

UNLEARN

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Acknowledgements:

I acknowledge and pay my respect to the traditional owners and custodians of this land: the Gadigal people of the Eora nation.

We meet on Aboriginal land, whose sovereignty was never ceded.



I acknowledge the people living with HIV and other people whose lives are directly affected by HIV, for their inspiration and support. This is for you, as it is for all of us.

Disclosures and conflicts of interest:

- Full-time employee of Monash Health
- President of the Victorian African Health Action Network
- Former Board member, AFAO

Thank you:

- ASHM organising committee, for inviting me
- The veterans and thinkers who spoke with me: I appreciate your frankness and generosity... discretion is assured.

Who?

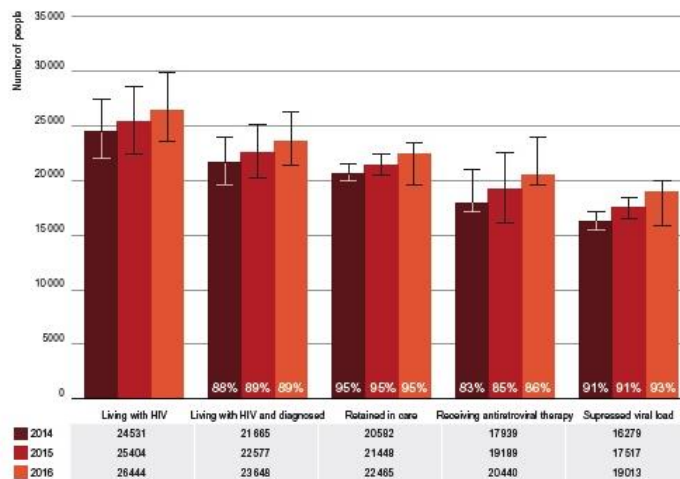


HIV in Australia today



HIV diagnosis and treatment

Figure 1.4.1 The HIV diagnosis and care cascade, 2014–2016



Source: See Methodology for details of mathematical modelling used to generate estimates.

HIV as a chronic illness

THE SPECTATOR

COFFEE HOUSE MAGAZINE WRITERS BOOKS & ARTS PODCASTS HEALTH LIFE MONEY SCHOOLS

FEATURES COLUMNISTS BOOKS ARTS LETTERS LIFE CARTOONS

As a doctor, I'd rather have HIV than diabetes

One of the most feared diseases in the world is now, for British doctors, a manageable chronic condition. It's a triumph we're oddly scared to talk about

Max Pemberton

ned 'highly active antiretroviral therapy' or Haart —
 maintain the infected person's immune system and
 ic infections that resulted in the development of Aids
 g in the centre of London with high-risk groups such
 I haven't seen someone die of HIV for years. It's now
 f HIV/Aids in this country. The most recent statistics
 cent of people with HIV died. This is about the same
 for the non-infected population. It's hard, now, to argue that HIV is a death sentence.

Those who are dangerously unwell with the disease are often immigrants who have been infected for years, and present to hospital late with the kind of infections that we no longer see in those on medication. One study suggested that around 75 per cent of HIV-related inpatient admissions are immigrants, with about 60 per cent from Africa. For the vast majority of people with HIV in this country, though, the disease is managed entirely in outpatient clinics. HIV/Aids wards and specialist units have closed

Who is left out?

- Barriers
 - Prevention
 - PrEP
 - Treatment
 - Support & care
- New HIV infections still rising
 - Indigenous people
 - Asian MSM
- Late diagnosis
 - Indigenous people
 - Heterosexually exposed
 - Women
 - Born abroad
 - Older people



Left Out Magpies. Kylie van Tol

POPULATION ≠ COMMUNITY

The last ten percent



Death for all ages

Figure 3.2: Leading underlying causes of death, by age group, 2014–2016

Age group	1st	2nd	3rd	4th	5th
Under 1	Perinatal and congenital conditions	Other ill-defined causes	SIDS	Spinal muscular atrophy	Accidental threats to breathing
1–14	Land transport accidents	Perinatal and congenital conditions	Accidental drowning and submersion	Brain cancer	Other ill-defined causes
15–24	Suicide	Land transport accidents	Accidental poisoning	Assault	Other ill-defined causes
25–44	Suicide	Accidental poisoning	Land transport accidents	Coronary heart disease	Other ill-defined causes
45–64	Coronary heart disease	Lung cancer	Suicide	Breast cancer	Colorectal cancer
65–74	Lung cancer	Coronary heart disease	COPD	Cerebrovascular disease	Colorectal cancer
75–84	Coronary heart disease	Dementia and Alzheimer disease	Cerebrovascular disease	Lung cancer	COPD
85 and over	Coronary heart disease	Dementia and Alzheimer disease	Cerebrovascular disease	COPD	Heart failure

