



Tuke Institute
FROM HUMAN SCIENCE TO MEDICINE

Evidence submitted to the House of Lords'
Select Committee on HIV and AIDS in the UK

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Summary

The Tuke Institute is an organisation of scientists, service-providers, and organisational-development professionals pursuing scientific research, policy, and civil capacity-development to create truly patient-centred medical services with the focus on health-effectiveness. It uses these methods to promote solutions to problems in the delivery of services in medicine and medical science and focuses on new methods of promoting and enabling civil participation in the design, delivery, and governance of such services. The fundamental goal is to make medicine about what ill people need to get well and to stay well.

HIV-related illness in the UK continues to be a significant burden to the public in terms of its financial, social, and personal costs. Despite the obvious fact that the HIV pandemic is driven by behaviour, expertise in behavioural science and behavioural medicine is inadequate or even absent in all areas of policy and service-delivery, and policy-setting is often a function primarily of political considerations within professions or provider-organisations, with the evidence-base informing these as a secondary concern.

There is also a primary problem in the lack of public participation in policy-setting, service-delivery, and governance, which relates to the themes common across all problem-areas: of complacency, a loss of vision, and a lack of leadership, particularly fresh leadership.

This submission consists of an expert opinion that identifies a number of problems and both individual and systemic solutions thereto. These include the development of:

1. an organisation that can represent the interests of people with HIV in terms of medical (including social) and scientific services delivered on behalf of people with HIV to people with HIV
2. Health-Outcome Delivery Standards for medical services, so that the health-effectiveness of medical services can be measured in reference to how they help people with HIV live healthy and productive lives
3. integrated medical services in reference to Health-Outcome Delivery-Standards that address the comprehensive physical, mental, and social health-needs of people with HIV, facilitated by case-management, to which behavioural medicine is key and which have been shown to be cheaper than the current physician-centred model
4. a new framework for HIV prevention, focusing on health-effectiveness and the measurement of health-outcomes in both those with HIV and those at risk for infection
5. a common and consistent message and approach for public education about HIV, to avoid the systemic problems inconsistent messages have caused to date
6. new means of public participation so as to ensure representativeness of solutions
7. a review of the representativeness of civil and provider-organisations in service-delivery generally and in medical practice and in scientific research in particular.
8. a blue-print for translational science in HIV research so as to ensure the validity and value of funded research done for the public benefit, including a system for surveillance of illness-burden and health-outcomes in HIV treatment
9. a coherent policy on criminalisation that might shift it from criminalising HIV-transmission to criminalising disability-discrimination
10. a strategic 10-year plan for a coherent, national response to HIV in the UK.

These solutions would facilitate great progress towards a modern and cost-effective national response to HIV in the 21st century and refresh the vision and model that HIV provided historically for the response to other costly chronic illnesses that burden society today, including breast cancer and neurological disorders.

Signed: 

Dr. Rupert Whitaker
Executive Chairman, on behalf of the Tuke Institute

Dated: 18.02.11

Monitoring

1. Monitoring systems in the UK are among the best globally in terms of surveilling the incidence and prevalence of HIV-infection.
2. The knowledge of HIV-prevalence and of the dynamics of HIV-transmission in the UK has never informed the size of the prevention-programmes, reflecting a lack of political will in funding and/or a loss of knowledge-translation from science to policy.
3. Despite the current excellence of surveillance systems of this sort, there is also a lack of knowledge of how to translate such good data into effective interventions, due in part to the failure to use the expertise of social and behavioural scientists in developing evidence-informed interventions in a coherent and national programme.
4. There is no adequate surveillance of illness-burden: i.e., how HIV affects the ability of people to live healthy lives or not. Such systems exist in other countries for certain chronic conditions. These data are essential if services for HIV are to be designed to deliver health-outcomes and the services are to be bench-marked and assessed for health-effectiveness and cost-effectiveness. Most assessments to date have been small-scale surveys initiated by community-groups that have then been used for advocacy and have entailed significant struggles with service-providers. Large-scale surveillance needs to be implemented.
5. Surveillance systems of this type need to use metrics that are also used in the clinic, also requiring a change in the way clinical services are delivered and how 'health' is defined as something more than a suppressed viral load and CD4 counts above 400. This means a new effort to join up public health with medical services in order to create more efficient synergy towards health-outcomes.

