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# The importance of integrated and participative health-services to public health in HIV

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## Summary

1. HIV is an infectious, behaviourally-driven pandemic. Its acquisition, course, and effects are influenced or mediated significantly by behaviour.
2. Both clinical and public health-services need to address behaviour to achieve the best possible health-outcomes.
3. As clinical and public health's goals are the same (i.e., health), their outcomes should be the same and they should exploit common aspects and methods.
4. As health is biopsychosocial, not just biological, both clinical and public health-services need to be biopsychosocial.
5. Integrating biological, behavioural, and social health-services clinically achieves optimal health-outcomes. It also promotes public health-outcomes.
6. Clinical health-services are a key point of intervention for people with HIV and at-risk of HIV-infection yet clinical health-services are inadequately utilised for the delivery of public health's outcomes.
7. Linking clinical health-services with community-based organisations increases significantly the health-effectiveness of clinical services as well as affecting public health's outcomes.
8. The empowerment of the individual and community through participation in the design and delivery of services is a key requirement of such effectiveness. This promotes ownership of solutions to health-problems, creates generalisable health-protective skills, protects rights, enables responsibilities, and promotes healthy community-expectations and standards.
9. These observations were evident in the era before 1996. We now have even better technologies to achieve these outcomes, but we use them less than before 1996.
10. Reducing patients to dependent consumers — whether in physician-centred clinics or in community-focused organisations — disempowers patients and promotes public health-problems. Solutions that are not owned by the affected patient or the affected community, but are simply delivered to them, are both poorly effective and counter-productive.
11. Empowerment enables health-promoting behaviours and a supportive social context, which happens most effectively through clinical services that use behavioural medicine. Behavioural medicine translates clinical health-outcomes to public health's outcomes in behaviourally-driven illnesses such as HIV.
12. We make three recommendations.

## Recommendations

1. Clinical health-services should be integrated, incorporating both behavioural medicine and social medicine with biological medicine, in order to link up with and augment public health's outcomes.
2. Modifying health-behaviours and community-expectations about behaviours and services require both clinical and community-based behavioural medicine. This should be implemented in all clinics as a primary interventional modality and linked with community-based (not -focused) interventions.
3. Patient-participation should be facilitated at all levels within the clinic and through integration with community-based (rather than community-focused) organisations. Solutions that are not owned by the affected patient or community, but are simply delivered to them as consumers, are both poorly effective and counter-productive.

## Rationale

### Problem

1. HIV is an infectious pandemic requiring direct contact with bodily fluids or tissues. The routes of contact are individuals' behaviours or the medical transplantation of fluids or tissues. The latter is now rare, which leaves behaviour as the almost exclusive mediator of infection. The behaviours in question relate almost exclusively to recreational or reproductive sex (including birthing) or intravenous drug use, which entail a wide range of social determinants of transmission. We monitor behaviours for the purposes of public health (Lansky et al., 2007) but we do not address them in clinical settings where it can be most effective.
2. HIV's burden lies at two levels: the individual and society. The burden on the individual relates to illness, incapacity, and death. The burden on society relates to the cumulative effects of the burden on individuals — such as their inability to work and self-sustain — within the context of societal attitudes and behaviours towards those who have, or are at risk of, HIV. Non-constructive societal attitudes and behaviours amplify the damage caused by HIV to society by promoting inequalities and reducing individuals' social function.
3. Eliminating the HIV-pandemic and its burden on society requires addressing the physical, mental, behavioural, and social determinants of transmission and illness-development. This

means the prevention of transmission and, failing that, treatment of the person with the infection, entailing specifically:

- a. primary prevention of risk-behaviours for transmission
- b. secondary prevention of infectiousness, typically through the use of condoms
- c. secondary prevention of disease-development, typically through the use of pharmaceuticals
- d. the secondary prevention of co-morbidities, including physical, mental, and social illnesses that increase the behavioural risks of transmission, such as infectious load, depressive disorders, and discrimination
- e. the treatment or cure of illnesses
- f. a return to best possible health to break the cycle of transmissible illness

