

# Preparing for and responding to global health emergencies

Learnings from the COVID-19 evidence response and recommendations for the future



Credit: NIAID-RML

Drawing on experiences of the COVID-19 pandemic, the inaugural Cochrane Convenes brought together leaders in health research and health evidence to explore and recommend the changes needed in evidence synthesis to prepare for and respond to future global health emergencies.

This report presents reflections and recommendations from seven roundtable meetings and incorporates points from discussions at the subsequent open plenary in October 2021. The online events were hosted by Cochrane, co-sponsored by the World Health Organization, and co-organized with COVID-END (COVID-19 Evidence Network to support Decision-making).

The work aims to help funders, policymakers, researchers and others to strengthen our collective preparedness in response to future global health emergencies.

"As a community of evidence producers and users, we needed to harvest what we've learned and Cochrane Convenes has given us the opportunity to start this. It has come out loud and clear that we need to remain connected as a community to shore up good practice in evidence production and use - for the good of all our health across the world. Promisingly, the participants have shown the collective will exists to get us fit for purpose and now we need to move towards putting these recommendations into action"

> Dr John Grove, Director of the Quality Assurance, Norms and Standards Department, World Health Organization

### **Organising partners**

The events were held by Cochrane Convenes, cosponsored by the World Health Organization (WHO), and co-organized with COVID-END (COVID-19 Evidence Network to support Decision-making).

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### Contents

Foreword	iv
Call to action	V
Glossary	vi
Summary	1
1. Introduction	5
2. Incentivizing and encouraging change at system level	10
Understanding needs and the role of evidence in decision making	12
Setting priorities and co-ordinating the evidence effort	13
Ensuring quality funding	15
3. Reviewing the way research and evidence syntheses are produced an	d shared 18
Reinforcing the links between primary and secondary research	20
(Re)evaluating evidence synthesis methods and quality	22
(Re)evaluating the way evidence synthesis is presented and shared	24
4. Reflecting on uncertainty and mis/disinformation	28
5. Next steps	33



### Foreword

I was both inspired and humbled to see that so many from the global evidence community were able to join us for the inaugural Cochrane Convenes.

We have all seen how the COVID-19 pandemic and its wider impacts have claimed many lives around the world. I, like many others, have been deeply concerned about the widening of existing inequities and the way that those already vulnerable have been disproportionately affected. Cochrane Convenes was organized out of a sense of responsibility to learn from our experiences of the evidence response so that we can be better equipped for future health emergencies.

I came out of Cochrane Convenes with the confirmation that, as a community of evidence producers and users, we were not as prepared to respond to the COVID-19 pandemic as we could have been. Now that we have had time to reflect, we have a better understanding of what we need to do to prepare for future global health emergencies, both in terms of building on the rigour and quality of the evidence we produce, and in working collaboratively with partners around the globe.

We now need to turn the theory of what we heard at Cochrane Convenes into action – urgently. The Cochrane community is a powerful and diverse global network, which we can harness to drive change. Of course, we cannot, and will not, do this in isolation. I hope that this report is therefore a call to action to you to join us in taking the recommendations forward.

Finally, I would like to share my sincere thanks to all the people who joined us in making Cochrane Convenes happen. I look forward to building a better evidence system together, which works for those who create the evidence and for those who use and benefit from the evidence.

Dr Karla Soares-Weiser, Editor in Chief, Cochrane



### Call to action: supporting evidence responses to global health emergencies

**THE PROBLEM** COVID-19 has created an unprecedented focus on health evidence for people working in governments, businesses and non-governmental organizations as well as members of the public.

Through Cochrane Convenes, a series of roundtable discussions involving healthcare policy makers, researchers, funders, journalists, science communicators and consumer representatives from around the world, it has become clear that:

- → the evidence response to the COVID-19 pandemic has been inequitable – both in terms of the focus of the evidence, who has been producing it and who it reaches
- → our methods, tools and processes have been pushed to their limits in trying to answer questions at the speed demanded
- → in the face of an infodemic, we have struggled to communicate scientific uncertainties and gain trust for the evidence available.

### **NEED FOR CHANGE**

Urgent action needs to be taken to ensure that the evidence community is adequately prepared to respond to future global health emergencies.

Some changes could be implemented quickly and could help with addressing the ongoing pandemic. Others will need to be done over a longer period and will also be used in 'peacetime'.

#### **CALL TO ACTION**

We call on you to join with us and help to build an evidence system which we can all trust, that caters for all users of evidence wherever they are in the world, and which is better prepared for the next global health emergency.

Cochrane, together with partners, aims to lead on:

- → building a case for support to secure funding for evidence synthesis units in low- and middleincome countries to help redress global imbalance
- → strengthening of tools, methods, processes and relationships to ensure a rapid and relevant evidence response at national and global levels for the next global health emergency.
- → investing in science communications:
  - building the capacity of the Cochrane community to communicate uncertainty (through webinars, social media campaigns, how-to guides)
  - improving and being more proactive about science communication

We call on our partners to prioritize the following.



- → Identify, prioritize and fund national and international research needs and address inequities
- → Fund evidence generation, communication, networks and infrastructure in low- and middleincome countries



- → Demand evidence and be about how (and what) evidence is used in decision making
- → Hold those deliberately creating and sharing mis/ disinformation to account

### O FIII RESEARCH COMMUNITY

- → Support research transparency and data sharing
- → Be alert to, and raise the alarm about, fraudulent studies
- → Improve communication about uncertainty and the evolving nature of the evidence
- → Learn what works in communicating uncertainty, generating trust in evidence and countering mis/ disinformation

### Glossary

### **Evidence synthesis**

### ightarrow What is evidence synthesis?

Evidence synthesis involves finding, combining and analyzing information from existing studies on a particular topic to come to an overall understanding of what we know about that topic. This process helps us to answer specific research questions. It also tells us how much confidence we can have in the existing evidence, sheds light on the quality of that evidence and highlights any evidence gaps.

The evidence synthesis community strives to provide high-quality outputs to inform health policy and practice in a relevant and timely manner. The goal of producing evidence synthesis is to improve evidence-informed decision making at individual, organizational, national, and global levels, leading to better health and social outcomes for all.

This report focuses on evidence synthesis, with primary research (for the purposes of this report, any information obtained 'first hand', including but not limited to randomized controlled trials) as an input to that process.

## → What kinds of evidence synthesis are there?

• Systematic reviews of interventions: seek to answer questions about the effectiveness of healthcare interventions (medicines, other treatments or policies) on the people who receive them. The authors of intervention reviews identify studies that compare one intervention with either another intervention, an inactive intervention (placebo), or no intervention. Depending on the number and reliability of the studies identified, intervention reviews may provide information on whether the intervention works, or whether we need more evidence before we can draw a conclusion. They may identify for whom the intervention works best, which version of the treatment works best, whether another option is just as effective, and whether it causes any unwanted effects.

- Living systematic reviews: evidence reviews in topics where a lot of research is emerging quickly. Living systematic reviews search for evidence much more regularly than standard reviews and incorporate relevant new evidence as it becomes available<sup>1</sup>
- **Rapid review:** a form of evidence synthesis that accelerates the process of conducting a traditional systematic review through streamlining or omitting specific methods to produce evidence for stakeholders in a resource-efficient manner.

1 Cochrane. (2020). *Living systematic reviews highlight latest evidence*. COVID-19 case story. www.cochrane.org/sites/default/files/public/uploads/covid case story - living systematic reviews v6.pdf

### **Glossary of other key terms**

**Citizen science**: members of the public volunteer to help carry out scientific research. Cochrane Crowd, where volunteers help to screen and identify randomized trials, is an example of a citizen science initiative; <u>crowd.cochrane.org</u>.

