# 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**:

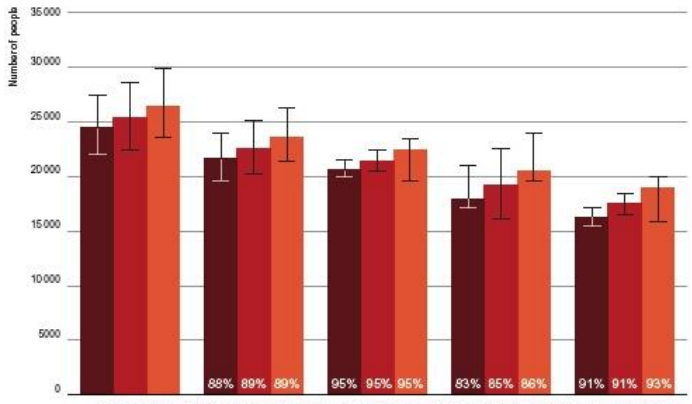
- ASHM organising committee, for inviting me
- The veterans and thinkers who spoke with me: I appreciate your frankness and generosity… discretion is assured.

# Who?

# HIV in Australia today


# HIV diagnosis and treatment

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




| | Living with HIV | Living with HIV and diagnosed | Retained in care | Receiving antiretroviral therapy | Supressed viral load |
|---|---|---|---|---|---|
| 2014 | 24531 | 21665 | 20582 | 17939 | 16279 |
| 2015 | 25404 | 22577 | 21448 | 19189 | 17517 |
| 2016 | 26444 | 23648 | 22465 | 20440 | 19013 |

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

FEATURES

**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

ıed 'highly active antiretroviral therapy' or Haart — intain the infected person's immune system and ıc infections that resulted in the development of Aids 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

Left Out Magpies. Kylie van Tol

- New HIV infections still rising
  - Indigenous people
  - Asian MSM
- Late diagnosis
  - Indigenous people
  - Heterosexually exposed
  - Women
  - Born abroad
  - Older people

**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

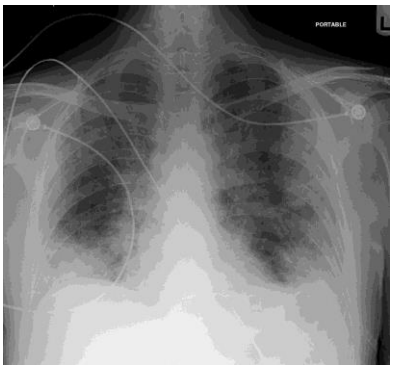
- Comorbidities
  - Cardiovascular
  - Malignancy
  - Dementia
  - Mental illness
- Frailty
- Social isolation
- Poverty

# 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 | | |

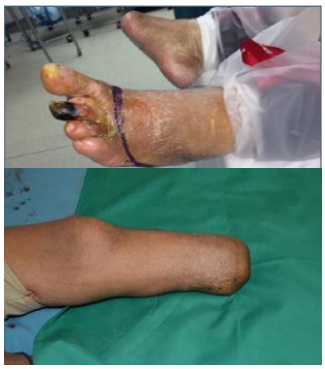
*Adapted from Swendeman et al. (Swendeman et al. 2009)

# Late diagnosis



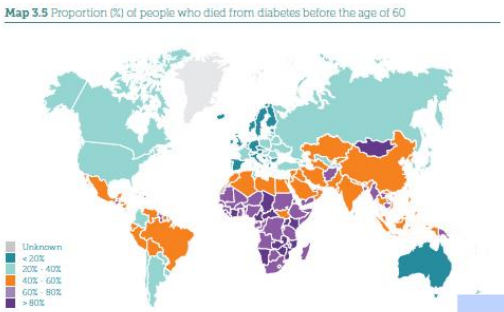

Pneumocystis jiroveci pneumonia in patient with HIV and CD4 count less than 200 cells/μL