Prevention

1. Prevention is conceived primarily as a public health (i.e., population-level) issue, rather than being equally a medical (i.e., individualised) issue. Furthermore, it is framed almost exclusively in terms of primary prevention: i.e., preventing uninfected people from becoming infected. Secondary prevention—of infected people becoming ill from related or unrelated illnesses—is not adequately conceptualised or implemented and this needs to be remedied.
2. Most people at risk of HIV-transmission are seen already by medical services and the translation of knowledge about prevention into clinical practice remains an unsolved problem. Prevention-efforts provided by clinicians in the UK are widely considered to be ineffective. This may be reasonably ascribed to the lack of trained competence in behavioural medicine and a lack of comprehensive services to back prevention-efforts up and to make them credible to recipients.
3. The targeting of interventions to specific groups (i.e., in public health) or specific individuals with certain risks (i.e., in medicine) is necessary. Yet, within public health, there is a need to recognise that there is no community as such within at-risk groups, especially following the introduction of effective pharmaceutical management in 1996 and the collapse of the gay community's participation in the response to HIV. Stereotyping of people with HIV as though we are behaviourally homogenous, due to a purely epidemiological perspective, has led to poor policy, poor decision-making, and inadequately sophisticated interventions. Social identity is not a predictor of community-identity and individuals can span communities; other at-risk groups have never had a community as such yet are still amenable to interventions based on social-group—e.g., injecting drug-users. Targeted interventions need to be responsive to these realities. The lack of expertise in social and behavioural sciences in understanding diversity of target-groups for prevention has hindered the design and efficacy of interventions through poor knowledge-translation.

4. The role of business in facilitating the effectiveness of interventions is underestimated. In the gay ‘community’, businesses have the greatest potential for impact on prevention. Yet professional, paraprofessional, and even some community-based organisations do not engage with them.
5. There has been a failure to deliver a balanced and consistent prevention-message to the public through a problem of competing and incompatible interests between public health and medicine, neither of which has helped meet the needs of people with HIV in the long-term. The first message has emerged through an effort to use public health to reduce discrimination, such that “HIV affects everyone”. Data are interpreted in such a way as to meet the needs of the media and the funding bodies, due to a lack of governmental leadership in curtailing discrimination through more direct (i.e., legal) means. The second, conflicting message is that ‘HIV is easy to treat’, which promotes a pharmaceutical solution to the socio-behavioural problem of HIV-transmission, a misperception that HIV is curable, and has thus led to increasing costs through a failure to integrate preventive interventions with medical services. A consistent and rational approach to responding to the problems of HIV needs to be developed.
6. Prevention and treatment requirements have become much more complex, but many conceptual frameworks are still essentially the same as in the 1980s, despite the use of newer technologies. First, ‘harm-elimination’ ceded to ‘harm-reduction’ as a framework; this should now move towards the more comprehensive framework of health-effectiveness encompassing prevention, diagnosis, treatment, and rehabilitation and resulting in meaningful health-outcomes, not simply the avoidance of HIV-transmission.
7. Rather than being grounded in scientific evidence within a health-effectiveness framework, prevention has moved instead to the lowest common denominator typical of the NHS: commercialism and commercial methods that promote the balkanisation of services through out-sourcing. It is symptomatic that, for example, within the now-quasi-commercial organisation, the Terrence Higgins Trust, of which I am deeply proud to be a Founder and Patron, prevention services are organised under Marketing. This is indicative of the challenges facing this sector and of the distance we have to travel in order to put the affected communities first.
8. Using more modern techniques (e.g., social media) does not mean that the techniques are more effective; the use of fashionable methods without understanding the theoretical and determinative issues in achieving and measuring health-outcomes means that such methods are often little more than good PR. The lack of expertise available in scientifically measuring health and health-outcomes in both public health and medicine (i.e., at multiple levels of the problem) is a primary concern. Again, measuring these factors is an area of expertise exclusively within behavioural science and behavioural medicine and input in these areas of expertise are lacking.
9. It should be noted that pharmaceutical companies have “health-outcomes” experts; however, these individuals are almost exclusively economists, measuring cost-outcomes, which are quite different from health-outcomes. The latter refer to how well a person is, how able s/he is to live a healthy life filled with meaningful activities of daily living, not the offsets of financial costs in medical services provided by the use of a commercial product. This confusion is an unfortunate result of PR-initiatives by commercial providers in selling their products to commissioners without adequate input from behavioural and social scientists and without awareness of critical theory in medicine and health. Again, this points to a need for the input of scientists—not just technical researchers.

