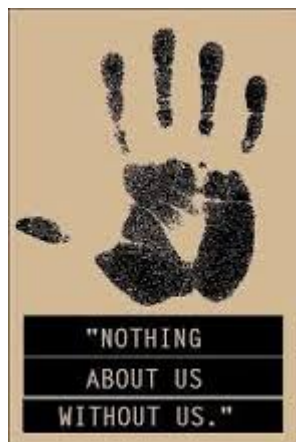


Nothing about us without us

written by Clive Bates | 4 October 2013



I want to give over a guest post to Gerry Stimson, David Dorn and Rick Lines to reproduce their excellent [rejoinder](#) to Professor Martin McKee. This is far more than a richly deserved put-down to the casual arrogance of McKee. It includes a quite fundamental challenge to the health, medical and campaigning organisations that work on 'tobacco control'. Why are they so far apart from the people they are supposedly trying to save or help? I like the slogan adopted by people with HIV/AIDS as they dealt with the huge interests chasing funding, with some bringing abstinence-only or other ideologically driven programmes into the field: [nothing about us, without us](#).

[The response is published on the BMJ website](#), but you can also read it here and comment freely. Let us know what you think in the comments. But please keep it polite!

Martin McKee seems [taken aback](#) the response he has had from e-cigarette users about his [article](#). Perhaps to many of them he appears a remote and unaccountable academic with easy access to influential publications in which he can declare opinions that bear no relation to their lived experience. Maybe they are concerned that McKee wishes to restrict or ban new technologies that they personally have found transformative to their health and welfare. It is easy to see why they may be agitated.

The tobacco control field has been marked by its lack of engagement with smokers. Understandable perhaps given that in the past the main consumer

groups were pro-smoking. The war on the tobacco industry was also a war on smokers. Yet the legitimate concerns of public health advocates about the tobacco industry and its products had the unintended consequence of also marginalising and stigmatising smokers. Electronic cigarettes are the big game changer. And the rise in their use has been marked by the rise of a new social activism by e-cigarette users ('vapers'). User Forums have been building alongside the growth in use of electronic cigarettes, but social activism took off across Europe from the beginning of this year. E-cigarette users are deathly scared about the Medicines and Health Care Products Regulatory Agency and European proposals in the Tobacco products Directive to regulate electronic cigarettes as medicines. They are also outraged that their views have not been considered by the MHRA, Department of Health and the European Commission.

The preamble of the WHO Constitution states that 'Informed opinion and active co-operation on the part of the public are of the utmost importance in the improvement of the health of the people' [1]. WHO Director-General Dr Margaret Chan has referred to 'the power of civil society and the activist community to generate the grassroots pressure that can ignite policy change' [2]. In most public health fields, community engagement is the norm: we welcome it, encourage it, and we learn from it. In AIDS, for example, engagement with affected populations has the highest priority - summed up in the slogan 'nothing about us without us'. This slogan was borrowed from the field of disability and indicates the idea that policy should not be decided without the full and direct participation of people affected by that policy. Martin McKee is surprised by the response from electronic cigarette users. The strength of feeling aroused should be cause for reflection and engagement rather than as McKee puts it 'academic analysis'.

Many public health experts and organisations in the tobacco control appear to have little understanding of the significance of the emergent population of e-cigarette users and their concern for protecting their health. We ignore public health activists at our peril: Michel Sidibé Executive Director of UNAIDS has written of 'the power of civil society to focus and generate transformational change' [4]. UNAIDS documents are replete with statements about 'meaningful and respectful partnership work with civil society'. That doesn't happen in the tobacco control field. Unfortunately, most tobacco control organisations are way behind the curve on e-cigarette consumers and have no strategy for

engaging with these populations. Making light of e-cigarette users ([Martin McKee has tweeted about 'e-cig trolls'](#) [4]), patients, consumers and others affected by public health policies is counter-productive. Mary Robinson Former UN High Commissioner for Human Rights sums it up:

'If only those with power ... would listen and incorporate the experience of those who have first hand knowledge of the reality of the situation on the ground - the results would transform the ideas of leadership and decision-making'.

[Gerry Stimson](#), Emeritus Professor Imperial College London

[David Dorn](#), [Vapoutrails.tv](#)

[Rick Lines](#), [Harm Reduction International](#)

Competing interests: GS was member of the National Institute for Health and Care Excellence guidelines development group on tobacco harm reduction; his company Knowledge-Action-Change has received a smoking research feasibility grant from a company developing a nicotine product. DD runs Vapoutrails.tv which receives advertising from electronic cigarette companies.

[1] World Health Organization, 'Preamble' [Constitution of the World Health Organization](#):

[2] WHO (2008), 'Launch of the Final Report of the Commission on Social Determinants of Health' [[statement to the press](#), Geneva, Switzerland, 28 August]

[3] [UNAIDS guidance for partnerships with civil society, including people living with HIV and key population](#), 2012. Joint United Nations Programme on HIV/AIDS (UNAIDS).

[4] Twitter [MartinMcKee@martinmckee](#) 6 Sept 2013

[5] M. Robinson (1996) 'Empowerment Through Partnership' [foreword] in B. Harbor, P. Morris and I. McCormac (eds) [Learning to Disagree - Peace and Economic Development in Ireland Dublin: UNISON and IMPACT](#).