## Current Solutions

1. The interventions that are currently available include social, behavioural, biological, and material technologies. These are rarely considered equally in the planning of interventions or integrated for the purpose of synergy and maximum impact on outcomes in public health.
2. Social technologies for general public health include information on preventive behaviours and technologies (Noar, 2011; Avert) and on pharmaceutical technologies (National AIDS Manual). Information on behavioural technologies is rare in the UK and identifies an undeveloped opportunity in community-focused education and civil capacity-development. Public participation and community-development in the design and implementation of solutions (Trapence et al, 2012) is crucial, and relates also to methods for promoting and managing community- and peer-expectations around health and health-behaviours, paralleled by infrastructural development of resources (e.g., health-services) and the public's access to them.
3. Behavioural technologies for public and clinical health include methods leading to the development of knowledge and understanding, motivation in both clinical and community-settings (Flickinger et al., 2013), clinical and peer-relationships as resources, and self-regulation skills (cf "self-management") in health-promoting and health-protecting behaviours (Swendeman et al., 2009; Millard et al., 2013; Creer, 2005; Brownlee et al., 2005). Behavioural technologies rely on structured approaches to knowledge-transfer and the latter's determinative linkage to individuals' health-behaviours, including:
  - a. monitoring of risks (including behavioural) and signs and symptoms of illness

- b. accessing resources, including health-focused technologies (e.g., online resources, mobile apps), health-services (Corless et al., 2012), and community-resources (Jackson et al., 2005; Webel et al., 2013)
  - c. clinical participation in jointly-owned clinical solutions, including case-formulation based in meaning and motivation for patients through participative and shared goal-setting; personalised treatment-formulation, including enablement of adherence (Free et al., 2013); personalised and participative monitoring of treatment-effectiveness; personalised and participative rehabilitation, from physiotherapy to vocational rehabilitation
  - d. community-participation, including sharing in discussions to increase awareness and understanding of issues; taking part in focused community-development and capacity-building; participating in health-services' development, delivery, and audit, as well as participative policy-development up to the national level (Whitaker, 2010)
4. Biological and material technologies include supportive/non-curative antiretroviral pharmaceuticals for primary treatment as well as surgical and pharmaceutical technologies for secondary treatment; chemical preventatives (cf. "treatment-as-prevention"); and material preventatives, such as condoms, microbicides, sterile needles, and decontaminants.

### Problems with the current solutions

1. There are significant problems with the application, usage and, therefore, effectiveness of such technologies.
2. Social technologies in themselves (e.g., information) are inadequate to achieve prevention and health. Even when supplemented with knowledge of preventive behaviours and access to preventive resources, there are problems with these latter's access and uptake (Gormley et al., 2011), problems with effective usage, and problems with maintenance of use (Adam et al., 2005).
3. Biological and material technologies, despite the evidentially unwarranted reliance on them and their excessive costs, suffer from the same problems of access and uptake (Ulett et al., 2009), maintenance of use (cf adherence: Wolf et al., 2007), and of effectiveness in real-world settings, as shown by DALYs, HEALYs (Hyder & Morrow, 1999; 2002), QALYs (Holtgrave & Pinkerton, 1997), or any outcomes in reference to the WHO definition of health (Breslow, 1972). Likewise, the health-inequalities that drive transmission and the need for biological technologies are not resolved by these technologies. The availability of biological technologies such as pharmaceuticals and chemical preventatives is inadequate to achieve prevention, treatment of primary or secondary disorders, or optimal health (World Health Organization HIV / AIDS Programs, 2013).

4. The integration of social and biological technologies is typically limited to the provision of information about, e.g., the nature of pharmaceutical products. When behavioural technologies are involved, it is typically limited to providing information (social tech) on how to use (behavioural tech) medications (biological tech), even though we know information does not translate into the appropriate behaviour automatically. Campaigns for dietary change are a good example of this.
5. This lack of translation occurs in all segments of society and is explained by the inherent inadequacies of the technologies, not of the users of those technologies.
6. Characteristics of the providers of the technologies provide further obstacles to the success of technologies, including a lack of competence to provide and use technologies properly (e.g., physicians providing information in a way that a patient can't use) and having obstructive attitudes (e.g., physician-attitudes towards non-biological technologies).
7. Characteristics of the users provide yet further obstacles to the success of technologies, including related personal ill-health, such as a lack of necessary cognitive and affective resources: substance abuse, depression, loneliness, ignorance.
8. Characteristics of the social context of the technologies and related social ill-health provide yet further obstacles to the success of technologies; e.g., stigmatising cultural and religious attitudes, nonprofit organisations' bureaucratisation and disempowerment of the beneficiary communities, and communities' attitudes (e.g., apathy).
9. The conclusion is that no single type of technology is effective in achieving any goal, be that illness-prevention or health-recovery. The technologies need to be integrated for greatest effect.