**CONSORT:** Consolidated Standards of Reporting Trials – a minimum set of recommendations to support the complete and transparent reporting of randomized controlled trials; <u>www.consort-statement.org</u>.

**Core outcome set:** an agreed upon, standardized set of outcomes that should be measured and reported, as a minimum, in all clinical trials in specific areas of health or health care; <u>www.comet-initiative.org/</u>.

**FAIR principles:** guidelines to improve the Findability, Accessibility, Interoperability, and Reuse of digital assets for scientific research; <u>www.go-fair.org/fair-principles/</u> **Infodemic:** the World Health Organization defines an 'infodemic' as "too much information including false or misleading information in digital and physical environments during a disease outbreak." (www.who.int/health-topics/infodemic)

**Individual participant data (IPD):** raw data collected on each individual participant during a research study.

**Misinformation:** regardless of intent, spreading false information that causes people to believe something which is not true; disinformation is the deliberate spread of false information.

**Preprints:** research articles shared publicly, usually online, before they have been peer-reviewed.<sup>2</sup>

<sup>2</sup> Bero L, Lawrence R, Leslie L, Chui K, McDonald S, Page MJ, *et al.* (2021). Cross-sectional study of preprints and final journal publications from COVID-19 studies: discrepancies in results reporting and spin in interpretation. BMJ Open 2021, 11:e051821. doi: 10.1136/bmjopen-2021-051821



## Summary

The arrival of COVID-19 created an unprecedented focus on health evidence for governments, businesses and nongovernmental organizations as well as members of the public. The need for evidence to support decision making has sparked some notable innovations and fast-tracked collaboration among decision makers and researchers – but it has also laid bare shortfalls in the production and sharing of quality evidence synthesis.

In October 2021, Cochrane Convenes

invited key thought leaders from around the world to reflect on their experiences of producing, sharing and using evidence during the pandemic with a view to making a collaborative call to action on areas identified by the community for improvement.

This paper attempts to summarize and organize the recommendations arising from the online events. The full set of recommendations arising from each of the seven online roundtable events is available from: <u>convenes.cochrane.org/</u>.

### **Key reflections**

- → The pandemic has exacerbated pre-existing inequities in society, including social determinants of health, and to date, the evidence response has also been unequal – across sectors, countries, regions and populations.
- → The rapidly changing (highly politically charged) context and rapidly evolving evidence of mixed quality have challenged research methods, tools, processes, partnerships and communication, especially without additional resources. In particular, we have struggled to convey

uncertainty, what is known (right now) and what is not known (yet), and how the evidence and broader response to the pandemic might evolve.

→ In spite of the evolution in information and communications technology since the 2009 H1N1 pandemic, we have been unable to promote evidence, to counter mis/ disinformation, or to hold to account those intentionally creating and spreading mis/ disinformation – this continues to threaten lives.

### **Key recommendations**

## Incentivizing and encouraging change at system level

In order to minimize research gaps and better respond to the needs of decision makers with high-quality evidence during the next global health emergency, Cochrane Convenes participants recommend the following.

- → Working with decision makers at national and international levels to arrive at a common and mutual understanding of decision-making needs in relation to global health emergencies, and what research can deliver in response, working towards:
  - greater transparency about how (and what) evidence is needed and used in decision making
  - a better understanding of uncertainty, the evolving nature of evidence, and how to work with and communicate this
  - a common and mutual understanding of quality and what is 'good enough'.

- → Working towards a common understanding of global research needs and who might be best placed to meet or coordinate these and how – for example, discussing what a global evidence system, or 'systems', or 'service' might look like – in order to ensure more equitable coverage and reduce research duplication and waste.
- → Funding and commissioning research wisely to meet global needs:
  - invest in research and research communications in addition to funding short-term projects – notably to enable better sharing of data and to understand 'what works' in terms of communicating evidence
  - use the funding process to help identify, prioritize, fund and meet national and international research needs equitably
  - provide more financial support for evidence generation, communication, networks and infrastructure development in low- and middle income countries.



## Producing and sharing research and evidence synthesis

By way of preparing to deliver timely, relevant, high-quality evidence during future emergencies Cochrane Convenes participants recommend:

- → further developing or reviewing research tools, processes, methods and standards to meet the challenges of rapid onset health emergencies more effectively
- → investing in and using new technology to facilitate review processes (using study repositories and databases, citizen science and artificial intelligence) and enhance transparency and data sharing
- → evaluating the suitability of faster, more agile editorial processes and formats (such as rapid and living reviews and preprints)
- → investing time and resources in science communications on an ongoing basis – including in people, technology and learning:

- ensure that people know where to go to find evidence
- ensure that we know 'what works' in terms of formats and delivery
- build trust in 'peacetime'
- build information literacy
- build partnerships between disciplines and sectors – to understand needs, share experiences and work to communicate uncertainty more effectively.

In addition, the participants highlight the value of being 'good partners' in support of the changes and made recommendations at system and communication levels, including:

- → being alert to and communicating about fraudulent trials and studies
- $\rightarrow$  reducing duplication and research waste
- → playing a role in building capacity in lowand middle-income countries
- → engaging with evidence users directly and in partnership with others – to help communicate uncertainty and its evolving nature.

### Reflecting on uncertainty and mis/ disinformation

Beyond communicating what we want to say accurately and responsibly, there is also the question of listening to a wider audience and understanding what they need to hear and how they need to hear it. This may require us to open up the discussion with other professionals and other disciplines (social and behavioural science for example) in order to further refine our reflections to develop recommendations and a plan of action. In addition to the above recommendations, top-line recommendations on what is needed include:

- → researching what works (and where) in terms of both communicating uncertainty and countering mis/disinformation
- → building trust through increased collaboration between evidence producers, evidence users and clinical partners
- → increasing transparency around public decision-making processes (see 'System-level change')
- → raising awareness of the evolving nature of both evidence and context in a health emergency – this might include direct engagement with decision makers as well as with intermediaries (and training)
- → considering a form of accreditation and 'quality' approval for official sources of evidence that has met certain qualitycontrol standards, making it easier for people to access trustworthy information – considering, for example, the increased engagement of information scientists to help increase both 'push' (ensuring people receive and can act on evidence) and 'pull' (helping people to find and use evidence), as well as using non-traditional formats, channels and champions

→ forming multidisciplinary coalitions to hold to account those deliberately creating and sharing mis/disinformation.

### Next steps:

During 2022 and beyond, Cochrane will be engaging with a wider group of experts in relevant disciplines in order to take forward the most pressing of these recommendations. In particular, it will work towards:

- → more support for evidence synthesis in low and middle-income countries to address global imbalances
- → the development of a system (or systems) – tools, methods, processes and relationships – at national and global levels to ensure that we are prepared for the next global health emergency
- → more investment in science communications – including working to act on mis/disinformation and to hold those responsible to account.

During 2022, Cochrane will be:

- → incorporating the recommendations and learnings from Cochrane Convenes into its own future strategic direction
- → building a consortium of current and new partners to mobilize around addressing the key issues identified in this report – and, where established initiatives already exist, joining up with these
- → developing campaigns to advocate for the conditions that will support an improved evidence response at key moments, including the World Health Assembly

We call on you to join with us and help to build a system that we can all trust, that caters for all users of evidence wherever they are in the world, and that is sufficiently prepared for the next global health emergency.



