Engaging for Equity: An Approach to Mitigating Pandemic Impact on the Underserved

K "Vish" Viswanath

Harvard School of Public Health
Dana-Farber Cancer Institute
Dana-Farber/Harvard Cancer Center





The Problem....

We were alerted to flu like symptoms in late December 2019/January 2020.

We did not talk about how it was affecting different groups differently – "disparities," until March or even well into April 2020.

Why?



Why...

To answer this question, we have to understand the orthodoxy in our current thinking....

- Invisibility of the "underserved"
 - "Streetlamp" syndrome
- The "log cabin myth"
 - Individualism: ignore social contextual conditions
- Data absenteeism
- Misunderstanding about "expertise"
- Little attention to the impact of environmental and policy interventions
- Research: Communities as "sites" and residents as "subjects"
- Reliance on top-down approaches



Typology of Community Research: Context for Engagement

- Community Research
- Community-Based Research

• Community-Based Participatory Research

PracticeBased Research

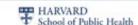
Highly
Controlled
Academic
Research

Research

Research

Research

Research





Engagement: Community-Based Participatory Research

.....is a collaborative approach to research that equitably involves, for example, community members, organizational representatives, and researchers in all aspects of the research process. The partners contribute "unique strengths and shared responsibilities"...... (Israel, 1998)

Barbara A. Israel, Amy J. Schulz, Edith A. Parker & Adam B. Becker. REVIEW OF COMMUNITY-BASED RESEARCH: Assessing Partnership Approaches to Improve Public Health. Annu. Rev. Public Health. 1998. 19:173–202



Key Principles of CBPR

- Draw on community strengths and assets through collaboration with existing community coalitions.
- Critical role of community partners in all aspects of research
- Promote a co-learning and empowering process
- Disseminate findings and knowledge gained to all partners
- Address health from both positive and ecological perspectives
- Facilitate collaborative, equitable involvement of all partners in all phases of the research

Barbara A. Israel, Amy J. Schulz, Edith A. Parker & Adam B. Becker. REVIEW OF COMMUNITY-BASED RESEARCH: Assessing Partnership Approaches to Improve Public Health. Annu. Rev. Public Health. 1998. 19:173–202



The Participatory Knowledge Translation Framework

Evaluate

Execute

Revise

Key Process Inputs

Institutionalized Participation

Ongoing engagement

Investment in Communities

•Human & social capital, resource sharing

Knowledge Production and Transfer Infrastructure Impacts

Individual Level

- KT capacity
- Activities
- Facilitators/Constraints

Organizational Level

- Network Dev.
- Activities
- •Facilitators/Constraints

Community Level

• Community capacity, mobilization

Long Term Outcomes

Community Health

- Improve pop health
- Reduce disparities

System Supports

<u>Organizational</u>

<u>Level</u>

- Institutionalize KT
- Sustained engagement

Community Level

Action to improve health





Key Components

Major inputs

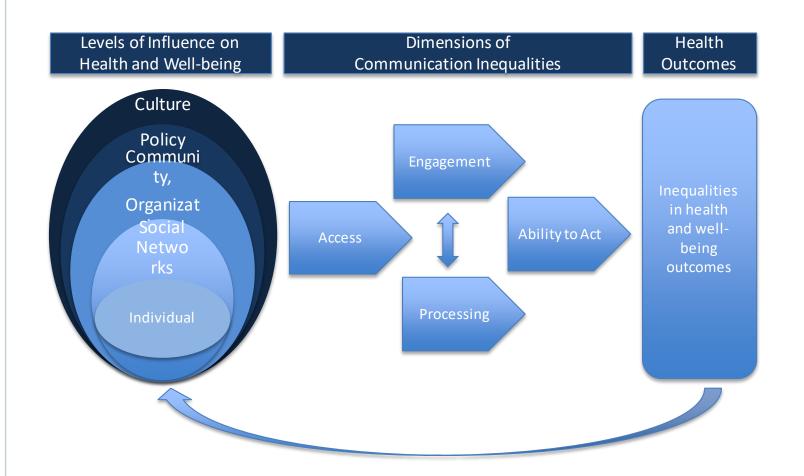
- Institutionalized participation
 - Allows for engagement of diverse partners
- Investment in communities
 - Opportunities to share resources and build capacity
- Knowledge co-production/transfer
 - Produces and spreads relevant, accessible knowledge to diverse partners
- Harnesses ecological and systems perspectives
 - Emphasizes cycles within KT process
- All linked to infrastructure impacts and long-term outcomes