Testing

1. There are very significant problems in the uptake of testing for HIV-infection. The uneven and less than wholly salutary response to HIV in the 1980s created an approach to HIV that we are still struggling with, primarily with the problem of discrimination on the one hand and the perception that HIV-infection is trivial on the other (*vide supra*).
2. The “Halve It” initiative is an excellent and notable one with broad support, aiming to reduce the number of people diagnosed with HIV when they have already progressed to AIDS. Again, an emphasis on introducing social and behavioural science into policy and delivery-formulation is necessary in order to deliver the hoped-for outcomes.

3. A synergistic initiative should focus not solely on reducing the number of late diagnoses but on reducing the time between infection and diagnosis in those, particularly, who acquire HIV within the UK. This latter is yet another issue within the purview of behavioural medicine, as it relates to self-managed health and awareness of symptoms and behaviour within the affected.
4. Similarly, programmes promoting testing need to communicate the benefits of diagnosis as early as possible, consonant with the emerging framework of health-effectiveness. However, these benefits need to be more than just the availability of pills.
5. A primary problem lies in getting clinicians to adhere to standards and to change their behaviours within clinical practice. Creating incentives in both public and providers is a behavioural issue and is amenable to expertise held by applied behavioural scientists (e.g., organisational health psychologists) and clinicians qualified in behavioural medicine. Thus, interventions need to be targeted to both the public and to providers, to ensure the latter's adherence to testing-guidelines.
6. Criminalisation of HIV-transmission is counter-productive and socially damaging. As with many others in positions of responsibility—politicians, for example—deniability of knowledge is a tool for self-protection; for someone at risk of having HIV infection, this means avoiding testing. Criminalisation may have a role in the response to HIV (*vide infra*: “Stigma”), but not in reference to HIV-transmission and personal responsibility.

Treatment

1. It is significant that the health of people with HIV is not cited in the call for evidence, only treatment. This may reflect a belief that, as long as a person's viral load is controlled and his/her CD4 count is above a certain level, then that person will be healthy. Relatedly, a prevalent perception that HIV is simple to treat and is even curable: all one has to do is take some pills. Neither is true.
2. A related perception is that people with undetectable viral load and a CD4 count above 400 are therefore fit to work. In tandem with the fact that the Department of Work and Pensions' process of assessment for Disability Living Allowance is not based on clinical judgement of function but on a legal definition of disability, it is clear that the reality of living with HIV in designing and delivering health-effective services is inadequately considered.
3. These perceptions are grounded in the failure to deliver a balanced and consistent message to the public about the nature of living with HIV and are typical of a physician-centred approach to clinical services. Physician-centred medicine as a service is defined by what physicians do rather than by what people suffering from illness need in order to get and to stay well. “What physicians do” may be characterised by the diagnosis of physical disease and the prescription of pharmaceutical products or surgery for the resolution of that disease. However, corollaries of this definition of medicine are: that only the services that are provided by a physician are actually necessary to create health; if a disease is treated, then the person is necessarily healthy; and, if a physician has provided his services, then either the patient is healthy or the condition is not treatable. There are decades of critical literature on this approach and definition of medicine.
4. The diagnosis and treatment of physical diseases does not necessarily include an inability to assess or treat losses of function that result from those disorders. Losses of function relate to illness in a person, rather than disease in a body and getting people well requires addressing the person, not just their body. Physician-centred services (as provided by both general and specialist clinics) are inadequate to help meet the challenges of living well with chronic conditions in general, due to the pervasive and enduring effects that such conditions have on physical, mental, and social ('biopsychosocial') function and the way in which they interact. Consequently, health-effective services need to reflect the needs of the person in overcoming the consequences of disease, not just the presence of disease.
5. Relatedly, there is a pervasive culture of amateurishness in service-provision: competence in the clinical delivery of both primary and secondary prevention can not be taught on a weekend course attended by clinicians acting outside

their area of professional expertise any more than the competent prescribing of pharmaceuticals for HIV can be taught to hospital porters by their attending weekend courses. The issue of physician-centredness underlying this problem is the same as that underlying health-ineffective medical services generally.