## **1. Introduction**

COVID-19 created an unprecedented focus on health evidence for governments, businesses and non-governmental organizations as well as members of the public. But while the pandemic sparked some notable innovations and fast-tracked collaboration among decision makers and researchers, it has also laid bare shortfalls in the production and sharing of quality evidence synthesis.

The rapid onset of the pandemic created a huge demand for evidence across a number

of sectors – including health and social care, education and finance – and increased the challenge of promptly identifying and addressing the right research questions in the face of rapidly changing needs and rapidly changing evidence. As the evidence community attempted to rise to this extraordinary challenge, a lack of coordination led to waste and a duplication of efforts on the one hand, and to evidence gaps on the other. Not just across sectors but also across countries and regions. Misinformation and disinformation have quickly served to fill the vacuum left behind by the evidence gaps - and to widen them. Aided and abetted by fraudulent - and sometimes simply low-quality – studies and poor (or deliberately misleading) communication, mistrust and distrust have flourished, leading to a crisis of confidence. COVID-19 is the first pandemic in history to be able to leverage technology and social media to keep people safe, informed, productive and connected on such a wide scale.<sup>3</sup> But the same technology has also enabled and amplified an 'infodemic' that continues to undermine the global response to the pandemic and jeopardize measures to control it.

This 'perfect storm' has also exposed the difficulties in producing and sharing timely, rigorous, transparent and accessible evidence synthesis for decision making. With its ability to assess and synthesize information from existing studies in order to extract a summary understanding in response to a research question – and to tell us how much confidence we can have in that evidence – evidence synthesis should have been, and should be, more important than ever.<sup>4</sup> This is why we need to act now to understand the challenges and harness both technical and other opportunities to respond better to the next global health emergency.

The pandemic has spawned too many uninformative clinical trials and reviews. Reform is needed to ensure the world gets the high-quality evidence it needs

Evidence-based medicine: how COVID can drive positive change. Nature 593, 168 (2021).

<sup>3</sup> World Health Organization (WHO). (2020). *Managing the COVID-19 infodemic: promoting healthy behaviours and mitigating the harm from misinformation and disinformation*. <u>www.who.int/news/item/23-09-2020-managing-the-covid-19-infodemic-promoting-healthy-behaviours-and-mitigating-the-harm-from-misinformation-and-disinformation</u>

<sup>4</sup> Springer Nature (2021). The value of evidence synthesis. *Nature Human Behaviour, 5*, 539. doi.org/10.1038/s41562-021-01131-7

### What is evidence synthesis?

Evidence synthesis definitions and methods vary. Generally speaking, evidence synthesis (a systematic review) is a research method that aims to answer a specific research question by finding individual studies that have investigated the same topic and analyzing the data from the studies in a standardized, systematic way. This produces an objective and transparent overview of all the evidence surrounding a particular question. Systematic reviews aim to minimize bias by using explicit, systematic methods documented in advance with a protocol. Cochrane Reviews are recognized internationally as the gold standard for highquality, trusted information.

### How was evidence synthesis challenged during the pandemic?

During the Cochrane Convenes events, we heard how the pandemic had intensified the demand for rapid answers to questions, in many cases exacerbating existing tensions associated with producing and sharing quality evidence for decision making, for example:

- → maintaining relevance the focus of evidence synthesis is on responding to a specific question, or set of questions, and these changed rapidly as the pandemic progressed
- → ensuring quality tight timeframes forced

some tough trade-offs in terms of quality and methods – and at the same time, there was a tsunami of trials and other primary research inputs to take account of, some of low quality

- → being timely established methods, tools and processes for producing and sharing evidence (from both research and editorial perspectives) can simply take too long
- → resources funding is weighted towards high-income countries; the focus is often on primary rather than secondary research; communication of research is often underfunded, or funded for shortterm projects and programmes; publishing open access is to be encouraged – but costs money, and low- and middle-income countries need support to be able to do this; research funding needs to allow for longer-term infrastructure, skills and capacity development in order to build or upgrade infrastructure and skills that can take advantage of new methods and technology
- → feedback loop the needs of all stakeholders (primary and secondary researchers; users; citizens) need to be accounted for at the start of the process in order to meet needs
- → finding and using evidence we need to evaluate systematically and understand what works in terms of accessible and engaging evidence products, harnessing information technology and social media.

<sup>5</sup> Lasserson TJ, Thomas J, Higgins JP. Chapter 1: Starting a review. In: Higgins JP, Thomas J, Chandler J, Cumpston M, Li T, Page MJ, Welch VA editor(s). *Cochrane Handbook for Systematic Reviews of Interventions* Version 6.2 (updated February 2021). Cochrane, 2021. Available from <u>www.training.cochrane.org/handbook</u>.



In October 2021, Cochrane Convenes invited key thought leaders from around the world to reflect on their experiences of producing, sharing and using evidence during the COVID-19 pandemic, discuss the challenges and develop recommendations.

In an initial step, over 90 healthcare policy makers, researchers, funders, journalists, science communicators and consumer representatives from 30 countries participated in seven roundtable discussions (see box). Their recommendations were reviewed by an expert advisory panel, and a summary was presented and discussed at an open plenary attended by 320 people from 68 countries. This report presents the recommendations arising from this process in three interconnected sections:

- → incentivizing and encouraging change at a 'system' level – what does the evidence community need to see at national and international levels, and what does it need to do, in order to serve the evidence needs of decision makers during global health emergencies more effectively?
- → producing and sharing research and evidence synthesis – what can we do as researchers and research institutions in 'peacetime' to be better prepared for the next global health emergency?
- → communicating uncertainty and countering mis/disinformation – what can we do to help people better engage with and have trust in evidence-informed information?

Over the course of 2022, Cochrane will be engaging with a wider group of experts in relevant disciplines in order to take forward the most pressing recommendations.

### **The Cochrane Convenes process**

This report groups the main reflections and recommendations arising from the Cochrane Convenes online events (seven roundtables and an open plenary, October 2021) into three common themes.



### a call to action

#### The seven roundtable discussions

- Roundtable 1 Prioritizing and identifying evidence needs of users
- Roundtable 2 Connecting primary and secondary research
- Roundtable 3 Producing timely and relevant evidence synthesis
- Roundtable 4 Getting the right evidence to people
- Roundtable 5 Helping people find and use evidence
- **Roundtable 6** Engaging with decision-makers to support evidence-informed policy and practice
- Roundtable 7 Getting political buy-in for research

Simple summaries of the key questions explored in each of these roundtable sessions, together with the resulting recommendations, are available from: <u>convenes.cochrane.org/</u>



## 2. Incentivizing and encouraging change at system level

### **Key recommendations**

In summary, at system level, in order to prepare to serve the needs of decision makers equitably and with high-quality evidence during the next global health emergency, Cochrane Convenes participants recommend:

- → providing more financial support for evidence generation, communication, networks and infrastructure in low- and middle-income countries
- → working with national and international stakeholders to describe the ideal global evidence system, or service, and what this might require – and then advocating for the necessary conditions
- → working towards greater transparency about how (and what) evidence is used in decision making
- → harnessing research commissioning and financing as tools to help identify, prioritize, fund and meet national and international research needs equitably.

This section sets out what the evidence community represented at the Cochrane Convenes events recommend at national and international levels better to serve the evidence needs of decision makers during global health emergencies.