Communication Inequalities

- Communication inequalities manifest at multiple levels
 - Macro-Level: Differences in generation, processing and distribution of health information between different groups and institutions
 - Individual-Level: Differences in accessing, processing and using health information → precluding certain groups from taking advantage of the information revolution







JUL 2020

SOCIAL MEDIA USE AROUND THE WORLD

THE NUMBER OF PEOPLE WHO ACTIVELY USE SOCIAL NETWORKS AND MESSENGER SERVICES

TOTAL NUMBER OF ACTIVE SOCIAL MEDIA USERS SOCIAL MEDIA
PENETRATION (USERS
vs. TOTAL POPULATION*)

ANNUAL GROWTH IN THE TOTAL NUMBER OF SOCIAL MEDIA USERS TOTAL NUMBER OF SOCIAL MEDIA USERS ACCESSING VIA MOBILE PHONES

PERCENTAGE OF TOTAL SOCIAL MEDIA USERS ACCESSING VIA MOBILE











3.96 BILLION

51%

+10.5%

3.91 BILLION

99%

58

SOURCES: KEPIOS ANALYSIS; SOCIAL MEDIA COMPANY STATEMENTS AND EARNINGS ANNOUNCEMENTS; SOCIAL MEDIA PLATFORMS' SELF-SERVICE ADVERTISING TOOLS; CNNIC; MEDIASCOPE; CAFEBAZAAR (ALL LATEST DATA AVAILABLE IN JULY 2020). *NOTES: PENETRATION FIGURES ARE FOR TOTAL POPULATION, REGARDLESS OF AGE.

© COMPARABILITY ADVISORY: SOURCE AND BASE CHANGES.











https://www.socialmediatoday.com/user_media/diveimage/internet_minute_info2.jpg







COVID-19

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Books

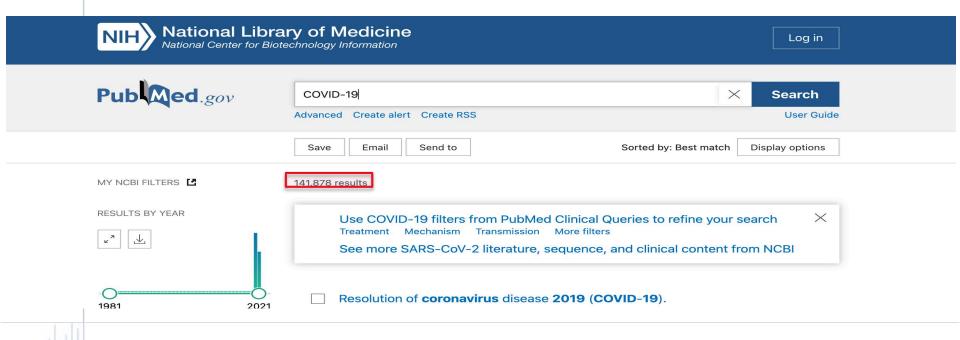
Images

▶ Videos

More

Settings Tools

About 1,520,000,000 results (0.70 seconds)





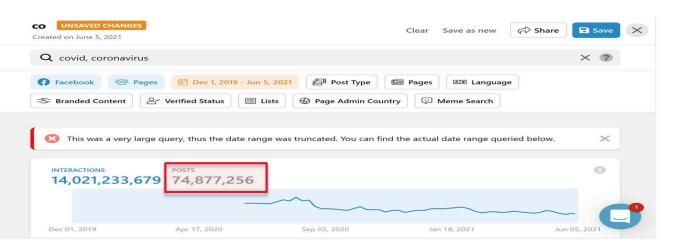
Data from Dec 2019 to June 5th, 2020





Data from June 6 2020 to June 5 2021







Twitter

Statistics Summary (v2.49)

Number of Tweets : 1,549,449,110

Language breakdown of top 10 most prevalent languages :

Language	ISO	No. tweets	% total Tweets
English	en	992,110,473	64.03%
Spanish	es	197,848,137	12.77%
Portuguese	pt	67,787,853	4.37%
French	fr	46,489,632	3.0%
Undefined	und	44,339,531	2.86%
Indonesian	in	41,172,308	2.66%
German	de	27,703,802	1.79%
Japanese	ja	18,440,812	1.19%
Thai	th	17,251,109	1.11%
Italian	it	16,392,297	1.06%



