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**Epistemic injustice  
in health research:  
From study underrepresentation  
to global marginalisation**

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# EPISTEMIC INJUSTICE

Miranda Fricker (2007): Wrong done to someone specifically in their capacity as a knower

## Testimonial Injustice

Someone is wronged in their capacity as a giver of knowledge

## Hermeneutic Injustice

Someone is wronged in their capacity as subject of social understanding

**Distributive Epistemic Justice in Science\***  
 Gürol Irzik and Faik Kurtulmuş †  
*The British Journal for the Philosophy of Science*  
 Volume 75, Number 2, June 2024

This article develops an account of distributive epistemic justice in the production of scientific knowledge. We identify four requirements: (a) science should produce the knowledge citizens need in order to reason about the common good, their individual good and pursuit thereof; (b) science should produce the knowledge those serving the public need to pursue justice effectively; (c) science should be organized in such a way that it does not aid the wilful manufacturing of ignorance; and (d) when making decisions about epistemic risks, scientists should make sure that there aren't social groups or weighty interests that are neglected. After discussing these requirements, we examine the relationship between discriminatory and distributive epistemic injustice in science and argue that they often compound each other.

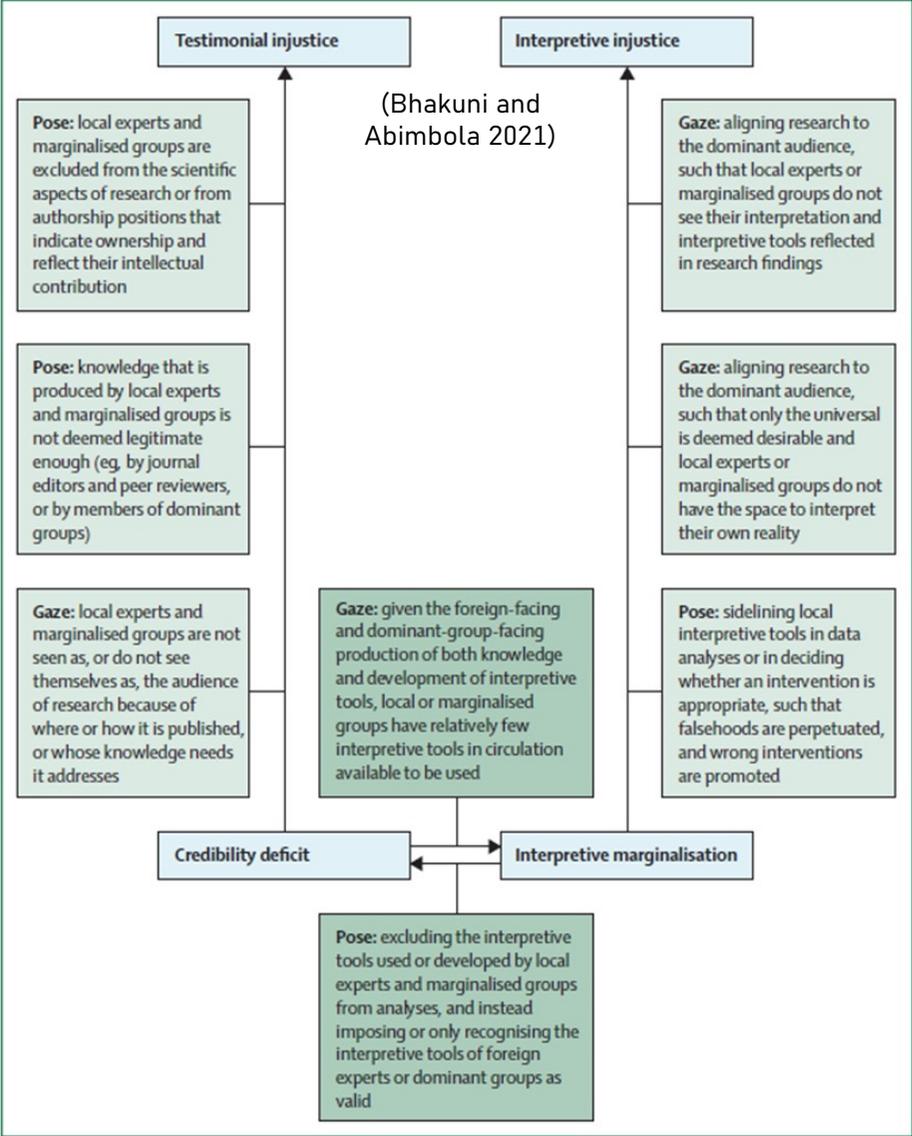


Figure: Examples of credibility deficit and interpretive marginalisation in academic global health