AIHW. (2018, 18 July 2018). Deaths in Australia

HIV and ageing

- Comorbidities
 - Cardiovascular
 - Malignancy
 - Dementia
 - Mental illness
- Frailty
- Social isolation
- Poverty



Chronic illness

Tasks and challenges of HIV and chronic disease self-management*		
Physical	Psychological	Social
Understanding illness	Empowerment	Collaboration with health professionals
Health-promoting behaviour	Cognitive skills of self-management	Self-disclosure/coping with stigma
Adherence to treatment	Positive emotional states	Positive relationships
Self-monitoring	Identity normalization	Social support
Accessing services		
Preventing transmission		

*Adapted from Swendeman et al. (Swendeman et al. 2009)



Late diagnosis



Pneumocystis jirovecii pneumonia in patient with HIV and CD4 count less than 200 cells/ μ L

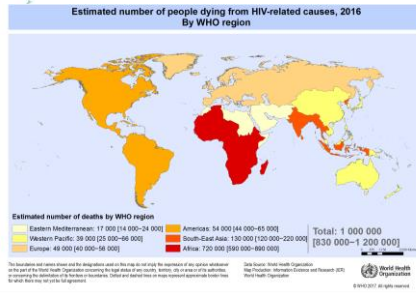
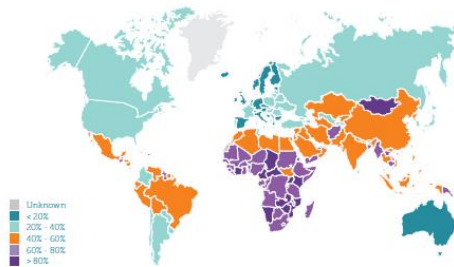
(Dr Behrang Amiri , Radiopaedia.org, rID: 35823)



Severe foot infection in patient with poorly-controlled diabetes mellitus

Plus ça change...

Map 3.5 Proportion (%) of people who died from diabetes before the age of 60



Cost of injustice

In 2012-13, after age-adjustment, Aboriginal and Torres Strait Islander people were four times more likely to be hospitalised for diabetes than non-Indigenous people. They were nearly two times more likely to be hospitalised for type 1 diabetes and GDM, and four times more likely to be hospitalised for type 2 diabetes, than their non-Indigenous counterparts.

In 2013, diabetes (excluding GDM) was the second leading underlying cause of death among Aboriginal and Torres Strait Islander people, with an age-adjusted death rate six times higher than that for non-Indigenous people.

Between 2009 and 2013, the number of Aboriginal and Torres Strait Islander females dying from diabetes increased by 15.2%, compared with a 2.1% increase in deaths among non-Indigenous females [9]. In this period, the greatest disparity in Indigenous: non-Indigenous age-specific death rates occurred in the 45-54 year age group [73]. In this age group Aboriginal and Torres Strait Islander people were 17 times more likely to die from diabetes than their non-Indigenous counterparts (rate ratios were 26.5 for females



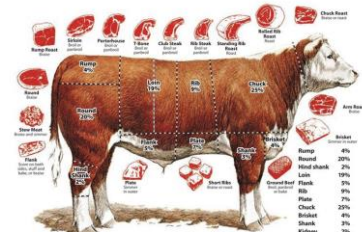
Social Conditions as Fundamental Causes of Health Inequalities: Theory, Evidence, and Policy Implications