- 1.5 billion tweets!
- January 2020-June 2021
- Research from USC has been scraping tweets and making them publicly available @

https://github.com/echen102/COVID-19-TweetIDs

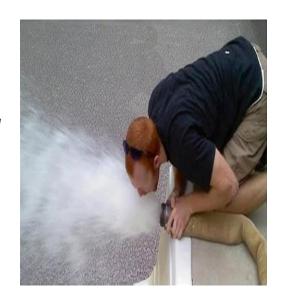
Chen E, Lerman K, Ferrara E. Tracking Social Media Discourse About the COVID-19 Pandemic: Development of a Public Coronavirus Twitter Data Set. JMIR Public Health Surveill. 2020;6(2):e19273. Published 2020 May 29. doi:10.2196/19273





Two key features of this data deluge

- Information Deluge.....
- Limited or no gatekeeping





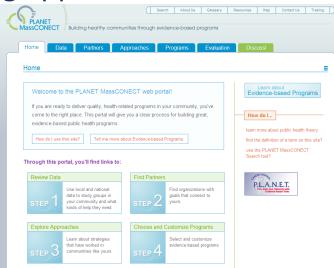
Viswanath Lab Project Exemplars

PLANET MassCONECT

VISWANATH LAB

- Developing skills among CBO staff members for a systematic approach to find, adapt, and evaluate EBPs
 - Human capital-built CBO capacity
 - Financial capital-provided pilot grants, financial support
 - Social capital- hosted networking opportunities





- Communication in a crisis
 - Trust
 - Transparency
 - Credibility



CONTACT

COVID-19 Dashboard



Evidence-based programs for healthy communities

WHAT'S NEW



Given the global pandemic, there is an urgent need for reliable information that is technically and scientifically sound and easily understandable. It has become increasingly difficult to separate truth from fiction even though

"Planet MassCONECT gives you the tools to identify successful evidence-based programs [and] get immediate access to important data... I utilize the website regularly to research evidence-based programs that might work in my community."



Rev. Albert Whitaker NE Regional Director of Community Health Strategies, American Diabetes



COVID-19 Dashboard

LEIA EM PORTUGUÊS । LEER EN ESPAÑOL । हिंदी में पढ़े

Welcome to the site. The rapid spread of COVID-19 virus across the globe is affecting millions of people and is at the same time resulting in the spread of information, misinformation (false information spread without malicious intent) and disinformation (false information spread with the intent to deceive). Our intention is not to create additional information but to bring together credible COVID-19 related information that is easy to access, understand and act upon. Here, we try and address how to navigate the large amounts of information and will update this page as more evidence becomes available. Our target audiences are people we have been working with: journalists, non-governmental organizations and members of the communities we are engaging in. Others too may find this useful.

We will regularly expand, modify and update this information. Please visit as often as you can and let us know how this site can be more helpful.



Vaccines

Frequently Asked

Questions and Resources
about Vaccines

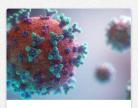
READ MORE>



FAQs

Frequently asked questions about COVID-

READ MORE>



Mythbusters

False information about COVID-19 with facts debunking these myths

READ MORE>



Infographics and Resources

Infographics and reliable resources for information on COVID-19



Health and Wellbeing

Tips to manage stress and promote mental, physical and social wellbeing



Data Spotlight

Latest numbers on COVID-19 cases around the word Search ... Q

COVID-19 Dashboard

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NEW Vaccines: Frequently Asked Questions and Resources about Vaccines

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Twitter Timeline

Tweets by @ViswanathLab





Dr. @vishplus was interviewed about effectively addressing uncertainty around science, research, and public health information. The full article can be found here: hsph.harvard.edu/ecpe/how-to-





COVID-19 Panel de Información

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¡Bienvenido!

La rápida propagación del virus COVID-19 (Coronavirus) en todo el mundo está afectando a millones de personas. Esto está resultando en la distribución de información errónea (información falsa propagada sin intención maliciosa) e información engañosa (información falsa propagada con la intención de engañar). Nuestra intención no es crear más información, sino recopilar información correcta sobre el COVID-19 que le sea fácil de acceder, entender y usar. Aquí, le enseñamos/presentamos cómo navegar la gran cantidad de información. Actualizaremos esta página según se disponga de más evidencia. Esta página está dirigida a personas con las que hemos estado trabajando como periodistas, organizaciones no gubernamentales y miembros de las comunidades. Otras personas también pueden encontrar esto útil.