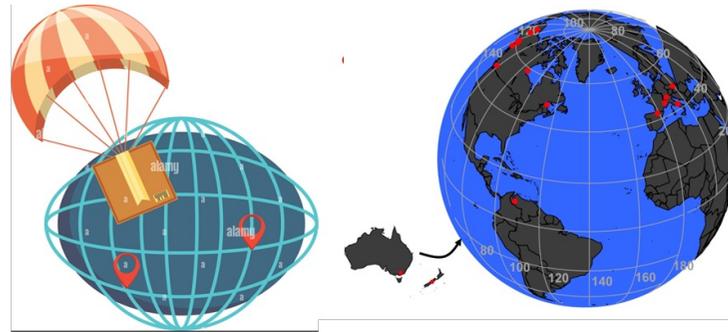
# Semicolonial research models

(Costello and Zumla 2000)



## Postal research

Western researchers request colleagues in Africa to courier to them biological samples



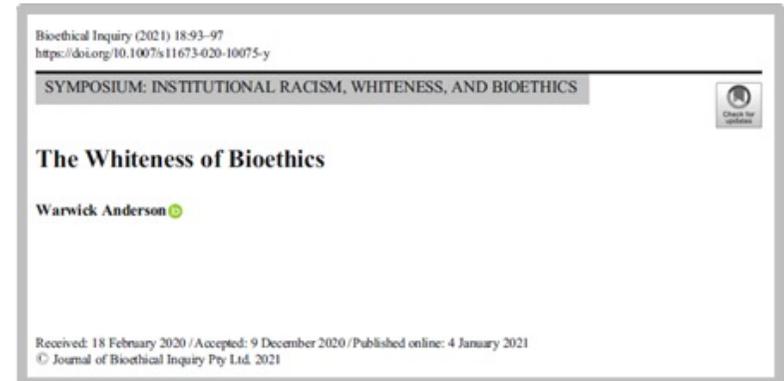
## Parachute research

Western researchers travel to Africa or Asia for short periods of time and take back biological samples

## Annexed sites

Field research is led and managed by expatriate staff

[https://as2.ftcdn.net/v2/img/05/51/56/99/1000\\_F\\_551569926\\_887MgNUGfclmPSImusp409IRjMnTY11.jpg](https://as2.ftcdn.net/v2/img/05/51/56/99/1000_F_551569926_887MgNUGfclmPSImusp409IRjMnTY11.jpg); <https://c8.alamy.com/comp/RJANRF/parachute-flying-with-box-delivery-service-vector-illustration-design-RJANRF.jpg>; <https://images.squarespace-cdn.com/content/v1/50e85615e4b0d5ee8b76c698/1432163953038-1MWAD2WYSVXTMCYBJKXP/image-asset.jpeg>



## Eastern highlands of New Guinea

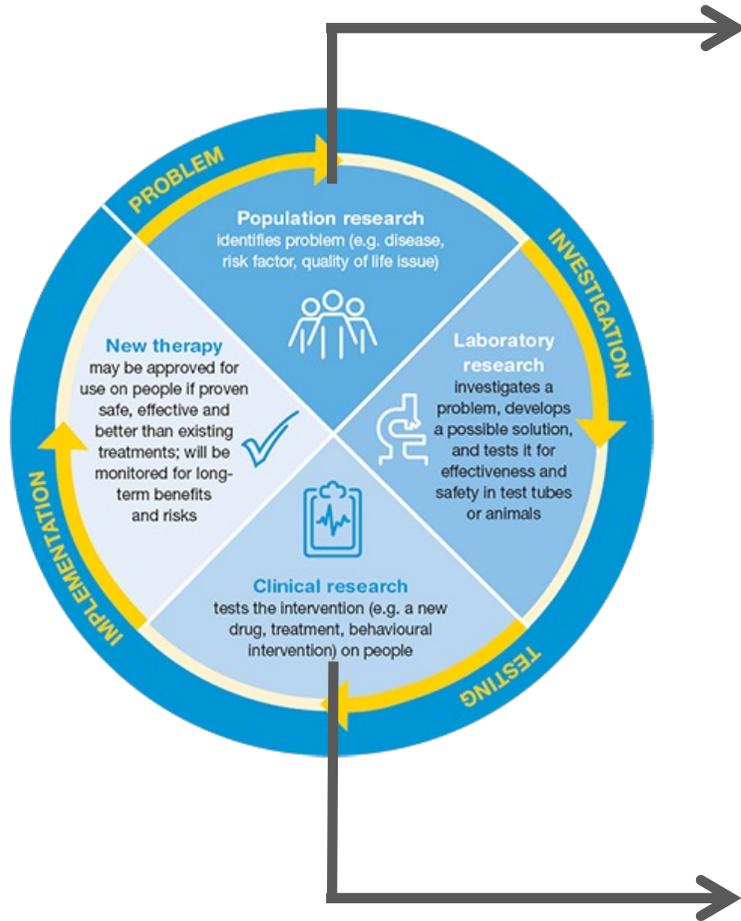
Read out, in Tok Pisin, information on the study along with a request for oral consent from each individual, all of which an interpreter rendered into Fore.

