



Long COVID's Impact on Patients, Workers & Society

Webinar Nov. 1st, 2023

<https://healthconference.org>



Combating Disinformation regarding Long COVID and COVID-19

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Significant activity limitations from long COVID, as a percentage of all adults

Significant activity limitations from long COVID, as a percentage of all adults

Phase Time Period Group	Phase 3.10			
	Sep 20 - Oct 2, Percent	95% CI	Aug 23 - Sep 4, Percent	95% CI
National Estimate				
United States	1,3	1.1 - 1.5	1,4	1.2 - 1.5
By Age				
18 - 29 years	1,1	0.7 - 1.7	1,1	0.7 - 1.6
30 - 39 years	1,0	0.7 - 1.5	1,5	1.1 - 2.0
40 - 49 years	1,8	1.3 - 2.4	1,5	1.2 - 2.0
50 - 59 years	1,8	1.6 - 2.2	1,8	1.4 - 2.3
60 - 69 years	1,0	0.8 - 1.4	1,2	0.9 - 1.5
70 - 79 years	0,8	0.6 - 1.1	1,0	0.7 - 1.5
80 years and above	1,3	0.8 - 1.9	0,7	0.2 - 1.5
By Sex				
Female	1,6	1.4 - 1.7	1,7	1.5 - 1.9
Male	1,0	0.8 - 1.3	1,0	0.8 - 1.3
By Gender identity				
Cis-gender male	1,0	0.7 - 1.2	0,9	0.7 - 1.2
Cis-gender female	1,5	1.3 - 1.7	1,6	1.4 - 1.9
Transgender	4,5	2.3 - 8.0		
By Sexual orientation				
Gay or lesbian	1,4	0.8 - 2.2	2,0	1.2 - 3.1

NOTE: All estimates shown meet the NCHS standards of reliability. See Technical No

SOURCE: U.S. Census Bureau. Household Pulse Survey. 2022-2023

National Center for Health Statistics. U.S. Census Bureau, Household Pulse Survey, 2022-2023. Long COVID.

Generated interactively: from <https://www.cdc.gov/nchs/covid19/pulse/long-covid.htm>

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	LC	Pre-LC	COVID only, no LC	Pre-pandemic	Contemporary non-COVID
N	282,080	282,080	1,112,370	1,031,285	1,118,360
Per year					
GP consultation n	13.43 (19.73)	4.95 (5.68)	11.73 (28.50)	5.62 (6.71)	8.50 (10.75)
Excess¹		-8.48 [-8.56 -8.41]	-1.62 [-1.69 -1.56]	-7.81 [-7.85 -7.77]	-4.90 [-4.94 -4.85]
Outpatient appointment n	3.317 (6.491)	2.19 (3.95)	2.11 (5.78)	2.51 (4.90)	1.82 (4.33)
		-1.13 [-1.16 -1.10]	-1.17 [-1.18 -1.15]	-0.78 [-0.80 -0.77]	-1.48 [-1.49 -1.46]
Inpatient admission n	0.87 (6.03)	0.40 (2.13)	1.12 (9.70)	0.54 (2.73)	0.38 (2.35)
Excess		-0.47 [-0.49 -0.45]	0.27 [0.25 0.29]	-0.35 [-0.36 -0.34]	-0.49 [-0.50 -0.47]
Duration²	2.53 (20.12)	0.526 (3.84)	5.42 (37.04)	0.93 (6.40)	0.91 (7.32)
Excess		-2.00 [-2.08 -1.93]	2.94 [2.86 3.01]	-1.72 [-1.76 -1.68]	-1.61 [-1.64 -1.57]
Critical Care Duration ²	0.21 (6.76)	0.00 (0.00)	0.57 (12.12)	0.03 (0.63)	0.03 (1.23)
Excess		-0.21 [-0.24 -0.19]	0.36 [0.33 0.38]	-0.19 [-0.21 -0.18]	-0.18 [-0.19 -0.17]
ED Attendance N	0.77 (4.56)	0.22 (0.58)	0.98 (8.45)	0.19 (0.57)	0.33 (1.29)
Excess		-0.55 [-0.57 -0.53]	0.22 [0.20 0.24]	-0.58 [-0.59 -0.57]	-0.44 [-0.44 -0.42]
Cost (£)³	3,335.40	870.21	5960.51	1210.19	1282.76
Excess		-2,465.19 [-2554.01-2376.37]	2,683.24 [2592.75-2773.74]	-2,235.14 [-2283.67-2186.62]	-2,034 [-2080.55-1989.04]

...

Healthcare Utilisation of 282,080 Individuals with Long COVID over Two Years: A Multiple Matched Control Cohort Analysis.

Yi Mu^{1*}, Ashkan Dashtban^{1*}, Mehrdad A. Mizani^{1, 2}, Chris Tomlinson¹, Mohamed Mohamed^{1,3}, Mark Ashworth⁴, Mamas Mamas^{5, 6, 7}, Rouven Priedon, Steffen Petersen⁸, Evan Kontopantelis⁹, Christina Pagel¹⁰, Mevhibe Hocaoglu¹¹, Kamlesh Khunti¹², Richard Williams¹³, Johan Thygesen¹, Paula Lorgelly¹⁴, Manuel Gomes¹⁵, Melissa Heightman¹⁶, Amitava Banerjee^{1, 3, 16, 17}, on behalf of the CVD-COVID-UK/COVID-IMPACT Consortium



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Gaslight, 1944

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gaslighting

1 of 2 noun

gas·light·ing ('gas-ˌli-tɪŋ) -'li-



- 1 : psychological manipulation of a person usually over an extended period of time that causes the victim to question the validity of their own thoughts, perception of reality, or memories and typically leads to confusion, loss of confidence and self-esteem, uncertainty of one's emotional or mental stability, and a dependency on the perpetrator

The toxic power dynamics of gaslighting in medicine

Canadian Family Physician | Le Médecin de famille canadien ▶ Vol 67: MAY | MAI 2021

Sarah Fraser MSc MD CCFP



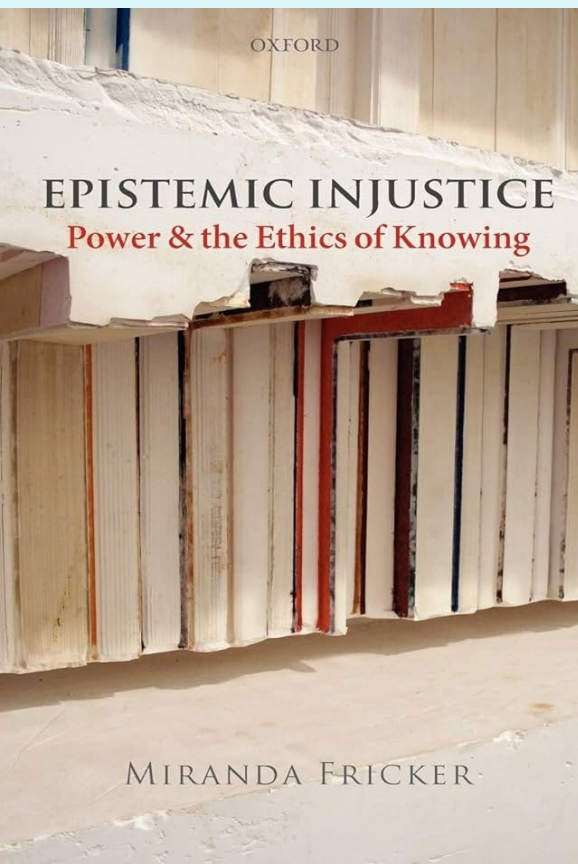


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Testimonial injustice (a legitimacy deficit)
Hermeneutical injustice (no framework)



And the pathway
from epistemic injustice
to epistemic solidarity

Epistemic solidarity in medicine and healthcare

Mirjam Pot¹ 



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Too many symptoms

Absence of a paraclinical endpoint

Previously undiagnosed pathology?

