Multi-Faceted Problems: Trans-disciplinary Solutions?

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R & D in the NHS: Size Matters

• Over 1.7m employees: almost 40,000 GPS, over 370,000 nurses, nearly 19,000 ambulance staff, and well over 100,000 hospital and community health staff.

• Over 1 million patients every 36 hours.

• **NHS budget has grown from** £437 million in 1948 (c. £9 billion today) to over £108.9 billion.

• 38% of NHS staff report feeling unwell due to everyday stress in the workplace. (Nuffield Trust/Health Foundation report, 2014)

• So in this complex environment, and under these pressures, why add more complexity? Why be ‘trans-disciplinary’? (and why ask a historian?)
Engaging Publics, Politics and Practice
Ethnicity and Health Disparities: what are the questions?

- **NOT ‘if’ ethnic health disparities exist.**

- **2004 Health Survey for England** (last to assess ethnic health) noted worse outcomes in cardiovascular disease [CVD] for men of Bangladeshi, Indian, and Pakistani ancestry.
  - Men of Irish ancestry had the highest prevalence of CVD of any group.
  - Rates of undiagnosed previous myocardial infarction and angina among men and women of African Caribbean origin, respectively, were significantly higher.
  - Men of Chinese and Black African ancestry showed markedly lower risks of CVD across all age groups.

- **Diabetes incidence rates highest and rising most swiftly among all non-white ethnic groups except the Chinese.**
  - Men of Indian and Bangladesh ancestry are 3+ times more likely to be diagnosed with diabetes than the general population.
  - Women of Pakistani ancestry are 5 times more likely to be diabetic than the general population.
  - Women of African Caribbean, Bangladeshi and Indian ancestry experience 2.5-3 times higher rates. Only Irish men had rates lower than those of the general population.
Ethnicity and Health Disparities: so what are the questions?

• **What factors cause ethnic health disadvantages?** Ethnicity, education, environment, and socioeconomics all play well-documented roles. *What about biological difference? What about institutional racism?*

• **What about ethnic health advantages?** Members of all major ethnic groups other than the Irish ate more fruit and vegetables than the majority population, and less fat. What can ethnic minorities teach the NHS about improving the diets of the general population?

• **What interventions have successfully improved health outcomes for ethnic minority populations either in the UK or elsewhere?** Who can or should play a role in reducing ethnic health disparities by spreading best practice?
Trans-Disciplinary Approaches to Engaging the Public
Example 1: History as a laboratory for practice
Health campaigns: How do they work? Who do they work for?

• Historically 2 kinds: entire population of an area (or nation), and those that target ‘risk’ or groups;
• Whole population campaigns cost more per campaign, but often less per person affected; tend to attract more ‘free’ resource from private sector and media;
• Targeted campaigns can be tailored for cultural acceptability – but risk be seen as ‘singling out’ some and excluding others
Whole Population: Glasgow 1957
‘Tuberculosis: Let’s Stamp It Out’
Whole Population: Glasgow 1957
‘Tuberculosis: Let’s Stamp It Out’

- Glasgow’s TB rate highest in the nation and rising: 25/1000;
- 40% of population still inadequately housed;
- ‘Tenement class’ regarded as resistant to public health messages, neglectful of ‘civic duty’ in relation to health;
- Campaign required 37 MMR units, daily mass media coverage (TV, radio, newspapers, film) AND house-to-house visits by volunteers

Results:
- 714,915 Glaswegians (76% of total population) voluntarily x-rayed;
- 2,755 new cases of active tuberculosis identified;
- 5379 suspect cases referred for further screening;
- 48 undiagnosed cases of lung cancer identified (also new cases of CHD, pneumoconiosis, etc).

Cost: £114,269
- 3s.2d (approx. £3.01 per examination)
- £16 4s per new TB case identified (approx £305 per new case)
Ethnically Defined ‘Risk Group’: 1981-2 ‘Stop Rickets’

Mild (L) and severe (R) Asian rickets. The severe case will require osteotomy.
Ethnically Defined ‘Risk Group’: 1981-2 ‘Stop Rickets’

- ‘Stop Rickets’ DHSS and Save the Children, 1980-81 Cost £70,000, year 1 (approx £197,000 in 2010)
- Ministerial initiative (top-down) with recruited advisory panel of British Asian ‘community leaders’
- Direct response to political pressures
- Targeted campaign intended to reach Asian ethnic minority population

But:
- Rickets not regarded as a significant problem by local health workers or targeted community members (women)
- Campaign focused on changing long-term behaviour but only operated in the short term
- Communities and LHAs assumed most costs, with campaigns receiving as little as £250 (approx. £703 in 2010) from central government.