- Fore interlocutors became agitated and offended before the end of the ritual. They told me this is not the way they interacted with others, it seemed to imply distrust.

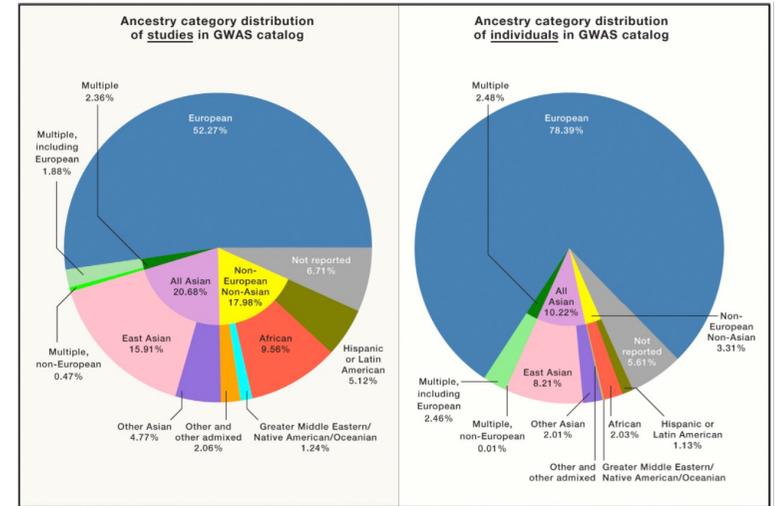
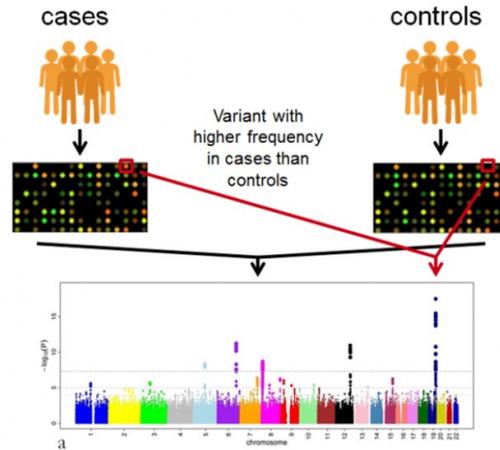
**Mentioned hesitantly that I could withhold their name, if they wanted**

- They always demanded to know if I thought them liars and charlatans.
- They were proud of their contributions to science—as they perceived it—and they insisted that I recognize their achievements, not disguise them.

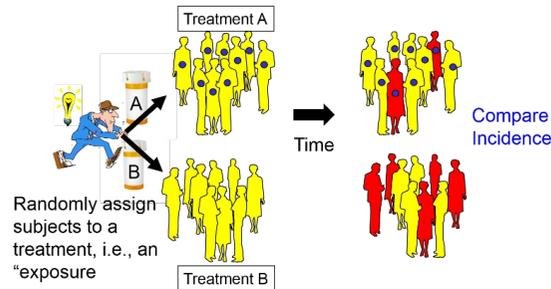
# HEALTH RESEARCH



## Genome-wide association studies

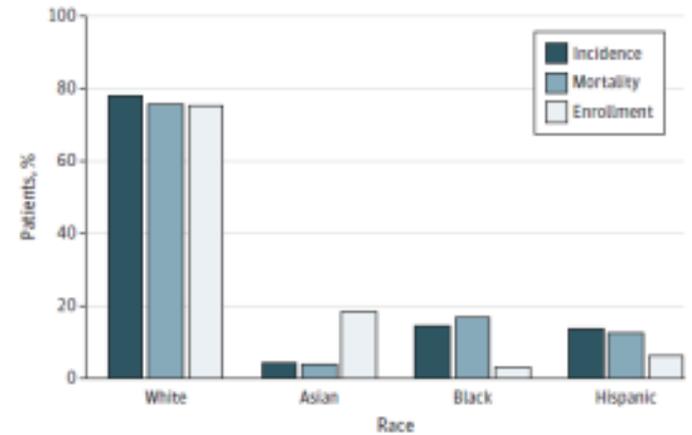


koff 2019)