Gender



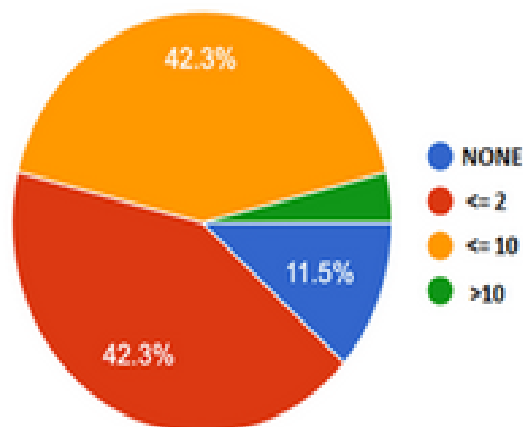
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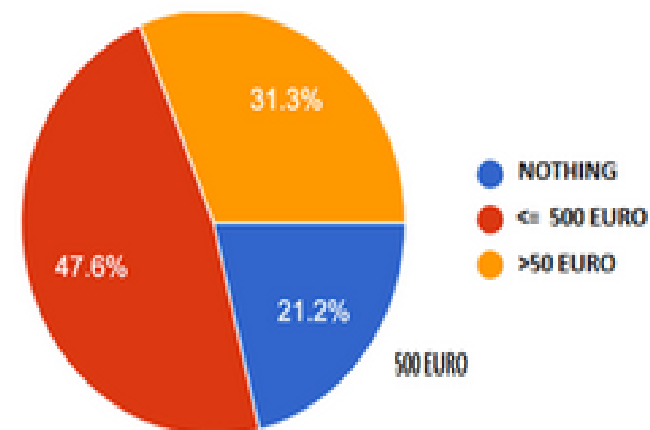
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HOW MANY DOCTORS HAVE YOU VISITED DUE TO LONG COVID



HOW MUCH MONEY HAVE YOU SPENT ON DOCTORS APPOINTMENTS?



have visited more than ten different doctors to find a solution to symptoms. Similarly, when asked whether they've encountered doctors with awareness of the ailment, 46.6% responded having encountered doctors who are unaware of Long COVID, 25% responded in negation, and 28.4% believe doctors they encountered are aware but without any active engagement. Regarding health care utilization costs, 47.6% have spent at least 500 euro on medical care,



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5.1. Dismissal of illness experiences

At the level of the individual clinical encounter, respondents reported being treated as unreliable reporters of their symptoms, an experience that many of them characterized as the *dismissal of their illness experiences* (n=114, 34%). It was in these passages that our respondents most commonly invoked the term “gaslighting” as a rhetorical weapon in a struggle of ontological politics, a struggle over what counts as “real” versus “imagined”. Some 91 (27%) of our respondents

It is important to emphasize that mistrust of doctors was not simply caused by a lack of available treatments, but because doctors routinely failed, at least from the patient's perspective, to put in the effort and genuine concern to find out about effective remedial procedures. What compounded patients' negative impression of doctors was also their lack of adequate knowledge about the status of emerging research on Long Covid and a sense that they lacked epistemic humility—the will to acknowledge the limits of medical expertise amid deep uncertainty:

Long covid and medical gaslighting: Dismissal, delayed diagnosis, and deferred treatment

Larry Au^{a,*}, Cristian Capotescu^b, Gil Eyal^c, Gabrielle Finestone^c



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The GP: "We've been left to rot"

Kerry Smith, 51, was working as a part time salaried GP before she developed long covid.

"I've now learnt to avoid NHS doctors in general. I'd heard of gaslighting happening to lay people but I didn't expect it to happen to a medical professional. If I suggested certain treatments, I was dismissed. If I suggested certain dietary approaches, I was ridiculed. One doctor refused to accept that my urticarial rash was part of long covid. At one point I was told, "Remember you are the patient." What does that say about how we view patients? I was also made to feel that by falling sick I had suddenly lost my medical knowledge and all credibility.

COVID-19

Long covid: the doctors' lives destroyed by an illness they caught while doing their jobs

Unable to work or to play with their children, forced to sell their homes or facing insolvency—doctors with long covid deserve more support from the government and the NHS, writes **Adele Waters**

London

adele.waters@rme.com

Cite this as: *BMJ* 2023;382:p1983

<http://dx.doi.org/10.1136/bmj.p1983>

Published: 20 September 2023



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challenge of communication and self-advocacy (quote 13). Moreover, articulating the specifics of the 'brain fog' experience to healthcare professionals was a particular issue, and frustration, anger and hopelessness were commonly experienced when the impact of neurocognitive symptoms was 'downplayed', dismissed as being all 'in your head' or secondary to depression or anxiety, or deprioritised relative to other COVID-19 sequelae. Some participants felt that the fact they were middle-aged and female contributed to health professionals not taking them seriously.

Conversely, some participants described huge relief and validation at feeling believed and acknowledged (quote 14), particularly in the context of continuity, wise counselling and healthcare professionals bearing witness within therapeutic relationships (quote 15). Several participants had undergone brain imaging or neuropsychological testing, which were overwhelmingly normal and thus often enabled participants to focus on self-management, frequently supported by allied health professionals, including occupational therapists and physiotherapists. None reported having seen a psychologist or psychiatrist in any context.

BMJ Open 'I can't cope with multiple inputs': a qualitative study of the lived experience of 'brain fog' after COVID-19

Caitriona Callan,¹ Emma Ladds ,¹ Laiba Husain,¹ Kyle Pattinson,² Trisha Greenhalgh ¹



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Participants described the hard work involved in finding a GP who believed that the symptoms were real:

Most participants recognised the lack of knowledge and evidence about long-COVID symptoms and management, and could understand the uncertainty faced by doctors:

Some participants described how interactions with GPs had compounded difficulties in how their ongoing symptoms were viewed at home:

Finding the 'right' GP: a qualitative study of the experiences of people with long-COVID

Tom Kingstone^{1,2*}, Anna K Taylor³, Catherine A O'Donnell⁴, Helen Atherton⁵, David N Blane⁴, Carolyn A Chew-Graham^{1,2}



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remote technology). However, they were less forgiving when clinicians' professionalism appeared deficient – for example, when they refused to accept the legitimacy of the patient's symptoms or the condition more generally; when they 'fobbed off' their patients (advising them, for example, to attend the Accident and Emergency Department rather than offering a consultation, or offering benzodiazepines for assumed anxiety); when they dismissed requests for tests even when these were perceived to be indicated (for example, cardiac tests in people with chest pain) and when they failed to provide therapeutic attention and active listening. Individual testimonies of such experiences gained credibility as Gaslighting – deliberately psychologically tormenting and undermining the patient's account of their illness – was mentioned in several interview and focus group accounts (*"I'm very, very angry with quite a few GPs because I felt like they gaslighted me quite significantly"* – participant in lay focus group FG1). Clinically-

Long Covid – The illness narratives

Alex Rushforth^{a,1}, Emma Ladds^{a,1}, Sietse Wieringa^a, Sharon Taylor^{b,c}, Laiba Husain^a, Trisha Greenhalgh^{a,*}



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with those presenting with acute COVID-19. In several cases, symptoms presented by interviewees were labeled by doctors as psychogenic or rooted in pandemic-related anxiety. Without results from formal medical tests to validate their illness, interviewees felt unable to defend their illness. One interviewee expressed frustration with healthcare professionals who were perceived as dismissive and pushed back against medical evaluations attributing her Long COVID symptoms to pandemic-related anxiety.