En las próximas semanas ampliaremos, modificaremos y actualizaremos esta información. Por favor, continúe visitando esta página para información actualizada. Háganos saber cómo esta página puede ser más útil.



Vacunas

Preguntas frecuentes y recursos sobre vacunas

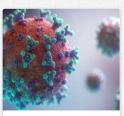
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Preguntas frecuentes

Preguntas frecuentes sobre COVID-19

LEER MÁS>



Mitos vs Hechos

Información falsa sobre COVID-19 con hechos que desacreditan estos mitos

LEER MÁS>



Infografías y Recursos



Salud y Bienestar



Foco de datos

Search ...

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Painel de Informações COVID-19

READ IN ENGLISH | LEER EN ESPAÑOL | हिंदी में पढ़े

Bem vindo ao nosso site. A rápida transmissão do COVID-19 ao redor do mundo está afetando milhões de pessoas e ao mesmo tempo está resultando na propagação de informações verdadeiras e falsas, tanto com o intuito malicioso ou não. Nossa intenção não é de criar informações adicionais e sim criar um conjunto de informações oriundas de sites confláveis sobre COVID-19 que seja de fácil acesso, fácil entendimento e de como agir. Aqui, nós abordamos como navegar grandes quantidades de informações e vamos atualizar a página quando mais evidências estiverem disponíveis. Nossa audiência alvo são pessoas com quem temos trabalhado: jornalistas, organizações não governamentais e membros das comunidades com quem nos engajamos. Esse site também pode ser útil para outras pessoas. Durante as

Próximas semanas nós vamos expandir, modificar e atualizar essas informações. Por favors, acesse o site o máximo possível e nos informe de como esse site pode ser melhorado.



Vacinas

Perguntas frequentes e recursos sobre vacinas

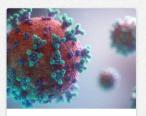
IR PARA VACINAS>



Perguntas Frequentes

Perguntas Frequentes sobre COVID-19

IR PARA PERGUNTAS FREQUENTES>



Mitos vs. Verdades

Informações incorretas sobre COVID-19 com fatos desmistificando esses mitos

IR PARA MITOS VS. VERDADES



Infográficos e Recursos

Infográficos e fontes confiáveis para informações sobre



Dicas sobre midias sociais

Como usar as mídias sociais de forma



Dados em destaque

Últimos dados de casos de COVID-19 no mundo Search ...

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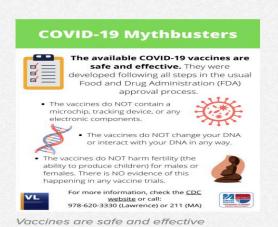
Updated on July 22, 2021

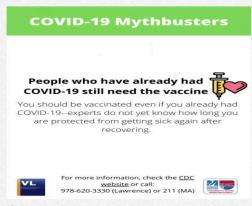
In a time of information overload, it is difficult to discern between misinformation, disinformation and credible reliable information. Here, we have made available **infographics** (in English, Spanish Portuguese) that have been developed based on the latest guidelines. These are available for download and circulation for personal or organizational use. To download the infographics, click on the image and it will show in full screen mode. Then, right click on the image and click, "Save image as." This will prompt you to save the image on your computer. We have also collated a region-specific **list of resources** on COVID-19. We will continue to update this list as we vet them.

COMMUNICATION MATERIALS: English:



COVID-19 Vaccines help slow the spread of the pandemic





COVID-19 Mythbusters

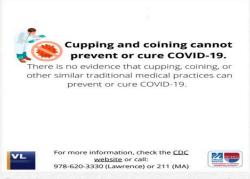


Vaccine cannot make you sick with COVID-19



Re-opening our Communities: Putting on and removing your Mask





Cupping and coining cannot prevent/ cure COVID-19



Re-opening our Communities: When to wear a Mask





Health and Well-being during COVID-19

It is difficult to maintain a healthy lifestyle when we are in the middle of a crisis like this. The uncertainty, and worries related to finances, childcare, elderly parents, and job security disrupt our routines, our lifestyles and mental health. The uncertainty about the future, the ceaseless news coverage and constant social media driven flood of messages can increase our sense of anxiety. Stress is a normal response to these types of situations. Stress disturbs our sleeping and eating patterns, leads to irritability or emotional outbursts, low motivation, and changes in use of alcohol or other drugs. Please do not hesitate to seek help if you are experiencing anything like this.* It is also important to maintain a healthy lifestyle and get back into a routine.