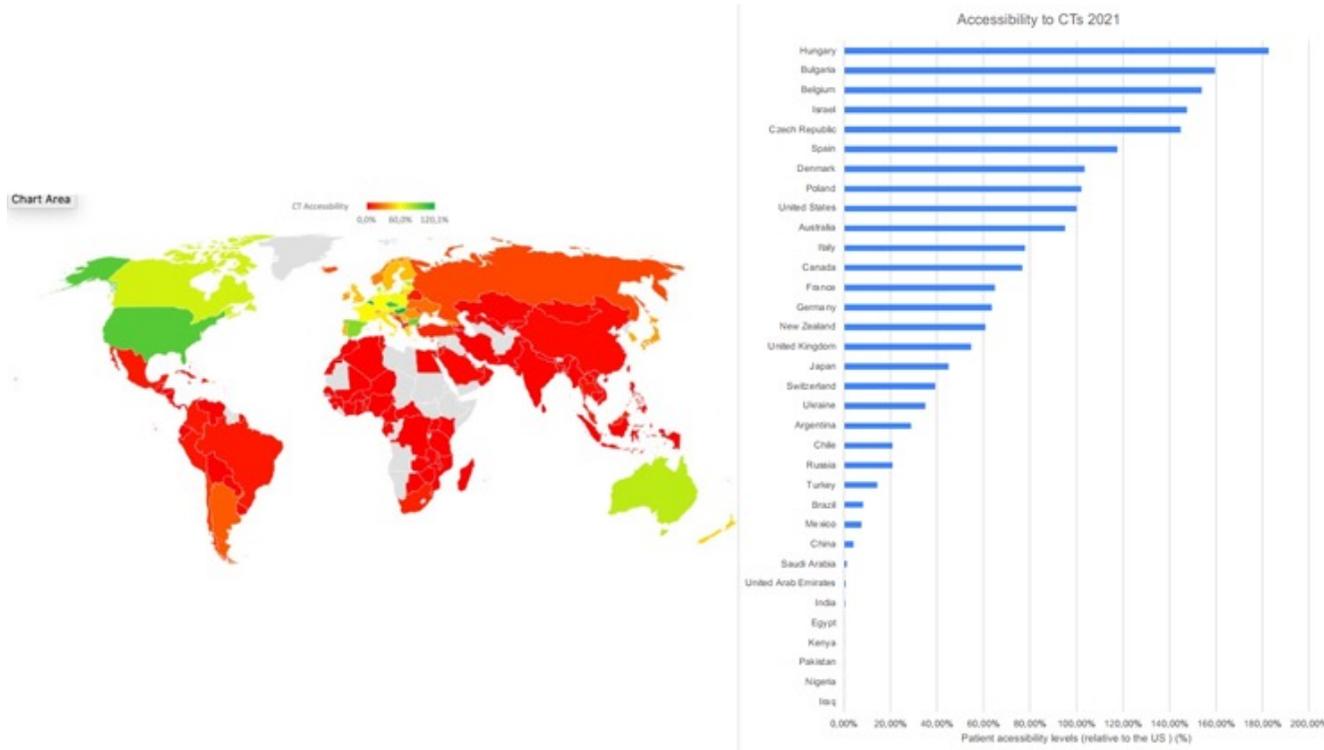
## Interventional studies

**B** Comparison of incidence and mortality of patients with cancer vs trial enrollment (Loree et al. 2019)

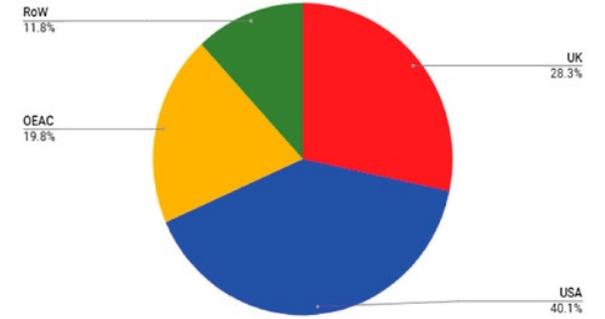


**Accessibility to clinical industry clinical trials, calculated as number of industry clinical trial sites per 1 million in population relative to the U.S. levels**