Several interviewees described a gaslighting phenomenon in which they felt mentally manipulated by healthcare professionals. Gaslighting has been defined as evaluations, tests and exams failed to identify recognizable abnormalities. These interactions produced a surreal social environment in which interviewees' medical claims, notably those expressed by women, were dismissed and deemed non-credible (Fielding-Singh & Dmowska, 2022). One interviewee described:

Support amid uncertainty: Long COVID illness experiences and the role of online communities

David Russell^{a,*}, Naomi J. Spence^b, Jo-Ana D. Chase^c, Tatum Schwartz^a,
Christa M. Tumminello^d, Erin Bouldin^e

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Medical gaslighting was experienced by 46% of participants. PwLC felt dismissed, disbelieved, and not taken seriously by HCPs as well as being misdiagnosed and prescribed anti-depressants to resolve their physiological symptoms. Supplementary material further

Patient's feelings and recommendations for long COVID Support

Feelings of the patients:

Patients feel **IGNORED** and disbelieved
Patients are **LOSING FAITH** and **TRUST** in healthcare services.
Patients are **DESPERATE** for support.

Consideration of symptoms:

LISTEN, BELIEVE and **EMPATHISE** with patients.
Be **PATIENT** and acknowledge **PHYSICAL** and **COGNITIVE** impairments.
SYMPATHISE with the **IMPACT** that long COVID has had

Awareness of living with long COVID:

Symptom profiles are **UNIQUE**
Symptoms are **DEBILITATING** and impact **QUALITY OF LIFE**.
Patients are struggling despite '**NORMAL**' test results and investigations.

Acknowledge the challenges:

Long COVID is a **MULTISYSTEM** condition.
Understand the **PRESENCE, RANGE, SEVERITY** and **FLUCTUATION** of symptoms
Be aware of **RESEARCH** into **TREATMENTS** and **SUPPORT** for long COVID patients.



Long COVID quality of life and healthcare experiences in the UK: a mixed method online survey

Rebecca Owen¹ · Ruth E. Ashton¹ · Lindsay Skipper² · Bethan E. Phillips³ · James Yates¹ · Callum Thomas¹ · Francesco Ferraro¹ · Tom Bewick⁴ · Kate Haggan⁴ · Mark A. Faghy^{1,5}

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*Gaslighting is only a part of
mis-/dis-/mal-information on LC*

The “benefits” of disinformation on LC

- It means the pandemic can be considered over
- It means that it was just the flu
- It means that endemicity is acceptable
- There is no need to spend funds on it
- There is no need for further mitigation
- There is no need for complex decisions



Andrzej Pagowski

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Who “benefits” from disinformation on LC

- State: no measure, no costs, no difficult decisions
- Society: hygienic racism at play
- Media: no difficult reporting
- HC personnel: no need to study, no helplessness
- AND...

THE USUAL SUSPECTS



Andrzej Pagowski



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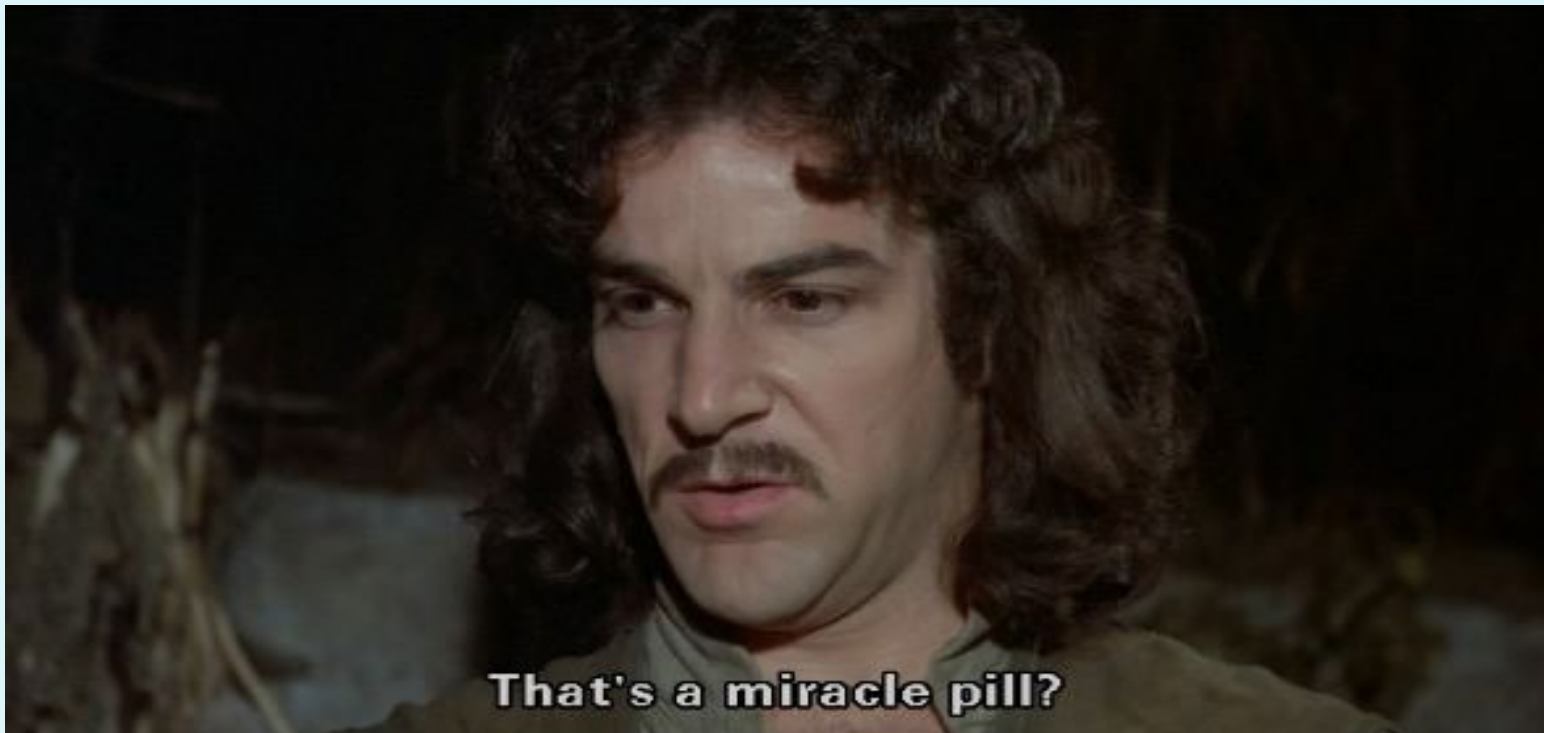
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*Disinformation is not only denial,
is profiteering mal-information too*

