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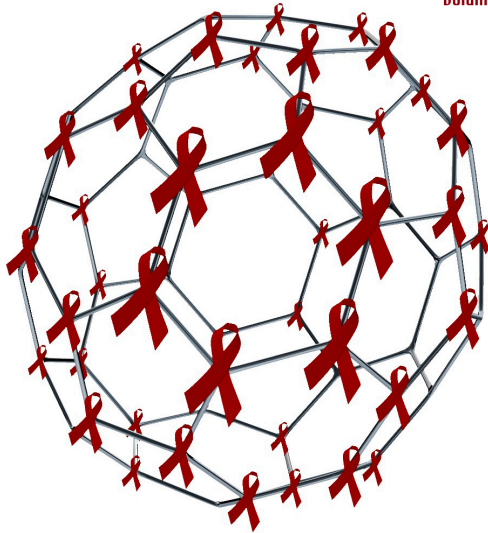## Playing public health: building the HIVe

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The HIVe

Prevention is a Solution !

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Epilogue

Playing public health: Building the HIVe

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Epilogue

Playing public health: Building the HIVe

Thomas Apperley & Christopher S Walsh

Abstract

In thinking through the impact of digital media on how frontline workers, activists, practitioners and researchers understand and fight HIV and AIDS, it is important to acknowledge that digital media does not only provide new channels and strategies for communicating information around HIV prevention and education. It also establishes innovative domains for conceiving of, and building, 'resilient communities' like The HIVe. Such digital interventions are cultural assets that confront biomedical and behavioural approaches to HIV prevention and education. Immersive and social technologies, network ubiquity and low cost mobile phones provide new tools for aggregating, representing, collecting and disseminating community-based and led data that 'plays' public health differently. This play involves fore-fronting the success of social science HIV prevention and education against the essentialist logic of dominant biomedical approaches. 'Playing public health' provides an entirely new and comprehensive picture of the agency of the HIV virus that goes beyond the pathology of the individual. This paper proposes the goal of putting HIV prevention back into the 'game' of public health and playing it to win by building The HIVe.

Keywords: Bourdieu, culture, digital media, education, games, innovation, HIV, play, prevention, public health, The HIVe

Introduction

> Produced by experience of the game, and therefore of the objective
> structures within which it is played out, the 'feel for the game' is what
> gives the game its subjective sense. (Bourdieu, 1990, p. 66)

Digital media provides considerable affordances to meet the growing sense among researchers and practitioners that more energy and thought must be directed at a long term response to the AIDS pandemic (Auerbach et al., 2011). However, thinking about digital responses to HIV and AIDS inevitably requires the development and implementation of programmes that are conceived more widely than solely from public health and biomedical perspectives. Paramount are innovative, sustainable and practical yet theoretically-informed HIV prevention and education approaches that aim to modify social conditions by addressing those key underlying principles that produce the drivers and practices of HIV vulnerability and risk. These digitally mediated drivers affect the ability—in both positive and negative ways—of individuals to protect themselves and others from HIV infection, and enjoy pleasure, intimacy and well being as human rights. After four decades of HIV and AIDS, we are staggered because a new

167

discursive construction advocating the need to 'redesign the AIDS response' (Larson, Bertozi and Piot, 2011) falls short of advocating prevention as a solution, alongside the critical advances in biomedical science that now provide life-saving antiretroviral therapies (ARTs).

Suspending our belief in the biomedical game of HIV and AIDS for a brief moment to escape its reductive sensibilities, we question the highly limited understanding of prevention that is found in the 'treatment as prevention' approach (Singh & Walsh, this issue; Adams, 2012). This approach is arbitrary and dangerous because it ignores the possibilities of prevention as a solution to HIV. Instead, what is at stake in a strategic digitally informed cost-effective approach to HIV prevention and education is nothing less than Universal Access to health and human rights.

Playing public health

While identifying and treating individuals will always be a core component of any response to HIV and AIDS, a long term community-based and led approach that 'plays' the game of public health reflexively can leverage digital technologies and simultaneously prioritise 'prevention as a solution' (Singh & Walsh, this issue). Playing dismantles stigma and discrimination while promoting human rights with digital resources. Central to playing is investigating how digital media can be used effectively across and within overlapping cultures, networks and institutions to educate—with the goal of ameliorating—individuals' and communities' risk and vulnerability to HIV.

This Special Issue of *Digital Culture & Education (DCE)* demonstrates how the strategic use of digital technologies in contextualised ways can produce health and human rights goals across diverse global contexts. These strategies remind us of playing digital games where the local relevance of particular actions has consequences as individuals learn to play a game. Digital games are rule-based systems. When individuals play digital games, they are reflective in the action of playing the game (Salen, 2007; 2008). They think about what move they are going to make and the possible consequences of the move on the remainder of the game. Much the same can be said of the players within HIV grassroots activism movements who work from *within* their communities. Like the players of a popular digital game such as World of Warcraft, they benefit by learning how to play the system, in this case the system of public health. In playing public health, they have the choice and opportunity to strategically collaborate with other players with technologies to develop flexible multi-channel communication and collaboration between local productions and larger-scale efforts. Through this kind of gameplay, new modes of cooperation between community groups, civil society actors, and aid organisations can produce contextualised and politically savvy campaigns. These campaigns are able to address peculiarly local concerns in ways that 'mod' the biomedical logic of public health that promotes 'treatment as prevention'. By 'modding' the game, the contributors to this Special Edition are putting HIV prevention and education back into the game of public health. This time, they are playing *to win*.