### Next-generation and last-generation solutions

1. The primary elements missing in these solutions are the behavioural technologies, in how they link up both the social with the biological and material technologies, and also link up the goals of the clinical health-services with the public health-services.
2. Solutions require both population-focused (public health) and individual-focused (clinical health) services. These solutions also require — absolutely — the participation of the affected communities in achieving the elimination of HIV's burden on individuals and on society. Both pharmaceuticals and public health information that are not used properly are of little use. To have them used properly requires the understanding and skilled participation of the individuals affected.
3. To be effective, information needs to be translated into knowledge and understanding within given individuals, then put into skilled practice in an environment that supports and validates that practice. This is true for both public health-services and clinical health-

services. The development of such knowledge, understanding, and skilled practice requires expert enablement, which typically occurs best in clinical or similar settings, through the application of behavioural medicine by fully-qualified providers.

4. Behavioural medicine is the practice that bridges both public health with clinical health, as well as biological medicine with social medicine. It facilitates the integration of public health interventions in clinical services. This is especially needed and effective in chronic conditions that are driven or maintained by behaviours. Thus, it is the key to success in linking up changes in individuals' health-behaviours with changes in population-health.
5. All HIV-transmissions require behavioural interaction with someone who already has HIV, whether they know it or not. A significant proportion of people with HIV use clinical services, even before they receive a diagnosis of HIV; likewise, a significant proportion of people most at risk of HIV use sexual health-clinics. It makes sense to integrate behavioural medicine and social medicine with biological medicine in clinical services. To date, there are no services that do this in London.
6. This proposal has precedent. The community led the response to the HIV pandemic, creating a linkage between clinical health-services and ASOs (Shilts, 2011; Guaraniere & Hollander, 2006; Power, 2011; Pimenta et al., 2011; Triquett & Pequnat, 2005; Brown, 1997; Stockdill, 2003; Epstein, 1996). This was evident pre-1996 in the presence of ASOs within the clinics, taking part in both the design and delivery of service-pathways, case-formulation, and integrating treatment-delivery across social, mental, behavioural, and physical domains (Porterfield et al., 2012). It was significantly nurse-led although generalist-physicians' practices (being privatised practices) were largely excepted.
7. Rates of transmission of HIV flattened from the mid-1980s through to 1996 (Health Protection Agency, 2012; p.7), when antiretroviral pharmaceuticals became available and the physician-centred model (the 'medical model') of services resumed, which had been abandoned pre-1996 in favour of a more integrated model, due to its lack of effectiveness in the absence of antiretroviral medication.
8. This linkage pre-1996 resulted in both better clinical health-outcomes, within the severe limits of a service-model lacking antiretroviral medication, as well as much better public health-outcomes. These outcomes relied on the fact that the community-based organisations were an inherent part of the response to the pandemic and they formed a major translational bridge between services to the individual and services to the affected population, linking up clinical with public health-goals.
9. This last-generation model holds the promise for the next-generation model. Social, behavioural, and biological technologies have advanced as have the models for integrated services, including the integration of behavioural medicine (Cummings et al., 2001;

Cummings & O'Donohue, 2011; O'Donohue et al., 2005; O'Donohue et al., 2006) and social medicine (Mancoske & Smith, 2004; Poindexter, 2010; Willinger and Rice, 2012).

10. The rise in transmission-rates post-1996 reflect the re-emergence of obstacles to service-outcomes, including the re-imposition of physician-centred services, the disempowerment of the public through exclusion from participation by both health-services and increasingly bureaucratised organisations that are no longer community-based but community-focused. Former participants are disempowered and reduced to consumers, community-expectations about personal responsibilities have lowered, and dependency on medications as the answer to social and behavioural problems is promoted, with negative effects on health-outcomes. There has been a loss of vision about joining up the dots, resulting in poorer health-outcomes and reduced effectiveness of services that have been increasingly fractionated.
11. We know already how to do things better and this is encapsulated in the recommendations above.



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