Who else “benefits” from disinformation on LC

•The Merchants of Hope





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As noted earlier, the dissatisfaction of many long-haulers with the medical care they received also translated into a general critique of “Western” or “school” medicine, seen as unwilling or unable to recognize their symptoms as “real”. Some affected long-haulers gave credence to their poor experience with the “Western” medical system through explicit reference to gaslighting. For instance, one respondent wrote: “A nightmare. Gaslighting and denial and doubt. Dismissal. Western medicine has absolutely failed us” (Respondent #80). As a result of their frustration, some patients turned toward complementary and alternative medicines (CAM) (n=26, 8%), a field they perceived to be more willing to acknowledge illness symptoms that were not measurable through standard diagnostic practice. This

Long covid and medical gaslighting: Dismissal, delayed diagnosis, and deferred treatment

Larry Au ^{a,*}, Cristian Capotescu ^b, Gil Eyal ^c, Gabrielle Finestone ^c



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BMJ INVESTIGATION

Long covid patients travel abroad for expensive and experimental “blood washing”

Patients with long covid are travelling to private clinics in Cyprus, Germany, and Switzerland for blood filtering apheresis and anticoagulation drugs. Experts question whether these invasive treatments should be offered without sufficient evidence. **Madlen Davies** reports

Madlen Davies investigations editor

Businesses marketing purported stem cell treatments and exosome therapies for COVID-19: An analysis of direct-to-consumer online advertising claims

Leigh Turner,^{1,2,3,*} Juan Ramon Martinez, Jr.,¹ Shemms Najjar,¹ Thevin Rajapaksha Arachchilage,¹ and Jia Chieng Wang¹

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²Sue and Bill Gross Stem Cell Research Center, University of California, Irvine, Irvine, CA, USA

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<https://doi.org/10.1016/j.stemcr.2023.09.015>



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Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial

P D White, K A Goldsmith, A L Johnson, L Potts, R Walwyn, J C DeCesare, H L Baber, M Burgess, L V Clark, D L Cox, J Bavinton, B J Angus, G Murphy, M Murphy, H O'Dowd, D Wilks, P McCrone, T Chalder, M Sharpe*, on behalf of the PACE trial management group†*

An open letter to Dr. Richard Horton and The Lancet

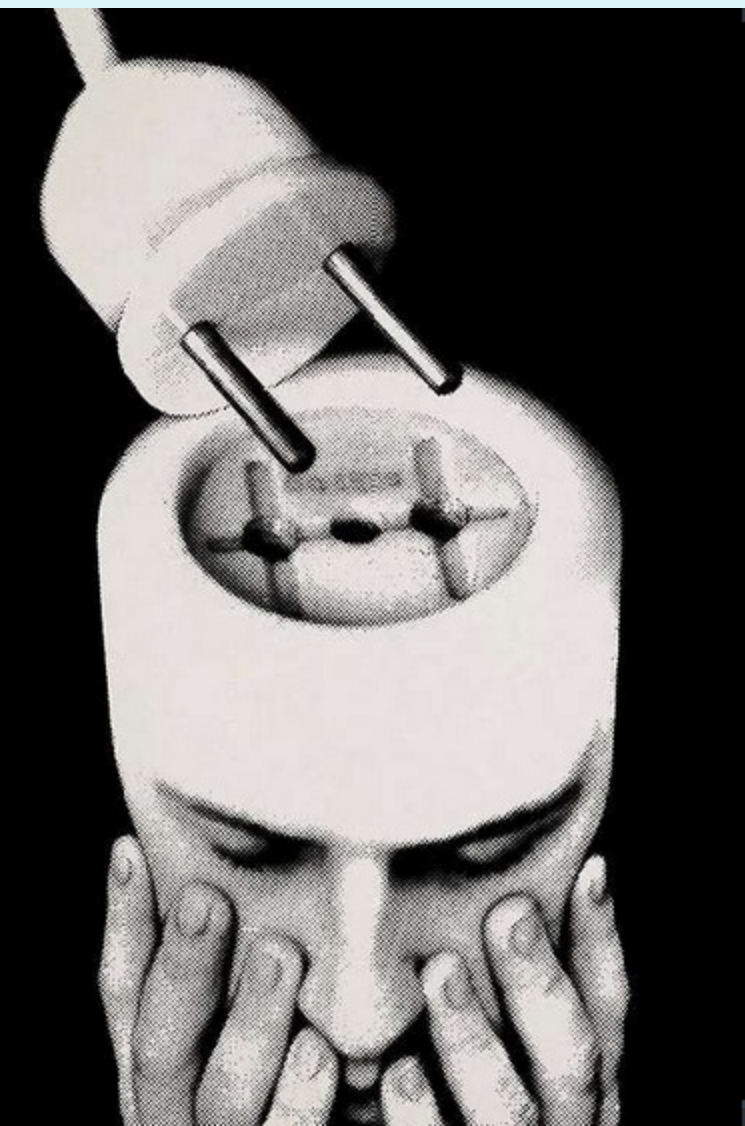
82 Comments / By Vincent Racaniello / 13 November 2015



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Combatting disinformation on LC: The HIV example

From Patient-Led Collaboration Data
to
Ed Yong
to
Eric Topol

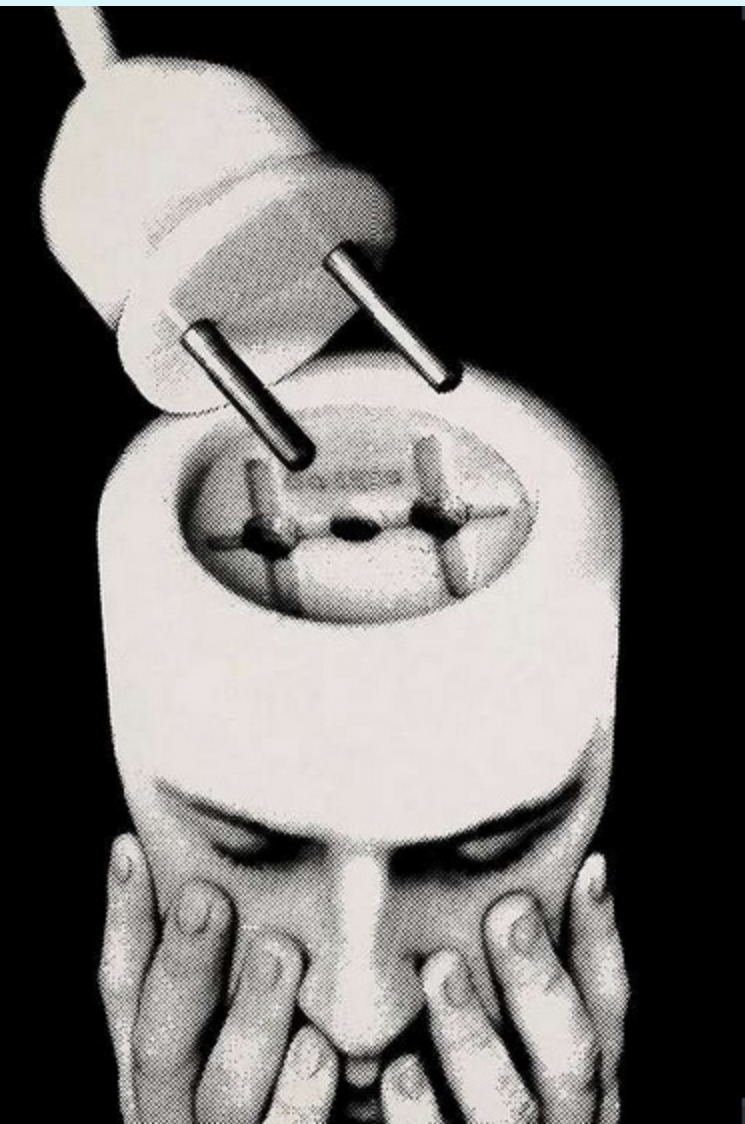
Francis Collins' "the citizen scientists"



