles:

1. Direct communication of a single study from researcher (or research team) to policymakers
2. Communication of a single study through engaging multiple stakeholders
3. Collaboration with other research teams and other stakeholders to pool research evidence and drive advocacy.

I think there are multiple examples of #3 - indeed perhaps this is the most common approach and effective in practice?

However, the spirit of our original question was "How can a researcher (or research team) communicate their single study to policymakers with more impact?". Can anyone describe a single piece of research that they have done (or know about) and how this was communicated (or not) to policymakers?

How often is there a direct line between a single piece of primary research and policymakers?

Best wishes, Neil

Joint Coordinator, HIFA Communicating health research <https://www.hifa.org/projects/new-effective-communication-health-research...>

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Communicating health research (66) Have *you* ever published a research paper? What happened?

24 September, 2022

Dear HIFA colleagues, and especially the many health researchers among us,

It has been estimated that 'New medical articles are appearing at a rate of at least one every 26 seconds, and if a physician were to read every medical journal published they would need to read 5000 articles per day' [<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3191655/>]. And yet we know very little (almost nothing?) about the impact (or lack of it) of all this research on health policymakers.

Have *you* ever published a research paper (or several - some researchers publish more than one every week!)? Did you want your paper to make a difference? And *did* it make a difference - or was it ignored?

Has your work led to a change in policy, whether Policy (with a big P, as in national/subnational policy) or policy with a small p (eg project/programme implementation)? What were the key ingredients to make this happen in terms of research communication? What was the role of your research team? What was the role of your institution?

Here's an example from HIFA: The last research paper HIFA published was a systematic review in 2020 'How primary healthcare workers obtain information for safe prescribing in LMICs' with the London School of Hygiene and Tropical Medicine and Nagasaki University.

<https://www.hifa.org/news/hifas-first-systematic-review-how-primary-heal...>

The findings confirmed a lack of up-to-date and relevant information on medicines in low and lower middle-income settings. We concluded that 'Up-to-date medicine information and the means of making it accessible and acceptable to prescribers at the point of care must

accompany the expanding access to medicines if those seeking medical care are to benefit. Such information needs to go beyond information about individual medicines, to include guidance on the selection of medicines.' Despite advocacy on these issues since 2013 led by the HIFA project on Information for Prescribers and Users of Medicines, I regret to say there has been no demonstrable impact on political and/or financial commitment to reliable information on medicines.

My feeling is that individual research papers, whether primary or secondary, are unlikely to result in a change of policy. At best they can underpin wider advocacy efforts, driven by all the available evidence and only exceptionally by a single study.

What has been your experience?

Best wishes, Neil

Joint Coordinator, HIFA Communicating health research <https://www.hifa.org/projects/new-effective-communication-health-research...>

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Communicating health research (67) Have you ever published a research paper? What happened? (2)

24 September, 2022

According to the article cited by Neil, "New medical articles are appearing at a rate of at least one every 26 seconds, and if a physician were to read every medical journal published they would need to read 5000 articles per day" (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3191655/>).

It should be noted that the first part of this quote (from a paper published in 2010) is based on papers published almost 40 years ago, and the second part on papers published more than 20 years ago. The original data cited in those papers must be older still. Does anyone have any newer data?

Having said that, the information overload and redundancy is certainly getting more and more severe as the information age progresses. In fact, there is so much redundancy in the information age that, according to one article, there are over 75 names for it – information revolution, age of access, communications age... [it's another ancient article - Doctor, R.

1992. Social Equity and Information Technologies: Moving toward Information Democracy, Annual Review of Information and Science Technology (ARIST), Volume 27, Chapter 2.]

Time for someone to come up with contemporary data on this age-old problem.

Best,

Chris

Chris Zielinski

chris@chriszielinski.com

Blogs: <http://ziggytheblue.wordpress.com> and <http://ziggytheblue.tumblr.com>

Research publications: <http://www.researchgate.net>

HIFA profile: Chris Zielinski: As a Visiting Fellow and Lecturer at the Centre for Global Health, University of Winchester, Chris leads the Partnerships in Health Information (Phi) programme. Formerly an NGO, Phi supports knowledge development and brokers healthcare information exchanges of all kinds. Chris has held senior positions in publishing and knowledge management with WHO in Brazzaville, Geneva, Cairo and New Delhi, with FAO in Rome, ILO in Geneva, and UNIDO in Vienna. Chris also spent three years in London as Chief Executive of the Authors Licensing and Collecting Society. He served on WHO's Ethical Review Committee, and was an originator of the African Health Observatory. Chris is the elected Vice President (and President-in-Waiting) of the World Association of Medical Editors. He has been a director of the UK Copyright Licensing Agency, Educational Recording Agency, and International Association of Audiovisual Writers and Directors. He has served on the boards of several NGOs and ethics groupings (information and computer ethics and bioethics). chris AT chriszielinski.com. His publications are at <https://www.researchgate.net/profile/Chris-Zielinski> and <https://winchester.academia.edu/ChrisZielinski/> and his blogs are <http://ziggytheblue.wordpress.com> and <https://www.tumblr.com/blog/ziggytheblue>

Communicating health research (69) Responses to Q1, Q2, Q3, Q4 and Q5 (3)

24 September, 2022

[*Note from NPW, moderator: Our thanks to Emily Vargas, Mexico, for this thoughtful contribution. The original message was in Spanish and can be read in two parts here:

<https://www.hifa.org/dgroups-rss/comunicaci%C3%B3n-de-la-investigaci%C3%...>

and here:

<https://www.hifa.org/dgroups-rss/comunicaci%C3%B3n-de-la-investigaci%C3%...>

The text below is a Google translation into English - I am currently relearning my Spanish but I think Google will do a better job and is a lot quicker!]

Dear Jackeline and Neil

I allow myself to refer, my first part of the contribution to the discussion. Next week, I will send some concrete examples, successful experiences and

not so successful.

Note: I keep sharing with colleagues and social networks to promote their participation,

[1] *What does “effective communication of research results to decision makers” mean to you?*

The moments of the political process, although not linear and not necessarily systematic as studied in theory; if they are a frame of reference to understand the spaces and strategies that can be used to communicate information from the evidence and that can favor the decision-making, in this context, effectively communicating research results means disseminating relevant information and useful for a moment in the political process that helps, supports or strengthens decision-making in health, in favor of a common good.

[2] *What strategies do you consider most effective for communicating research results to decision makers (government, managers, coordinators, health professionals)?*

The strategy, route or channel to share or disseminate scientific evidence will depend on the political moment (phase of the public policy process), as well as the closeness or influence (lobbying capacity) that the researcher or the organization to which he is linked has with the decision-maker. The identification and assessment of it requires an analysis of the environment, the key actors, their interests and the issues surrounding it.

To be concrete, the most effective strategy is identified in an analysis of the context at the moment a window of opportunity is identified.

[3] *Is it the duty of researchers to communicate the results of their research to decision makers? o It is an obligation of science communicators, editors, media, among others.*

Communicating science is a global duty, it is everyone's duty, however, emphasis is placed on researchers who, first-hand, have the results of their work, even so and by virtue of the new measurements of scientific work, it is not possible to spread something without having previously been published in a scientific article, much less if a patent or invention right is implied. This creates a barrier, but also an opportunity, because it implies that everything that is published by a researcher or research team is usable, that is, it is for the use of the general public.

In this sense, I would not limit the obligation/duty to effectively communicate the results of the research expressly to the researcher or his team, anyone who has an interest in public policy being informed by best practices or the best research results can and it must have the powers to do so, however, if this communication is backed by investigators, much better. But it should not be a premise.

[4] * What are the information needs of a decision maker, how do you prefer to be informed and what are the tools or ways of it? *

Based on my experience in Colombia and Mexico, the political process, decision-making in the health sector, is affected by a number of interests, not only scientific, with different gradients of weight and opportunity; in LATAM, organizations such as WHO/PAHO and the IDB have a important influence on the lines of action that are promoted as a country, especially in relation to health programs, projects and strategies public. Others are the actors, when we refer to the Health and Social Security Systems, in this, the actors and interests vary, and appear in the scenario entities such as the World Bank, private companies, politics and depending on the political tendency, the interests of the populations and the right to health proclaimed in the Magna Cartas; and with considerable weight the secretariats of finance and public credit and economy.

Under this scenario, the degree, level and amount of information required by a decision maker, at the government level, is enough; here your advisers and technical team are key players, since they are the ones who carry out the analysis of the context and share with the decision maker in short meetings, in the corridors, in a specific report that is sent to your email or WhatsApp.

[5] *What can we do to encourage effective communication of research results? *

Some strategies:

1. That researchers and research centers make executive summaries of the research results, in plain language and be spread in different ways.
2. Creation of a team specialized in promoting the use of evidence in decision-making in health, which has the ability not only to lobby, but also to identify

*Emily V. *

HIFA profile: Emily Vargas is a knowledge management researcher based in Mexico.
emilymariavr AT gmail.com

Communicating health research (70) Q2. What are the different approaches? (16)

25 September, 2022

Dear HIFA colleagues,

One of the key objectives of our discussion is to compare and contrast the different approaches to communicating health research, to help inform health researchers to achieve increased impact. We especially want to hear about the experience of health researchers.

1. What is your experience of communicating research to policymakers?
2. Which approaches have you used? (eg academic journals, policy briefs, interaction with

policymakers, press releases, social media, television, radio...)

3. Can you share one example of *successful* communication to policymakers? What approach worked for you? How did you know it was successful?

4. Can you share an example of *failed* communication to policymakers? Perhaps an example where the relevant policymakers remained unaware of your research? Or an example where they ignored it or failed to use it in policy and implementation?

We have touched on:

- Academic journals
- Open access
- Pre-prints
- Blogs
- Policy briefs
- Social media
- Mass media (TV, newspapers...)
- Popular culture
- Interaction with policymakers, funders, academia, other stakeholders
- Engaging the public
- Press releases
- Storytelling
- Framing the message clearly and concisely

We have noted the many factors to consider when planning the communication strategy:

- Primary versus secondary research
- Global versus local research
- Stage in research cycle (before, during, after)
- Operational level of intended change
- Political and personality factors of policymakers

Looking forward to learn from your experience.

Best wishes, Neil

Joint Coordinator, HIFA Communicating health research <https://www.hifa.org/projects/new-effective-communication-health-research...>

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universal access to reliable healthcare information. HIFA is administered by Global Healthcare Information Network, a UK based non-profit in official relations with the World Health Organization. Twitter: @hifa_org neil@hifa.org

Communicating health research (71) Have you ever published a research paper? What happened? (4)

25 September, 2022

Dear Neil,

I'm confused and, yes, disappointed. Comments on the last issue of HIFA, i.e. "communicating health research" are many and of interest. However they seem to me an exageration something like an academic exercise: medicine and the health of people are far from it, far indeed. I've been in Africa for the past 40 years, I've witnessed a transformation in healthcare that to me is bad and deserves comments, in primis by African colleagues.

Today medicine is mainly curative (1) more and more private, (2) based on prescription of drugs (3) and lab tests (4), people are empowerished by this trend (5). I feel this last point to be serious, poor deserve respect and not exploitation, certainly so by their professionists in their countries.

I 'point the finger to others' and this is bad but what else could I write in front of data showing the:

- over-prescription of drugs both in public and private settings (data are available)

- excessive number of pharmacies (illegal), health centres (illegal), delivery of drugs in the same setting of prescription (dangerous), labs of poor/nil creditation, selling of drugs on the road, open air. Health authorities become concerned when national insurance system collapses for the excessive "drugalization" of people.

Medicine is reduced to a pill, an injected antibiotic, a Widal test that is 'obviously' positive most of times.

Greetings from DODOMA

Massimo

HIFA profile: Massimo Serventi is a long-standing Pediatrician working in Africa since 1982. He has worked for several NGOs in 6 African/2 Asian countries. His interests include clinical and community pediatrics, adherence to clinical guidelines and school education as the major determinant of good health.

Email: [massimoser20 AT gmail.com](mailto:massimoser20@gmail.com)

Communicating health research (72) Q1. What do we mean by Effective communication? (18) Q2. What are the different approaches? (18)

25 September, 2022

Bit dramatic but here are a few pieces of research that affected policy

John Snow, Soho and the battle to defeat cholera: Ertblog [robskinner.net]

(<https://robskinner.net/2014/05/10/john-snow-soho-and-the-battle-to-defea...>)

Edward Jenner and the history of smallpox and vaccination: [PMC- nih.gov]

(<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1200696/>)

The paper quotes: In science credit goes to the man who convinces the world, not the man to whom the idea first occurs.

Ignaz Semmelweis [Wikipedia]

<https://en.wikipedia.org/wiki/Ignaz_Semmelweis>

Semmelweis's hypothesis, that there was only one cause, that all that mattered was cleanliness, was extreme at the time and was largely ignored, rejected, or ridiculed. He was dismissed from the hospital for political reasons and harassed by the medical community in Vienna, being eventually forced to move to Budapest.

And one that affected us in primary care in 1985 though the side effect frequency prompted us to make patients use lifestyle changes rather than medications

MRC trial of treatment of mild hypertension: principal results. Medical

Research Council Working Party- [PMC- nih.gov]

(<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1416260/>)

The main aim of the trial was to determine whether drug treatment of mild hypertension (phase V diastolic pressure 90-109 mm Hg) reduced the rates of stroke, of death due to hypertension, and of coronary events in men and women aged 35-64 years. Subsidiary aims were: to compare the course of blood pressure in two groups, one taking bendrofluazide and one taking propranolol, and to compare the incidence of suspected adverse reactions to these two drugs. The study was single blind and based almost entirely in general practices; 17354 patients were recruited, and 85572 patient years of observation have accrued. Patients were randomly allocated at entry to take bendrofluazide or propranolol or placebo tablets. The primary results were as follows. The stroke rate was reduced on active treatment: 60 strokes occurred in the treated group and 109 in the placebo group, giving rates of 1.4 and 2.6 per 1000 patient years of observation respectively (p less than 0.01 on sequential analysis). Treatment made no difference, however, to the overall rates of coronary events: 222 events occurred on active treatment and 234 in the placebo group (5.2 and 5.5 per 1000 patient years respectively). The incidence of all cardiovascular events was reduced on active treatment: 286 events occurred in the treated group and 352 in the placebo group, giving rates of 6.7 and 8.2 per 1000 patient years respectively (p less than 0.05 on sequential analysis). For mortality from all causes treatment made no difference to the rates. There were 248 deaths in the

treated group and 253 in the placebo group (rates 5.8 and 5.9 per 1000 patient years respectively). Several post hoc analyses of subgroup results were also performed but they require very cautious interpretation.

The all cause mortality was reduced in men on active treatment (157 deaths versus 181 in the placebo group; 7.1 and 8.2 per 1000 patient years respectively) but increased in women on active treatment (91 deaths versus 72; 4.4 and 3.5 per 1000 patient years respectively). The difference between the sexes in their response to treatment was significant ($p = 0.05$). Comparison of the two active drugs showed that the reduction in stroke rate on bendrofluazide was greater than that on propranolol ($p = 0.002$). The stroke rate was reduced in both smokers and non-smokers taking bendrofluazide but only in non-smokers taking propranolol. This difference between the responses to the two drugs was significant ($p = 0.03$).

Numbers and cumulative percentages of people withdrawn from randomised treatment because they developed either suspected adverse reactions to the primary regimen (discussed in detail elsewhere) or levels of blood pressure above the upper limit for the trial are shown in table Vm and fig 2m. The protocol for the follow up routine was the same for these people as for those whose treatment was unchanged. The five and a half year cumulative percentages of people lapsing from follow up (fig 3m) were about 190° and include losses of about 3-50/" due to participants moving house.

The total five and a half year cumulative percentages of men who stopped taking their randomised treatment, including both those withdrawn from their randomly allocated regimen but continuing on follow up and those lapsing from the trial, were 4300 of the bendro fluazide group, 42% of the propranolol group, and 47% of the placebo group. For women the figures were 33%, 40%, and 40% respectively. The cumulative percentages of people not taking either primary active drug by five and a half years were smaller: 33% of men originally randomised to bendrofluazide and 34% of men randomised to propranolol and 28% and 31% respectively of women.