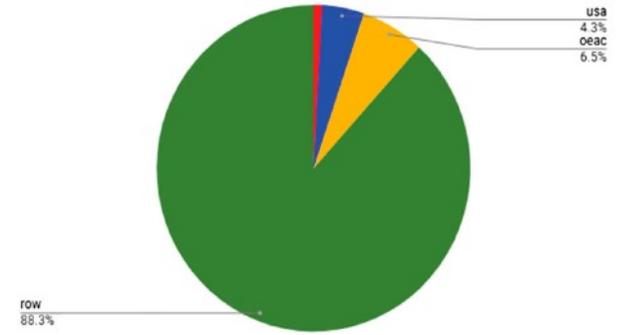
*(Misk 2023)*



Regions of the world contribution to the literature



Regions of the world by population (2017)



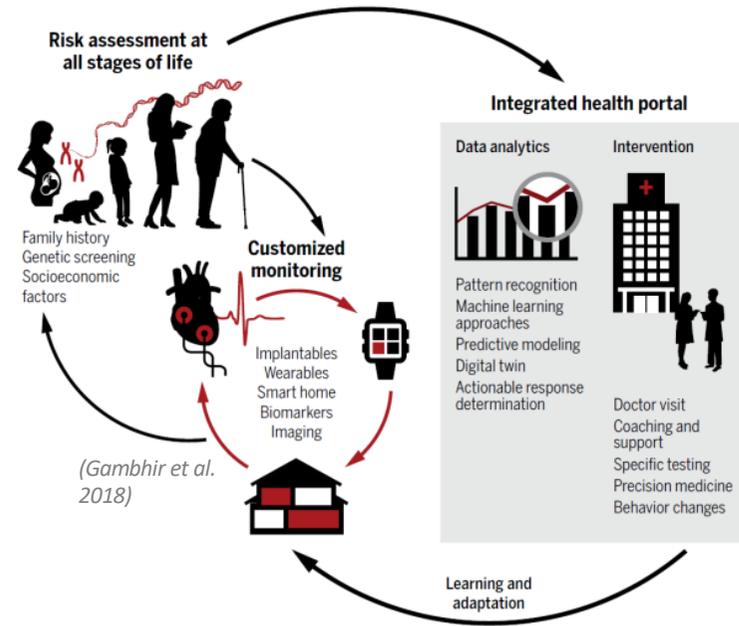
- British Medical Journal (BMJ)
- The Lancet
- New England Journal of Medicine (NEJM)
- Annals of Internal Medicine (AIM)
- Journal of the American Medical Association (JAMA)

*(Woods et al. 2023)*

# BMJ Open Trends and gaps in precision health research: a scoping review

To cite: Viana JN, Edney S, Gondalia S, et al. Trends and gaps in precision health research: a scoping review. *BMJ Open* 2021;0:e056938. doi:10.1136/bmjopen-2021-056938

John Noel Viana<sup>1,2</sup>, Sarah Edney<sup>3</sup>, Shakuntla Gondalia<sup>4</sup>, Chelsea Mauch<sup>5</sup>, Hamza Sellak<sup>4,6</sup>, Nathan O'Callaghan<sup>4</sup>, Jillian C Ryan<sup>4</sup>



Database	Search String
Medline (OVID)	((precision or personali* or individuali* or stratif* or Tailo*) adj health).ti. or ((precision or personali* or individuali* or stratif* or Tailo*) adj health).ab.

+APA (PsycInfo), Scopus, Embase, Web of Science, Google Scholar

**225 ARTICLES** FOR FULL-TEXT SCREENING

Articles that mentioned participants' sex:  
**(153/225, 68.0%)**

Articles reporting participant race/ethnicity:  
**(87/225, 38.7%)**

Articles included participants from disadvantaged socio-economic backgrounds:  
**(46/225, 20.4%)**

*People who have low income or are unemployed, low literacy, limited education, limited internet or technology access and/or no insurance; live in a rural area; and/or are migrants*

Ten most common countries (study setting)

USA	85	37.8
The Netherlands	20	8.9
China	13	5.8
Australia	12	5.3
Korea	12	5.3
Canada	11	4.9
UK	9	4.0
Finland	5	2.2
Taiwan	5	2.2
Germany	4	1.8