6. HIV as a condition (not just an infection) is managed health-effectively—and therefore cost-effectively—by a comprehensive service-model that includes behavioural medicine, nurse-led clinics, case-management, and integration with social services. Such integrated, biopsychosocial service-models have been shown in American research to deliver highly significant savings in financial costs. It is also noteworthy that this research on cost-savings has been done in the privatised system of American medicine; a partially public system of medicine such as the NHS provides could be expected to deliver even greater cost-savings due to its potential for integration with publicly-owned social services.
7. Prior to the introduction of effective pharmaceutical management of HIV infection in 1996, various low-level versions of a biopsychosocial service-model had emerged and relied heavily on the participation of the affected public in providing services of this type. After 1996, in tandem with the collapse of the gay community's participation through burn-out, the physician-centred model regained precedence with a consequent loss of many of the medical and public health gains achieved prior to 1996.
8. The problems caused by physician-centred practice has resulted in costly and unnecessary secondary problems such as co-morbidities and excess disability, which have left individuals in desperate situations that have been amplified by their lack of access to adequate community-based services as these latter have become increasingly commercial and balkanised.
9. The balkanisation of services (i.e., where they are neither comprehensive, integrated, nor co-localised geographically or temporally) promotes loss in follow-up and reduced health-effectiveness, and this is amplified by a pervasive lack of case-management.
10. Commercialism has occurred due to the absence of any significant vision or leadership and the loss of valid community representation and participation in service-design and -delivery. As with prevention, a commercialist approach has resulted in organisations cherry-picking services that maximise their funding streams without reference to a larger plan for meeting the needs of people with HIV.
11. Providing over-the-counter tests and cost-defined pharmaceutical management has a negative effect on the government's ability to deliver adequate health-outcomes, especially when it is viewed by providers or the public as a replacement for health-effective medical services.
12. It is expected that the physician-centred model will be promoted by the new GP-based commissioning framework set out in the British Government's White Paper "Equity and Excellent: Liberating the NHS". A short critical analysis of these problems in terms of a failure of patient-centred practice and health-effectiveness has been published by the Tuke Institute (Reference 1). Most obviously, the problem of physician-centred practice and its relatively poor health-effectiveness will be promoted.
13. While it is inevitable that some services for HIV will be delivered in primary medical practice (be that physician-centred or biopsychosocial), it is important to consider other models such as the provision of general medical services within a specialist unit. Scientific research needs to be done on the health-effectiveness of all service-models and should form part of a rational and evidence-based approach to the design and delivery of medical services in HIV. Such models should be developed on the basis of Health-Outcome Delivery-Standards.
14. Health-Outcome Delivery-Standards—i.e., standards of services that are developed in reference to what a person with a chronic condition needs in a clinical service in order to get and stay well—have not been developed to date, only treatment-standards for disease, such as the British HIV Association (BHIVA) Standards and the NHS Quality Improvement Scotland Draft Clinical Standards for HIV Services (References 2 and 3). These are symptomatic of the core problem, reflecting physicians' perceptions of what people with HIV need and on what physicians deliver, and based on a purely NHS model of what can be done within the current organisational design rather than what needs to be done, and without reference to the reality of living with HIV or to the relevant scientific evidence base in social and behavioural sciences or in social or behavioural medicine. Clearly, more meaningful standards need to be developed.