Here are some tips to manage stress and promote your mental, physical and social well-being.

*USA: The Disaster Distress Helpline, 1-800-985-5990, is a 24/7, 365-day-a-year, national hotline dedicated to providing immediate crisis counseling for people who are experiencing emotional distress related to any natural or human-caused disaster, including disease outbreaks like COVID-19. This toll-free, multilingual, and confidential crisis support service is available to all residents in the United States and its territories. Or text TalkWithUs to 66746

*India: A psycho-social toll-free helpline number 08046110007 has been started by the National Institute of Mental Health and Neurosciences (NIMHANS) with the Ministry of Health and Family Welfare.



Mental Well Being

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Physical Well Being

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Social Well Being

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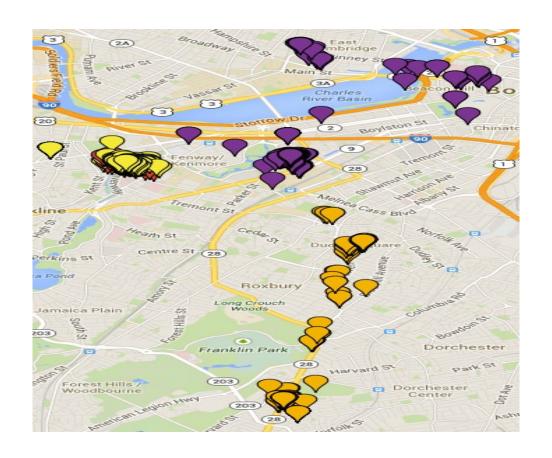
Tweets by @ViswanathLab





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Participatory science





Responsive Feedback

Elderline – 14567

Delhi

Guidance on COVID information asked by the callers

Following are some of the major questions that are being asked by the callers, which the call officers feels that they are not able to provide satisfactory answers. We seek your guidance on the same, to give our caller more satisfactory answer and solutions to their problems.

- 1. Elderly has taken the 1st dose of Covaxin and wants to take another dose for the same, but he/she is unable to get Covaxin right now in Delhi.
- 2. I have been vaccinated with both the doses but did not get any an option on Aarogya Setu to download the certificate.
- 3. Unable to register for vaccination?
- 4. Elderly have taken 1st dose of vaccination from hospital but have not received any certificate.

Date	Name	Designation	Organisation	Feedback	Next Steps/Comments
05/27/2 021	XXXX	Vice President	XXXX Foundation	Dear XXX, Thanks a lot for sharing the toolkit. It is very well compiled. Many congratulations to the Harvard Chan India Research Center & Project Sanchar for this accomplishment. We will certainly share this within our network of stakeholders. Since our wider audience is resource challenged adolescerts & their families from the urban slums, I was wondering if there was a way to take the toolkit to them as well. Do you think someone from the center can guide us on what aspects of this toolkit would be more relevant for such adolescents? Also do let us know if there are any plans for the translation of the tookit in the local Indian languages - only asking it if we are to take some aspects to these adolescents, the vernacular version would be helpful. The above suggestions are only from the perspective of having a larger consumer base for this toolkit and for whomit would be very relevant as well. Having said that, the content is very comprehensive, simple to understand and narrated in an interesting way. Congrats again for this endeavor!! Best Regards,	
05/29/2 021	Dr. XXXX	Founder, XXXX	NAME WITH HELD	Dear XXXX Thank you for thiswe are initiating on our social media channelsparticularly our WhatsApp groups which we use to reach out to people for countering misinformation. Maybe we could speak next week to see what or how else we can add to this effort Best Wishes, XXXX	





New alternative approach

- What can be done?
 - Science of message construction
 - Science of Engagement
 - Participatory science; Responsive feedback
- Community strengths and assets
- Build on resilience
- Expertise is diffused; lies in the community too



Funding

- National Cancer Institute/National Institutes of Health
 - 5U54 CA156732-10
 - 5 P30 CA06516
 - R01 CA230355-01A1
- Bill and Melinda Gates Foundation
- Lee Kum Sheung Center for Health and Happiness,
 Harvard T.H. Chan School of Public Health





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- Sara Minsky
- Ramya Pinnamaneni
- Manvi Poddar
- Abby Shain
- Marina Texeira

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