HIFA profile: Richard Fitton is a retired family doctor - GP. Professional interests: Health literacy, patient partnership of trust and implementation of healthcare with professionals, family and public involvement in the prevention of modern lifestyle diseases, patients using access to professional records to overcome confidentiality barriers to care, patients as part of the policing of the use of their patient data

Email address: richardpeterfitton7 AT gmail.com

Communicating health research (73) Q2. What are the different approaches? (17)

25 September, 2022

We have previously noted the paper by HIFA working group members Rob Terry, Tanja Kuchenmuller and colleagues:

CITATION: Assessing the impact of knowledge communication and dissemination strategies targeted at health policy-makers and managers: an overview of systematic reviews. Evelina

Chapman et al. Health Research Policy and Systems volume 19, Article number: 140 (2021) <https://health-policy-systems.biomedcentral.com/articles/10.1186/s12961-...>

The main conclusion is: 'There is limited evidence regarding the effectiveness of interventions targeting health managers and policy-makers, as well as the mechanisms required for achieving impact.'

What does this tell us, if anything, about the wide variety of communication approaches that have been reported by HIFA members during this discussion?

In one sense, given what we have learned during the past 3 weeks, the lack of demonstrable effectiveness is not surprising. First, we see that research communication is a complex, non-linear process. Second, the definition of 'effective communication' is highly variable. Third, we note that there is no one-size-fits-all approach to research communication - the strategy needs to reflect the specific objectives of the communication, and these perceived objectives may vary from one perspective to another. Fourth, there is no agreed indicator or measure of effectiveness - it varies case by case.

Another finding of this study is: 'Regarding dissemination strategies, interventions that aimed at improving only the reach of evidence did not have an impact on its use in decisions, while interventions aimed at enhancing users' ability to use and apply evidence had a positive effect on decision-making processes.' I look forward to hear more about this from Rob and Tanja.

Looking again at our discussion over the past 3 weeks, this second finding seems to align with our emerging narrative. Namely, we started with a simplistic view that a researcher/research team has a finding that they want to communicate *to* policymakers, and increasingly we note the importance of interaction *with* policymakers and other stakeholders throughout the research cycle. And when we look at research communication from a public health perspective rather than a researcher perspective, we note the importance of collaboration and research synthesis rather than competition and direct impact of single studies.

In terms of supporting research communication in the future, Mark Storey (USA) suggested: "It would be useful to develop a toolkit (describing the different types of interventions) together with a number of brief case studies providing examples of different approaches used at many of the different operational levels and local settings in which changes have successfully (or even unsuccessfully) been promoted." Is anyone aware of previous work in this area? What already exists in terms of guidance for researchers to increase the visibility and impact of their work?

Looking forward to your continuing contributions.

Meanwhile I take note of Massimo's point that some of our discussion is academic. I encourage everyone to share an example of research from your own lived experience. Stories and anecdotes are especially welcome. Email: hifa@hifaforums.org

Best wishes, Neil

Joint Coordinator, HIFA Communicating health research <https://www.hifa.org/projects/new-effective-communication-health-research...>

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HIFA profile: Neil Pakenham-Walsh is coordinator of the HIFA global health movement (Healthcare Information For All - www.hifa.org), a global community with more than 20,000 members in 180 countries, interacting on six global forums in four languages in collaboration with WHO. HIFA brings stakeholders together to accelerate progress towards universal access to reliable healthcare information. HIFA is administered by Global Healthcare Information Network, a UK based non-profit in official relations with the World Health Organization. Twitter: @hifa_org neil@hifa.org

Communicating health research (74) Q2. What are the different approaches? (18)

25 September, 2022

In my last message I wrote:

'In terms of supporting research communication in the future, Mark Storey (USA) suggested: "It would be useful to develop a toolkit (describing the different types of interventions) together with a number of brief case studies providing examples of different approaches used at many of the different operational levels and local settings in which changes have successfully (or even unsuccessfully) been promoted." Is anyone aware of previous work in this area? What already exists in terms of guidance for researchers to increase the visibility and impact of their work?'

I am reminded that Irina Ibaghimova recommended three texts:

1. Helpful hints for sharing research with people in policy (the UK) <https://www.emeraldgrouppublishing.com/opinion-and-blog/helpful-hints-sh...>
2. Connecting research with policy: Guide to writing for policy-makers (Australia, National Environmental Science Program) <https://www.nespthreatenedspecies.edu.au/publications-and-tools/connecti...>
3. Research Engagement with Policy Makers: a practical guide to writing policy briefs (the UK, NIHR Policy Research Unit in Behavioural Science) <https://osf.io/m25qp>

Is anyone aware of other guides?

Best wishes, Neil

Joint Coordinator, HIFA Communicating health research <https://www.hifa.org/projects/new-effective-communication-health-research...>

Communicating health research (75) Q4. What are the needs and preferences of policymakers? (2)

25 September, 2022

Dear HIFA colleagues,

We are now entering our fourth and penultimate week of our deep-dive into effective research communication.

Our guiding question for this week is:

Q4. What are the needs and preferences of policymakers?

Are you, or have you been, in a decision-making role? We are interested to hear how you used evidence for Policymaking with a big P (national and subnational policy), or policymaking with a small p (eg programme managers and senior staff of health facilities). Please share your experience with us for the benefit of others: hifa@hifaforums.org

WHAT WE HAVE LEARNED SO FAR

There seems to be general agreement that researchers must have some understanding of the needs and preferences of the relevant policymakers if they hope to have an impact.

Several people have pointed to the need to engage policymakers before, during and after the actual research. They have also pointed to the importance of engaging with other stakeholders such as other academics, journalists, the public...

We have noted that policymakers may typically not have time to read a journal article or perhaps even a policy brief. And we have seen that there is little evidence for the effectiveness of any particular approach, although perhaps empowering policymakers to use evidence may be more effective than extending dissemination reach.

Here are some other points raised by HIFA members:

Richard Fitton (UK): UN: "We are not asking scientists to tell us what to do. We are asking scientists to show us the options"

Chikezie Nwankwor (Nigeria): [1] Communications: How to communicate effectively to policy makers - A guide for Academics

https://www.bennettinstitute.cam.ac.uk/publications/effective_communicat... [1]

Introduction: The difficulty of communicating complex knowledge to policy makers has generated a substantial literature. Ironically despite this wealth of literature the evidence on what works in communicating scientific findings is mixed[1] although there is a growing consensus that the starting point should always be your audience(s). This may seem obvious

but understanding how policy makers process evidence and the context in which they operate is key [2]. Policy makers often have too much information to digest so will use heuristics to filter information and make decisions quickly. So ask yourself how can I help policy makers process what it is I want to say? What should my communication strategy be? What format should I communicate in and when should I communicate? Finding the right time to communicate can also effect whether you have a receptive audience or not...

Khin Thet Wai (Myanmar): Considerable understanding of the needs and concerns of policymakers from the outset should be in place by taking into account of the annual reports, keynote addresses, recent health regulations and acts, donor evaluation reports, meeting minutes etc.

Best wishes, Neil

Joint Coordinator, HIFA Communicating health research <https://www.hifa.org/projects/new-effective-communication-health-research...>

Communicating health research (76) Have you ever published a research paper? What happened? (5)

25 September, 2022

Massimo makes a very important point when he says, 'Today medicine is mainly curative (1) more and more private, (2) based on prescription of drugs (3) and lab tests (4), people are empowerished by this trend', and I suppose he is referring particularly to Africa even though other regions of the world may face the same challenge.

But I think that this thematic discussion on taking research to policymakers so that they frame their policy guided by it, has the potential to produce actionable recommendations that will steer policy makers and implementers in the right direction, i.e. away from undue and over concentration on curative health which is expensive for patients and the system and portends worse prognosis. If policy makers embrace the many research backed evidence that the promotion of health and wellbeing and prevention of illness, are easier to implement at the primary health care level, which serves majority of the population because they live and work in the rural areas, this discussion would have achieved a nagging global challenge to delivering quality care, including rational prescribing and use of drugs, provision of facilities fit for purpose and ready (e.g. appropriate infrastructure, potable water, 24/7 power, clean and efficient waste management, etc). And that both promotion and prevention are cheaper too, a very important consideration for any policymakers in these days of diminishing resources for health!

Joseph Ana

Prof Joseph Ana

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HIFA profile: Joseph Ana is the Lead Senior Fellow/Medical Consultant at the Centre for Clinical Governance Research and Patient Safety in Calabar, Nigeria, established by HRI Global (former HRIWA). He is a member of the World Health Organisation's Technical Advisory Group on Integrated Care in primary, emergency, operative, and critical care (TAG-IC2). As the Cross River State Commissioner for Health, he led the introduction of the Homegrown Quality Tool, the 12-Pillar Clinical Governance Programme, in Nigeria (2004-2008). For sustainability, he established the Department of Clinical Governance, Servicem & e-health in the Cross River State Ministry of Health, Nigeria. His main interest is in whole health sector and system strengthening in Lower, Low and Middle Income Countries (LLMICs). He has written six books on the 12-Pillar Clinical Governance programme, suitable for LLMICs, including the TOOLS for Implementation. He served as Chairman of the Nigerian Medical Association's Standing Committee on Clinical Governance (2012-2022), and he won the Nigeria Medical Association's Award of Excellence on three consecutive occasions for the innovation. He served as Chairman, Quality & Performance, of the Technical Working Group for the implementation of the Nigeria Health Act 2014. He is member, National Tertiary Health Institutions Standards Committee of the Federal Ministry of Health. He is the pioneer Secretary General/Trustee-Director of the NMF (Nigerian Medical Forum) which took the BMJ to West Africa in 1995. Joseph is a member of the HIFA Steering Group and the HIFA working group on Community Health Workers. (<http://www.hifa.org/support/members/joseph-0> <http://www.hifa.org/people/steering-group>).

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Communicating health research (76) Q2. What are the different approaches? (19)

25 September, 2022

Dear Neil,

The following paper from the UK could be of interest from a practical point of view:

'Localising and tailoring research evidence helps public health decision making'

<https://onlinelibrary.wiley.com/doi/10.1111/hir.12219>

"This paper explores the mechanisms used by information professionals with a specific knowledge mobilisation role to make evidence useful for local decision making and planning of public health interventions...Published research evidence is made fit for local

commissioning and planning purposes by information professionals through two mechanisms. They localise evidence (relate evidence to local context and needs) and tailor it (present actionable messages)".

Irina

HIFA profile: Irina Ibraghimova is an independent consultant with a PhD. in library sciences and more than 20 years' international experience in ICT for health projects. She now serves as a Co-editor for the International Journal of Health Governance (Emerald Publishing). Professional interests: Information and health literacy, evidence-based practice, science communication and medical journals editing. <http://www.healthconnect-intl.org/> She is a HIFA country representative for Croatia: <https://www.hifa.org/support/members/irina>

Communicating health research (77) Q4. What are the needs and preferences of policymakers? (3) Global and local synthesis

26 September, 2022

Re: 'Localising and tailoring research evidence helps public health decision making' <https://onlinelibrary.wiley.com/doi/10.1111/hir.12219>

Thank you Irina for pointing us to this paper. Here are the key messages:

Key Messages

- Information professionals carry out many activities involved in mobilising research into practice but this is often not recognised.
- Localising and tailoring are two key mobilising mechanisms that information professionals can use to increase the use of evidence in practice.
- Information professionals make evidence fit for decision making by localising evidence which relates to local context and needs.
- Information professionals tailor the format of evidence to present commissioners and planners with actionable messages.
- Information professionals' expertise could be used more systematically to champion a culture and infrastructure within and between health organisations that encourage knowledge mobilisation.

Arguably, what policymakers need most is not the results of single primary research studies (although these can be paramount in selected situations), and not even the results of systematic reviews. Most often, they need a synthesis of global (secondary) evidence and local evidence, provided by expert information professionals. This critical process of global and local synthesis is not only important and complex, it is also (in my view) a neglected part of knowledge translation.

Synthesis of global and local research is crucial for national and subnational policymaking. It is the basis of WHO's knowledge sharing approach whereby WHO provides rigorous international guidance that can be used and adapted by Member States.

I would like to ask HIFA members: Do you have any experience you can share on global and local synthesis? We are especially keen to hear from information professionals at country level:

- How can global evidence (for example WHO guidance) be improved to make it more easily adaptable to national/local context?
- Are you aware of any resources to guide global and local synthesis?

Have you been involved in WHO guidance development? Or Cochrane?? Or the Global Evidence Synthesis Initiative? We would love to hear from you.

hifa@hifaforums.org

Best wishes, Neil

Joint Coordinator, HIFA Communicating health research <https://www.hifa.org/projects/new-effective-communication-health-research...>

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Communicating health research (78) Q4. What are the needs and preferences of policymakers? (4) Global and local synthesis (2)

26 September, 2022

Dear HIFA colleagues,

I can share my experience in global evidence synthesis (as an information professional). [*see note below]

In 2011 I was invited as a consultant for the systematic literature review that was conducted by the African Palliative Care Association "A REVIEW OF HOME BASED CARE MODELS AND SERVICES FOR PEOPLE LIVING WITH HIV/AIDS WITHIN AND

OUTSIDE AFRICA”

(http://www.palliativecareassociationofmalawi.org/media/data/hbc_review_r...). I was asked to review the executed search strategy and the way it had been presented. The literature search entailed a comprehensive review of existing information on home based care for people living with HIV/AIDS in resource poor settings while the situational analysis was a cross-sectional study using qualitative and quantitative methods to explore the nature of existing home based care models in four African countries, including Tanzania, Zambia, Malawi and Kenya. The final report provided the findings both of the literature review and of the situation analysis. The aim was to make clear and practical recommendations for the integration of all aspects of palliative care within existing HBC services. I was quite excited to help with this project, which included many organizations and country representatives. The problem from my part was that I was asked to review the search strategy after it has been already executed and the initial version of literature review results written, while it is always recommended to include library/information professionals while the search strategy is being developed. I've never been informed on how the report findings were actually implemented.

In 2020 I have co-authored a mapping review of research literature on refugee health in Europe (<https://doi.org/10.1108/IJHG-04-2020-0031>). The topic of refugee health was recommended by the Editorial Advisory Board of the International Journal of Health Governance (where I served as a Regional Editor for Europe), as there “remained critical gaps in the knowledge base on a wide range of determinants of health service delivery and access for refugees and migrants in the WHO European Region”. While preparing a protocol for our review we have contacted representatives of several agencies working with refugees in Europe to find out if they were interested in that kind of research and what particular findings would help them in their practical work. We were assured that the topic and type of review was highly relevant, and have been specifically advised to analyze in which settings and in which countries the research has been conducted (besides many other parameters). We realized that other similar reviews only had two types of settings (clinical and non-clinical), while we had defined 11 different settings. And that analysis by country usually related to the author affiliation, not the country where the research was actually conducted. We were very pleased to see that our findings are cited in the recent WHO publication “Continuum of care for noncommunicable disease management during the migration cycle“ from a series on “Global Evidence Review on Migration and Health” (<https://apps.who.int/iris/handle/10665/352261>)

Irina

HIFA profile: Irina Ibraghimova is an independent consultant with a PhD. in library sciences and more than 20 years' international experience in ICT for health projects. She now serves as a Co-editor for the International Journal of Health Governance (Emerald Publishing). Professional interests: Information and health literacy, evidence-based practice, science communication and medical journals editing. <http://www.healthconnect-intl.org/> She is a HIFA country representative for Croatia: <https://www.hifa.org/support/members/irina>

Communicating health research (79) Q4. What are the needs and preferences of policymakers? (5) Global and local synthesis (3)

26 September, 2022

Two more papers from the UK, trying to find some answers to those questions

Boulding H, Kamenetzky A, Ghiga I, Ioppolo B, Herrera F, Parks S, Manville C, Guthrie S, Hinrichs-Krapels S. Mechanisms and pathways to impact in public health research: a preliminary analysis of research funded by the National Institute for Health Research (NIHR). *BMC Med Res Methodol*. 2020 Feb 19;20(1):34. doi: 10.1186/s12874-020-0905-7. PMID: 32075580; PMCID: PMC7031933.

[<https://bmcmedresmethodol.biomedcentral.com/articles/10.1186/s12874-020-...>]

Lakin K, Meadmore K, Recio Saucedo A, Baker G, Worswick L, Thomas S. Researchers' perspective of real-world impact from UK public health research: A qualitative study. *PLoS One*. 2022 Jun 27;17(6):e0268675. doi: 10.1371/journal.pone.0268675. PMID: 35759461; PMCID: PMC9236254.

[<https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0268675>]

It looks like researches in the UK are required to plan the impact of their research, but it is realistic only when it is planned together with policymakers.