Cost

1. In a nationalised system of universal medical services, one can not consider cost-effectiveness without reference to health-effectiveness.
2. Cost-assessments must include financial, social, and personal costs of programmes or their absence. Purely financial assessments are no longer credible, even when illness-burden is translated into financial losses to society.
3. Financial costs, most obviously, are driven by behaviours that cause new HIV infections and promote illness, that reduce the effectiveness of pharmaceutical management of infection through inadequate adherence or other behaviours that complicate pharmaceutical management through co-morbid infections, and—most importantly—by a failure to help people with HIV become and/or stay healthy. Costs are of immediate concern due to the rationing of services.
4. A physician-centred model of services is known to be poorly health-effective and also poorly cost-effective. Comprehensive, integrated services reduce the need for medications and increase their efficacy, thereby reducing unnecessary financial and social costs and extending the reach of budgets in providing services to an expanding patient population.
5. In terms of current surveillance practices, it is not possible to judge the adequacy (and therefore cost-effectiveness) of services in public health or medicine using just indices of incidence, prevalence, morbidity, and mortality. All cost-analyses should be based in auditable health-outcomes as part of medical records gathered by a national system of surveillance. Such health-outcomes need to relate to credible clinical measures, not administrative or legal ones.
6. Short-term approaches to funding, framed by the needs of the financial controllers in government at all levels, has been counter-productive in developing long-term solutions. Provider-organisations are therefore reactive, not proactive and solutions are typically based on consumerist models (e.g., patient-choice, market-surveys; customer-service approaches to complaint-handling), rather than health-effective models (i.e., comprehensive, integrated services). This increases costs by reducing the effectiveness, sustainability, and reach of solutions.
7. A failure to ground services in the needs of people with HIV in reference to an overarching and evidence-informed framework—and to maintain it through participative governance—means that the only way to change service-delivery is to shut down particular services provided by one organisation and start them up again through another organisation. This is burdensome to people with HIV and incurs undue financial and social costs in the long-term. Participative governance is a method to prevent this, if suitably implemented.
8. Research and research-funding is considered separately, below, and is considered separately from surveillance-research.

Scientific Research

1. There is a general lack of adequate scientific expertise used in applied research into HIV in the UK. Much clinical research is methodologically low-level and, cost-wise, consists primarily of me-too pharmaceutical trials that translate poorly into health-effectiveness of services
2. Phase-IV (post-marketing) studies of pharmaceuticals are inadequate and often absent, especially in reference to long-term outcomes. This results in a reduced health-effectiveness of services and, thus, excess financial, social, and personal costs when people become sick from medications. The majority of illness in HIV requiring medical attention is related directly or indirectly to the toxicity of medication, although this is not necessarily the cause of most financial costs.

3. Other research is often akin to market-research and provides results of questionable scientific rather than political value. The exceptions are the methodologically rigorous research by Sigma and, increasingly, research done in partnership by civil and scientific organisations.
4. There is a common perception that a low-level, undergraduate education in a field of science (e.g., physiology) provides an adequate view of the theoretical and methodological issues in translational science and policy-setting. There is a related failure to understand the difference in training and expertise between clinicians, research-clinicians, clinician-scientists, clinical scientists, applied scientists, and basic scientists, with an assumption that they are interchangeable. This allows professional politics to dominate the way in which policy is framed and set; hence the reason why we have bodies informing medical and public health priorities formed primarily by physicians—rather than by qualified scientists and policy-makers assisted by consultative input from clinicians as one among several providers.
5. A review of all the bodies considered to address the needs of people with HIV (BHIVA, CHIVA, NHIVNA, MedFASH, THT, NAM and AIDSmap, EAGA, IAGSHH, etc.) suggests a worrying lack of qualified scientific input, particularly in the social and behavioural sciences. In some—e.g., EAGA—there has been overt resistance to the inclusion of social and behavioural scientists due to the lack of fresh vision and leadership. In most, there is also a lack of input from a balanced sample of clinicians, including nurses, physicians, psychologists, and social workers. It is worth noting that the National AIDS Trust is an exception to this rule in general due to the way in which it develops *ad hoc* expert consultation.
6. Such groups represent the perceptions of the constituents and funders—i.e., physician-groups promote physician-centred solutions, nursing-groups promote nursing-centred solutions, etc. Relatedly, the pervasive political need for physicians' buy-in biases the outcomes of policy-setting away from the needs of people with HIV and becomes, once more, about physicians' needs. This is why the model of clinical services in the UK is not based on current scientific knowledge and may be said to be at least two decades behind leading-edge service-designs in the USA.
7. A comprehensive review of the translation of HIV-research from patient-needs to science and back to patient-needs is necessary to create an adequate blue-print for research that can deliver health to people with HIV and at-risk for HIV. An overview of such a framework for health-research in general, predicated on the delivery of public benefit, has been published by the Tuke Institute (Reference 4) and relates to work done by its Executive Chairman for the National Institute for Health Research in designing a national clinical research infrastructure that delivers public benefit and ensures translation from science to health-outcomes. A similar one needs to be done for HIV. Needless to say, it should be led by qualified scientists not just clinician-researchers.
8. Such a blue-print would allow a more reasonable assessment of the prioritisation of funding into research, and in relation to the quality of research, than is feasible now.