Continent			
Author affiliation	Context	Number of articles	Percentage (%) of total articles
North America		118	52.44
	North America	97	43.11
Europe		84	37.33
	Europe	61	27.11
Asia		40	17.78
	Asia	40	17.78
Oceania		18	8
	Oceania	13	5.78
Africa		12	5.33
	Africa	12	5.33
South America		2	0.89
	South America	2	0.89
	Not applicable, not supplied	16	7.11

# COVID-19 SYSTEMS BIOLOGY

- Aims to determine metabolomic, proteomic, lipidomics, and transcriptomic changes in people infected with COVID-19: 6 and 12-months post infection
- Cases and controls
- Geelong, Victoria
- 18-month participant observation (team meetings, site visits, semi-formal conversations with researchers); Six semi-structured interviews

## 1. Study site

*“Yeah, Geelong – yeah, Geelong is – like it might be. I might just be hanging out in the wrong places. But it’s not a very largely diverse area.” [Researcher 4]*

### Birthplace - Ranked by size

export  r

Geelong - Overseas born (Usual residence)		2021		2016		
Birthplace	Number	%	Greater Melbourne %	Number	%	Greater Melbourne %
 United Kingdom	249	3.9	3.3	229	4.0	3.6
India	164	2.6	4.9	142	2.5	3.6
China	107	1.7	3.4	100	1.7	3.5
 Italy	95	1.5	1.2	111	1.9	1.4
Malaysia	65	1.0	1.2	44	0.8	1.1
New Zealand	60	0.9	1.7	59	1.0	1.8
Philippines	44	0.7	1.2	25	0.4	1.0
Nepal	40	0.6	0.4	11	0.2	0.2
Sri Lanka	37	0.6	1.3	30	0.5	1.2
United States of America	35	0.5	0.4	23	0.4	0.4

## 2. Research objectives

*“This study is not meant to study the difference between different genetic individuals; otherwise, it will become very biased, because then there are, like, different strata will be included then you need to have – you need to cover for all the genetics, like you need to cover for the **Southeast Asian, the Far East and Near East Asian, Chinese, Korean, Japanese, and then you have to cater for Indians, then you have to cater for the Middle East Asian, then people from Caucasian countries, then people from European backgrounds.** So how much stratification you’ll make and then getting the number of samples for each of those, ah, stratifications, it’s – it’s not going to happen.” [Researcher 2]*

Race and Hispanic Origin	
1 White alone, percent	76.3%
2 Black or African American alone, percent (a)	13.4%
3 American Indian and Alaska Native alone, percent (a)	1.3%
4 Asian alone, percent (a)	5.9%
5 Native Hawaiian and Other Pacific Islander alone, percent (a)	0.2%
6 Two or More Races, percent	2.8%
7 Hispanic or Latino, percent (b)	18.5%
8 White alone, not Hispanic or Latino, percent	60.1%

### Broad group level

The first level of the classification, the broad group level, comprises nine categories to provide a broad overall view of the geographic proximity of cultural and ethnic groups in terms of the location in which they originated or developed and are represented by one digit codes.

They are:

- 1 Oceanian
- 2 North-West European
- 3 Southern and Eastern European
- 4 North African and Middle Eastern
- 5 South-East Asian
- 6 North-East Asian
- 7 Southern and Central Asian
- 8 People of the Americas
- 9 Sub-Saharan African

### 3. Recruitment strategy

*“We didn’t – we didn’t go out of our ways, um, mainly because it’s really hard to book an interpreter through ... I just **had a list of names and phone numbers**. So we were cold calling participants, um, and if people didn’t want to talk to you they would hang up. We sent – I sent out text messages first ... If you didn’t reply to that text message I called and some of them were, um, **people who English wasn’t their first language but they had family members**. So I – I spoke to a lot of daughters of parents or sons of parents who would translate for them. Um, ultimately most of them **decided they didn’t want to be involved**.” [Researcher 4]*

*“There are also the **people less likely to go and seek help**, medical care, less likely to declare themselves as COVID-positive because it means they lose income.” [Researcher 1]*

*“When it comes to recruiting **people for the controls**, you have to depend on the **Australian electoral rolls**. Now that’s where it – of course, see a problem. Not all people who are from diverse backgrounds currently living in Australia on the electoral rolls. This could be because they just have **work visas, they’re not permanent residents**. So I think that really hinders participation.” [Researcher 2]*