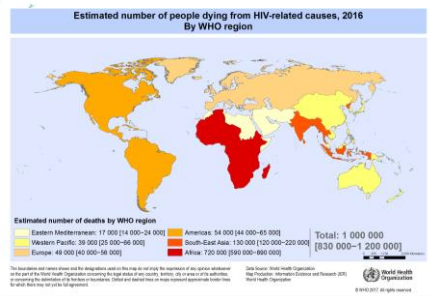
(Dr Behrang Amini , Radiopaedia.org, rID: 35823)



Severe foot infection in patient with poorly-controlled diabetes mellitus

# Plus ça change…



# 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



# Power, money & medicine

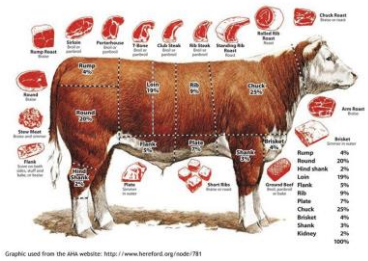
$ugar

$hoes

Cigarette$

Medicine$

Exerci$e



Grocerie$

Dre$$ings

Tran$port

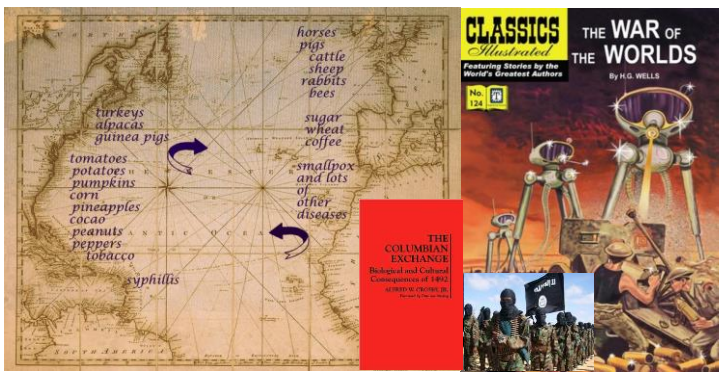
$ick days

$urgery

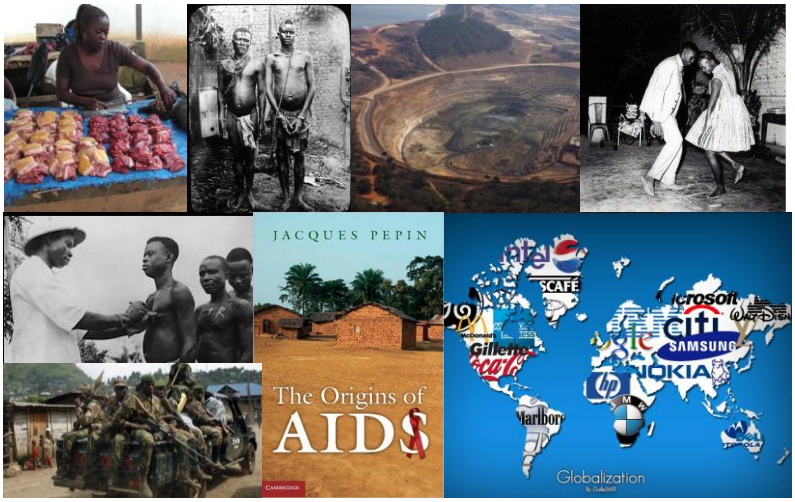
Blood gluco$e monitoring

# Response to HIV vs diabetes

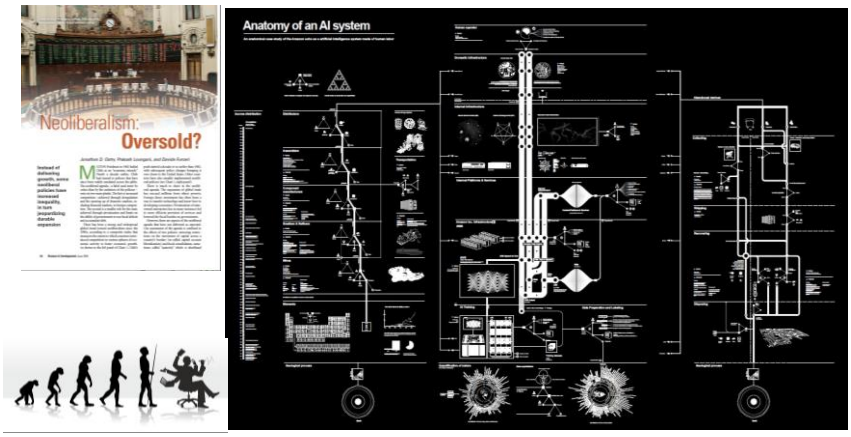

# The Columbian Exchange



# Colonial epidemic




# Postcolonial malaise



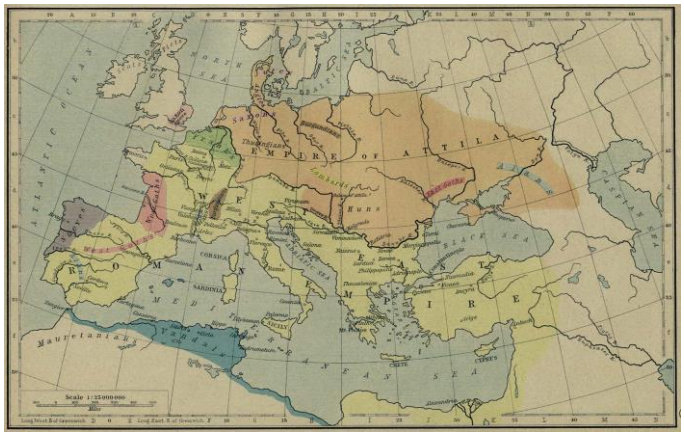