Irina

HIFA profile: Irina Ibraghimova is an independent consultant with a PhD. in library sciences and more than 20 years' international experience in ICT for health projects. She now serves as a Co-editor for the *International Journal of Health Governance* (Emerald Publishing). Professional interests: Information and health literacy, evidence-based practice, science communication and medical journals editing. <http://www.healthconnect-intl.org/> She is a HIFA country representative for Croatia: <https://www.hifa.org/support/members/irina>

Communicating health research (80) Have you ever published a research paper? What happened? (4)

26 September, 2022

"Medicine is mainly curative...."

Medicine provides a passive role for patients. "I am helpless, doctor. Please do medicine to me."

Non communicable diseases are prevented by cultural norms, values, basic assumptions and artefacts (TVs, cars, adverts, packaging and sales etc) and not much by medicines. Despite having the most expensive health service in the world, the life expectancy in the USA is falling.

My hope for the WHO digitization strategy, UHC and SDGs is for interactive two way communicating EHRs for 7.9 billion registered citizens/patients who become co-creators and agencies of health along with Big Pharma, "medicine" and governments.

HIFA profile: Richard Fitton is a retired family doctor - GP. Professional interests: Health literacy, patient partnership of trust and implementation of healthcare with professionals, family and public involvement in the prevention of modern lifestyle diseases, patients using access to professional records to overcome confidentiality barriers to care, patients as part of the policing of the use of their patient data.

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Communicating health research (81) Q2. What are the different approaches? (20) Five steps for research-to-policy/practice strategies

26 September, 2022

Hi everyone

As another contribution to this lively discussion on communicating health research and picking up on some of the ideas already shared in this forum, here are five steps on how I usually approach research-to-policy/practice strategies. All of these I have seen work well in the past, if not necessarily at the same time and for all types of research and evidence.

1. Know who to talk to: Conduct a basic stakeholder mapping/listing based on your findings. I usually find it best to avoid complex mapping techniques, power matrix or support vs. opposition charts (they are often unnecessarily complicated). Simply ask “who needs to know” about your research findings and list names, contact details etc.

-> TDR’s SORT IT/Knowledge Management module has a great template for this (maybe not yet publicly available).

2. Get consent on desired change: Connect 2-3 stakeholders, decision-makers, or implementers to outcomes you would like to see based on the evidence. Define what change you are recommending - and get consent from co-authors, partners, etc. (that way, you create a shared vision of change and widen the perspective). Consider breaking up the change into incremental steps (for instance, what would you expect, like, love to see in a short-, mid-, or long-term perspective) - and remain stakeholder-oriented (who needs to do what). This is essentially a theory of change exercise, but it can be done in a quick and light format. (This is ideally done at the design stage of a study/review already, but can still be put together after publication, too).

-> I found outcome mapping works great, ODI’s Roma guide has some great tools, see: <https://odi.org/en/about/features/roma-a-guide-to-policy-engagement-and-...>

3. Craft your message: Translate your findings and recommendations into an actionable message targeted at your main stakeholders. This can be done in multiple formats: a full-fledged policy brief, a two-page an evidence-brief format, or a simple presentation. At the very least, the format should include a) some background and context, b) why/how findings matter, c) a factual account of key findings, and d) actionable, stakeholder-related recommendations (who should do what).

-> There are multiple evidence/policy brief templates available across the internet: This

SUPPORT Tool article [<https://health-policy-systems.biomedcentral.com/articles/10.1186/1478-45...>] discusses some strategic considerations, and the EVIPNet guiding manual [<https://apps.who.int/iris/handle/10665/337950>] offers fairly detailed guide for comprehensive policy brief development.

-> Notably, I often found that this to be the time to bring in additional evidence from other studies, programme data, evaluations etc., as a single piece of evidence may only provide limited ground to recommend practical action.

4. Choose your main channels: Decide how to best reach key stakeholders. I often found that merely sharing the study or sending an anonymous evidence brief is the worst option! Is there someone in your network that can connect you directly to a decision-maker (or, even better, have they been involved in a study from the beginning)? Can you present your findings in the actual study setting (to practitioners, in the community?). Are there organisations/partners that may be able to leverage your findings from their work? What do stakeholders care for the most (see 1)?

-> Going back to the stakeholder list often already defines a basic communication strategy, which can be revised and updated regularly.

5. Consider amplifying your message on additional channels: It's usually only at this point I would consider investing in developing additional formats such as traditional print, audiovisual, or social media (podcasts, video clips, social media etc.) - for two reasons. For one, there is a risk of getting lost in content strategies and production processes, good audiovisual and social media content takes time to produce. The other reason is that many of these formats require to be very short, visual and (at times) dramatic, posing a challenge to translate factual evidence into suitable messages. Ideally, this wider communications strategy supports the more targeted research communication to strategic decision-makers.

-> This is where collaboration between researchers, knowledge translators and communication professionals (journalists etc.) is both the most challenging and the most promising. (And that is not to say that researchers who are active on social media should not feel encouraged to post their findings!)

I found these steps to work across many types of evidence (e.g., primary and secondary research), but also realized when writing this that there are differences. Apologies in advance, therefore, if this remains still somewhat abstract or academic (as Massimo rightly pointed out). I too will try and think of some more tangible case studies.

Best regards and happy Monday,

Sam

Samuel Sieber PhD

Knowledge Translation and Engagement Specialist

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Communicating health research (82) Q4. What are the needs and preferences of policymakers? (5) Informing versus persuading policymakers

26 September, 2022

Dear HIFA colleagues,

Claire Glenton has kindly forwarded me this checklist for dissemination of Cochrane systematic reviews. The accompanying guidance is quite detailed: <https://training.cochrane.org/sites/training.cochrane.org/files/public/u...>

Some of these are perhaps applicable only to systematic reviews while others may be more widely applicable. I think each of them are worth consideration as we explore how to improve the impact of health research communication to policymakers. Here is the list and below are a few initial comments from me.

The dissemination checklist: 1-page overview

1. Have you involved your target audience or sought their feedback?
2. Have you used plain language?
3. Have you used words in your title that your target audience is likely to search for, recognize, and find relevant?
4. Have you communicated to your target audience that this product is relevant for them?
5. Have you structured the content so people can find key messages, then access more detail if they want?
6. Have you made the content easy for people to quickly scan and read?
7. Have you shown that the evidence involves real people?

8. Have you specified the populations, interventions, comparisons, and outcomes?
9. Have you stated that this information is from a systematic review?
10. Have you specified how up to date the review is?
11. Have you avoided misleading presentations and interpretations of the effects?
12. If you have used numbers to present the findings, have you used absolute numbers and labelled numbers clearly?
13. Have you described the certainty of the evidence?
14. Have you presented the findings in more than one way?
15. Where the topic or findings may be upsetting, controversial, or disappointing: have you handled this sensitively?
16. Have you made it clear (a) that the review was prepared by Cochrane and (b) who prepared the dissemination product?
17. Is it easy for people to find information about who the review authors are, how they were funded, and any conflicts of interest?
18. Have you avoided giving recommendations?

COMMENT (NPW):

I invite discussion on any of the above, and especially on the last point:

18. Have you avoided giving recommendations?

Here, the Cochrane guidance says:

At a minimum:

- Do not give recommendations in your dissemination product.

Ideally, also:

- State explicitly that recommendations are not included.
- Think about how you can help people reach their own decisions.

The aim of a Cochrane Review is to provide the best available evidence, and then let people make their own decisions.

In the case of Cochrane reviews it is clear that 'effective research communication' is about providing information and not about recommending a particular course of action.

And yet repeatedly in the wider health literature we see both primary researchers and secondary researchers go beyond informing, towards making recommendations and even lobbying for specific policy change. If (some) systematic reviewers specifically avoid making recommendations, then why do so many primary research studies make recommendations?

In what circumstances is it appropriate for a researcher/research team to persuade policymakers to take a specific course of action, rather than to focus on providing the information that policymakers need to make their own decisions?

I am reminded of Richard Fitton's message last week, when he quoted the UN Assembly President: "We are not asking scientists to tell us what to do. We are asking scientists to show us the options"

It would be good to hear from policymakers as well as researchers on this issue. Please email to: hifa@hifaforums.org

Best wishes, Neil

Joint Coordinator, HIFA Communicating health research <https://www.hifa.org/projects/new-effective-communication-health-research...>

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HIFA profile: Neil Pakenham-Walsh is coordinator of the HIFA global health movement (Healthcare Information For All - www.hifa.org), a global community with more than 20,000 members in 180 countries, interacting on six global forums in four languages in collaboration with WHO. HIFA brings stakeholders together to accelerate progress towards universal access to reliable healthcare information. HIFA is administered by Global Healthcare Information Network, a UK based non-profit in official relations with the World Health Organization. Twitter: @hifa_org neil AT hifa.org

Communicating health research (83) Q4. What are the needs and preferences of policymakers? (6) Global and local synthesis (4)

26 September, 2022

I have a question for you. Do you have any experience with the WHO approach to policymaking, whether from the point of view of a guideline developer, researcher, information professional or policymaker? Whether at global or country level?

My (basic) understanding is that WHO produces international guidance that is made available to member states to help inform policy. Member states consider the global guidance in their own context and alongside relevant local research, and use these to develop policy.

Can anyone describe in more detail how this works? In particular, can you describe a case study where WHO guidance was adapted to inform national policy?

Also, what actually happens when global evidence (for example from WHO guidance) is synthesised with local evidence? Can you describe a situation where this has worked (or where it hasn't?).

Best wishes, Neil

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Communicating health research (84) Q3. Role of researchers (6) Improving health outcomes

27 September, 2022

My greetings to all medical corp, researchers, and their assistants;

I think that communication health research is related to highly noble decisions made by researchers and qualified doctors.

These two later actors have normally a higher degree of Humanism which may be sacred to disclose to all. However, research depended logically on recognized programs of research guested by thousands of advanced-rank universities. Indeed, it needs a developed environment of equipment, perfect laboratories, and in firsthand state of well-being of researchers and their staff. unlike be utopian, each advanced country believes make returns for their medical investments. The problem is more obvious if these researchers depend on large firms with a lucrative nature and with a commercial statutes. Everyone has his or her causes and everyone is right. Nevertheless, how to satisfy the wolf without a shepherd crying out in loss?

Here comes the global movement of open access, denial of self, super humanism, international talent, and expertise in nobility, allied with the efforts of the WHO.

The two great actors it is them according to their degree of humanism and their sacred life in the service of Humanity, push them to decide to deliver what was needed to other worldwide researchers without consideration of the facts of race, gender, ethnicity, religion, or political views.

HIFA Profile: Mohsen Hassani is President of AHALINA Association, Tunisia. Professional interests: International and community development. Provision of socioeconomic information in rural areas. Giving a voice to citizens. Conduct research concerning the socio-economic situation in Skhira region (eastern south of Tunisia). Email: ahalina.kenitra AT gmail.com

Communicating health research (85) Q3. Role of researchers (7) Researcher motivation

27 September, 2022

Many thanks to Hassani Mohsen (Tunisia) for your comments reminding us of the importance of researcher motivation for the public good.

In an ideal world all health researchers would be focused on improving health outcomes, and I am sure that this is the reason that almost all researchers start on their chosen career. Just in the same way that (some) politicians go into politics "to make society better".

But, just as politicians can become increasingly self-interested, the same is possible with researchers.

The system tends to push researchers in this direction. Their professional success is determined largely by the number of papers they produce, and the impact factor of the journals where they publish those papers. Furthermore, researchers spend a lot of their time chasing research funding from a relatively small number of funders. The competition with other researchers is intense.

As we have heard earlier in this discussion, the funding agencies themselves are often driven by research 'successes' in the sense of discovery and translation into policy and practice. So researchers are motivated to get their findings directly into policy.

'Getting findings directly into policy' may sometimes be appropriate, but perhaps more often it deviates policymakers from an evidence-informed approach whereby policy is based on research synthesis rather than single studies. Funding agencies are perhaps less interested in research that adds to the cumulative evidence base as compared with research that directly changes policy and practice.

I would be interested to hear from researchers and others about these pressures and incentives, and how this might impact on the impartiality of their communication with policymakers.

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Working in official relations with WHO

Communicating health research (86) Global and local synthesis (5) Role of information professionals

27 September, 2022

May I please echo one of the important points Irina makes: when planning a systematic review it is always recommended to include library/information professionals while the search strategy is being developed. Asking for their advice or comments after the event is too late.

Best regards, Mark

HIFA profile: Mark Lodge is Director of Programme Development at the International Network for Cancer Treatment and Research, Oxford, UK. The INCTR is dedicated to helping to build capacity for cancer treatment and research in countries in which such capacity is presently limited, and thereby to create a foundation on which to build strategies designed to lessen the suffering, limit the number of lives lost, and promote the highest quality of life for children and adults with cancer in these countries, and to increase the quantity and quality of cancer research throughout the world. www.inctr.org mlodge AT canet.org

Communicating health research (87) Q3. Role of researchers (8) Researcher motivation (2)

27 September, 2022

Dear HIFA colleagues,

As we look this week at the role of researchers in research communication, and reflect on their/your motivations, it was serendipitous that PLOS (a leading open access publisher) sent out today a survey with the title "What motivates you as a researcher?"

<https://plos.org/values-assessment/>

Here are the aspects they consider, followed by a comment from me below:

What matters:

Improving the peer review process so that it is fair and impartial

Improving public trust in science

Teaching and guiding younger researchers in order to help them build their careers

Allocating fair and accurate credit to help researchers build their careers

Improving how we validate and verify published research

Improving how we demonstrate that even small contributions to science can make a big difference in the world

I want....

I want others to trust and build on my research

I want to try new ways of sharing research

I want to demonstrate that all evidence is worth sharing, even if it results in a negative or null outcome

I want to demonstrate that I conduct the most high-quality, rigorous research possible

I want to ensure that everyone can publish in an OA journal if they choose

I want my research to help shape public policy

I want to promote and support peers in my community

I want to be globally recognized for my accomplishments in my field

I want my research to inform decision-making at both the societal and individual levels

I want to exchange knowledge and learn from different perspectives

I want my research to forge a path for others

I want to learn something new everyday

I want the freedom to set my own research agenda based on questions I think are important

I want everyone to have the freedom to read and access research

By the end of my career in research, I most hope my colleagues will think of me as ...

- a researcher who shares freely, assesses work fairly, and acknowledges all contributions to research.

- a researcher whose work is always high-quality, reproducible, and reliable.

- a researcher who has made a tangible difference in the field and in the world.

- an innovative researcher and mentor, and a leader in my field or region.

- a creative and dedicated researcher with deep experience in my area of interest.

Your responses suggest that you value the potential to **CREATE CHANGE**. You want your research to have an impact — to leave your mark on your field, and to create positive real-world change, through public policy, improved health outcomes, and more informed decision-making.

1. You believe in the power of knowledge

That more information in the hands of the public, teachers, government, policy makers, and fellow researchers leads to a better world—to improved health outcomes, more conscientious decision-making and a brighter future.

2. You believe that collaboration can accelerate

That sharing small as well as significant scientific advances with the broadest possible audience, and sharing early whenever possible drives progress and increases the pace of advancement.

3. You believe in egalitarianism

That when scientific research is freely accessible and easily discoverable it's more likely to be read, and to influence future research, public policy, curriculum, and opinion. That everyone should have access to rigorous research, and the power to apply their knowledge in practical ways in the real world.

COMMENT (NPW): Do the above attributes speak to you? What motivates you as a researcher? How does this relate to how you *communicate* your research?

Best wishes, Neil

Joint Coordinator, HIFA Communicating health research <https://www.hifa.org/projects/new-effective-communication-health-research...>

Let's build a future where every person has access to reliable healthcare information and is protected from misinformation - Join HIFA: www.hifa.org

HIFA profile: Neil Pakenham-Walsh is coordinator of the HIFA global health movement (Healthcare Information For All - www.hifa.org), a global community with more than 20,000 members in 180 countries, interacting on six global forums in four languages in collaboration with WHO. HIFA brings stakeholders together to accelerate progress towards universal access to reliable healthcare information. HIFA is administered by Global Healthcare Information Network, a UK based non-profit in official relations with the World Health Organization. Twitter: @hifa_org neil AT hifa.org

Communicating health research (88) Q4. What are the needs and preferences of policymakers? (7)

27 September, 2022

Great contributions to an important topic!