### 4. Research team

*“Well, by the **time** [organisation] came on board, we already had all these protocols.” [Researcher 4]*

*“We **joined late** in the studies so we – we **couldn’t influence**, like, on certain things.” [Researcher 3]*

*“Um, so when I say it’s a room full of white scientists most of our **epidemiologists, white people**.” [Researcher 4]*

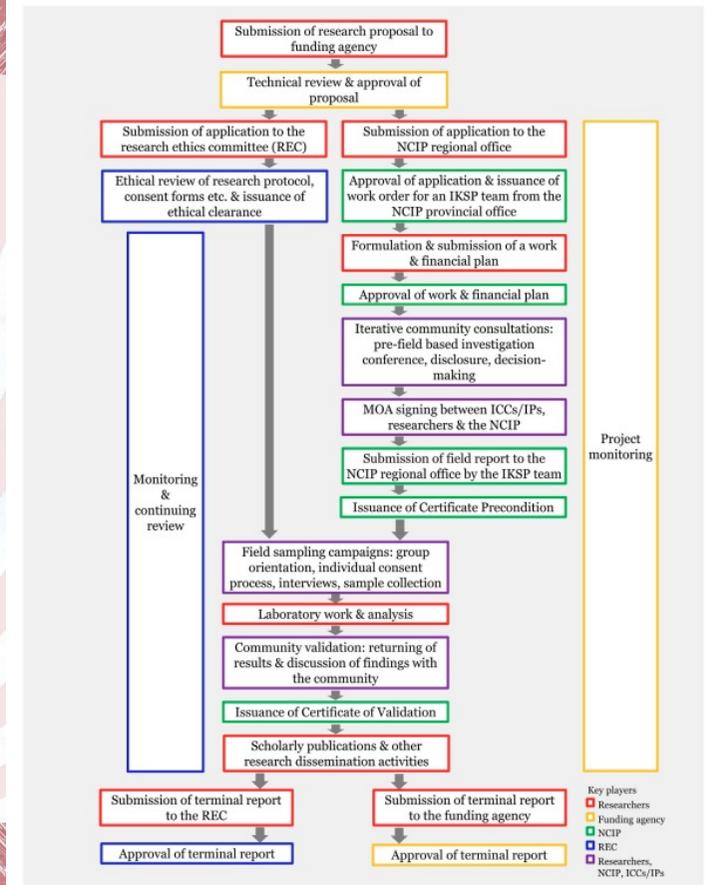
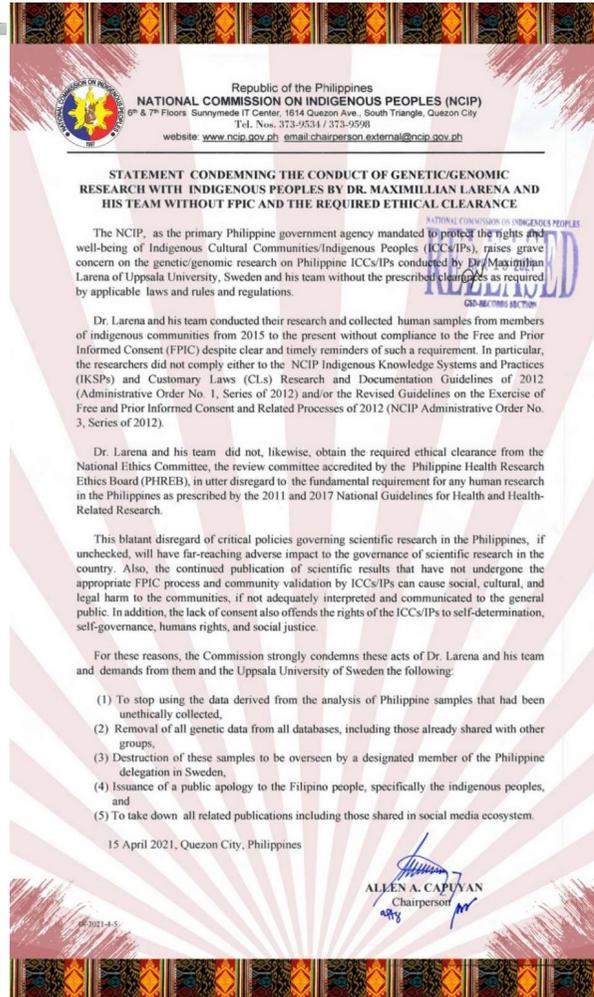
# Multiple migrations to the Philippines during the last 50,000 years