The recommendations set out by the participants are based on the desire to provide a timely and rigorous response that meaningfully contributes to decision making globally, which, in the case of the COVID-19 pandemic, was set against a backdrop of rapidly changing questions, rapidly changing evidence, high volumes of primary research of varying quality, and uncertainty. Further, a perceived lack of global strategy left producers and users of evidence in many sectors, countries and regions (particularly in low- and middle-income countries) totally unsupported. To avoid or help mitigate similar risks in the future, the recommendations centre on:

- → building a mutual understanding of evidence needs in decision making and the role or contribution that evidence has to make
- → looking at ways to improve identification, prioritization and co-ordination of evidence needs at global and local levels
- → reviewing approaches to funding.

## Understanding needs and the role of evidence in decision making

The evidence synthesis community strives to provide high-quality outputs to inform health policy and practice in a relevant and timely manner with the goal of improving evidenceinformed decision making at individual, organizational, national, and global levels, leading to better health and social outcomes for all. With challenges at every stage along the evidence pipeline, how can we, as part of the evidence synthesis community play our part in a useful and effective way – and in real time?

For success, strong relationships between the evidence-producing and decision-making communities are crucial so that both sides can better understand and anticipate each other's needs.

By way of exploring this issue, roundtable participants reflected on examples of good evidence-to-decision-making structures and processes in high-, middle-, and low-income countries, and the type of intermediaries that were best able to work within them and leverage them.

They also reflected on the role of international organizations in supporting evidenceinformed decision making during a global health emergency. Decision makers receive advice from multiple sources and they must balance political, economic, social and ethical concerns when making policy choices, often within rapid timelines.

> UN Research Roadmap for COVID-19 Recovery

### Recommendations

- → The evidence synthesis community should work with national and international policymakers and other key stakeholders to:
  - create a shared understanding of what 'evidence' is, and what 'evidence for decision making' needs to be
  - identify the key features and partnerships of a global evidencesupport system – or service – and what this would cost
  - identify the key features and partnerships of a transparent evidenceinformed decision-making system that works at global, national and local levels
  - build understanding of the features of rigorous evidence and the advantages of evidence synthesis in particular
  - explore the use of evidence synthesis outside clinical and public health settings.

## Setting priorities and co-ordinating the evidence effort

Setting priorities is an essential part of the research and policy-making processes. Having a suitable priority-setting process in place helps us to understand the evidence needs of policymakers, health professionals, and the public at institutional, national and global levels. Priority setting for research can be a challenging process – particularly during emergencies, as evidence and evidence needs evolve rapidly.

Both the roundtable and plenary discussions reflected on the processes, mechanisms and relationships required to identify, prioritize and co-ordinate a response to evidence needs globally – that is, across countries, disciplines and stakeholders.

### Recommendations

- → The evidence synthesis community and international policymakers should consider:
  - creating a global, co-ordinated evidence network
    - a limited number of global agencies might lead the effort, and local agencies might focus on local prioritization, contextualization and audit
    - data modellers might help identify how to get the evidence we need and how to plan for present-, medium-, and long-term data collection and how this can be adapted to specific contexts
    - closer collaboration between public health agencies and the evidence synthesis community could support better decision-making – such partnerships should be prioritized so that they are in place before the next global health emergency

It really became about reducing infections at all cost. That initial reaction continued throughout the pandemic. We did not hear enough from voices who talked about other outcomes ... mental health ... economic vitality ... All these outcomes that are incredibly important to humanity were not priorities at all. And that's where we started to lose a lot of citizens.

Roundtable participant

- creating global forums for senior representatives to routinely communicate, so that these partnerships can be leveraged for prioritization when needed in an emergency
- → Funders should introduce and encourage more co-ordination in the commissioning of both primary (e.g. trials) and secondary (meta analysis and synthesis) research. Ideally this would include:
  - ensuring a link and data sharing between primary and secondary research
  - encouraging and incentivizing shared or co-ordinated research agendas, priorities, methodology, data, and results across organizations and countries, as well as funding open access platforms for sharing

### Examples of priority setting and co-ordination initiatives

The **James Lind Alliance** is a non-profitmaking initiative established in the UK in 2004. It brings patients, carers and clinicians together in priority-setting partnerships (PSPs) to identify and prioritize the 'Top 10 unanswered questions' or evidence uncertainties that they agree are the most important. Priority-setting exercises such as this, which are based on tried and tested methodological approaches, might provide a basis for a model for use in future pandemics. <u>www.jla.nihr.ac.uk/</u>

The **COVID-END initiative** is a time-limited network that brings together more than 50 of the world's leading evidence-synthesis, technology-assessment and guidelinedevelopment groups around the world. It covers the full spectrum of the pandemic response, from public-health measures and clinical management to health-system arrangements and economic and social responses. It also covers the full spectrum of contexts where the pandemic response is playing out, including low-, middle- and high-income countries. It produces two products:

- → global spotlights that include updates to the 'best' living evidence syntheses and new 'best' evidence syntheses (which draw on the COVID-END inventory of best evidence syntheses in the world on COVID-19-related decisions)
- → horizon scan documents that include a briefing note about emerging COVID-19 issues and a panel summary about priority COVID-19 issues (which capture the insights from COVID-END's global panel of leading doers and thinkers)

www.mcmasterforum.org/networks/ covid-end

The eCOVID-19 living map of recommendations map is a living map of the latest evidence-based COVID-19 recommendations, which also provides a gateway to contextualization to support decision making. All recommendations are supported by a description of its PICO elements and links to interactive Summary of Findings tables and the Evidence to Decision tables populated on GRADEPro and other information, if available. It is a product of collaboration between Cochrane Canada; American University of Beirut; Cochrane South Africa; South African Medical Research Council, the Postgraduate Institute of Medical Education and Research Chandigarh, India; the WHO Collaborating Centre for Infectious Diseases, Research Methods and Recommendations at McMaster University; Evidence Prime; the Norwegian Institute of Public Health; the **Guidelines International Network and** many other institutions and organizations. covid19.recmap.org/

The **R&D Blueprint**, convened by WHO, is a global strategy and preparedness plan that allows the rapid activation of research and development activities during epidemics. As part of WHO's response to the COVID-19 outbreak, the R&D Blueprint has been activated to accelerate diagnostics, vaccines and therapeutics.

www.who.int/teams/blueprint/covid-19

### **Ensuring quality funding**

The availability of funding (independent of commercial interest) of course underpins research activity and its future development – including many of the recommendations outlined in this synopsis. Some of the recommendations though are not just about the money – but the way in which resources are allocated and spent. Broadly, Cochrane Convenes participants noted a need to:

- → resource research more equitably across and within sectors, countries and regions

   – in high-income as well as low- and middleincome countries
- → co-ordinate and prioritize evidence needs (to reduce duplication and waste) – including consideration of other diseases, especially in low- and middle-income countries
- → support and incentivize the development of and adherence to quality standards
- → support decision making, research infrastructure and networks, and evidence uptake and use

### Recommendations

- → In terms of providing funding for low- and middle-income countries, funders should:
  - increase public funding and local contributions for trials in low- and middle-income countries and foster capacity development and sustainability for research so that research is not primarily generated by high-income countries
  - support the key features of each country's evidence support system as part of a commitment to equitably distributed capacities for evidence

There is a need to fund quality information science. It's a systemic issue around how we fund and develop skills of people who provide access and help people find evidence and that it's something that requires better standards, but also more open, and transparent collaboration across all these different organizations.