I spent 30 years, as an analyst and manager of analysts, working with health service policy makers and managers. Sometimes this was “hands on” research and analysis, sometimes it entailed commissioning research and sometimes it involved acting as a “broker” between academic researchers and policy makers.

Given that background I offer a few comments about helping communication between researchers and policymakers to meet their needs of the latter. Some of these comments of course echo ones already made in this discussion. Some of the lessons were learnt the hard way!

- Be aware - understand the policymakers' business, their needs and appreciate their environment. Talk, and if possible work closely, with them to improve this understanding. Be conscious of any difficulties handling research findings might present to policymakers.

- Be relevant - find out health policymakers' and managers' "hot topics" and consider how research can identify and inform "high impact changes" in these areas.

- Be timely - fit with the "zeitgeist" matters, and policymakers' timescales can be very short, which often does not sit easily with research timeframes. Communication about this needs to be realistic.

- Be visible - publish and publicise in the right way in the right places. For example do not publish only in research journals. Policymakers and managers are busy people and have little if any time to spend assimilating research reports.

- Be compelling - ensure messages are as robust and as simple as possible (though, to paraphrase Einstein, no simpler) and presented in a way that makes clear their policy relevance.

- Be a facilitator - make it easier for policymakers and managers to use research findings. For example computer models can help link research and policy; taking results from variety of research studies in their input and producing output that directly informs policy questions (the Lives Saved Tool (LIST) model is a well-known example). Such models also help indicate gaps in research needed to address policy issues - so they are a two-way communication tool.

As Chris Zielinski has noted, direct communication with policymakers is not the only way communicating research can influence thought and action. Research can get picked up by the media (with or without researchers' assistance) and this reporting can influence policymakers and indeed the public. This influence can be positive, for example in publicising an important health protection issue, or negative, for example where media publicity misrepresents a health risk. (There are numerous examples of both of these, not least in the context of Covid and other epidemics.)

Geoff

HIFA profile: Geoff Royston is an Independent Health Analyst and Researcher, former Head of Strategic Analysis and Operational Research in the Department of Health for England, and Past President of the UK Operational Research Society. His work has focused on informing the design, implementation and evaluation of policies and programmes in health and social care, and on fostering the capabilities of others to work in these areas. Associated activities have included modelling for understanding the performance of complex systems, analysis and communication of risk, and horizon scanning and futures thinking. He has also worked on

information and communication technology in the health sector, notably in leading the design and national launch of the telephone and online health information and advice service NHS Direct. He has served on both scientific and medical UK Research Council panels, and as an impact assessor for the UK higher education Research Excellence Framework. He is a member of the editorial board for the journal Health Care Management Science and in 2012 was Guest Editor for its special issue on Global Health. He has been a consultant for the World Health Organisation, is a long standing member of the EURO Working Group on Operational Research Applied to Health Services, and is an expert adviser to the mHIFA (mobile Healthcare Information for All) programme. <http://www.hifa.org/projects/mobile-hifa-mhifa> He is also a member of the main HIFA Steering Group and the HIFA working group on Evaluating the Impact of Healthcare Information.

<http://www.hifa.org/support/members/geoff>

geoff.royston AT gmail.com

Communicating health research (89) Global and local synthesis (6) Role of information professionals (2)

27 September, 2022

I want to thank Mark for that advice about getting in touch with a librarian as you set out to start a systematic review. The same applies to making sure you get a statistician involved in any research you want to undertake right at the first thought of it. You would not consult an architect after you have completed the building or put another way, that would not be the sensible approach if you want a livable and safe home.

If you wish a research result that policy makers would want to use to drive policy and implement, these preparatory steps and actions are important.

Joseph Ana

HIFA profile: Joseph Ana is the Lead Senior Fellow/Medical Consultant at the Centre for Clinical Governance Research and Patient Safety in Calabar, Nigeria, established by HRI Global (former HRIWA). He is a member of the World Health Organisation's Technical Advisory Group on Integrated Care in primary, emergency, operative, and critical care (TAG-IC2). As the Cross River State Commissioner for Health, he led the introduction of the Homegrown Quality Tool, the 12-Pillar Clinical Governance Programme, in Nigeria (2004-2008). For sustainability, he established the Department of Clinical Governance, Servicem & e-health in the Cross River State Ministry of Health, Nigeria. His main interest is in whole health sector and system strengthening in Lower, Low and Middle Income Countries (LLMICs). He has written six books on the 12-Pillar Clinical Governance programme, suitable for LLMICs, including the TOOLS for Implementation. He served as Chairman of the Nigerian Medical Association's Standing Committee on Clinical Governance (2012-2022), and he won the Nigeria Medical Association's Award of Excellence on three consecutive occasions for the innovation. He served as Chairman, Quality & Performance, of the Technical Working Group for the implementation of the Nigeria Health Act 2014. He is member, National Tertiary Health Institutions Standards Committee of the Federal Ministry of Health. He is the pioneer Secretary General/Trustee-Director of the NMF (Nigerian

Medical Forum) which took the BMJ to West Africa in 1995. Joseph is a member of the HIFA Steering Group and the HIFA working group on Community Health Workers. (<http://www.hifa.org/support/members/joseph-0> <http://www.hifa.org/people/steering-group>). Email: info AT hri-global.org and jneana AT yahoo.co.uk

Communicating health research (90) Q3. Role of editors

28 September, 2022

The second part of Q3 asks about the role of stakeholders (other than researchers) in research communication, and an important group is editors.

The World Association of Medical Editors newsletter refers to a blog that looks at the integrity of editors.

See the full newsletter here: <https://wame.org/global-access.php?id=102>

And the blog here: <http://deevybee.blogspot.com/2022/09/we-need-to-talk-about-editors.html>

"We need to talk about editors...Even if an editor starts off well, they may over time start to think 'What's in this for me?' and decide to exploit the opportunities for self-advancement offered by the position. The problem is that there seems little pressure to keep them on the straight and narrow; it's like when a police chief is corrupt. Nobody is there to hold them to account...we see clearcut instances of paper mill outputs [*see note below] that have apparently been approved by a regular journal editor...some preliminary suggestions:

1. Appointment to the post of editor should be made in open competition among academics who meet specified criteria.
2. It should be transparent who is responsible for final sign-off for each article that is published in the journal.
3. Journals where a single editor makes the bulk of editorial decisions should be discouraged...
4. There should be an editorial board consisting of reputable people from a wide range of institutional backgrounds, who share the editorial load, and meet regularly to consider how the journal is progressing and to discuss journal business.
5. Editors should be warned about the dangers of special issues and should not delegate responsibility for signing off on any papers appearing in a special issue.
6. Editors should be required to follow COPE guidelines about publishing in their own journal, and publishers should scrutinise the journal annually to check whether the recommended procedures were followed
7. Any editor who allows gibberish to be published in their journal should be relieved of their editorial position immediately."

From the blog: 'We can no longer take editorial honesty for granted, and systems need to change to weed out dodgy editors if academic publishing is to survive as a useful way of advancing science. In particular, the phenomenon of paper mills has shone a spotlight on editorial malpractice... the phenomenon of academic paper mills – defined in a recent report by the Committee on Publication Ethics (COPE) and the Association of Scientific, Technical and Medical Publishers (STM) as “the process by which manufactured manuscripts are submitted to a journal for a fee on behalf of researchers with the purpose of providing an easy publication for them, or to offer authorship for sale.” The report stated that “the submission of suspected fake research papers, also often associated with fake authorship, is growing and threatens to overwhelm the editorial processes of a significant number of journals.”

Best wishes, Neil

Joint Coordinator, HIFA Communicating health research <https://www.hifa.org/projects/new-effective-communication-health-research...>

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HIFA profile: Neil Pakenham-Walsh is coordinator of the HIFA global health movement (Healthcare Information For All - www.hifa.org), a global community with more than 20,000 members in 180 countries, interacting on six global forums in four languages in collaboration with WHO. HIFA brings stakeholders together to accelerate progress towards universal access to reliable healthcare information. HIFA is administered by Global Healthcare Information Network, a UK based non-profit in official relations with the World Health Organization. Twitter: @hifa_org neil AT hifa.org

Communicating health research (91) Q3. Role of editors (2)

28 September, 2022

A few minutes ago I forwarded an article about the very few editors who 'decide to exploit the opportunities for self-advancement'.

The vast majority of editors form a critical part of the research communication process. They typically have the needs of their readers in mind. They receive and initially assess manuscripts, manage the peer review process, and edit the final paper for accuracy and clarity.

When we consider question 5 in our discussion - What can be done to better support researchers in the communication of health research? - we might ask the same about editors. If you are an editor we would love to hear from you: hifa@hifaforums.org

Best wishes, Neil

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Communicating health research (92) The discussion so far

28 September, 2022

Dear HIFA colleagues,

Thank you to all who have contributed to the discussion so far.

We have extracted the key points and organised them into headings and subheadings here:

[https://www.hifa.org/sites/default/files/publications_pdf/Communicating ...](https://www.hifa.org/sites/default/files/publications_pdf/Communicating...)

We offer this in the hope that it will be helpful for HIFA members to follow and contribute.

You can review the full text of all messages here: <https://www.hifa.org/rss-feeds/17>

As always, please do send your thoughts and comments to the forum: hifa@hifaforums.org

OUR GUIDING QUESTIONS

1. What do we mean by 'Effective communication of health research to policymakers? How do we measure it?
2. What are the different approaches to communicating research (eg academic journals, policy briefs, interaction with policymakers, press releases, social media, infographics, use of video)? What is your experience with these approaches? What works and what doesn't?
3. What is the role of researchers in research communication, beyond publication of their paper? What is the role of other stakeholders (eg communication professionals, editors, media, public health professionals and critical thinkers)
4. What are the needs and preferences of policymakers?
5. What can be done to better support researchers in the communication of health research?

With thanks and best wishes,

Neil

Joint Coordinator, HIFA Communicating health research <https://www.hifa.org/projects/new-effective-communication-health-research...>

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Communicating health research (93) Examples of health research papers and their impact

28 September, 2022

Dear Richard (Fitton) and all,

Thank you for citing examples of health research that have had an impact on health, including John Snow, Edward Jenner, and Ignaz Semmelweis.

I'd like to turn our attention specifically to examples of how research is communicated.

John Snow is a good example. In 1854 he identified a water pump in London as the likely source of a cholera outbreak, based on mapping deaths in the vicinity and interviewing residents. He wrote to the editor of the Medical Times and Gazette:

"On proceeding to the spot, I found that nearly all the deaths had taken place within a short distance of the [Broad Street] pump...

The result of the inquiry, then, is, that there has been no particular outbreak or prevalence of cholera in this part of London except among the persons who were in the habit of drinking the water of the above-mentioned pump well. I had an interview with the Board of Guardians of St James's parish, on the evening of the 7th inst [7 September], and represented the above circumstances to them. In consequence of what I said, the handle of the pump was removed on the following day."

He included a map of the nearby streets, showing the locations of each death. Clearly this was sufficient to get the authorities (policymakers) to act. And all this was before the work of Pasteur, Koch and others established germ theory (whereby infections are caused by micro-organisms).

What about the millions of research papers that are published every year in the current era?

How well are these papers communicated?

I would like to invite HIFA members to describe a piece of research in which you were involved, perhaps as a co-author. How did you communicate this research? Did you publish in a peer-reviewed journal, and then move on to your next project? Or did you take action to raise the visibility of the research? Perhaps you listed and made contact with selected stakeholders, as suggested by Sam Sieber? Perhaps you issued a press release? Or contributed to a policy brief? Have you used social media to communicate your findings? What have you found to be most effective in communicating your research?

MY EXPERIENCE

I am not a researcher but have been involved in a systematic review, a qualitative study of HIFA discussions, a position paper for WHO, a white paper with HIFA and the New York Law School, and several analysis/advocacy papers. I don't think any of them have had a direct impact on policymaking (whether with a big P or a small p).

The position paper for WHO (written with Fiona Godlee and colleagues in 2004) apparently stimulated much discussion internally, but I believe its main impact was to provide the rationale for HIFA, which was subsequently launched in 2006.

Our white paper with the New York Law School (2012) demonstrated that governments have a legal obligation under international human rights law to ensure their citizens have access to reliable healthcare information, and yet it has had no demonstrable impact on policymakers. Indeed it was tragic to see, during COVID-19, how some heads of state not only ignored this responsibility but actively spread harmful misinformation.

In 2020 I co-authored a viewpoint/analysis paper with Geoff Royston and Chris Zielinski, where we argued that 'All stakeholders need to work together to accelerate progress towards universal access to essential health information; a catalyst for this would be the inclusion of universal access to essential health information in the relevant SDG target and associated monitoring indicators for UHC, a step that WHO could usefully endorse'. We failed to get the attention of the relevant stakeholders.

Have you published a paper (or several)? Did it have the impact you hoped for?

Please email your experience to: hifa@hifaforums.org

Best wishes, Neil

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Communicating health research (94) International Network for the Availability of Publications (INASP)

28 September, 2022

Before I started HIFA I used to work for the International Network for the Availability of Publications, INASP, an Oxford-based charity which works 'in partnership to strengthen the capacity of individuals and institutions to produce, share and use research and knowledge, in support of national development'. www.inasp.info

Below are some relevant extracts from their current website:

Research communication: Southern researchers face the same pressure to publish as Northern researchers, but often don't have access to the resources, information, training, and support networks they need. We support Southern researchers and their institutions to build the confidence, knowledge and skills so that their research can be published and communicated – to academic and non-academic audiences.

Our approach is to build the individual skills of researchers via:

- Massive open online courses (MOOCs) on research writing and publication. Our large-scale online courses in research writing, publishing and grant proposal writing are supported by expert facilitators from around the world.
- Thematic online courses on research communication and proposal writing. We deliver intensive courses on research communication and proposal writing, tailored to fit thematic areas, and country context.
- Supporting research communication to non-academic audiences, such as policymakers and practitioners. We design and implement research uptake strategies and skills training for projects aiming to influence policy.

INASP also runs the AuthorAID platform, which provides support and services for over 20,000 developing country researchers, including mentoring.

In 2021 INASP published Context Matters: A Framework to support knowledge into policy, 'a participatory tool to help detect and understand the best entry points to improve the use of knowledge in a public agency'. This framework

- Looks at internal factors within an organization as well as the external political economy and relationships .

- Addresses visible changes, such as new processes or behaviours, and invisible changes, such as incentives or cultures for knowledge use
- Builds on the experience of 50+ policymakers and practitioners
- [has been] Tried and tested with multiple government agencies in a wide range of countries, including Peru, Ghana, Uganda, Pakistan

I invite you to have a look and comment:

<https://www.inasp.info/contextmatters>

QUESTION: Are you aware of any useful practical guides for research communication? Please let us know by sending an email to: hifa@hifaforums.org

With thanks, Neil

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Communicating health research (95) Role of translators (1) International Translation Day, 30 September

29 September, 2022

It's International Translation Day on Friday, 30 September. As a result of a resolution of the United Nations General Assembly on May 24, 2017, every September 30 is celebrated as International Translation Day. The day is dedicated to honoring the role of language professionals in fostering peace, development, and camaraderie between linguistically distinct nations.

HIFA has had contact with Translators without Borders, an NGO set up to provide translation services for humanitarian non-profits. According to Wikipedia, it was established in 2010 as a sister organization of Traducteurs Sans Frontières, founded in 1993 by Lori Thicke and Ros Smith-Thomas of Lexcelera. They are providing valuable, though largely under-the-radar, service to disseminating health information.

In the context of our current discussion of research communication, I should note that we not only need to translate research into a level of language appropriate for policy makers and the general public, but often also into local languages - an almost completely neglected part of research communication. This has obvious practical implications - misunderstandings of language were one reason for attacks on health workers in the Congo trying to help with the Ebola outbreak a few years ago. There are also ethical issues, particularly when research is based on human subjects, since it is an obligation of ethical research to communicate the results to the subjects. Again, this ethical obligation is often ignored.