PNAS 2021 Vol. 118 No. 13 e2026132118

Maximilian Larena<sup>a,b,1</sup>, Federico Sanchez-Quinto<sup>a,b</sup>, Per Sjödin<sup>a</sup>, James McKenna<sup>a</sup>, Carlo Ebec<sup>c,d</sup>, Rebecca Reyes<sup>e,f</sup>, Ophelia Casel<sup>g</sup>, Jin-Yuan Huang<sup>h</sup>, Kim Pullupul Hagada<sup>i,j</sup>, Dennis Guilay<sup>j</sup>, Jennelyn Reyes<sup>k</sup>, Fatima Pir Allian<sup>l,m</sup>, Virgilio Mori<sup>m</sup>, Lahaina Sue Azarcon<sup>n</sup>, Alma Manera<sup>o</sup>, Celito Terando<sup>p,q</sup>, Lucio Jamero Jr<sup>r</sup>, Gauden Sireg<sup>s,t</sup>, Renefe Manginsay-Tremedal<sup>u</sup>, Maria Shiela Labos<sup>u,v</sup>, Richard Dian Vilar<sup>w,x</sup>, Acram Latiph<sup>y</sup>, Rodelio Linsahay Saway<sup>y</sup>, Erwin Marte<sup>z</sup>, Pablito Magbanua<sup>aa</sup>, Amor Morales<sup>bb</sup>, Ismael Java<sup>cc,dd</sup>, Rudy Reveche<sup>dd,ee</sup>, Becky Barrios<sup>ff,gg</sup>, Erlinda Burton<sup>hh,2</sup>, Jesus Christopher Salon<sup>hh,ii</sup>, Ma. Junaliah Tuazon Kels<sup>h</sup>, Adrian Albano<sup>jj,kk</sup>, Rose Beatrix Cruz-Angeles<sup>ll</sup>, Edison Molanida<sup>ll,mm</sup>, Lena Granehall<sup>nn</sup>, Mário Vicente<sup>oo</sup>, Hanna Edlund<sup>o</sup>, Jun-Hun Loo<sup>o</sup>, Jean Trejaut<sup>o</sup>, Simon Y. W. Ho<sup>oo</sup>, Lawrence Reid<sup>oo</sup>, Helena Malmström<sup>pp</sup>, Carina Schlebusch<sup>pp,qq</sup>, Kurt Lambeck<sup>rr</sup>, Phillip Endicott<sup>ss</sup>, and Mattias Jakobsson<sup>pp,qq,1</sup>

## Significance

A key link to understand human history in Island Southeast Asia is the Philippine archipelago and its poorly investigated genetic diversity. We analyzed the most comprehensive set of population-genomic data for the Philippines: 1,028 individuals covering 115 indigenous communities. We demonstrate that the Philippines were populated by at least five waves of human migration. The Cordillerans migrated into the Philippines prior to the arrival of rice agriculture, where some remain as the least admixed East Asians carrying an ancestry shared by all Austronesian-speaking populations, thereby challenging an exclusive out-of-Taiwan model of joint farming-language-people dispersal. Altogether, our findings portray the Philippines as a crucial gateway, with a multilayered history, that ultimately changed the genetic landscape of the Asia-Pacific region.



(Rodriguez et al. 2022)

## Black bodies and Bioethics: Debunking Mythologies of Benevolence and Beneficence in Contemporary Indigenous Health Research in Colonial Australia

Chelsea J. Bond · David Singh · Sissy Tyson

*“We articulate a Black bioethics that is not premised upon a false logic of beneficence, rather we think through a Black bioethics premised upon an unconditional love for the Black body.”*

*“A Black bioethics, therefore, must attend to power explicitly and transformatively, rather than the adornment of principles that work to maintain the status quo. Given the longstanding refusal to see Indigenous people as either human or as existing—an Indigenous bioethics demands a redefinition by the defined; one that starts with a reclaiming of our bones, flesh, bodies, and behaviours as well as the children they birthed. It means research about Indigenous peoples being undertaken by Indigenous peoples ...”*

*“We model a bioethics that insists upon truth telling, including the fundamental truth that the same scientific logic and reasoning that exacts violence upon the Black body in contemporary health research is the same logic and reasoning that rationalized the theft of Black land. “*



(<https://www.nhmrc.gov.au/guidelinesforguidelines/plan/consumer-involvement>; Cancer Australia)