Stigma

1. The burden of stigma (as an experience or a perceptual filter on others) has reduced over time generally, but it is still very high within black African and West Indian communities. The separate burden of the discrimination as an overt act has remained unacceptably high throughout society.
2. The failure to implement appropriate methods to prevent discrimination has meant that criminalisation has been allowed to emerge and cause significant problems. Relatedly, there is a lack of access to justice in instances of discrimination, as it requires being able to pay for legal services in order to uphold the law; when the majority of instances of overt disability discrimination in employment, for example, do not even come to the notice of the legal system and when a typical incident can cost £30,000 in legal fees, it is reasonable to say that the current protection against disability discrimination is tokenistic at best.

3. Similarly, the lack of a coherent and credible policy on the immigration of people who have or may have HIV is counter-productive to national efforts to address the problem of HIV. This requires political leadership informed by vision within the communities affected.
4. The majority of stigmatisation experienced by most people with HIV currently continues to be within medical services; for instance, long-term survivors who have a history of participation dating from pre-1996 are called pejoratively “professional patients” by physicians while efforts by affected communities to create patient-advisory boards have met with significant resistance by clinical providers. This has fed into the problem of physician-centred services noted above.
5. Discrimination against people with HIV can not be separated from discrimination based on related social issues, such as ethnicity, sexual orientation, or indeed other unrelated medical conditions. For example, in the Kobler clinic in London, gay and lesbian patients seeking assisted conception services to raise a family have been told to go abroad “where they don’t care so much about child-welfare”; only heterosexuals are allowed access to assisted-conception services. There is no significant recourse in these instances and they form part of a larger and pervasive problem of the blaming of patients for shortcomings within providers and of overt discrimination.
6. Blaming ‘others’ and dis-identifying with people who have HIV is a primary causative problem in stigma and discrimination; initiatives promoting the criminalisation of HIV-transmission have amplified this. Marketing-based health- and welfare-promotion is unable to address this and a new framework is needed.

Participation and Representation

1. Any review of the state of the response to HIV in the UK needs to emphasise the need for both participation by and representation of the affected part of society. British governmental initiatives have slowly moved towards participatory values, although participatory democracy has a history of over half a century. The value and methods of such participation has also developed significantly over this period and new frameworks—such as the Big Society—represent efforts to expand its reach. While public participation in the formulation and delivery of civil services has struggled most in the areas of medicine and medical research, it has an essential function in creating meaningful and useful services to the public.
2. Public participation lies in three distinct but linked domains: participation in clinical and scientific practice; participation in the review of such services, including in their audit and governance; and participation in commissioning and policy, right up to the national level. A thorough review of this and its role in delivering health-effective medical services has been published by the Tuke Institute along with a briefing on the role of public participation in science (References 5 and 6).
3. There is no credible participation in the audit and governance of any clinical HIV services. This is generally true also of educational, research-, and outreach-services too, although rare instances may exist.
4. As noted above, most of the bodies considered to address the needs of people with HIV (BHIVA, CHIVA, NHIVNA, MedFASH, THT, NAM and AIDSmap, EAGA, IAGSHH, etc.) do not receive input that is actually representative of the needs of people with HIV. Despite the positioning of some highly knowledgeable and experienced advocates on various boards, it is not possible to ensure that these bodies represent the needs of people with HIV due to the lack of comprehensive medical and scientific input as to what those needs are. Furthermore, many such advocates labour against tokenism, especially in clinician-dominated groups, due to problems of stigmatisation and discrimination (see above).
5. The move towards quasi-commercial service-provision by non-profit sector bodies has resulted in a lack of access by people with HIV, a consequent lack of representativeness, a lack of responsiveness to their needs, and services no longer being driven by those needs but purely by funding priorities—priorities that are set in the first place by organisations with non-representative involvement in funding bodies.

6. As a consequence of these factors, there has been a significant move towards quasi-commercialisation and balkanisation of services within a franchise-model, a lack of integration of service-delivery across the sectors, a lack of collaboration, and competitive monopolisation of funding-streams by providers rather than a broader civil capacity-development and skills-transfer across a variety of organisations. This means that the geographical location and type of services available are constantly changing and can shift dramatically in the face of funding-losses to the leading organisation providing a particular service. This causes excess burden on people already living with a burdensome illness and can result in the failure to access necessary services for long-term health, which is financially and socially costly. Appropriate methods of public participation can prevent these problems from occurring.