Roundtable participant

production, communication and use

- ensure a balanced portfolio of trials so that all resources are not diverted towards a single disease.
- → In terms of helping to identify and prioritize evidence needs, and to co-ordinate the evidence response, funders should:
  - develop co-ordinated funding packages that follow the entire process from primary research through to secondary research and communication to ensure the right evidence flows through to decision makers

- this should include funding for independent fact checkers (organizations that scrutinize rumours and media stories and provide information), who analyze the evidence base for claims made in the media or that circulate online
- seek a balanced portfolio of trials so that the focus is not at the expense of research on other diseases
- provide medium- and longer-term funding (as well as short-term project funding) that supports the development of sound underlying evidence production structures (such as methods and stakeholder co-production processes – see next section)
  - notably, researchers pointed out the need for investment in technology that supports real-time collaboration and sharing of standardized data
- consider building and consolidating global evidence networks
- fund large trials rather than smaller, duplicative trials (though well-designed small trials and purposeful duplication do have a place)
- incentivize data sharing. For example, require that the full data – ideally individual participant data (IPD) – from trials they fund is made accessible as early as possible for evidence synthesis, and offer adequate resources to support trialists to share data in accordance with

FAIR principles (Findability, Accessibility, Interoperability and Reuse of digital assets).<sup>6</sup>

- → In terms of ensuring quality, funders should:
  - ensure that all smaller national components of global trials are appropriately registered and adhere, as far as possible, to standard protocols to minimize data fragmentation at the analysis stage
  - ensure trials assess core outcome sets and are disseminated (results posted on registries and published as possible) and are reported transparently (adherence to CONSORT (Consolidated Standards of Reporting Trials)).<sup>7</sup>
  - fund research integrity work, which can contribute to raising the quality and standards of research in general.
- → Invest in evaluating what works in terms of effective evidence products.
- → Invest in science communication capacity and the professionalization of this function, which is key to communicating risk and uncertainty.
- → Invest in evaluating what works in terms of communication and evidence use in a health emergency. This should take into account non-traditional media channels, community-led initiatives and influencers, and might include:

<sup>6</sup> FAIR principles (Findability, Accessibility, Interoperability and Reuse of digital assets). <u>www.go-fair.org/fair-principles/</u>

<sup>7</sup> Schulz KF, Altman DG, Moher D, for the CONSORT Group. CONSORT 2010 Statement: updated guidelines for reporting parallel group randomised trials. Annals of Internal Medicine 2010;152. Epub 24 March. (CONSORT website: www.consort-statement.org/)

- funding capacity building and training for scientists, politicians, or other spokespeople/communicators, to increase understanding as well as the reach and use of this evidence
- investigating the engagement of a new generation of spokespeople, such as influencers or social media figures
- learning from the spread of mis/ disinformation – what made it successful? Why was it trusted more than formal sources? What does that say about evidence and what we need to do?
- reviewing practice at local level, including the role of community-led dissemination in hand with local public health groups, led by trusted community figures.





## 3. Reviewing the way research and evidence syntheses are produced and shared

### **Key recommendations**

In summary, at a research and research institution level, Cochrane Convenes participants recommend:

- → further developing or reviewing research tools, processes, methods and standards to meet the challenges of rapid onset global health emergencies more effectively
- → investing in and using new technology to facilitate review processes (using study repositories and databases, crowd screening, and artificial intelligence) and enhance transparency and data sharing
- → evaluating the suitability of faster, more agile editorial processes and formats (rapid/ living reviews and preprints)
- → investing time and resources in science communications on an ongoing basis including in people, technology and learning, as well as evaluating what works.

Other recommendations highlight the value of being good partners in support of the changes and recommendations made at system and communication levels, including:

- → being alert to and communicating about fraudulent trials and studies
- $\rightarrow$  reducing duplication and research waste
- ightarrow playing a role in building capacity in low- and middle-income countries
- → engaging with evidence users directly and in partnership with others to help communicate uncertainty and the evolving nature of the evidence.

At the outset of the COVID-19 crisis, researchers and research organizations pivoted towards producing evidence syntheses to try to help address evidence needs with rigorous science and the best available evidence. The need for rapid answers to a rapidly changing set of questions against a backdrop of rapidly changing evidence and a growing number of trials posed considerable challenges to established ways of working and thinking about evidence synthesis. Many emerging methods and approaches were adopted and accepted on a wider scale than might have otherwise been the case (rapid reviews and living systematic reviews), and technology was leveraged to facilitate review processes (using study

repositories and databases, crowd screening, and artificial intelligence). Faster ways of publishing were also explored (especially through preprints).

Many discussions at the Cochrane Convenes events pointed to the need to continue to develop and evaluate these tools, methods and processes in 'peacetime' – most notably ensuring sufficient timeliness, relevance and quality to influence decision making faced with evolving priorities and growing volumes of primary research. They also underscored the need for better sharing (of priorities and agendas, as well as data, methods and platforms) in order to cover global needs more effectively and efficiently while reducing research waste and duplication.

## Reinforcing the links between primary and secondary research

Secondary research summarizes all available primary research in response to a research question and, while doing so, also identifies knowledge gaps for which additional primary research is needed.

Thousands of randomized clinical trials have started since the beginning of the pandemic. The volume of evidence challenged the evidence synthesis community, who were faced with an enormous amount of primary research of varying quality – not to mention fraudulent trials – while attempting to remain responsive to evolving research questions.

### Dealing with a large number of randomized controlled trials (RCTs)

Several initiatives were started to help overcome this challenge.

- → The <u>COVID-NMA (network meta-analysis)</u> project developed a living mapping of all trials and a comprehensive living synthesis of all available evidence that evaluated the effect of interventions for the prevention or treatment of COVID-19.
- → Large platform trials were set up, which were able to evaluate multiple treatments simultaneously. <u>RECOVERY</u> and <u>Solidarity</u> are wellknown examples. Use of efficient trial designs (such as adaptive platform trials and common protocols) offered flexibility, including the ability to add new interventions to be tested during the ongoing trial or to be more readily adaptable for various contexts.

### Recommendations

- → Researchers and research institutions must play a role in developing better connections between primary research, evidence synthesis and decision makers to allow for an aligned system that can generate the right evidence to support decision making in emergencies (see section on system-level changes).
- → Primary researchers and institutions should:
  - work with people experienced in research methodology and evidence synthesis who can support an evidence-informed choice of potential interventions and study designs at an early stage, and review the emerging evidence to continually support decisions during the trial
  - prioritize large, co-ordinated trials involving many participants rather than small, duplicative studies
    - where smaller trials are necessary, use standardized protocols or adaptable trial designs, which can be more easily synthesized
  - share research agendas and work with the evidence synthesis community in order to avoid fragmentation and unnecessary duplication of efforts
  - ensure that global trials involve adequate input from – and representation of – low- and middleincome countries

- develop appropriate structures to be able to involve patients and the public early in the planning and design of trials under emergency circumstances – and respond to their contributions
- register trials as early as possible
- define core outcome sets as early as possible
- share the results of all clinical trials transparently and completely in registries and publications as soon as possible – adhering to CONSORT (Consolidated Standards of Reporting Trials) guidelines<sup>8</sup>
- share individual participant data (IPD)
- evaluate the methods used in COVID-19 trials and use findings to inform future trials
- for global trials, ensure that all smaller national components are appropriately registered and adhere, as far as possible, to standardized protocols to minimize data fragmentation at the analysis stage.