Best,

Chris

Chris Zielinski

chris@chriszielinski.com

Blogs: <http://ziggytheblue.wordpress.com> and <http://ziggytheblue.tumblr.com>

Research publications: <http://www.researchgate.net>

HIFA profile: Chris Zielinski: As a Visiting Fellow and Lecturer at the Centre for Global Health, University of Winchester, Chris leads the Partnerships in Health Information (Phi) programme, which supports knowledge development and brokers healthcare information exchanges of all kinds. He is the elected Vice President (and President-in-Waiting) of the World Association of Medical Editors. Chris has held senior positions in publishing and knowledge management with WHO in Brazzaville, Geneva, Cairo and New Delhi, with FAO in Rome, ILO in Geneva, and UNIDO in Vienna. He served on WHO's Ethical Review Committee, and was an originator of the African Health Observatory. He also spent three years in London as Chief Executive of the Authors Licensing and Collecting Society. Chris has been a director of the UK Copyright Licensing Agency, Educational Recording Agency, and International Association of Audiovisual Writers and Directors. He has served on the boards of several NGOs and ethics groupings (information and computer ethics and bioethics). chris AT chriszielinski.com. His publications are at <https://www.researchgate.net/profile/Chris-Zielinski> and <https://winchester.academia.edu/ChrisZielinski/> and his blogs are <http://ziggytheblue.wordpress.com> and <https://www.tumblr.com/blog/ziggytheblue>

Communicating health research (96) Q4. What are the needs and preferences of policymakers? (8)

29 September, 2022

I have only limited, and certainly not generalisable experience about the WHO approach to policymaking, but I did participate in the preparation of an evidence brief for policy <<https://apps.who.int/iris/handle/10665/346592>> , on the production of which we also recently published an evaluation <<https://health-policy-systems.biomedcentral.com/articles/10.1186/s12961-...> . One thing that seems very important to me - in line with what Wilbber Sabiiti noted upon the example of COVID-19, or following

Kingdon's model <<https://www.amazon.com/Alternatives-Policies-Epilogue-Classics-Political...> of policy streams - is agenda setting.

The main problem is not that much that policy makers don't understand research but that they are not interested in it, unless they perceive the problem which that piece of research may address as urgent and important for them to solve. This is why the media, blogs, etc. that Chris Zielinski and Joseph Ana very rightly emphasised are in my view very important. However, there are a lot of different, often competing voices in the media, and policy makers, especially politicians, are the very experts of forging their own narrative and agenda using those, so I don't think we can expect that researchers will ever be able to outcompete them in this contest for society's interest.

Therefore, I think that our ambition as researchers should rather be to spread our ideas within the expert circles of policy administration, and wait for the opportunity to arise. High-level policy interest may or may not come, but if a case is well built and mid-level policy makers are convinced about the effectiveness of a proposed solution, it has a chance to go through when "the stars are aligned". At that point at the latest, it is also key to have policy brokers with a sound understanding of - and preferably informal ties to - the world of politics, who can explain to decision makers why the proposed solution is beneficial to all the stakeholders involved. Therefore, the more these mid-level policy makers are involved in the research communication process, the more chance one has to be effective, but one may often have to wait to see that.

Best regards,

Balázs

HIFA profile: Balazs Babarczy is a Senior researcher at the Syreon Research Institute, Budapest, Hungary. www.syreon.eu balazs.babarczy AT syreon.eu

<https://www.hifa.org/support/members/balazs>

Communicating health research (97) Top 10 rapid review methodology research priorities

1 October, 2022

This paper looks specifically at rapid reviews, and includes two questions on dissemination (#7 and #9 below). The authors note that 'published evidence on the optimal methods of planning, doing, and sharing the results of these reviews is lacking...'. I suspect the same is true for evidence on the optimal methods of sharing the results of *any* research, including primary research. Are you aware of any research on this topic? Please email hifa@hifaforums.org

CITATION: Original article| volume 151, p151-160, november 01, 2022

Priority III: top 10 rapid review methodology research priorities identified using a James Lind Alliance Priority Setting Partnership

'A rapid review is a form of evidence synthesis considered a resource-efficient alternative to the conventional systematic review. Despite a dramatic rise in the number of rapid reviews commissioned and conducted in response to the coronavirus disease 2019 pandemic, published evidence on the optimal methods of planning, doing, and sharing the results of these reviews is lacking...

'Priority III engaged with patients and the public, researchers, reviewers, clinicians, policymakers, and funders to identify and prioritize the top 10 unanswered research questions about rapid review methodology...

'Top 10 questions prioritized

1 What are the best approaches to identify people or groups who will use the results of a rapid review (e.g. stakeholders such as patients and the public, clinicians, policymakers), and how can they have meaningful (i.e., purposeful, relevant) involvement in planning and doing a rapid review, and in reporting and sharing the findings?

2 Do rapid reviews generate similar findings to full systematic reviews, and should the findings from all rapid reviews be considered at lower certainty compared to full systematic reviews?

3 How best can underserved stakeholder groups (e.g. ethnic minorities, socio-economically disadvantaged) and stakeholders from under represented countries (e.g. countries of different income levels) be identified and have meaningful (i.e., purposeful, relevant) involvement in planning and doing rapid reviews, and in sharing the results?

4 When deciding if a research question would benefit from being the focus of a rapid review, rather than a full systematic review, what criteria are helpful?

5 What simplified or omitted methods of a systematic review (e.g. single versus dual screening of citations for inclusion, restrictions on types of studies included) are appropriate to apply in a rapid review, and what are the effects of these simplifications or omissions (e.g. effect on the methods, conclusions, funding available)?

6 What are the best approaches to assess the quality of studies included in a rapid review, and if a quality assessment is either limited or excluded, how should the findings be interpreted?

#7 How best can information on ongoing and completed rapid reviews be shared in a way that minimises research waste?

8 What are the best approaches for developing a search strategy for use in a rapid review, and what is the impact of applying restrictions (e.g. years of inclusion, language, phase of study)?

#9 What are the best approaches for reporting the findings of a rapid review in a clear, succinct way without limiting information on the complete methods, findings and strength of

the evidence?

10 What are the most useful processes to use when developing a rapid review research question?'
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With thanks, Neil

Joint Coordinator, HIFA Communicating health research <https://www.hifa.org/projects/new-effective-communication-health-research...>

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HIFA profile: Neil Pakenham-Walsh is coordinator of the HIFA global health movement (Healthcare Information For All - www.hifa.org), a global community with more than 20,000 members in 180 countries, interacting on six global forums in four languages in collaboration with WHO. HIFA brings stakeholders together to accelerate progress towards universal access to reliable healthcare information. HIFA is administered by Global Healthcare Information Network, a UK based non-profit in official relations with the World Health Organization. Twitter: @hifa_org neil AT hifa.org

Communicating health research (97) Top 10 rapid review methodology research priorities

1 October, 2022

This paper looks specifically at rapid reviews, and includes two questions on dissemination (#7 and #9 below). The authors note that 'published evidence on the optimal methods of planning, doing, and sharing the results of these reviews is lacking...'. I suspect the same is true for evidence on the optimal methods of sharing the results of *any* research, including primary research. Are you aware of any research on this topic? Please email hifa@hifaforums.org

CITATION: Original article| volume 151, p151-160, november 01, 2022

Priority III: top 10 rapid review methodology research priorities identified using a James Lind Alliance Priority Setting Partnership

Claire Beecher et al. Journal of Clinical Epidemiology 2022

[https://www.jclinepi.com/article/S0895-4356\(22\)00190-1/fulltext](https://www.jclinepi.com/article/S0895-4356(22)00190-1/fulltext)

'A rapid review is a form of evidence synthesis considered a resource-efficient alternative to the conventional systematic review. Despite a dramatic rise in the number of rapid reviews commissioned and conducted in response to the coronavirus disease 2019 pandemic,

published evidence on the optimal methods of planning, doing, and sharing the results of these reviews is lacking...

Priority III engaged with patients and the public, researchers, reviewers, clinicians, policymakers, and funders to identify and prioritize the top 10 unanswered research questions about rapid review methodology...

Top 10 questions prioritized

1 What are the best approaches to identify people or groups who will use the results of a rapid review (e.g. stakeholders such as patients and the public, clinicians, policymakers), and how can they have meaningful (i.e., purposeful, relevant) involvement in planning and doing a rapid review, and in reporting and sharing the findings?

2 Do rapid reviews generate similar findings to full systematic reviews, and should the findings from all rapid reviews be considered at lower certainty compared to full systematic reviews?

3 How best can underserved stakeholder groups (e.g. ethnic minorities, socio-economically disadvantaged) and stakeholders from under represented countries (e.g. countries of different income levels) be identified and have meaningful (i.e., purposeful, relevant) involvement in planning and doing rapid reviews, and in sharing the results?

4 When deciding if a research question would benefit from being the focus of a rapid review, rather than a full systematic review, what criteria are helpful?

5 What simplified or omitted methods of a systematic review (e.g. single versus dual screening of citations for inclusion, restrictions on types of studies included) are appropriate to apply in a rapid review, and what are the effects of these simplifications or omissions (e.g. effect on the methods, conclusions, funding available)?

6 What are the best approaches to assess the quality of studies included in a rapid review, and if a quality assessment is either limited or excluded, how should the findings be interpreted?

#7 How best can information on ongoing and completed rapid reviews be shared in a way that minimises research waste?

8 What are the best approaches for developing a search strategy for use in a rapid review, and what is the impact of applying restrictions (e.g. years of inclusion, language, phase of study)?

#9 What are the best approaches for reporting the findings of a rapid review in a clear, succinct way without limiting information on the complete methods, findings and strength of the evidence?

10 What are the most useful processes to use when developing a rapid review research question?

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With thanks, Neil

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Communicating health research (98) Q5. What can be done to better support researchers in the communication of health research?

1 October, 2022

Thank you to everyone who has contributed to the discussion so far. We now enter our final week and we invite you to comment on question 5:

Q5. What can be done to better support researchers in the communication of health research?

Here are some suggestions to date:

Emily Vargas (Mexico): Some strategies:

1. That researchers and research centers make executive summaries of the research results, in plain language and be spread in different ways.
2. Creation of a team specialized in promoting the use of evidence in decision-making in health, which has the ability not only to lobby, but also to identify

Hajime Takeuchi (Japan) says:

I think that solidarity with international society is important. In the Japanese medical community, there is a strong tendency to evaluate cutting-edge technologies such as iPS cells and genetic research and clinical medicine such as emergency medicine. Human resources development related to public health is not emphasised, the domestic sociological society is small, and the pediatric community has not yet formed an appropriate recognition of the field of social paediatrics. In such a situation, the Japanese medical community needs to incorporate the perspective of medicine as a social science that understands health problems in society. I think bringing in a wind of information from international organisations is essential.

A point I have learned from this discussion is the importance of perspective. The perspective that has introduced our discussion is implied in the question: What are the most impactful methods for researchers to communicate their research to policymakers so that the research is seen and applied? We have had suggestions on how researchers might do this. In terms of 'What can be done to better support researchers' in this regard, something that seems to be missing is reliable *guidance* for researchers. We look forward to hear about any guidance of which you may be aware. There are organisations and projects such as The Global Health Network and INASP's AuthorAid, which are dedicated to supporting researchers. Perhaps they can steer us in the right direction.

But there is another perspective that we have discussed that is perhaps more important: the public health perspective whereby the end goal is not to increase the visibility of a particular piece of research, but to contribute to a wider effort to support evidence-informed policymaking (which arguably is the surest way to improve health outcomes). This emphasises the collaborative nature and potential of health research.

Perhaps we need to be thinking of ways to promote both perspectives?

What do you think?

Best wishes, Neil

Joint Coordinator, HIFA Communicating health research

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Communicating health research (100) Q5. What can be done to better support researchers in the communication of health research? (3) Mentorship (2)

2 October, 2022

My comment to this question is that mentorship is fine and helpful but most researchers in LLMICs wake up every day wishing that they gave more than that, they wish to have more practical support on the ground from their governments and partners from elsewhere. Help in the form of more resourcing including provision of functional information resource centres with regular reliable connectivity, hard and soft copy reference texts, regular scheduled on-hands training and retraining on how to read, write and publish, including training on critical

appraisal of published material. They need help with free open access to publish their work to the world. These essential inputs are lacking in most LLMICs and in large part make it difficult for researchers to carry out studies on even conditions that afflict their countries more than HICs. The result for instance, is that original cutting-edge drugs and vaccine research on conditions like malaria that kills millions in these countries, has come from countries where mosquitos have to be grown in laboratories (mosquitos in LLMICs are free range and ubiquitous).

Joseph Ana

HIFA profile: Joseph Ana is the Lead Senior Fellow/Medical Consultant at the Centre for Clinical Governance Research and Patient Safety in Calabar, Nigeria, established by HRI Global (former HRIWA). He is a member of the World Health Organisation's Technical Advisory Group on Integrated Care in primary, emergency, operative, and critical care (TAG-IC2). As the Cross River State Commissioner for Health, he led the introduction of the Homegrown Quality Tool, the 12-Pillar Clinical Governance Programme, in Nigeria (2004-2008). For sustainability, he established the Department of Clinical Governance, Servicom & e-health in the Cross River State Ministry of Health, Nigeria. His main interest is in whole health sector and system strengthening in Lower, Low and Middle Income Countries (LLMICs). He has written six books on the 12-Pillar Clinical Governance programme, suitable for LLMICs, including the TOOLS for Implementation. He served as Chairman of the Nigerian Medical Association's Standing Committee on Clinical Governance (2012-2022), and he won the Nigeria Medical Association's Award of Excellence on three consecutive occasions for the innovation. He served as Chairman, Quality & Performance, of the Technical Working Group for the implementation of the Nigeria Health Act 2014. He is member, National Tertiary Health Institutions Standards Committee of the Federal Ministry of Health. He is the pioneer Secretary General/Trustee-Director of the NMF (Nigerian Medical Forum) which took the BMJ to West Africa in 1995. Joseph is a member of the HIFA Steering Group and the HIFA working group on Community Health Workers. (<http://www.hifa.org/support/members/joseph-0> <http://www.hifa.org/people/steering-group>). Email: info AT hri-global.org and jneana AT yahoo.co.uk

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Communicating health research (101) Q5. What can be done to better support researchers in the communication of health research? (4) Role of translators (2)

2 October, 2022

Most of all, communication needs to be in the language(s) of the people/country. Of course, we strive to translate from English to or other languages into English for LMIC at least abstracts but this does not necessarily happen in Europe, hence even in high income countries evidence is not necessarily translated. I realise there are many variables why communication is not effective but I have just been travelling through Germany, Denmark and Greece and am

amazed how much evidence based published literature with important outcomes for maternity care is not understood or implemented. My guess one reason this is so that those results were only published in English or other languages. In particular I noticed, People spoke and understood conversational English well, but when it came to academic and research words, many were at a loss. Reading an academic article in English as a second language needs sufficient research vocabulary and takes time to translate by the individual. For a simple example, the routine giving of an enema during labour has clearly shown no benefits, but can cause anxiety for the labouring woman etc. These were valid research results a long time ago but only published/communicated in English it seems. I do realise there are many variables affecting communication and the transfer of knowledge into practice, but let's start with the mantra I often use: 'the language of the heart (first language) is what speaks to the heart' and only that will effect long lasting change'. If translation work or translators for oral communication are too expensive, then maybe we need to offer focussed academic/research English or other language courses.

HIFA profile: Ruth Martis is a registered midwife, who holds a PhD from the Liggins Institute, The University of Auckland, New Zealand. Her research centred on glycaemic targets and experiences for women with GDM. Currently she is the Head of the Midwifery School at the Waikato Institute of Technology, Hamilton, New Zealand and a locum midwife for remote rural areas in New Zealand. She is passionate about midwifery education, physiological birth, impact of fear in childbirth, newborn examination, neonatal resuscitation, intermittent auscultation, fetal movements in labour, teenage pregnancies, lactation, gestational diabetes, knowledge transfer and research synthesis and refugee health. Ruth is a Cochrane systematic review author of several reviews. She was involved in the five year SEA-ORCHID research project as clinical educator in South East Asia.

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https://hifaforums.org/_/76dWRfuA

Communicating health research (102) The Lancet: Twitter remains the closest one can get to a global conversation about science and medicine (4)

2 October, 2022

I wonder if the "conversation" is an important feature of the research to policy implementation journey. We are data government digital technology conference in Westminster on 13th. At last year's conference it was apparent that government has no public conversation going on - just edicts and rules. Some one suggested a government public twitter during one of the break out sessions!!

R

HIFA profile: Richard Fitton is a retired family doctor - GP. Professional interests: Health literacy, patient partnership of trust and implementation of healthcare with professionals, family and public involvement in the prevention of modern lifestyle diseases, patients using access to professional records to overcome confidentiality barriers to care, patients as part of the policing of the use of their patient data

Email address: richardpeterfitton7 AT gmail.com

Source link:

<https://hifaforums.org/ /zRfzXxzw>

Communicating health research (103) Compilation of all messages 1-99

3 October, 2022

Thanks to HIFA volunteer Vedant Shekhar Jha (India) we have compiled all the messages so far into a single PDF document here:

https://www.hifa.org/sites/default/files/publications_pdf/Communicating_...