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Combatting disinformation on LC:

Combatting disinformation in general



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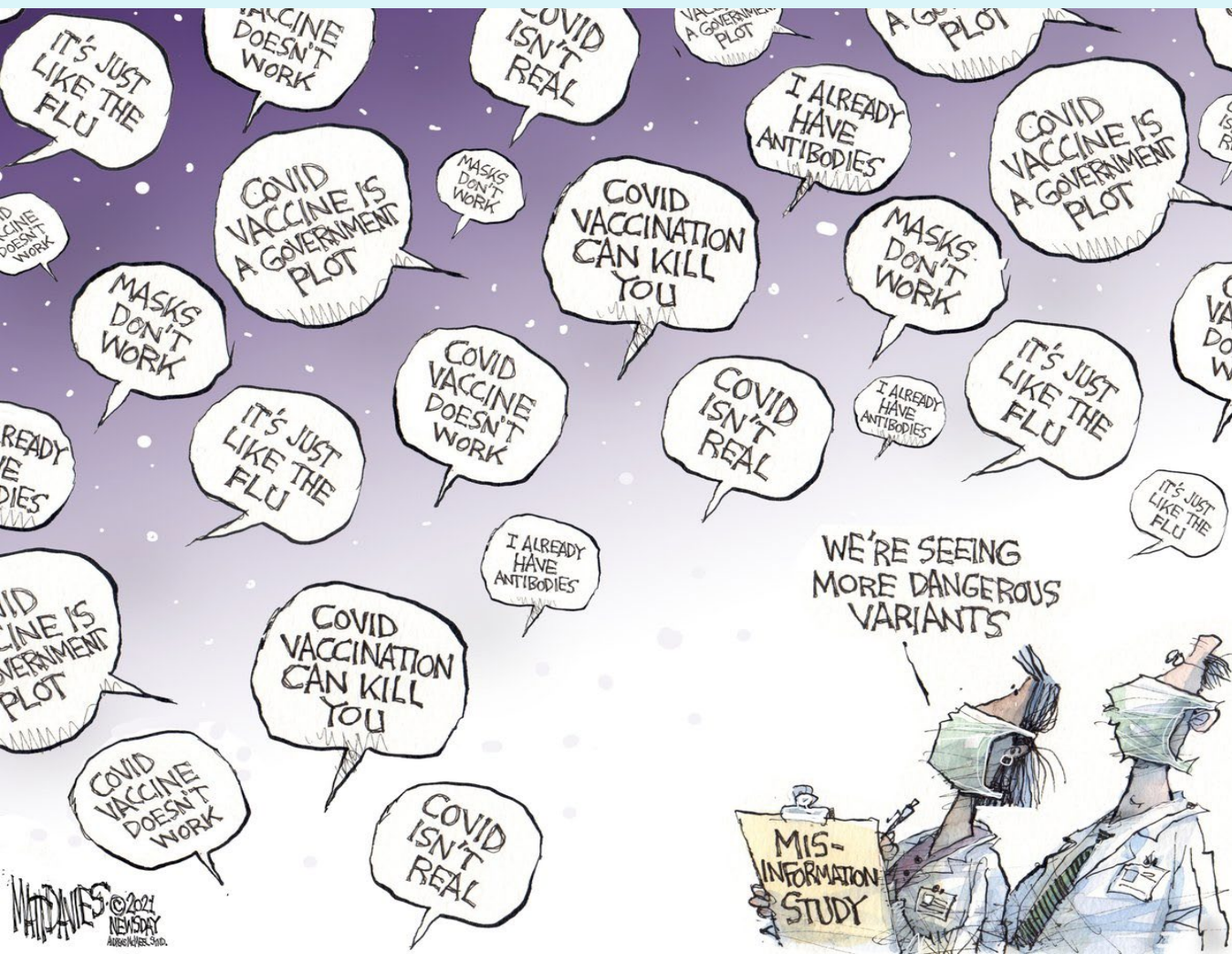
Misconception

Combating disinformation in general

Misinformation

Disinformation

Malinformation





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The era of post-truth and attention deficit True is the sensorially powerful



Our planet that gets smaller every year, with its fantastic proliferation of mass media, is witnessing a process that escapes definition, characterized by a refusal to remember....

We are surrounded today by fictions about the past, contrary to common sense and to an elementary perception of good and evil...

a foreboding of a not distant future when history will be reduced to what appears on television, while the truth, as it is too complicated, will be buried in the archives, if not totally annihilated
(Czeslaw Milos, Nobel Lecture 1980)



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**The era of post-truth
True is the sensorially powerful
Or simply the louder**



"I'm sorry, Jeannie, your answer was correct, but Kevin shouted his incorrect answer over yours, so he gets the points."



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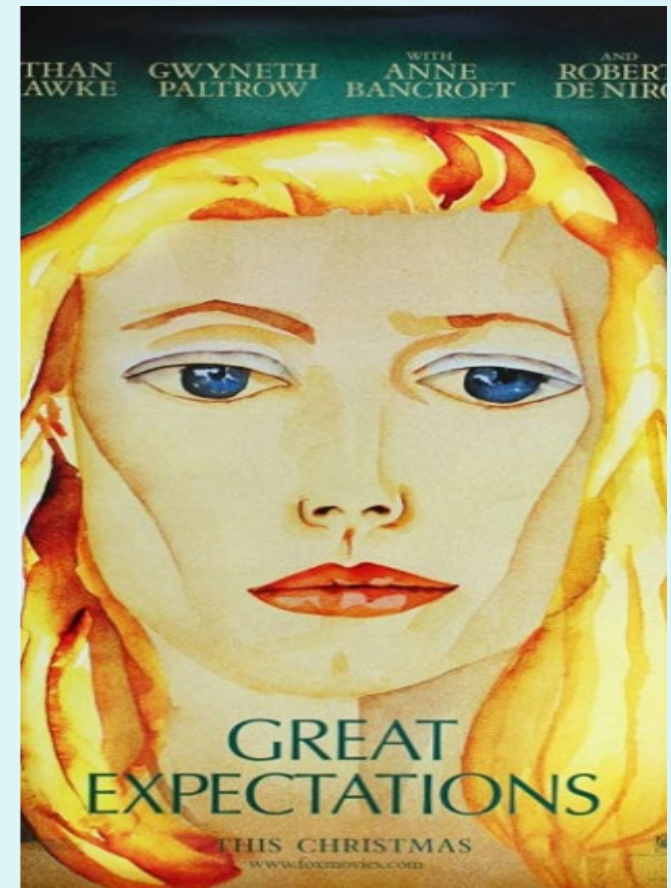