The evidence synthesis community should:

- proactively co-ordinate and work closely with people developing clinical trials and guidelines
- plan evidence synthesis from the outset rather than reacting to the trials that might emerge and check whether goodquality reviews on the topic are already underway before starting
- consider prospective IPD meta-analysis as a way of co-ordinating trial efforts, sharing data and supporting cohesive synthesis
- proactively work with trialists to improve the 'implications for future research' section in systematic reviews so that they provide a good guide for the design of future trials
- continue to develop early warning signs for problematic studies, which can be used to improve the quality of evidence synthesis and correct the literature
- use IPD to enable more detailed and flexible analysis
- work with people with lived experience.

<sup>8</sup> Schulz KF, Altman DG, Moher D, for the CONSORT Group. CONSORT 2010 Statement: updated guidelines for reporting parallel group randomised trials. Annals of Internal Medicine 2010;152. Epub 24 March. (CONSORT website: <u>http://www.consort-statement.org/</u>)

## (Re)evaluating evidence synthesis methods and quality

Discussions during the Cochrane Convenes events highlighted a desire to take the opportunity of 'peacetime' to evaluate the methods used in COVID-19 evidence synthesis and use this to inform future practice. The pandemic demonstrated that high-quality evidence can be produced quickly if it is properly resourced – but for some, especially politicians, evidence synthesis still comes too late in a health emergency. Nevertheless, there was a strong commitment to retaining and building on some of its key strengths.

### Recommendations

- → In addition to reviewing ways of working with primary researchers (see above section), researchers and research institutions need to:
  - build capacity in methods of assessing evidence quality for non-randomized controlled trial evidence, such as observational trials and modelling studies
  - agree standards for data structures and evidence synthesis infrastructure to support efficient sharing of data
  - carry out meta-epidemiological research to understand the risks and benefits of evidence synthesis – and rapid reviews in particular – to help develop minimum standards
  - consider the production of evidence relevant to the emergency while waiting for the evidence on the emergency – this is particularly crucial for fields like rehabilitation or chronic diseases, or for specific populations like disabled people for whom it takes much more

time to have good evidence available

- evaluate the relative merits and weaknesses of editorial processes and peer review to see if any efficiency gains are to be made
- be transparent about what is known, not known, or not yet known and communicate uncertainty.
- → In terms of 'being good partners', researchers and research institutions should:
  - build trust in 'peacetime', work as amplifiers of high-quality evidence, and support initiatives to build health and media literacy (see communications section)
    - be alert to and communicate about
       fraudulent trials and studies
    - be transparent about what is withdrawn
    - engage on evidence directly and in partnership with others – to help communicate uncertainty and its evolving nature
  - play a part in reducing duplication and research waste
    - share work (including plans, methods and data) widely
  - play a role in building capacity in lowand middle-income countries.
- → At the institutional level, research institutions need to:
  - work to increase the global pool of systematic reviewers
  - invest in technology to assist realtime collaboration and sharing of standardized data

- work collaboratively to introduce better ways to acknowledge the contributions of researchers working on large platform or other collaborative trials or research projects – the current practices regarding the possible number of 'first authors' are too rigid and incentivize duplication over collaboration for impact
- incentivize researchers to develop science communication skills

- encourage engagement including with policymakers, intermediaries and other research institutions locally, nationally and globally
  - ensure diversity within and between research institutions, generate data in all parts of the world and do more to combine the work done in highincome countries with work done in low- and middle-income countries.

#### **Evidence platforms and networks**

- → National COVID-19 Clinical Evidence Taskforce: facilitated by the Australian Living Evidence Consortium, a collaboration with health professional bodies to deliver living guidelines on COVID-19 clinical care. <u>covid19evidence.net.au/</u>
- → eCOVID-19 living map of recommendations: living map of the latest evidence-based COVID-19 recommendations, which also provides a gateway to contextualization to support decision making. <u>covid19.recmap.org/</u>
- → COVID-19 Research Project Tracker: live database of funded research projects on COVID-19 mapped against the priorities in the WHO Roadmap for COVID-19. www.ukcdr.org.uk/covid-circle/covid-19-research-project-tracker
- → COVID-NMA: a living mapping and living systematic review of COVID-19 trials. <u>covid-nma.com/</u>
- → L-OVE: a database with health systematic reviews. <u>iloveevidence.com/</u>
- → Cochrane COVID-19 Study Register: a collection of human primary studies on COVID-19. <u>covid-19.cochrane.org/</u>
- → COKA initiative (the COVID-19 Knowledge Accelerator): developing machine readable standards for rapid synthesis.

confluence.hl7.org/pages/viewpage.action?pageId=97468919

- → COVID-END: an informal network involving 50 evidence synthesis or evidence support organizations.<u>www.mcmasterforum.org/networks/covid-end</u>
- → Evidence Collaborative on COVID-19 (ECC-19): led by WHO; aimed at information sharing and collaboration around evidence retrieval efforts to combat COVID-19. <u>sites.google.com/view/ecc19</u>

## (Re)evaluating the way evidence synthesis is presented and shared

A full evidence synthesis can take a long time to produce during 'peacetime'. According to Cochrane, for example, writing a protocol in 'peacetime' can take two to six months, while writing a complete review might take one to two years, depending on the complexity of the topic and the time and resources available to the team.<sup>9</sup> On top of the research and drafting, editorial processes (peer review and preparing for publication) can also add to lead times – as can the development of that content into other packages and formats, such as infographics and shareable social media content.

Some participants in the Cochrane Convenes events reported having managed to gain some time savings by adding more resources or revising methods (rapid reviews, living reviews and preprints, for example) in order to keep up with demand during the early stages of the pandemic – and probably at times a judicious mixture of both.

How do we know what works and for whom? Were people able to find what they needed? What support needs to be in place for intermediaries and their audiences in future – including those with diverse cultural backgrounds, those who speak languages other than English or a state's official language, those who are disabled, or those with limited access to information (online and otherwise)?

### Recommendations

→ Evaluate the relative merits and weaknesses of formats and editorial processes that accelerate publication, including, for example, living systematic reviews, rapid reviews, preprints and peer review:

- review the publishing decisions made during the pandemic
- in considering formats, build in consideration about what successful use of the synthesis looks like
- publish raw data and methods as well as results for transparency as well as replication.
- → Invest in research that can tell us what works in terms of knowledge translation and understanding what users want and how they consume information – this might also mean learning from the spread of misinformation. Ideas as to what might work include:
  - delivering messages simply, in plain language
  - considering carefully who delivers the messages as well as what is said – the individual, network, forum, channel could be as important as the evidence itself
  - acknowledging the role of local, community-led dissemination in hand with local public health groups, led by trusted community figures
  - funding the education of a new generation of spokespeople, such as influencers and social media figures
  - telling stories through video, audio, infographics, social media and apps
  - making evidence sites look more like media sites
  - continuing to work with traditional media – high-quality science reporting through traditional media outlets remains very important in communicating evidence.