You can track the latest HIFA forum messages here: <https://www.hifa.org/rss-feeds/17>

We continue this week with a focus on Question 5:

Q5. What can be done to better support researchers in the communication of health research?

Looking forward to your email contributions to: hifa@hifaforums.org

Many thanks, Neil

Joint Coordinator, HIFA Communicating health research <https://www.hifa.org/projects/new-effective-communication-health-research...>

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Communicating health research (104) Q5. What can be done to better support researchers in the communication of health research? (5) Role of The Global Health Network and AuthorAid

3 October, 2022

Dear HIFA colleagues,

Below are extracts from The Global Health Network website.

'The Global Health Network enables easier, faster, and better research in the world's most challenging settings.'

'The Global Health Network drives faster progress by sharing methods and processes to raise standards, remove duplication and enable faster transfer of evidence into practice.'

It would be great to hear from TGHN members (and other health researchers) about our question 5:

Q5. What can be done to better support researchers in the communication of health research?

TGHN has a wide variety of knowledge sharing hubs and resources but I could not find one on research communication.

I had a look on the AuthorAid website and could not find guidance there either.

There are resources on how to write a paper, but I couldn't find other guidance on how to communicate research.

I expect there is much tacit knowledge on this subject across both networks.

<https://tghn.org/>

<https://www.authoraid.info>

What kind of guidance (or other practical support) do health researchers need to communicate their research, beyond publication of the paper itself?

Are HIFA members aware of other organisations that support researchers in this way?

Best wishes, Neil

Joint Coordinator, HIFA Communicating health research <https://www.hifa.org/projects/new-effective-communication-health-research...>

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https://hifaforums.org/_/wammwwwj

Communicating health research (104) NIH Checklist for Communicating Science and Health Research to the Public

3 October, 2022

This checklist from the National Institutes of Health (US) is written for the public but may be equally useful for communicating research to policymakers.

See the full checklist here: <https://www.nih.gov/about-nih/what-we-do/science-health-public-trust/che...>

Below are some extracts with my comments:

"As science and health communicators, our main goal is to share our institutions' wealth of science and health knowledge"

Is this the main goal, or is it to contribute to evidence-informed policy and practice? They are not synonymous.

"Take care to not overstate the importance or statistical significance of a study, finding, or emerging situation when relaying what's interesting or exciting about a scientific development."

This seems to me to be especially important. Too often we read or hear the mass media (and those who work in and with them?) misrepresenting and misleading the p[ublic and policymakers. A finding from a small or poorly designed study is put forward inappropriately as a truth, perhaps ignoring the wealth of contradictory evidence from existing research.

There is a bias here also to new primary research, which is typically given prominence over secondary research and systematic review. It is as if the media (and researchers?) can sometimes exploit the lack of understanding about knowledge synthesis and uncertainty.

"Use conditional language when appropriate (language that hedges or highlights the potential gaps or unknowns)."

This links with the previous point.

"Explicitly state whether the study shows an association or causation. An association is a relationship, or correlation. A positive association means as one goes up, so does the other. A negative association means as one goes up, the other goes down. Causation is when an event or variable is shown to cause a specific outcome. Whether a study shows association or causation depends on the study design."

This is commonly misrepresented too.

"Discuss both the benefits and drawbacks of any potential treatment, as health care decisions must take many different factors into account, e.g. treatment effectiveness, side effects, and overall risk of the intervention."

Some researchers may be able to discuss this impartially, others not.

What do you think? Email hifa@hifaforums.org

Best wishes, Neil

Joint Coordinator, HIFA Communicating health research [https://www.hifa.org/projects/new-effective-communication-health-research...](https://www.hifa.org/projects/new-effective-communication-health-research)

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https://hifaforums.org/_/ng94xygt

Communicating health research (105) Q5. What can be done to better support researchers in the communication of health research? (6)

3 October, 2022

Greetings to all.

I'd like to share some thoughts in response to Q5. What can be done to better support researchers in the communication of health research?

As a knowledge management mentor on the TDR SORT IT course, I know that hands-on capacity-building initiatives such as this one are very effective in supporting researchers in communicating their research findings to relevant stakeholders. The researchers who have participated in the knowledge management module have reported that their findings have gained traction within places of work because of the skills in packaging their evidence to be relevant to the target audiences/ decision-makers within their contexts.

Another way through which researchers may be supported to communicate their research findings is through awareness creation within the broader research community of the importance of disseminating their findings beyond publication for career progression, and the potential that their research evidence has to inform better decision-making at a higher level. Creating this awareness may serve as motivation for them to seek out formal/ informal opportunities to gain the relevant skills for communicating the research findings.

The sensitization on the importance of dissemination of research findings to foster cross-learning should also encompass the sponsors/ funders of the research. Often times the findings of evaluations research are termed as being for 'internal consumption' despite the inherent rich lessons that may enrich the implementation of future public health projects/ programs. Additionally, the research budget does not factor in the dissemination of the evidence that emerges from the research right at the start so it may not be perceived as a priority by these members of the research community. However, perhaps if the funders are sensitized they may prioritize the dissemination of research findings, and even set it as an expectation coupled with the financial support for it.

Kind regards,

Jacklyne Ashubwe-Jalemba

HIFA profile: Jacklyne Ashubwe-Jalemba is a medical doctor and health systems researcher based in Nairobi, Kenya. She is a member of the HIFA project on Communicating health research, supported by TDR

<https://www.hifa.org/projects/new-communicating-health-research-support-...>

<https://www.hifa.org/support/members/jacklyne>

Email: jashubwe AT live.com

Communicating health research (106) Q5. What can be done to better support researchers in the communication of health research? (7)

3 October, 2022

In a previous message today we saw the US National Institutes for Health Checklist for Communicating Science and Health Research to the Public.

A different but related checklist is offered by HIFA members Claire Glenton, Simon Lewin and colleagues: A checklist for people communicating evidence-based information about the effects of healthcare interventions. This is a critical aspect of research communication that we have barely touched on. It is also an area where research can be easily misrepresented or misunderstood.

Citation, abstract, recommendations and a (perhaps provocative) comment from me below.

CITATION: BMJ Open 2020 Jul 21;10(7):e036348. doi: 10.1136/bmjopen-2019-036348.

Development of a checklist for people communicating evidence-based information about the effects of healthcare interventions: a mixed methods study

Andrew D Oxman, Claire Glenton, Signe Flottorp, Simon Lewin, Sarah Rosenbaum, Atle Fretheim

PMID: 32699132 PMCID: PMC7375421 DOI: 10.1136/bmjopen-2019-036348

ABSTRACT

Objectives: To make informed decisions about healthcare, patients and the public, health professionals and policymakers need information about the effects of interventions. People need information that is based on the best available evidence; that is presented in a complete and unbiased way; and that is relevant, trustworthy and easy to use and to understand. The aim of this paper is to provide guidance and a checklist to those producing and communicating evidence-based information about the effects of interventions intended to inform decisions about healthcare.

Design: To inform the development of this checklist, we identified research relevant to communicating evidence-based information about the effects of interventions. We used an iterative, informal consensus process to synthesise our recommendations. We began by discussing and agreeing on some initial recommendations, based on our own experience and research over the past 20-30 years. Subsequent revisions were informed by the literature we examined and feedback. We also compared our recommendations to those made by others. We sought structured feedback from people with relevant expertise, including people who prepare and use information about the effects of interventions for the public, health professionals or policymakers.

Results: We produced a checklist with 10 recommendations. Three recommendations focus on making it easy to quickly determine the relevance of the information and find the key messages. Five recommendations are about helping the reader understand the size of effects and how sure we are about those estimates [these five seem to have expanded to eight in the list below]. Two recommendations are about helping the reader put information about intervention effects in context and understand if and why the information is trustworthy.

Conclusions: These 10 recommendations summarise lessons we have learnt developing and evaluating ways of helping people to make well-informed decisions by making research evidence more understandable and useful for them. We welcome feedback for how to improve our advice.

CHECKLIST FOR COMMUNICATING EFFECTS

Make it easy for your target audience to quickly determine the relevance of the information, and to find the key messages.

- Clearly state the problem and the options (interventions) that you address, using language that is familiar to your target audience—so that people can determine whether the information is relevant to them.
- Present key messages up front, using language that is appropriate for your audience and make it easy for those who are interested to dig deeper and find information that is more detailed.
- Report the most important benefits and harms, including outcomes for which no evidence was found—so that there is no ambiguity about what was found for each outcome that was considered.

For each outcome, help your target audience to understand the size of the effect and how sure we can be about that; and avoid presentations that are misleading.

- Explicitly assess and report the certainty of the evidence.
- Use language and numerical formats that are consistent and easy to understand.
- Present both numbers and words and consider using tables to summarise benefits and harms, for instance, using Grading of Recommendations Assessment, Development and Evaluation (GRADE) summary of finding tables or similar tables.
- Report absolute effects.
- Avoid misleading presentations and interpretations of effects.
- Help your audience to avoid misinterpreting continuous outcome measures.
- Explicitly assess and report the credibility of subgroup effects.
- Avoid confusing ‘statistically significant’ with ‘important’ or a ‘lack of evidence’ with a ‘lack of effect’.

Help your target audience to put information about the effects of interventions in context and to understand why the information is trustworthy.

- Provide relevant background information, help people weigh the advantages against the disadvantages of interventions and provide a sufficient description of the interventions.

- Tell your audience how the information was prepared, what it is based on, the last search date, who prepared it and whether the people who prepared the information had conflicts of interest.

COMMENT (NPW): The 'five recommendations about helping the reader understand the size of effects and how sure we are about those estimates' seem to have expanded to eight in the actual checklist. Notwithstanding, it is notable that all 10/13 recommendations are about providing information, and none of them are about persuading the reader to take action.

My takeaway from this whole discussion is that the motivation for effective research communication is (or should be) all (or nearly all) about providing reliable information and understanding, and it is not (or should not be) about persuading changes in policy and practice. (The latter is advocacy - researchers may choose also to be advocates, but I would suggest that their primary role is to inform and be understood.)

To stimulate further discussion, I would propose that policymakers need balanced information from health research. They do not need individual primary researchers to persuade them to act on the basis of 'their' research findings.

So, where should financial and political support be provided to improve the effectiveness of research communication? I would argue that it should be directed more to improve balanced information and understanding (especially through research synthesis), and relatively less to strengthen researchers' ability to effect policy change (especially from a single primary study).

I look forward to hear your thoughts.

Best wishes, Neil

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Communicating health research (107) Q5. What can be done to better support researchers in the communication of health research? (8)

3 October, 2022

Research communication: Insights from practice (UK Government)

A working paper of the Research Communication Strategy Group

Edited by Isabel Carter and Kurt Paulus

<https://assets.publishing.service.gov.uk/media/57a08afc40f0b649740008bc/...>

This working paper of the Research Communication Strategy Group is more than 10 years old but includes a section on 'Supporting researchers to communicate':

'Researchers who make the challenging decision to engage with users early, strategically and imaginatively, may be surprised by the positive results. In addition to success within the academic field, the opportunity to share findings in the form of articles for web portals, press releases for the media or opportunities to present findings in conferences and workshop, brings satisfaction, increased impact and also enhances feedback.

'To enable researchers to have a significant impact on poverty, there needs to be a wider appreciation of the context they work within and the pressures they experience in producing robust research findings, so that they gain both sufficient support and

understanding and the necessary skills to equip them as effective research communicators.

'Research communication is a skilled activity addressing a range of audiences from policy makers to end users. The role of the researcher therefore needs to be complemented by the contribution of communication professionals. Skills and abilities to interpret complex findings and translate them into usable information for non-expert users without over simplification and 'dumbing down', are essential for researchers, journalists, intermediaries and CSOs.

'For effective communication there is a need to build working coalitions based on relationships of trust between those generating and those communicating research.

'Communicators need to understand that timing is key to influencing policy makers. Researchers and CSOs tend to communicate when they have findings ready to share and at their convenience, but findings that relate to policy makers have to be communicated when they are ready and willing to listen.'

Neil Pakenham-Walsh, Global Coordinator HIFA, www.hifa.org neil@hifa.org

Global Healthcare Information Network: Working in official relations with WHO

Communicating health research (108) Q5. What can be done to better support researchers in the communication of health research? (9)

3 October, 2022

A few contributors have mentioned the importance of narratives and storytelling as a tool for 'effective research communication'.

Below are the citation, abstract of a paper on this topic, and a comment from me

CITATION: Using narratives to impact health policy-making: a systematic review

Racha Fadlallah et al.

Health Research Policy and Systems volume 17, Article number: 26 (2019)

<https://link.springer.com/article/10.1186/s12961-019-0423-4>

ABSTRACT

Background: There is increased interest in using narratives or storytelling to influence health policies. We aimed to systematically review the evidence on the use of narratives to impact the health policy-making process.

Methods: Eligible study designs included randomised studies, non-randomised studies, process evaluation studies, economic studies, qualitative studies, stakeholder analyses, policy analyses, and case studies...

Results: Eighteen studies met the eligibility criteria, and included case studies (n = 15), participatory action research (n = 1), documentary analysis (n = 1) and biographical method (n = 1). The majority were of very low methodological quality. In addition, none of the studies formally evaluated the effectiveness of the narrative-based interventions. Findings suggest that narratives may have a positive influence when used as inspiration and empowerment tools to stimulate policy inquiries, as educational and awareness tools to

initiate policy discussions and gain public support, and as advocacy and lobbying tools to formulate, adopt or implement policy. There is also evidence of undesirable effects of using narratives. In one case study, narrative use led to widespread insurance reimbursement of a therapy for breast cancer that was later proven to be ineffective. Another case study described how the use of narrative inappropriately exaggerated the perceived risk of a procedure, which led to limiting its use and preventing a large number of patients from its benefits. A third case study described how optimistic 'cure' or 'hope' stories of children with cancer were selectively used to raise money for cancer research that ignored the negative realities. The majority of included studies did not provide information on the definition or content of narratives, the theoretical framework underlying the narrative intervention or the possible predictors of the success of narrative interventions.

Conclusion: The existing evidence base precludes any robust inferences about the impact of narrative interventions on health policy-making. We discuss the implications of the findings for research and policy.

COMMENT (NPW): The negative outcomes described above are, paradoxically, the result of effective research communication. The findings of individual papers were inappropriately translated into changes in policy and practice that led to negative health outcomes. I suspect that most negative outcomes from research communication have their source in primary studies and not in research syntheses. What do you think?

Neil Pakenham-Walsh, Global Coordinator HIFA, www.hifa.org neil@hifa.org

Global Healthcare Information Network: Working in official relations with WHO

Communicating health research (109) Can you think of an example where health research communication was effective, or ineffective?

3 October, 2022

Dear HIFA colleagues,

Can you think of an example where health research communication was effective, or ineffective? An example from your own experience would be ideal, but any example would be welcome.

In what ways was this communication effective? What worked well and not so well? What can we learn from it?

I look forward to hear from you. Email: hifa@hifaforums.org

Best wishes, Neil

Neil Pakenham-Walsh, Global Coordinator HIFA, www.hifa.org neil@hifa.org

Global Healthcare Information Network: Working in official relations with WHO

Communicating health research (109) Five ways media and journalists can support climate action while tackling misinformation UN News

5 October, 2022

Five ways media and journalists can support climate action while tackling misinformation | | 1UN News

<https://news.un.org/en/story/2022/10/1129162>

Some of this article may relate the current HIFA discussions?

1. Stop being so (overly) dramatic
2. A climate change story goes beyond (the) climate
3. Get local and think more about climate justice
4. Build trust and engagement that can combat dis/misinformation
5. Be guided by science and embrace yes

"Drawing on Mr. Revkin's broad experience, and the expertise of UNESCO and the IPCC, here are five ways in which journalism can support fight misinformation.

1. Stop being so (overly) dramatic

"According to UNESCO, and studies carried out by the Thomson Reuters Institute, the doom and gloom narrative can also make some people simply turn off and lose interest.

2. A climate change story goes beyond (the) climate

Realize that climate change is not just a story, but a context in which so many other stories will unfold.