**The era of post-truth
True is the sensorially powerful
Or simply the louder OR the most famous!**

*Transiting from EBM & SBM to
media- and celebrity- based medicine*

Gwyneth Paltrow: NHS boss urges
caution over star's long Covid regime

© 24 February



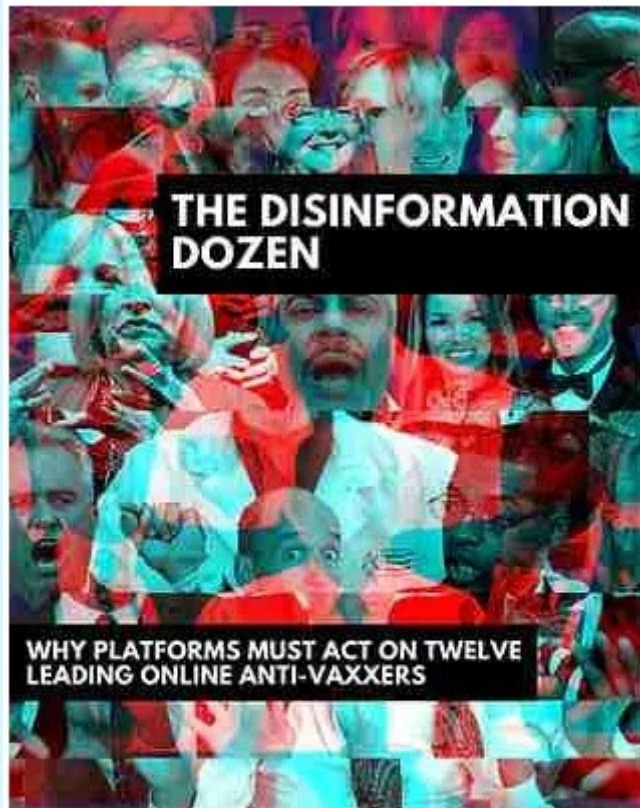
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Who disinforms? (Who profits?)



Top Russian and Chinese IO Narratives



RANK	RUSSIA	CHINA
1	<ul style="list-style-type: none">Sputnik V demonstrates Russia's scientific prowess	<ul style="list-style-type: none">Chinese vaccine development
2	<ul style="list-style-type: none">Western governments are not be trusted and are massively incompetent	<ul style="list-style-type: none">China is a leader in providing medical assistance to struggling nations
3	<ul style="list-style-type: none">The West derails global efforts to combat COVID-19	<ul style="list-style-type: none">CCP brings unparalleled resources and organization to combatting COVID-19

Though not reflected in this chart, as expected, messaging from both actors had a significant focus on updates of COVID-19 deaths and cases. These factual updates were crucial in establishing outlets as reliable sources of information and attracting regular audiences. These narratives fit within larger IO trends for Russia and China, but were less propagandistic and conspiratorial than the other narratives highlighted here.

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OPERATION INFEKTION

Who disinformers? (Who profits?)

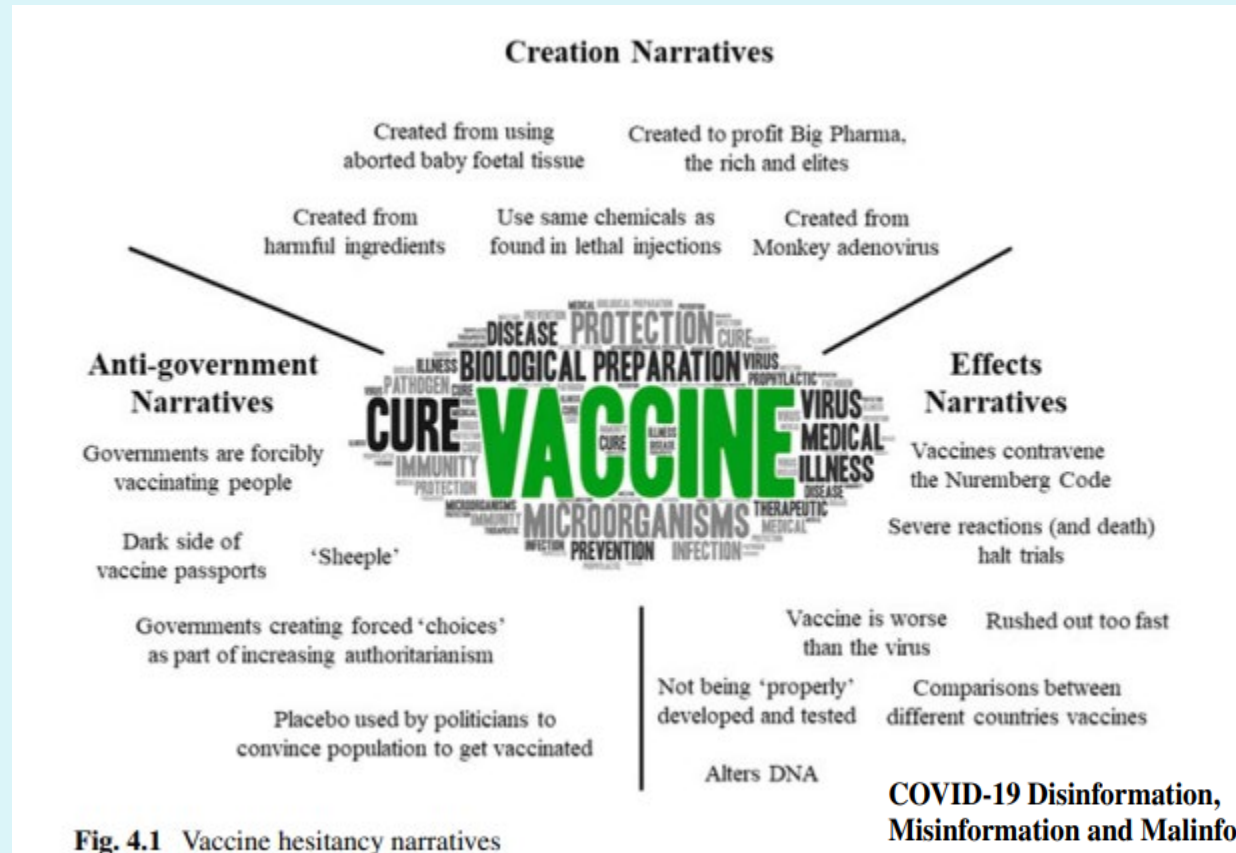


Fig. 4.1 Vaccine hesitancy narratives

COVID-19 Disinformation, Misinformation and Malinformation During the Pandemic Infodemic: A View from the United Kingdom

Neil Verrall

Advanced Sciences and Technologies for Security Applications

Ritu Gill
Rebecca Goolsby Editors

**COVID-19
Disinformation:
A Multi-National,
Whole of Society
Perspective**

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Who disinformers? (Who profits?)