<sup>9</sup> community.cochrane.org/review-production/production-resources/proposing-and-registering-new-cochranereviews

## What does a typical evidence synthesis process look like?

Steps to produce a traditional evidence synthesis or 'systematic review' will vary but include:

- → defining the research question for the review (working with partners and users to refine it)
- → defining eligibility criteria- that is, the population, setting, interventions, comparisons, outcomes and types of studies that will be included)
- → designing a search strategy (working with information specialists)
- → developing, registering and publishing a protocol that explains what you are setting out to do (this is crucial for transparency – so the final review can be compared against it)<sup>10</sup>
- → searching for relevant studies on electronic research databases and trials registries, and manually searching other sources for further studies)
- → screening the titles and abstracts of potentially relevant studies and deciding which studies to include based on the eligibility criteria – ideally this is done independently and in duplicate by at least two review authors

- → retrieving and screening the full texts of potentially eligible studies and deciding what to include or exclude based on the eligibility criteria – ideally this is done independently and in duplicate by at least two review authors
- → extracting data from included studies
- → assessing the risk of bias of the included studies
- → analyzing the evidence and synthesizing data where possible
- → assessing the certainty of the evidence using the GRADE approach
- $\rightarrow$  writing up the findings
- → submitting the finished manuscript for peer review
- → publishing the findings, most usually in a long report format, with a summary of findings table.<sup>11</sup>

<sup>10</sup> Moher D, Shamseer L, Clarke M, Ghersi D, Liberati A, Petticrew M, et al. Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. Systematic Review 4, 1 (2015). <u>https://doi.org/10.1186/2046-4053-4-1</u>

<sup>11</sup> Based on: Higgins JP, Thomas J, Chandler J, Cumpston M, Li T, Page MJ, Welch VA editor(s). (2021). *Cochrane Handbook for Systematic Reviews of Interventions* Version 6.2 (updated February 2021). Available from training.cochrane.org/handbook

Other formats seen during the COVID-19 pandemic include:

- → Rapid review: a form of evidence synthesis that accelerates the process of conducting a traditional systematic review through streamlining or omitting specific methods to produce evidence for stakeholders in a resource-efficient manner.
- → Living systematic reviews: evidence reviews in topics where a lot of research is emerging quickly. Living systematic reviews search for evidence much more regularly than standard reviews and incorporate relevant new evidence as it becomes available<sup>12</sup>
- → Preprints: research articles shared publicly, such as on a preprint server, before they have been peer-reviewed.<sup>13</sup>

## Do we need a 'one-stop shop' platform for evidence during a health emergency?

Many organizations involved in commissioning, producing or using evidence synthesis launched or developed initiatives and platforms to facilitate access to a 'trusted source' of evidence during the COVID-19 pandemic. Examples include:

- → Public Health England Knowledge and Library Services – helps first responders identify and access emerging evidence as it is published <u>ukhsalibrary.koha-ptfs.co.uk/</u> <u>coronavirusinformation/</u>
- → COVID-19 knowledge hubs (by COVID-END) – a publicly available platform to collate and share relevant data, research, and other evidence <u>www.mcmasterforum.org/</u> <u>networks/covid-end/resources-to-support-</u> <u>decision-makers/living-hub/covid-19-</u> <u>knowledgehubs</u>
- → WHO provides a public page, as well as updates and technical guidance for health workers and decision makers <u>www.</u> <u>who.int/emergencies/diseases/novel-</u> <u>coronavirus-2019</u>
- → COVID-19 rapid evidence reviews collects

research questions for rapid evidence reviews to minimize duplication and facilitate collaboration <u>www.nccmt.ca/</u> <u>covid-19/covid-19-evidence-reviews</u>

→ Oxford COVID-19 evidence service – rapid evidence reviews and data analysis relating to the pandemic. <u>www.cebm.net/oxford-</u> <u>covid-19-evidence-service/</u>

Criticisms levelled at initiatives such as these included that they were very specific and lacked the broad scope needed to reach a wide and diverse audience. Others found the competition between sites unhelpful, seeing them as 'a barrier to collaboration and integration of diverse evidence sources'.

Discussions have started to centre on a 'one-stop shop' for evidence – but greater consideration needs to be given as to what this might look like, how it would differ from other platforms, and how sustainable (or even widely desirable) it would be. Elsewhere, discussions highlighted the importance of local contextualization and communication – so one size may not fit all.

<sup>12</sup> Cochrane. (2020). *Living systematic reviews highlight latest evidence*. COVID-19 case story. <u>www.cochrane.org/sites/</u> default/files/public/uploads/covid\_case\_story\_- living\_systematic\_reviews\_v6.pdf

<sup>13</sup> Bero L, Lawrence R, Leslie L, Chui K, McDonald S, Page MJ, et al. (2021). Cross-sectional study of preprints and final journal publications from COVID-19 studies: discrepancies in results reporting and spin in interpretation. BMJ Open 2021, 2021, 11:e051821. doi: 10.1136/bmjopen-2021-051821

## What participants in the roundtables thought worked or might have worked during the pandemic

- → Making outputs more journalistic (infographics, style of writing, length, presentation)
- → Video explainers by the researcher (context, and a sense of who they are)
- $\rightarrow$  Standards and guidelines for evidence use
- → Increasing the public profile of organizations like Cochrane

- → Responding to or challenging misinformation and misinformation 'campaigns'
- ightarrow Starting or being active on Twitter threads
- → Engaging with social media influencers





## 4. Reflecting on uncertainty, misinformation and disinformation

### **Key reflections**

Cochrane Convenes participants offered their experiences of producing and sharing evidence during the COVID-19 pandemic, and their ideas for strategies at system and research levels to help ensure that high-quality evidence – and decision maker confidence in it – is at the forefront of the next global health emergency. Many of these strategies stem from a shared experience of trying to communicate science more directly (beyond traditional peer networks), more rapidly (adapting timescales and workflows), with a different set of tools (adapting formats and channels) and on a larger scale than ever before – against a background of confusion, fear and mistrust. But beyond communicating what we want to say accurately and responsibly, there is also the question of listening to a wider audience and understanding what they need to hear when and how. This may require us to open up the discussion with other professionals and other disciplines (social and behavioural science for example) in order to further refine recommendations and develop a plan of action.

Top-line recommendations on what is needed include:

- $\rightarrow\,$  researching what works (and where) in terms of both communicating uncertainty and countering mis/disinformation
- $\rightarrow\,$  building trust through increased collaboration between evidence producers, evidence users and clinical partners
- → increasing transparency around public decision-making processes (see 'System-level change')
- → raising awareness of the evolving nature of both evidence and context in a health emergency – this might include direct engagement with decision makers as well as with intermediaries (and training)
- → considering a form of accreditation and quality approval for official sources of evidence that has met certain quality-control standards making it easier for people to access trustworthy information – considering, for example, the increased engagement of information scientists to help increase both 'push' (ensuring people receive and can act on evidence) and 'pull' (helping people to find and use evidence), as well as using nontraditional formats, channels and champions
- → forming multidisciplinary coalitions to hold those deliberately creating and sharing mis/disinformation to account.

In both our professional and personal lives, it is imperative that we have access to trustworthy and timely information in order to make informed choices. In the case of pandemics, such information can help ensure optimal care for patients, protect the public and decrease risk-taking behaviours. Many of us now have access to multiple information sources and formats. But what happens when the information is unclear or conflicting? Or when we are unable to interpret or use it? Or when it does not answer the questions we need the answers to? Or when it does not come from a source we trust?

Challenges associated with communicating scientific uncertainty, misinterpretation of data, suppression of information, lack of trust in or access to official sources, and the promotion of falsehoods all contributed to the cacophony during COVID-19. Within this context, mistrust and conspiracy theories have flourished on social media – from the scepticism about the use of masks and vaccines, to the promotion of unproven treatments such as ivermectin and hydroxychloroquine.<sup>14</sup>

WHO has organized a series of online discussions, training events and resources aimed at good practice and 'infodemic management'. Many of the ideas and strategies discussed by Cochrane Convenes participants around building trust and countering mis/disinformation echoed the good practices reflected there. One of the reasons that misinformation spreads and also ends up being more acceptable is that scientific information deals with uncertainties, is often dynamic, and is rarely dogmatic. Misinformation has the opposite characteristics.