3. Get local and think more about climate justice

By analysing local contexts and social factors, create stories related to climate justice.

4. Build trust and engagement that can combat dis/misinformation

Normalizing and creating a simple way to have a risk formulation in stories would be a tool to combat misinformation.

5. Be guided by science

A shifting relationship between journalism and scientists that he sees as positive.

Scientists are coming into the newsroom that requires a whole new learning curve. he explains.

UN Climate communication guidelines.

<https://www.un.org/en/climatechange/communicating-climate-change>

HIFA profile: Richard Fitton is a retired family doctor - GP. Professional interests: Health literacy, patient partnership of trust and implementation of healthcare with professionals, family and public involvement in the prevention of modern lifestyle diseases, patients using access to professional records to overcome confidentiality barriers to care, patients as part of the policing of the use of their patient data

Email address: richardpeterfitton7 AT gmail.com

Communicating health research (111) Five ways media and journalists can support climate action while tackling misinformation UN News (2)

6 October, 2022

Dear Richard,

Thanks for forwarding the UN article.

<https://www.hifa.org/dgroups-rss/communicating-health-research-109-five-...>

I would like to comment on the first point:

"1. Stop being so (overly) dramatic. According to UNESCO, and studies carried out by the Thomson Reuters Institute, the doom and gloom narrative can also make some people simply turn off and lose interest."

The same point can be made about the communication of health research, relevant to our current discussion.

We have noted the importance of the mass media in the communication of health research, not only for the general public but also for policymakers. It is clear to anyone who watches TV, listens to the radio or reads a newspaper that we have a HUGE problem here. The mass media shapes public (and policymaker) opinion and yet reporting of health research in the media is

very often inaccurate, incomplete, biased, misleading, and ultimately damaging to individual understanding, trust in science, health policy and health outcomes.

What can be done to address this issue? We need to better understand why it is such a big problem. One aspect is that the media's motivation is largely to make profits, to exert influence, or at least attract the largest possible audience. A headline that honestly says "Studies have not established the effect of chocolate on breast cancer" is less likely to 'sell' than one that says misleadingly "Chocolate causes breast cancer".

A second aspect is that researchers themselves, and the research institutions and communication teams that support them, can overemphasise the importance and interpretation of their research. This can be further distorted by the journalist copywriters who change the wording for dramatic effect. For example, "A is associated with B" is not qualified with an explanation of the possible causes of the association or, worse, it is misreported as "A causes B".

What are the implications in terms of research communication? First, I believe there should be much more political and financial investment in understanding the causes of misreporting in the media and what can be done to improve it. Second, journalist and researcher professional associations should lead the conversation on how to improve the quality of research communication and restore trust in science. Third, high-quality support and training should be made readily available to journalists and researchers, together with incentives to report more honestly and with less bias.

What do you think?

Best wishes, Neil

Joint Coordinator, HIFA Communicating health research <https://www.hifa.org/projects/new-effective-communication-health-research...>

Let's build a future where every person has access to reliable healthcare information and is protected from misinformation - Join HIFA: www.hifa.org

HIFA profile: Neil Pakenham-Walsh is coordinator of the HIFA global health movement (Healthcare Information For All - www.hifa.org), a global community with more than 20,000 members in 180 countries, interacting on six global forums in four languages in collaboration with WHO. HIFA brings stakeholders together to accelerate progress towards universal access to reliable healthcare information. HIFA is administered by Global Healthcare Information Network, a UK based non-profit in official relations with the World Health Organization. Twitter: @hifa_org neil@hifa.org

Communicating health research (112) Q5. What can be done to better support researchers in the communication of health research? (10)

6 October, 2022

Hi Jacklyne, hi all

Thanks for these great inputs. Agree that the TDR SORT IT training approach – and especially the knowledge management module – are great and impactful initiative. Fully agree with your assessments that hands-on capacity building (for research and knowledge translation), more awareness in the research community, and sensitizing donors play an important role.

As capacity building tends to be resource-intensive, and unfortunately not everybody can attend a SORT IT course, I also keep wondering if and how key success factors of the format could be made more broadly available? The close 1:1 mentoring is hard to replace, but the SORT IT approach to me successfully operationalizes some principles that could be applied for improved research communication in general:

- * Consider and plan for communicating for policy or practice change from the design stage of research (consider, for instance, making decision-makers and implementation partners co-authors. Look for key policy moments or major communication opportunities such as thematic days, conferences etc.)
- * Prioritize communication objectives and target audience over complex formats and reach: try to reach key decision-makers and implementers first, rather than trying to reach a diffuse mass
- * Use available templates (of briefs, presentations, elevator pitches), and write with a clear message and audience in mind
- * Collaborate closely with communication and knowledge translation colleagues (such as your comms department, colleagues or friends working in communications etc.)
- * Apply the same principles of (peer-)review to communication materials – share and improve content as much as possible with colleagues and friends

Would you agree? There are likely other elements we could add to the list here....

Best regards

Sam

HIFA profile: Samuel Sieber is a Knowledge Translation and Communication Specialist, Global Coordination Mechanism on NCDs, Global NCD Platform, Deputy Director General's Office, WHO, Geneva, Switzerland. He is a member of the HIFA working group on Communicating health research. [https://www.hifa.org/support/members/samuel siebers AT who.int](https://www.hifa.org/support/members/samuel%20siebers%40who.int)

Communicating health research (113) Five ways media and journalists can support climate action (3)

6 October, 2022

Dear Richard, dear all

A quick reaction to your suggested link and relevance of communicating climate change/action and health research. I thought the article you shared is a brilliant find! It made me realize that I apply all five principles when communicating evidence and supporting knowledge translation:

1. Stop being so (overly) dramatic

-> important to always stay true to the actual evidence and not too unnecessarily dramatize in the sheer interest of storytelling or to gain attention. In my experience, this marks the exact line between evidence-informed communication and advocacy - the latter often exaggerating or accusing beyond the available evidence.

2. A climate change story goes beyond (the) climate

-> when communicating health research, situating the evidence in context (and describing it sufficiently) is key. Also helps to create compelling content that is of interest for different audiences.

3. Get local and think more about climate justice

-> For health research, this principle could be translated into one of reflecting the implication of evidence for patients (or, better: individuals with lived experience), communities, and practitioners and implementers. I usually try to create content that tells the story of a piece of evidence from one or several personal perspective(s). This also helps shedding light on different aspects such as social, economic, environmental etc. determinants of health and health inequalities.

4. Build trust and engagement that can combat dis/misinformation

-> this also requires collaborating across disciplines and actors (e.g., between scientists and communication specialists, with patient organizations and non-state actors), and makes communicating health research into more of a dialog format than a one-sided dissemination process. An important shift!

5. Be guided by science and embrace yes

-> This highlights the importance of including some form of “so what?” and “way forward” in science communication. Can be tricky where a study/review does not have any concrete recommendations, but can be mitigated with (above) strategies to personalize evidence with examples, and discuss problem-solving strategies based on complementary evidence (other studies, narratives from people with lived experience etc.)

Best regards and thanks again for sharing,

Sam

HIFA profile: Samuel Sieber is a Knowledge Translation and Communication Specialist, Global Coordination Mechanism on NCDs, Global NCD Platform, Deputy Director General's

Office, WHO, Geneva, Switzerland. He is a member of the HIFA working group on Communicating health research. https://www.hifa.org/support/members/samuel_siebers_AT_who.int

Communicating health research (114) Five ways media and journalists can support climate action (4) Logos, ethos, pathos

7 October, 2022

Sam,

I was talking with a friend in London about classical literature and public debate. Aristotle apparently wrote that public and group conversations are a combination of Logos - the facts, Ethos - the emotional and body language presentation of the speaker, and pathos - the emotional and body language of the audience.

People tend to listen and attend to the words (logos) of people they know and like and trust. So HIFA getting to be known may be a help?

As we have discussed before, Cristiano Ronaldo has 420,000,000 followers and Nicki Minage (a singer) has 12,000,000 followers.

Perhaps we need to start playing football and or singing?

R

HIFA profile: Richard Fitton is a retired family doctor - GP. Professional interests: Health literacy, patient partnership of trust and implementation of healthcare with professionals, family and public involvement in the prevention of modern lifestyle diseases, patients using access to professional records to overcome confidentiality barriers to care, patients as part of the policing of the use of their patient data Email address: richardpeterfitton7 AT gmail.com

Communicating health research (115) Five ways media and journalists can support climate action (5) Outrage and hazard

8 October, 2022

[Re: <https://www.hifa.org/dgroups-rss/communicating-health-research-111-five-...>]

Thanks Neil.

I'm reminded of excellent thinking by Peter Sandman on risk communication - apologies if it's already been cited - been too many messages to read all so I'm only now paying attention! It considers two dimensions - outrage and hazard. Is there sufficient or insufficient in relation to any particular topic and how can communication strategies rebalance. <https://www.psandman.com/index-OM.htm>

I think scientific publications may be better at describing the hazard than in considering the outrage factor. Maybe the role for good journalism and advocacy by scientists, clinicians and public can focus on the outrage through narrative. So many publications start with "3rd leading cause of..." " will be the 4th leading cause of..." which may be aiming to produce outrage, but actually just falls flat due to repetition....they can't all be?

We also have to offer policy-makers hope. That might be by suggesting cross-cutting themes and solutions as no decision-maker can handle so many demands for investment. It would also be by a greater focus on areas of disinvestment....

Thanks

Sian

HIFA profile: Sian Williams is Chief Executive Officer at the International Primary Care Respiratory Group in the UK. Professional interests: Implementation science, NCDs, primary care, respiratory health, education, evaluation, value, breaking down silos. sian.health AT gmail.com

**Communicating health research (116) Q2. What are the different approaches? (21)
Engaging policymakers in knowledge synthesis (2)**

8 October, 2022

Adding to Samuel Sieber's mention of SUPPORT tools [<https://www.hifa.org/dgroups-rss/communicating-health-research-81-q2-wha...>], I'd like to point to another study from the SUPPORT project, where we developed a template for presenting evidence from systematic reviews to policy makers in LMIC's:

Evidence summaries tailored to health policy-makers in low- and middle-income countries

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3040014/>

We carried out this work through extensive user testing of an early prototype in several countries, where researchers in our network interviewed policy makers in their local contexts. My role was as information designer and researcher. Some of the more persistent challenges we encountered are echoed many comments in this forum:

- participants had a poor understanding of what a systematic review was
- they expected information not found in the systematic reviews (e.g. recommendations, broader scope)
- they wanted shorter, clearer summaries.

We addressed these issues in using several strategies, outlined in the article (too much to write here).

I would like to point to one of most appreciated features in these summaries was the a table we added with authors' interpretation of the relevance of the evidence and intervention for LMICs, which I was reminded of when reading the article Irina pointed to about localizing and tailoring research. By explicitly mapping findings to researcher's interpretations of the possible applicability of each of these, you can transparently provide an opinion about possible applicability, something users found very valuable.

The other highly appreciated feature was the front page with key messages up front. We based this on a graded-entry principle of presenting in layers: key messages in a top layer, a middle layer with more information, and access to the full text for those who want unedited information. In my view, this is one of the most robust principles people can use in presenting research evidence in any kind of format, because it caters to the very different needs of both expert and less-expert audiences.

Something that is not included in the article is the reaction of the researchers who did user testing of these formats with policy makers in their settings. Several mentioned that it was a really good opportunity to engage with those stakeholders, observe first hand their reactions when reading research results, and strengthen a relationship. I would recommend this as a technique for opening doors, especially since user testing of any dissemination formats you develop is an invaluable method to improving them.

This last bit reminds me of a paper about communication theory in implementation science, describing two paradigms of communication as transactional (transferring information) and transformative (building shared understanding). <https://implementationscience.biomedcentral.com/articles/10.1186/s13012-....> I would venture to say that optimizing evidence presentation falls under "transactional" communication, while listening to how people experience your evidence dissemination falls under "transformative". A good read for anyone following this thread.

I've uploaded a copy of the template file
here: https://www.dropbox.com/s/4ibonr558nhiz0m/SUPPORT%20Summary%20template_C...

More about the SUPPORT Summary work here: <https://www.cochrane.no/support-summaries>

Best regards,

Sarah Rosenbaum

Sarah Rosenbaum

Design forsker/ Design researcher

Centre for Epidemic Interventions Research

Folkehelseinstituttet/Norwegian Institute of Public Health

saro@fhi.no<mailto:saro@fhi.no> | www.fhi.no<http://www.fhi.no>

HIFA profile: Sarah Rosenbaum works at the Norwegian Institute of Public Health. sarah AT rosenbaum.no

Communicating health research (117) Q2. What are the different approaches? (22) Live presentation

9 October, 2022

Thanks to HIFA member Irina Ibraghimova and LRC Network, here is a short paper on giving virtual presentations. Citation, abstract and a comment from me.

CITATION: Arch Dis Child Educ Pract Ed. 2022 Oct 6:edpract-2022-323787. doi: 10.1136/archdischild-2022-323787. Online ahead of print.

Presentation design and delivery to improve knowledge translation in a remote world.

Leo GSY et al.

<https://ep.bmj.com/content/early/2022/10/06/archdischild-2022-323787>

ABSTRACT: The practical dissemination of new knowledge is not given adequate attention despite large investment in undertaking high-quality research and the desire for evidence-based practice. It is important that those involved in knowledge translation and continuing medical education understand the fundamental principles of effective presentations, whether at scientific conferences, workshops or group teaching sessions. The switch to remote presentations has made this a more challenging endeavour. We describe established presentation techniques that improve knowledge translation and how to use them in both face-to-face and remote settings.

COMMENT (NPW): Live presentation of research (whether virtual or in-person) is an important aspect of effective research communication. Would anyone like to share examples of how this has been done successfully (or unsuccessfully)?

Best wishes, Neil

Joint Coordinator, HIFA Communicating health research <https://www.hifa.org/projects/new-effective-communication-health-research...>

Let's build a future where every person has access to reliable healthcare information and is protected from misinformation - Join HIFA: www.hifa.org

HIFA profile: Neil Pakenham-Walsh is coordinator of the HIFA global health movement (Healthcare Information For All - www.hifa.org), a global community with more than

20,000 members in 180 countries, interacting on six global forums in four languages in collaboration with WHO. HIFA brings stakeholders together to accelerate progress towards universal access to reliable healthcare information. HIFA is administered by Global Healthcare Information Network, a UK based non-profit in official relations with the World Health Organization. Twitter: @hifa_org neil@hifa.org

Communicating health research (118) Q5. What can be done to better support researchers in the communication of health research? (11) Using pictures

10 October, 2022

Could we add "using" pictures to the 8 points of communicating research? [*see note below] Much research suggests that patients remember 15% of what they're told face to face, 25% if they are given written supplementary information and 80% if they are given pictures. Current technology makes this feasible and I would suggest the supportive use of music if this supports the messages?

The global literacy rate for all people aged 15 and above is 86.3%. The global literacy rate for all males is 90.0%, and the rate for all females is 82.7%. The rate varies throughout the world, with developed nations having a rate of 99.2% (2013), South and West Asia having 70.2% (2015), and sub-Saharan Africa at 64.0% (2015).[3] Over 75% of the world's 781 million illiterate adults are found in South Asia, West Asia, and sub-Saharan Africa, and women represent almost two-thirds of all illiterate adults globally.[4]

25% of the population in literate countries at the lowest level of literacy skill, termed NALS level 1, can only perform basic tasks such as signing their name or finding a word or fact in a short written article.

23% of the population at level 2 have somewhat more advanced skills but are still substantially limited in their ability to read and understand text. They are considered marginally literate.

Patients remember about 15% of what they are told in face to face in consultations, 25% if they are given accompanying written (semantic) information, 80% if they are given pictures.

These figures would be much more skewed for "children" with pictures being more important still?

HIFA profile: Richard Fitton is a retired family doctor - GP. Professional interests: Health literacy, patient partnership of trust and implementation of healthcare with professionals, family and public involvement in the prevention of modern lifestyle diseases, patients using access to professional records to overcome confidentiality barriers to care, patients as part of the policing of the use of their patient data Email address: richardpeterfitton7 AT gmail.com

[*Note from NPW, moderator: The original paper [as described in <https://www.hifa.org/dgroups-rss/communicating-health-research-106-q5-wh...>] was looking broadly at the information needs of all stakeholders, including patients. The current discussion is looking particularly at the needs of policymakers. In the context of our current

discussion, I invite HIFA members to consider the use of pictures to help communicate health research to policymakers. I can think of two examples: infographics (where information is presented visually to enhance understanding) and presentations (where pictures, photographs and video may be used to increase impact).