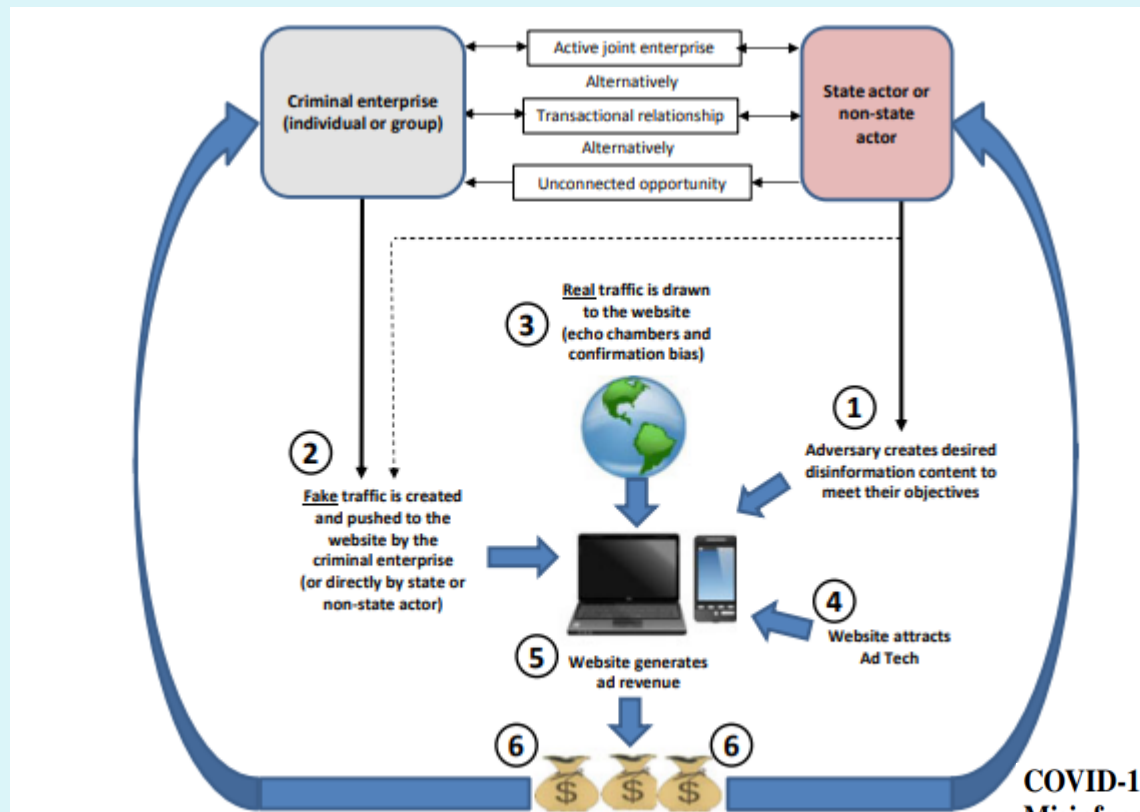


Fig. 4.3 The disinformation ad tech complex

COVID-19 Disinformation, Misinformation and Malinformation During the Pandemic Infodemic: A View from the United Kingdom

Advanced Sciences and Technologies for Security Applications

Ritu Gill
Rebecca Goolsby Editors

**COVID-19
Disinformation:
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Who disinforms? *(Who profits?)*

*The far-right QAnon
meets
the left counterculture of “natural treatments”*





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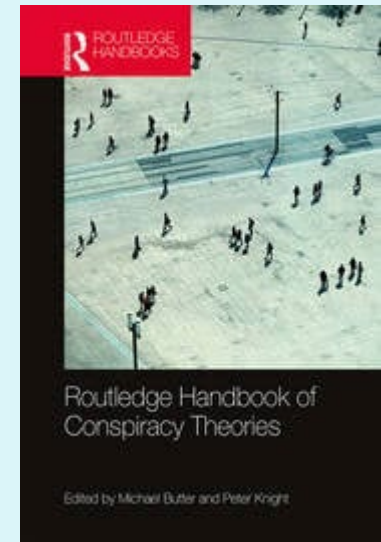
The fertile ground for disinformation

Conspiracy theories as a means to fight uncertainty (simple solutions to complex problems, via “stigmatized knowledge”)

The effect of illiteracy (science-, med-, e-, media-)

Targeting inferiority complexes & dissatisfaction

Creating a sense of belonging and mission





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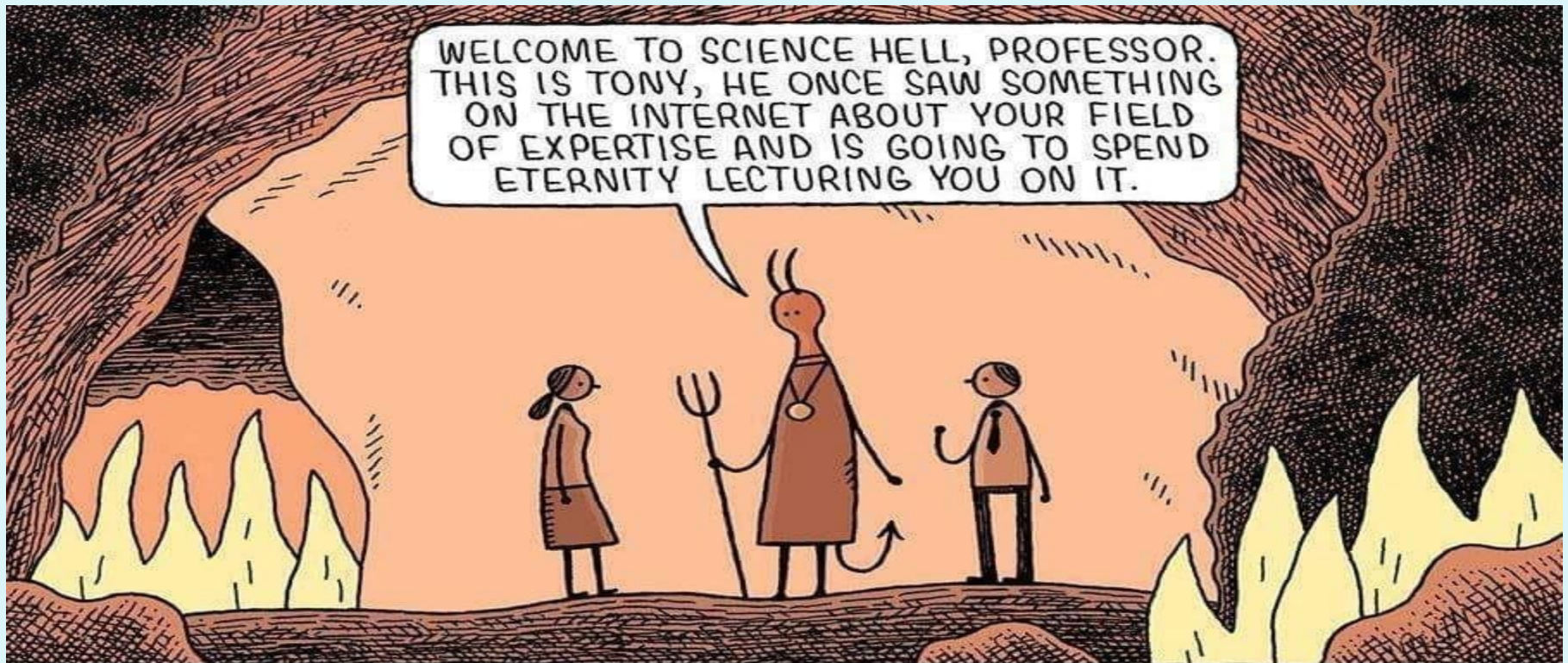
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The fertile ground for disinformation