Journal of Health and Social Behavior
 SAGE
 DOI: 10.1177/09214801141631418

Jo C. Phelan¹, Bruce G. Link^{1,2}, and Parisa Tehranifar¹



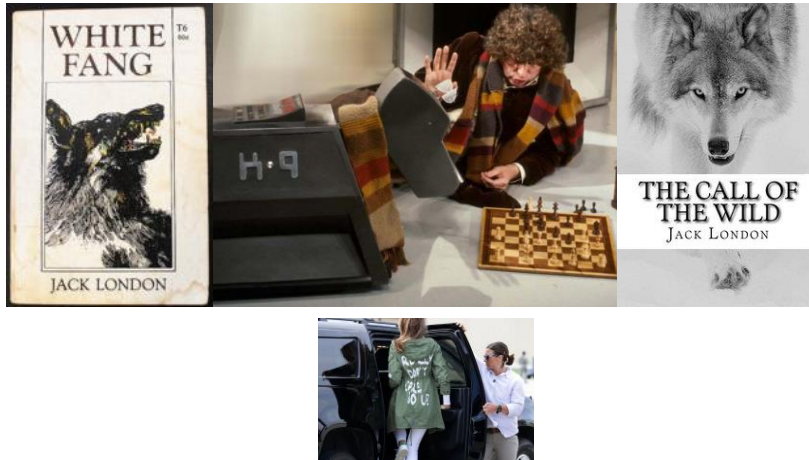
Power, money & medicine

Sugar Shoes Cigarette\$ Medicine\$
 Exercise\$  Groceries\$
 Dressings\$

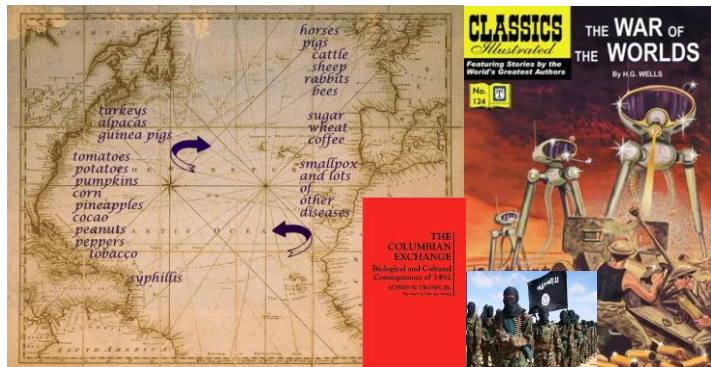
Beef	41%
Round	20%
Other	2%
Loin	19%
Flank	3%
Rib	7%
Plate	2%
Check	2%
Butter	4%
Shank	3%
Kidney	2%

 Transport\$
 Surgery Blood glucose monitoring\$ Sick days\$

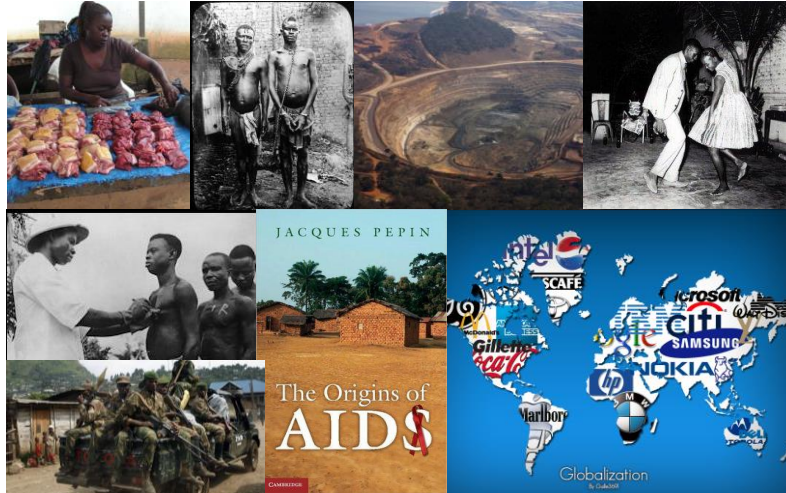
Response to HIV vs diabetes



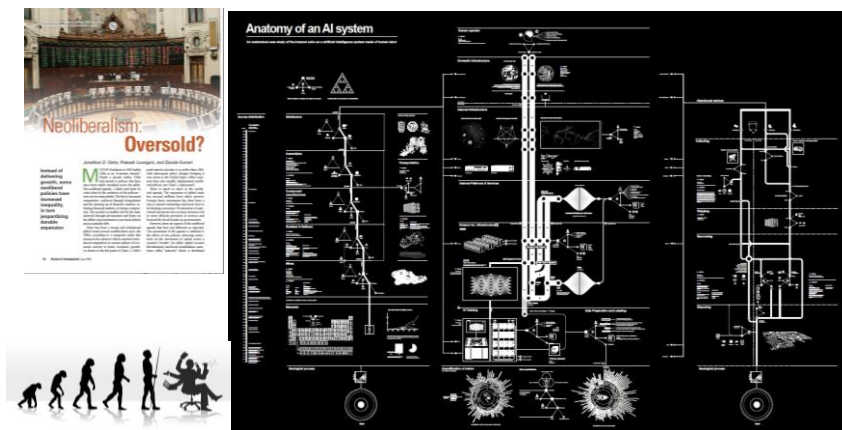
The Columbian Exchange



Colonial epidemic



Postcolonial malaise



Crawford, K., & Joier, V. (2018). Anatomy of an AI System
<https://anatomyof.ai>

Who are “we”, anyway?

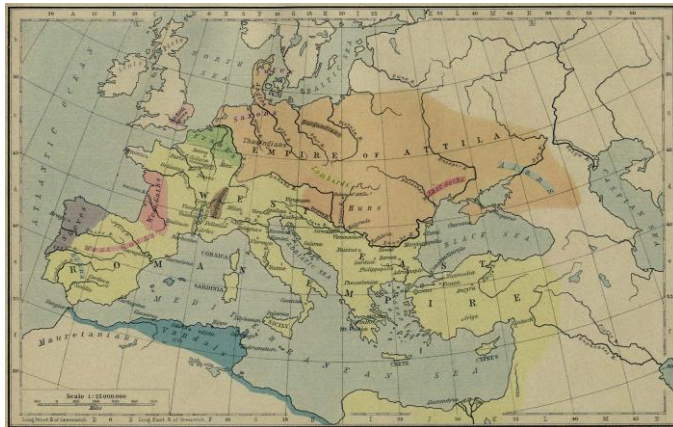


Power and knowledge



Naturhistorischesmuseum Wien

Knowledge & power



“The Empire was simply the known area and who controlled the known area. Out beyond the known area of the Empire, you came to some very dangerous people and beyond there, you came to dragons and beyond there, you’d better not go.”