Communicating health research (119) Evidence Week in Parliament 2022

13 October, 2022

This initiative aims to bring researchers and policymakers together, with a focus on the UK. Extracts below and a comment from me.

Where constituents and MPs meet researchers to discuss the evidence for policies

<https://senseaboutscience.org/evidence-week/>

'Evidence matters to people, and our elected representatives must be able to scrutinise the evidence behind important decisions and policies. By asking the right questions MPs can increase the quality of evidence used in policymaking, and make better decisions.

'Sense about Science has partnered with the Parliamentary Office of Science and Technology (POST) and London School of Economics and Political Science (LSE) to host Evidence Week at Westminster on 14-18 November 2022, bringing together MPs, researchers, and the public to discuss how the evidence used to make policy decisions is scrutinised.

'Evidence Week is an opportunity for people from all over the UK to ask for the evidence behind policy issues that are important to them. With the support of their constituency MP, we will try to get answers to as many questions as possible in our livestream expert panel discussion....'

--

'We'll feature as many questions as possible in our launch event, so submit your question now for the chance to ask your question during the livestreamed opening public panel discussion at 5pm on Monday 14 November [<https://senseaboutscience.org/evidence-week/event/opening-event/>], or get an answer by asking your MP to meet you for a policy briefing [<https://senseaboutscience.org/evidence-week/policy-briefings/>] from world-leading researchers in Westminster on Tuesday 15 or Wednesday 16 November.'

COMMENT (NPW): On 25 June 2015 the BMA [British Medical Association] Representatives approved unanimously: "That this meeting applauds efforts to bring essential healthcare information to citizens in low resource settings, welcomes the BMA's ongoing support for the Healthcare Information for All campaign, and calls upon the UK government to prioritise support for initiatives that improve the availability and use of health

information." On behalf of HIFA I shall ask again: "What, if anything, has the UK Government done to to prioritise support for initiatives that improve the availability and use of health information."

Best wishes, Neil

Let's build a future where every person has access to reliable healthcare information and is protected from misinformation - Join HIFA: www.hifa.org

HIFA profile: Neil Pakenham-Walsh is coordinator of the HIFA global health movement (Healthcare Information For All - www.hifa.org), a global community with more than 20,000 members in 180 countries, interacting on six global forums in four languages in collaboration with WHO. HIFA brings stakeholders together to accelerate progress towards universal access to reliable healthcare information. HIFA is administered by Global Healthcare Information Network, a UK based non-profit in official relations with the World Health Organization.

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Communicating health research (120) Uganda cleric urges people to believe in science

14 October, 2022

The support of faith leaders is vital in promoting the availability and use of reliable healthcare information. The following article is from today's BBC news: <https://www.bbc.co.uk/news/live/world-africa-62845571>

Uganda cleric urges people to believe in science

Patience Atuhaire

BBC News, Kampala

A prominent Christian cleric in Uganda has warned that extreme faith can sometimes lead to mistakes, and has urged religious leaders to believe in science.

Reverend Daniel Tokens Wejuli's comments came as Uganda grapples with an Ebola outbreak which has so far claimed 19 lives, including one in the capital, Kampala.

In the latest measure to curb the spread of the disease, President Yoweri Museveni ordered traditional healers and herbalists not to treat people who have Ebola-like systems.

In Uganda even highly religious people visit their traditional healers. For many, the two health systems back each other up - if one doesn't work, the other might.

The reverend, who is in charge of Spirituality and Mindset Change at the Inter-religious Council of Uganda, told the BBC he agreed with Mr Museveni's directive.

"Cultural and religious practices can spread the disease - for instance, touching or mixing with people who are infected.

"You can pray for someone from a distance, or even remotely using technology. Religious leaders have a responsibility to protect their flock," he added.

Hajjat Aisha Rashid Lukwago, who runs Corporate Herbalist, one of the biggest herbal care establishments in the country, said she would comply with the directive.

"With herbal medicine there are things you cannot handle. We do not have enough research on Ebola and therefore can't offer any solutions," she told the BBC.

Neil Pakenham-Walsh, Global Coordinator HIFA, www.hifa.org neil@hifa.org

Global Healthcare Information Network: Working in official relations with WHO

Communicating health research (121) Evidence Week in Parliament 2022 (2)

14 October, 2022

Neil,

Rather than ask again what the government has done, especially at such an uncertain time for this government, should not HIFA after such long deliberations, suggest what the government does, and perhaps suggest that HIFA assists the government in some way?

R

HIFA profile: Richard Fitton is a retired family doctor - GP. Professional interests: Health literacy, patient partnership of trust and implementation of healthcare with professionals, family and public involvement in the prevention of modern lifestyle diseases, patients using access to professional records to overcome confidentiality barriers to care, patients as part of the policing of the use of their patient data

Email address: [richardpeterfitton7 AT gmail.com](mailto:richardpeterfitton7@gmail.com)

Communicating health research (121) Evidence Week in Parliament 2022 (2)

14 October, 2022

Neil,

Rather than ask again what the government has done, especially at such an uncertain time for this government, should not HIFA after such long deliberations, suggest what the government does, and perhaps suggest that HIFA assists the government in some way?

R

HIFA profile: Richard Fitton is a retired family doctor - GP. Professional interests: Health literacy, patient partnership of trust and implementation of healthcare with professionals, family and public involvement in the prevention of modern lifestyle diseases, patients using

access to professional records to overcome confidentiality barriers to care, patients as part of the policing of the use of their patient data

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Communicating health research (122) Lancet: The scientific communication ecosystem: the responsibility of investigators

15 October, 2022

Interesting review and good recommendations about communicating science [*see note from HIFA moderator below]

[https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(22\)01898-0/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(22)01898-0/fulltext)

particularly insightful is the attention to use of language.

Misinformation, it appears, is not only limited to social media but also press releases by respected scientific institutions!

Goran Zangana

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HIFA profile: Goran Zangana is a medical doctor and Associate Research Fellow with the Middle East Research Institute, Iraq. He is a HIFA country representative for Iraq and is currently based in the UK. He is the current holder of Country Representative of the Year 2021.

<https://www.hifa.org/support/members/goran>

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[*Note from NPW, moderator: This Comment is restricted access. Here is the citation and some key points:

CITATION: The scientific communication ecosystem: the responsibility of investigators

Author links open overlay panelHoward BauchnerabFrederick P Rivaraab

[https://doi.org/10.1016/S0140-6736\(22\)01898-0](https://doi.org/10.1016/S0140-6736(22)01898-0)Get rights and content

Guidance exists for how members of the media should communicate science, but few guides are available for researchers...

Most investigators want the results of their studies to be communicated accurately, but they too have their biases... some researchers believe that their work will be more influential than is probably the case.

First, investigators should choose their words carefully... Some investigators also spin the results of their studies, emphasising secondary outcomes, underpowered or non-preplanned subgroup analyses or de-emphasising the results that did not support their hypotheses.⁶ Such tactics undermine the validity of the scientific process and can mislead the public and harm patients.

Second, investigators should review press releases from their institution, funder, and the publishing journal. A study that analysed 462 press releases (and their associated peer-reviewed manuscript) from 20 leading UK universities found that 40% of the press releases contained exaggerated advice and 33% causal claims...

Third, when investigators present the results of their studies at meetings, or in other venues, they should use language similar to that used in the article if it has already been published or is in preparation...

Fourth, relative differences between groups in a study can differ from absolute differences. Investigators should provide both... Not presenting the NNT exaggerates the success of a study.

Fifth, studies have limitations. Yet the limitations often do not appear in media reports or even in the scientific paper...

COMMENT (NPW): I suspect most researchers would be able to list the points above, and many more. The problem is that many apparently do not keep these points in mind when communicating their health research. As we have discussed, some are driven by motivations such as 'making an impact' that can undermine their ability to provide unbiased contributions to the knowledge base. This paper also repeats our observation about the lack of guidance for researchers. We all continue to be unaware of such guidance.

Communicating health research (123) Reflections on our thematic discussion

15 October, 2022

We have been discussing and defining the issues of communicating research to policymakers makers. We should report our findings and considerations and recommendation in a short paper that can be read in 30 minutes and that does not include specialist jargon.

The writers if the report could try to envision what the solutions are as much or more than what the problems are.

Although Sage had difficulties at time during Covid, I thought that the daily briefings with the prime minister and chief medical officer and ANother were a pretty perfect way of communicating policy?

I thought that General Practice failed absolutely to communicate the difficulties that it was facing as it went along especially as 66 million citizens had been using General Practice and A and E as a main doorway to free access to healthcare at the point of service.

R

HIFA profile: Richard Fitton is a retired family doctor - GP. Professional interests: Health literacy, patient partnership of trust and implementation of healthcare with professionals, family and public involvement in the prevention of modern lifestyle diseases, patients using access to professional records to overcome confidentiality barriers to care, patients as part of the policing of the use of their patient data

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Communicating health research (124) Novel Head-Up CPR Position Raises Odds of Survival of Out-Of-Hospital Heart Attacks (OHCA) - MEDSCAPE

15 October, 2022

[*Note from NPW, moderator: Thank you Joseph, I have included this message in our discussion on Communicating health research. I explain why in my comment at the bottom of your message.]

At the Centre for Clinical Governance Research and Patient Safety (CCGR&PS - www.hri-global.org), we had mixed emotions when we went through this article, because on one hand we were pleased that progress is being made to improve outcome for patients who suffer Out of Hospital Cardiac Arrest (OHCA) when they receive the novel Head-UP CPR (in the Traditional CPR the patient is supine), but on the other hand, we were, again, sad that while the populations in 'high-functioning systems' health shall benefit from this novel NP-CPR intervention, populations in lower-, low-, and middle income countries with low functioning health systems will not, for a long time, missing out on the increased chance of survival with neuro protection!.

A few points stand out for us as Take Home messages:

- when first responders use a novel CPR approach that includes gradual head-up positioning combined with basic but effective circulation-enhancing adjuncts, individuals who experience

out-of-hospital cardiac arrest (OHCA) with nonshockable presentations have a better chance of survival, as shown from data from more than 2000 patients.

- the study was presented at the American College of Emergency Physicians (ACEP) 2022 Scientific Assembly, Paul Pepe, MD, medical director for Dallas County Emergency Medical Services, in Texas, reviewed data from five EMS systems that had adopted the new approach.

- Traditional CPR supine chest compression techniques, if performed early and properly, can be lifesaving, but they are suboptimal, because the 'techniques create pressure waves that run up the arterial side, but they also create back-pressure on the venous side, increasing intracranial pressure (ICP), thus compromising optimal cerebral blood flow'

- therefore, a '--modified physiologic approach to CPR was designed. It involves an airway adjunct called an impedance threshold device (ITD) and active compression-decompression (ACD) with a device "resembling a toilet plunger," Pepe said. The devices draw more blood out of the brain and into the thorax in a complementary fashion.

- the new technology uses 'automated gradual head-up/torso-up positioning (AHUP) after first "priming the pump" with ITD-ACD-enhanced circulation', which was found to 'markedly augment that effect even further'. 'In the laboratory setting, this synergistic NP-CPR bundle has been shown to help normalize cerebral perfusion pressure, further promoting neuro-intact survival.'

- the combination of these two adjuncts had 'dramatically improved SURV-NI by 50% in a clinical trial'

- "All of these devices have now been cleared by the Food and Drug Administration and should be adopted by all first-inresponders," "But they should be implemented as a bundle and in the proper sequence and as soon as feasible." [*see note from HIFA moderator below]

- 'Training and implementation efforts continue to expand, and more lives can be saved as more firefighters and first-in response teams acquire equipment and training, which can cut the time to response'

We also noted additional very important Take Home messages, especially for those populations in low functioning health systems: that,

i) this new 'head-up CPR cannot yet be performed by laybystanders'.

ii) "Also, do not implement this unless you are going to do it right".

Always Remember: Primum non nocere – First Do No Harm!

NOW READ ON, courtesy of MEDSCAPE:

Novel Head-Up CPR Position Raises Odds of Survival of Out-Of-Hospital Heart Attacks

By Heidi Splete October 13, 2022

Novel Head-Up CPR Position Raises Odds of Survival

<https://www.medscape.com/viewarticle/982409>

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HIFA profile: Joseph Ana is the Lead Senior Fellow/Medical Consultant at the Centre for Clinical Governance Research and Patient Safety in Calabar, Nigeria, established by HRI Global (former HRIWA). He is a member of the World Health Organisation's Technical Advisory Group on Integrated Care in primary, emergency, operative, and critical care (TAG-IC2). As the Cross River State Commissioner for Health, he led the introduction of the Homegrown Quality Tool, the 12-Pillar Clinical Governance Programme, in Nigeria (2004-2008). For sustainability, he established the Department of Clinical Governance, Servicom & e-health in the Cross River State Ministry of Health, Nigeria. His main interest is in whole health sector and system strengthening in Lower, Low and Middle Income Countries (LLMICs). He has written six books on the 12-Pillar Clinical Governance programme, suitable for LLMICs, including the TOOLS for Implementation. He served as Chairman of the Nigerian Medical Association's Standing Committee on Clinical Governance (2012-2022), and he won the Nigeria Medical Association's Award of Excellence on three consecutive occasions for the innovation. He served as Chairman, Quality & Performance, of the Technical Working Group for the implementation of the Nigeria Health Act 2014. He is member, National Tertiary Health Institutions Standards Committee of the Federal Ministry of Health. He is the pioneer Secretary General/Trustee-Director of the NMF (Nigerian Medical Forum) which took the BMJ to West Africa in 1995. Joseph is a member of the HIFA Steering Group and the HIFA working group on Community Health Workers. (<http://www.hifa.org/support/members/joseph-0> <http://www.hifa.org/people/steering-group>). Email: [info AT hri-global.org](mailto:info@hri-global.org) and [jneana AT yahoo.co.uk](mailto:jneana@yahoo.co.uk)

[*Note from NPW, moderator: The article says: "All of these devices have now been cleared by the Food and Drug Administration and should be adopted by all first-in responders." But, let's be careful here. Who is saying this? It is Pepe, the lead author of the research. In my view researchers should focus on communicating the results of their research, and not on making major policy recommendations. It is reasonable to say "Our results suggest that this

method requires further exploration as a potential alternative to current CPR procedure". But I feel it is overstepping the role of a researcher to say everything "should" now change. Such change needs to be considered by the cardiovascular research community as a whole, taking into account all available evidence. Furthermore, I have checked the study itself - [https://www.annemergmed.com/article/S0196-0644\(22\)00609-6/fulltext#relatedArticles](https://www.annemergmed.com/article/S0196-0644(22)00609-6/fulltext#relatedArticles) - and it appears to be available only as an abstract. Indeed, it seems to be the abstract of a paper given at a conference. Furthermore, the authors disclosure statement says "Advanced CPR Solutions; Board Member/Officer/Trustee Advanced CPR Solutions' and at the end of the article it states that the research was partly funded by Advanced CPR Solutions. Advanced CPR Solutions. It is also notable that the abstract itself does not say 'should be adopted by all first-in responders'. This is what the journalist wrote, apparently reporting what Pepe had said verbally at the conference.

I think this case provides a good case study to explore the potential distortion that can take place when research is communicated. Pepe's 'novel' (it is amazing how often this word is used in the conference's several hundred abstracts) procedure may or may not contribute significantly to the cumulative knowledge on CPR - it is FAR too early to tell. I invite comments on the above. Neil PW]

Communicating health research (125) Reflections on our thematic discussion (2)

15 October, 2022

If it were me, I would summarise, in a few, simple, words, the conclusions of HIFA's 4 weeks of discussions on the transit of research to policymakers.

I would put key findings in the summary and make a small number of explicit solution recommendations. I would post this on the Hifa website.

I would then ask one question separately about each recommendation that we had made. For each question I would make a reference to the HIFA posted report. I would also add a reference, in each question, to any current parliamentary advice that we can find on the question that we raise. I would try to be complimentary about these parliamentary efforts - if we find there have been so far!!

Richard

HIFA profile: Richard Fitton is a retired family doctor - GP. Professional interests: Health literacy, patient partnership of trust and implementation of healthcare with professionals, family and public involvement in the prevention of modern lifestyle diseases, patients using access to professional records to overcome confidentiality barriers to care, patients as part of the policing of the use of their patient data

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