The democratization of information seeking



Le département des théories fumeuses
Book by Tom Gauld



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The fertile ground for disinformation

The democratization of information seeking

did not use social media to acquire information about the pandemic and a further 28% stated they undertook their own “independent online research to learn about COVID-19”. These

Evaluating the elevation of authoritative health content online during the COVID-19 pandemic

Michael James Walsh, Stephanie Alice Baker, Matthew Wade ▼

Online Information Review



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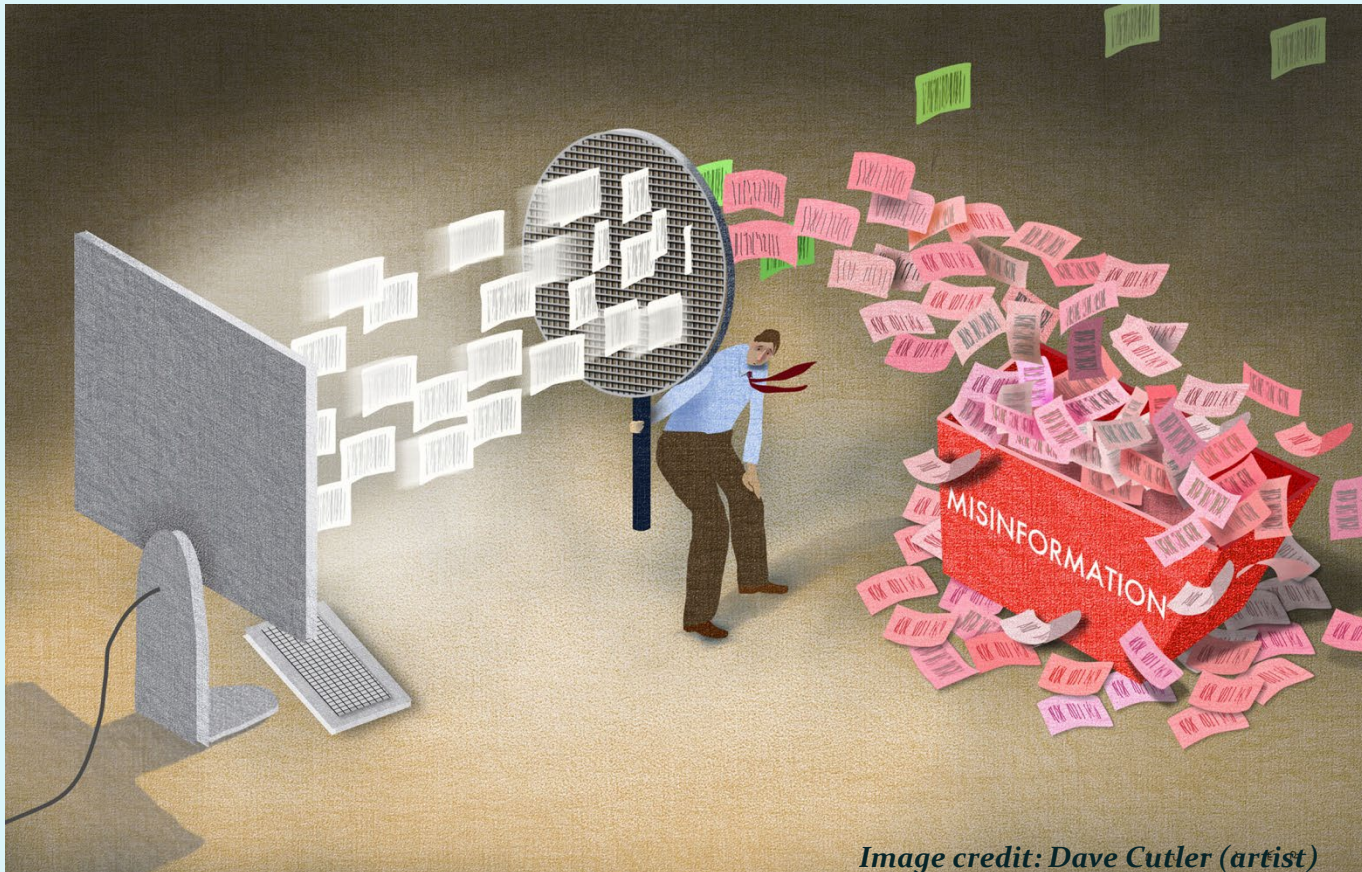


Image credit: Dave Cutler (artist)

PNAS

★ NEWS FEATURE

How to mitigate misinformation

Stymieing the deceptive notes and news that spread with reckless abandon via social media may require a new approach—or several of them.

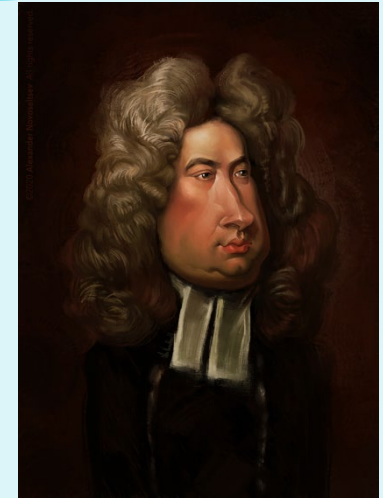
M. Mitchell Waldrop, Science Writer



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A. Debunk but you make it legitimate?

B. Prebunk but how much is feasible?

Jonathan Swift: "falsehood flies and truth comes limping after it"

C. Outline COIs of the “truthers” but does their audience really care?

D. Moderate content but do you moderate “innocent lies”? Can you moderate horizontally? Can you control all platforms?

E. Accountability (of truthers and digital platforms) but legal labyrinths

F. Educate/ Bridge the science confidence gap but this is long-term

G. All of the above



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Who educates?

(Who is trusted?)

-Community leaders

The “vaccination contagion” notion

-First-line HC workers

-The media, post getting educated



I'll see you on my rounds.



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Name the battlefield





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**BAD
NEWS**

From fake news to chaos! How bad are
you? Get as many followers as you
can.

GO VIRAL!

**A 5-MINUTE GAME THAT HELPS PROTECT
YOU AGAINST COVID-19 MISINFORMATION**

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The democratization of propaganda creation through AI (Sander van der Linden)

Globalised civilisation that is information and data-centric.

Future information civilization

Future threats

Adversary agility and innovation will exploit opportunities, fissures and loopholes in order to create and disseminate DMM.

How society responds to overt and covert threats and use of DMM (individual, group, national, cultural).

Future societal responses

Future information disorder

The interactions between DMM in a globalised hyper-connected digital world.

Fig. 4.5 From information civilization to information disorder

COVID-19 Disinformation, Misinformation and Malinformation During the Pandemic Infodemic: A View from the United Kingdom

Advanced Sciences and Technologies for Security Applications

Ritu Gill
Rebecca Goolsby Editors

COVID-19
Disinformation:
A Multi-National,
Whole of Society
Perspective



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The democratization of propaganda creation through AI (Sander van der Linden)



Will science be able to define truth?



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*Truth is not defined by our point of view.
But will it be?*