End result: slightly increased knowledge in wake of campaign; no difference after one year; no change in incidence.
(Compare to wartime and post-war national nutrition campaigns)

mother

don't forget baby's

COD LIVER OIL
AND ORANGE JUICE

EXTRAS

for the Expectant Mother
AND FOR CHILDREN UNDER 5
Reinventing the Wheel?

Since 1980 *Yellowlees Report* on immigrant health:
- Ethnicity and health/health disparities officially examined more than 20 times;
- Ethnic health units established within the Department of Health on at least 3 separate occasions
- Guidelines for addressing/including ethnic health issues developed and published at least 8 times

But:
- Ethnic health disadvantage: 30 years on from the Black Report, health inequality gap remains.
Alternative Model: Community-led Campaigns

1976- present OSCAR/SCC and UKTS

- Grassroots efforts, community-led
- Close ties with medical specialists and clinicians, who campaigned for central governmental action through MRC, professional networks, personal relationships with influential figures (e.g. CMO)
- majority funding from community members & their international connections
Alternative Model: Community-led Campaigns

1976- present OSCAR/SCC and UKTS
• Close relationships with (some) responsive local health authorities to produce community based services and educational materials
• Balance between emphasis on education and on innovations in treatment and service provision
• Engaged directly with pharmaceutical and medical device manufacturers
★This approach sees communities and their networks as assets (also e.g. Birmingham Health Exchange)
Alternative Model 2: Tailored Local Health Education and Campaigns
Alternative Model 3: Consultant-led clinical reforms

1988-present Manchester Diabetes Centre

• Shift from single discipline ‘clinic’ model to multidisciplinary ‘one-stop shop’
• Specific attention to identified ‘DNA’ groups in order to improve and tailor services/hours
• Stress on informal atmosphere and long-term engagement and monitoring
• Research on ethnically appropriate health education
• Patient protest helped scupper a 2004 attempt to disperse the service to GPs
Key points for research with the public:

• ASSUMED community preferences do not always match or reflect the preferences expressed by community members and community-based organisations [compare with selection of radical mastectomy over conservative treatment in breast cancer]

• Community engagement requires time, resources and two-way communication; communities cannot be expected to offer a ‘rubber-stamp’ for initiatives that do not meet their expectations or reflect their needs.

• Even if groups or individuals share a diagnosis, they may have different needs.

• Education alone is less effective at engaging communities long-term than approaches which combine educational and other interventions.
A Trans-disciplinary Approach to Engaging the Public

Example 2: Understanding and improving ethnic minority participation in clinical trials

Problem:
• NHS has a statutory duty to perform research in a representative and non-discriminatory fashion.
• BUT: it can be hard to recruit, retain ethnic minority participants.
• Moreover, there can be extra costs (and time) involved in managing such participation ethically and appropriately.
The NHS view of Clinical Trials (as presented to patients)

NHS Choices, ‘Clinical Trials and Medical Research’, May 30, 2014
A trans-disciplinary view of ethnicity and clinical trials

‘IDEA Workshop: Ethnicity and Clinical Trials’, 2011 (Annotated Bibliography)
research

clinical
groups

people

health

socioeconomic

ethnic

inequalities

rates

Black

health

minority

within

associated

make

related

used

example

trial

particular

reasons

specific

decision

clear

research

participants

across

factors

populations

sex

race

disease

Pakistan

power

participate

often

well

experiences

racial

language

high

Health

inequalities

make use

models

significant

particular

patients

throughout

critically

what

mean

interpreted

meaning

important

assess

effects

improvements
Questions

• Can a focus on ‘risk’ and ‘lifestyle’ adequately address social determinants of health?
• Without addressing social determinants can campaigns produce durable change and ‘active patients’?
• If a population is underrepresented in, e.g. clinical trials, who suffers? Who is responsible?
• How can we stop reinventing the wheel?
Researchers are institutionally supported in building in community engagement;

Engaged communities help shape research directions and practice

Evidence of feedback to participant communities is an assessed and monitored outcome.

Funding bodies signpost legal requirement for representative diversity in application forms

*Review panels scrutinise trial populations and rationale for their selection;
*Funding bodies offer ‘turn-key’ educational resources to researchers, supporting inclusion;
*Grants allow supplements for additional costs of inclusion.

Making public engagement count in the research ‘cycle’
And just two more word clouds?

HRA ‘What is a clinical trial’ (for patients & the public) June 2014
An NHS Research Team’s View of Ethnically Inclusive Clinical Trials