Sherwood and Pinch. ‘Unlearn’

Prophets of age

In those days activists took risks, we educated and mobilized ordinary people. We spread literacy about HIV, taught people about the law. We came to each other's aid. We were independent and not conflicted.

We hadn't been co-opted.

When we started fighting back nobody was on antiretroviral treatment. Through a continual mobilization we won great victories and helped to save millions of lives. Today an unthinkable 21.7 million people are on treatment worldwide. But eventually, in part because of our victories, we were tamed and became complacent.

We were co-opted with a cocktail of per diems, proximity to power and air travel.

We became part of the elite, part of the problem, we got a stake in the system. That means those who are left behind today got left behind because of us.

The future of AIDS activism: If we don't join the dots we are dead. *Spotlight* (2018)
Mark Heywood (Treatment Action Campaign, AIDS Law Project, SECTION27)



Sustaining activism...



“Revolution became Revolution Inc... coming at you courtesy of Sony, Nike...”

Listening to communities

TESTING AND DIAGNOSIS

1. Implement targeted HCP education strategies to address HCP knowledge gaps regarding HIV risk factors, diagnosis, benefits of testing and early treatment.
2. Improve understanding of risk, and accessibility to testing, for people at risk of HIV (especially those living in rural or remote areas or in culturally and linguistically diverse (CALD) communities) by providing peer-to-peer education and facilitating availability of innovative testing technology.

BARRIERS TO TREATMENT AND CARE

3. Implement strategies that mitigate the impact of time, distance, co-morbidities, Medicare ineligibility, and out-of-pocket costs to achieve optimum treatment rates.
4. Increase access to educational resources to improve HIV health literacy and community understanding of the benefits of early treatment.

STIGMA, DISCRIMINATION, AND QUALITY OF LIFE

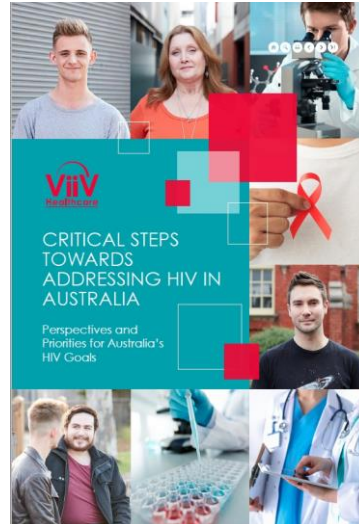
5. Augment focus on issues relating HIV QoL, stigma, discrimination¹ and implement objective measures of QoL to track the progress of formal programs.
6. Maintain continuing education in the health and aged care sector to address the risk of stigmatisation and its potential impact on people seeking diagnosis, treatment and ongoing care.

PREVENTION THROUGH ACCESS TO BIOMEDICAL INTERVENTIONS

7. Improve access to biomedical prevention by:
 - Making access to PrEP, PEP, and TasP more equitable and less dependent on where one lives, ability to pay or wait.
 - Ensuring that innovative HIV medicines continue to be made available on the Pharmaceutical Benefits Scheme (PBS) by addressing potential barriers for new treatment that can arise through unintended consequences of reimbursement policy.

PARTNERSHIP

8. Develop an Eighth National HIV Strategy with a clear implementation plan. It should be endorsed by all stakeholders and have an additional focus on the needs of minority populations.
9. Ensure community-based organisations are able to continue to meet community needs and expectations, and assist in delivering the goals of the National HIV Strategy, by:
 - Clearing disinvestment in the current community-based organisations.
 - Considering optional long-term funding models for community-based organisations to ensure services remain sustainable, diverse and non-duplicative.
10. Focus resources on training new HCP workforce entrants, given the generational workforce shift currently taking place.



<https://www.viivhealthcare.com.au/viiv-news/press-releases/2017/september/critical-steps-towards-addressing-hiv-in-australia-a-report-from-viiv-healthcare-australia/>

Wish list...

- Universal access to prevention, testing & treatment
- Flexible, responsive epidemiology & surveillance
- Substantial investment in HIV & sexual health literacy
- Critical reflection on structural racism & other discrimination by all stakeholders in HIV partnership
- Meaningful engagement with all communities affected by HIV
- Bring the energy of HIV activism to the rest of health