Systemic solutions

It is unhelpful to identify isolated solutions (as above) without reference also to larger, systemically effective solutions; individual solutions are inadequate because no problem exists in a vacuum. Systemic solutions include the following:

1. The development of an organisation that can represent the interests of people with HIV in terms of medical (including social) and scientific services delivered on behalf of people with HIV to people with HIV. Such an organisation would have three themes:
 - 1.1. a civil capacity-development theme, that develops a representative and advocacy-oriented body for all people with HIV and provides scientifically sound (not market-survey) evidence to inform policy in medicine and public health. The Tuke Institute has developed a model for this.
 - 1.2. a medical theme that provides a balanced representation of services focusing on health-outcomes; this would mean scientists and policy-experts working in consultation with primarily nurses, physicians, psychologists, and social workers equally who have expertise in providing services in the clinic and in the community to the young, adult, and elderly. Providers with HIV themselves have a special role in such an organisation as they bridge the experience of being a patient and being a provider (be that a scientist or a clinician). Here, it is worth noting that 'science' is used in its original, continental sense that includes all the human sciences, not just the biological, behavioural, or social sciences.
 - 1.3. a civil health theme that focuses on developing common and targeted interventions in public health, civil policy (e.g., on immigration), and consists of scientists, educators, media-professionals, lawyers, etc.
 - 1.4. This organisation would be built on thorough participation by the HIV-positive public and be governed participatively by HIV-positive advocates with expertise in HIV-related scientific, medical, or civil health themes.
2. This organisation would replace the stated need for professional advocacy bodies such as BHIVA, CHIVA, NHIVA, etc., and for advisory bodies such as EAGA, etc. but not service-providers or independent policy-organisations. The remit for such a task, with sufficient funding, could feasibly be given to the National AIDS Trust as the only independent organisation with evident expertise in policy in tandem with a comprehensive approach. Its primary products would include:
 - 2.1. Health-Outcome Standards for medical services to people with HIV, including those relating to disability and its assessment; the purpose of this would be to frame medical services in terms of what people need to get and/or stay well with HIV and would be informed by international evidence.
 - 2.2. Standards, methods, and policy for public participation in medical and scientific HIV services, including in audit and governance so as to ensure the continuing relevance and adaptiveness of putatively representative organisations.
 - 2.3. Standards, methods, and policy for the design and delivery of medical services in reference to §2.2

- 2.4. Standards, methods, and policy for the design and delivery of public health services in reference to §2.2 and §2.3; this would include sizing public health programmes according to need.
 - 2.5. Standards, methods, and policy for the design and delivery of scientific services in reference to §2.2, §2.3, and §2.4, delivering a blue-print for translational scientific research and ensuring that both advocacy and policy are based on adequate reasoning and evidence.
 - 2.6. Standards, methods, and policy for civil capacity-development among community-based organisations, including service-providers of various sorts; this would include a review of the value and design of service-delivery organisations in the civil sector and might recommend, for example, the separation of service-providers from advocacy functions in needs-assessment and priority-setting, due to conflict of interest.
 - 2.7. Governmental policies, such as a credible, balanced, and humane immigration policy in order to enhance prevention and testing up-take; policy on the role, if any, of criminalisation in HIV—e.g., in disability-discrimination—ensuring the government takes responsibility for addressing discrimination by moving it, for example, from the category of a luxury-law (i.e., for those who can afford civil litigation) to a criminal one in certain or all instances; etc.
 - 2.8. A 10-year strategic plan for a coherent national response to HIV, drawing together all these strands.
3. In the absence of the development of such an organisation, the following should be developed independently as a priority:
 - 3.1. Health-Outcome Delivery-Standards
 - 3.2. policy on the design and delivery of health-effective medical services
 - 3.3. a blue-print for translational scientific research in HIV, in reference to the Health-Outcome Delivery-Standards
 - 3.4. a large-scale surveillance system of health-outcomes in HIV, in order to assess illness-burden and inform policy-setting and funding. The metrics need to be based in measures that are used clinically, which requires a shift in the model of delivery of clinical services as physician-centred practice is unable to provide this.

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