**Roundtable** participant

### **WHO infodemic resources**

Infodemic management is the systematic use of risk and evidence-based analysis and approaches to manage the infodemic and reduce its impact on health behaviours during health emergencies. It aims to enable good health practices through:

- → listening to community concerns and questions
- → promoting understanding of risk and health expert advice
- → building resilience to misinformation
- → engaging and empowering communities to take positive action.

For further details, see: <u>www.who.int/</u> <u>teams/risk-communication/infodemic-</u> <u>management/1st-who-infodemiology-</u> <u>conference</u>

<sup>14</sup> See, for example: Gould S, Norris S. Contested effects and chaotic policies: the 2020 story of (hydroxy) chloroquine for treating COVID-19 [Editorial], *Cochrane Database of Systematic Reviews*. 2021 www.cochrane.org/news/cochrane-library-editorial-contested-effects-and-chaotic-policies-2020-story-hydroxy

### Recommendations

- → The evidence community needs to invest in researching what works in terms of understanding audience, communicating uncertainty and countering misinformation – this will require multidisciplinary partnerships across and within countries.
- → Invest in capacity building and training for users of evidence in 'peacetime':
  - more training is required to understand and communicate the results of research and evidence synthesis (in particular 'best available evidence' and uncertainty) more effectively
  - media coverage needs to provide more context and caution when covering single studies and preprints of primary research, which dominated before more robust evidence became available
  - preprints need to be framed more appropriately as subject to change from the peer review process; often they are more pre-peer review than preprint
  - media outlets should also print corrections and clarifications more prominently and pay attention to and communicate about research retractions
- → Invest in communications capacity building and media training for scientists, politicians, or other spokespeople and communicators, to increase understanding as well as the reach and use of this evidence.
- → Build and consolidate global evidence networks of evidence producers and users across sectors and geographies and across disciplines (see 'System-level change' for recommendation on the creation of a global forum). Better connections are needed between:

Initially scientists were caught up in the minutiae of explaining efficacy and study design, which caused confusion and mistrust towards the vaccines. We failed to communicate that well and gave space for people who were already vaccine hesitant. The quality of the science is essential but we need to work harder on communicating to the wider public.

**Roundtable** participant

- health and social services
- public health and evidence synthesis communities
- those conducting primary and secondary research
- researchers and decision makers
- local and national or international producers of evidence
- local community leaders
- local, national and international press.

In particular, communications need to enable and hear from voices from the ground, such as clinicians working on the frontline.

- → Encourage more collaboration between evidence producers, evidence users and clinical partners, creating a trusted, unified voice:
  - producers of high-quality evidence should enter the health information space as quickly as possible in a global emergency to reduce the risk of mis/ disinformation proliferating

- evidence producers have a role to play in responding to fake news – there needs to be capacity to respond quickly and to point people in the direction of trusted information sources.
- → Invest in health literacy:
  - public understanding of evidence needs to be improved in order to appraise health information critically and more effectively.
- → Consider the desirability, feasibility and sustainability of a 'one-stop shop' for trustworthy evidence (see box in previous section for brief description and caveats).
- → Consider a form of accreditation and quality approval for official sources of evidence that have met certain qualitycontrol standards, making it easier for people to access trustworthy information. Considering, for example, the increased engagement of information scientists to help increase both 'push' (ensuring people

When I lie about a disease that kills people with words, I am not being held accountable. But when I conduct a genocide I am taken to court.

Roundtable participant

receive and can act on evidence) and 'pull' (helping people to find and use evidence), as well as using non-traditional formats, channels and champions.

→ Form multidisciplinary coalitions to hold those deliberately creating and sharing mis/disinformation to account.

A report published by the Center for Countering Digital Hate (CCDH) in May 2021 found that just 12 people with a combined following of 59 million people were responsible for 73% of all anti-vaccine content on Facebook alone. It also found that 95% of the misinformation reported on Facebook and Twitter had not been removed.<sup>15</sup>

<sup>15</sup> Salam E. (2021). Majority of Covid misinformation came from 12 people, report finds. The Guardian, 17 July. www.theguardian.com/world/2021/jul/17/covid-misinformation-conspiracy-theories-ccdh-report



## 5. Next steps

COVID-19 has created an unprecedented focus on health evidence for people working in governments, businesses and non-governmental organizations as well as members of the public. The need for evidence to support decision making has sparked some notable innovations and fasttracked collaboration among decision makers and researchers – but it has also laid bare shortfalls in the production and sharing of quality evidence syntheses. A concern is that many of the lessons learned and initiatives generated during the pandemic will be lost or remain unapplied as the pandemic continues.

Ultimately Cochrane and partners aim to support preparedness for and appropriate response to global health emergencies – focused on the delivery of timely, high-quality evidence responses to global health priorities, which users (from global organizations to members of the public) help to define.

Cochrane calls on its partners for joint action for:

- → more support for evidence synthesis in lowand middle-income countries to address global imbalances
- → the development of a system (or systems) – tools, methods, processes and relationships – at national and global levels to ensure that we are prepared for the next global health emergency.

→ more investment in science communications – including working with regulatory authorities and other partners to act on mis/disinformation and to hold those responsible to account

Over the course of 2022, Cochrane will engage with a wider group of experts in relevant disciplines in order to take forward the most pressing recommendations.

In particular, Cochrane will:

- → incorporate the recommendations and learnings from Cochrane Convenes into its own future strategic direction
- → build a consortium of current and new partners to address the key issues identified in this report – and join up with established initiatives where they already exist
- → develop campaigns to advocate for the conditions that will support an improved evidence response at key moments, including the World Health Assembly.

We call on you to join with us and help to build a system that we can all trust, that caters for all users of evidence wherever they are in the world, and that is sufficiently prepared for the next global health emergency.

### What is Cochrane?

Cochrane focuses on producing relevant and timely synthesized evidence and is a global advocate for evidence-informed health and health care. We work towards a world of improved health where decisions about health and health care are informed by high-quality, relevant and up-to-date synthesized research evidence. Our members and supporters come from more than 130 countries, worldwide.

### What is Cochrane Convenes?

Cochrane Convenes is a meeting series hosted by Cochrane that focuses on the most pressing global health issues. It aims to provide space for reflection, critical thinking and innovation. This year's Cochrane Convenes was cosponsored by the World Health Organization (WHO), and co-organized with COVID-END (COVID-19 Evidence Network to support Decision-making). Drawing on experiences of the COVID-19 pandemic, it brought together leaders from across the world to explore and then recommend the changes needed in evidence synthesis to prepare for and respond better to future global health emergencies. Cochrane Convenes is supported by an advisory group and a steering group.

### Inaugural event, October 2021

The inaugural event was organized into a series of invitation-only thematic roundtables (5 and 6 October 2021) and a public plenary session (14 October 2021). Participants discussed lessons learned from the evidence synthesis response to COVID-19, including the communication of uncertain and rapidly changing evidence, the engagement with users to support evidence-informed decision making, and the need for political buy-in to research. The open plenary session featured high-level keynote presentations, alongside an interactive panel session discussing the key lessons and recommendations from the roundtables. Recordings from this session are available online.

### What happens next?

The meeting is the start of a conversation with leaders about what we need to do to improve the evidence response to future global health emergencies. We will create an environment for collaboration and to share experiences and innovative ideas.

The recommendations resulting from the meeting will be used to advocate for an improved evidence response and to stimulate further discussions with researchers, policymakers, funders and others to strengthen our collective preparedness. They will also inform Cochrane's own future strategy.



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