Crawford, K., & Joier, V. (2018). Anatomy of an AI System
https://anatomyof.ai

# 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.

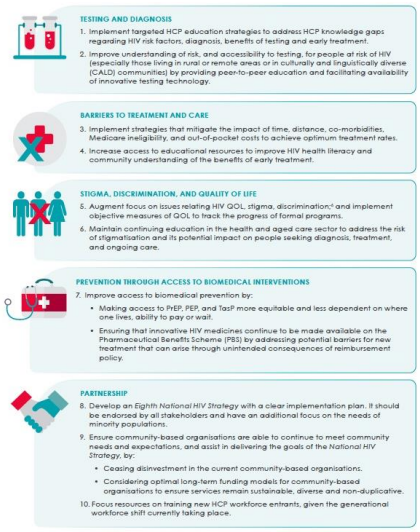
We became part of the elite, part of the problem, we got a stake in the system. That means those who are left behind today got left behind because of us.

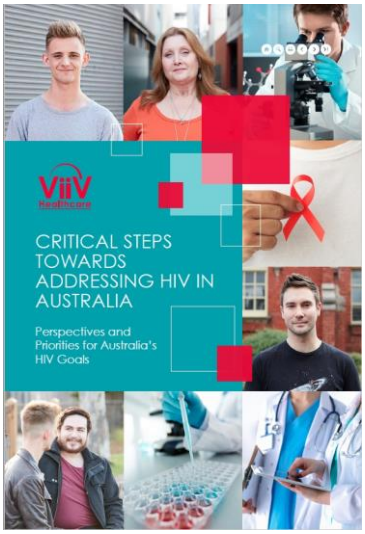
The future of AIDS activism: If we don't join the dots we are dead. *Spotlight* (2018)
Mark Heywood (Treatment Action Campaign, AIDS Law Project, SECTION27)

# Sustaining activism…

"Revolution became Revolution Inc… coming at you courtesy of Sony, Nike…"

# Listening to communities




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


label
Thank you
anger is an energy