By playing public health, frontline workers, educators, activists and researchers can use digital media to develop disruptive structural interventions from a range of disciplinary approaches (Kippax & Holt, 2009) informed by local practices and everyday life (Adams, 2012). This is important because globally, incidences of HIV and AIDS are still high among young people, gay men, other MSM and transgenders, indicating they are losing out in the public health game when it comes to preventing HIV infection. This is because their sexual practices—'playing'—can put them and their communities at risk. The fact that risk is part and parcel of playing the sexual game points to a

possible lack of impact of existing normative approaches to education around HIV prevention. The lack of effective educational HIV prevention strategies to disrupt the logic of sexual practices can thus fail to enable individuals from these communities to adequately enact a feel for the 'rules of the game' when it come to HIV prevention.

A salient example is young people globally. Currently 41% of all new HIV infections (roughly 2,500 a day) occur among young people aged 15-24 (UNAIDS, 2011). Without pointing fingers, we really need to ask, why? Why don't these young people understand personal risk to HIV? Why don't they understand personal risk to pregnancy and other sexually transmitted infections (STIs)? Surely it is not because HIV infection (as well as STIs and pregnancy) is considered a normal and adventurous consequence of having unprotected sex as part of mundane life in many places around the world. We will not attempt to answer the question because there is no simple answer given the complexity of cultures, norms, values, dispositions, and legal frameworks globally. But we do think a lack of commitment and dedicated resources to HIV prevention and education globally, nationally and locally is certainly part of the problem, especially in schools (Olson & MacInnis, this issue). Michel Sidibé, UNAIDS Executive Director puts it this way:

> If young people are empowered to protect themselves against HIV, they can lead us to an HIV free generation (UNAIDS, 2011)

Consider the situation of young people in developed nations today. One common feature over the last decade has been the proliferation and uptake of various personal mobile media such as smart phones, applications, social networking platforms, and digital games. This group includes children and adolescents who are younger than 15 years old. Growing up in a digitised world, they often have more sophisticated digital skills and literacies than their parents and know how to operate, program, hack and modify these devices—computers, mobile phones, Internet capable TV and other handheld devices—to find whatever information they so desire, sexual and otherwise. These devices also allow for the two-way communication space of the Internet, dominated by the 'Web 2.0' or 'social media' paradigm (Allman, et al., this issue). A paradigm that—despite hyperbole—is aimed at providing free, simple, and accessible person-to-many communications and collaboration at a scale which even five years ago was unimaginable. These advances in technology allow young people to often consume information about sex uncritically (Johansson and Hammarén, 2007) in decontextualised digital contexts that offer little or no information about the risk of HIV, STIs or pregnancy. Furthermore the social media paradigm, along with geosocial technologies, signals localised—in the case of Grindr or Blendr, by number of meters—faster, cheaper, and far greater access to potential sexual partners regardless of age, race, or class. Combined, these new digital realities put many young people at higher personal risk for HIV in ways that still remain to be critically explored.

Game Over?

While proposing a new social-ecological conceptual model for structural interventions that will be a 'game changer' (Ogden et. al., 2011), the aids 2031 consortium has omitted to define what exactly a game is in the social sciences. Worse, they have ignored to consider the importance of mobilising communities to not only, as they write, reduce vulnerability and promote agency to address the social drivers of HIV, but to know how to play the game of knowledge as power.

Communities of gay men, MSM and transgenders, for one, are playing sexual and social games all the time. These games are competitive, often ruthless, and have specific rules of engagement involving codes, gestures, rituals, and symbols, that interlock to produce risk-taking, adventure and pleasure, enacted and embodied in the body, and increasingly, through the digital culture. The fact is, playing the gay game is just not that hard anymore now that 'they're everywhere'. Yet, the game of reducing HIV gets harder for those who don't want to play the game they are offered by mainstream public health. This game is itself one of many games available to play for individuals in the game of life. Without addressing these challenges with a clear and multi-level theory of how to change the game, structural or combination HIV prevention interventions will not be game changers. Instead, focusing naively on trying to objectify the positive aspects of interventions that purport to build up hetero-normalising adjectives like 'resilience' and 'competence', they do not break out of the illusion of the game. Thereby continuing the reproduction of public health HIV and AIDS strategies within competing social sciences and biomedical paradigms.

Building the HIVe indicates that what is needed to improve HIV prevention and education is the theoretical exploration, development, funding and implementation of glocalised long-term strategies that play digital games in the fluid contexts that shape sexual and social practices. These games investigate what 'AIDS-resilience' and 'AIDS-competence' actually mean in the game for social, cultural and economic survival. Tactical responses might then begin to analyse and reflect tangible changes in the consumption and use of digital resources in everyday life towards resilience in playing the game of health, where groups at risk of HIV at least begin to understand risks while taking risks that are natural for them – 'in order to be carried along by the game without getting carried away by the game beyond the game' (Bourdieu, 1990, p. 81).

With this understanding, researchers can design public health games to engage in the tempo and rhythm of sexual practices that get the better of participants and play on the ambiguities, cues and innuendos of sexual thrills. Such games thus not only aim to produce generic outcomes such as understanding the risks and the consequences of certain sexual behaviours. Instead, these games are situated dialectically in the interplay of structure and agency, of an organised way of thinking and acting with pre-reflexive unconscious behaviours, to affect consciousness unconsciously—'One thus only has to go back to one's own games, one's own playing of the social game, to realise that the sense of the game is at once the realisation of the theory of the game and its negation *qua* theory' (Bourdieu, 1990, p.81).

Perceived as a game, the 'Arab Spring' of 2011 perfectly demonstrates how simple changes in interpersonal communication can impact on grassroots organisation, and connect local struggles to a global audience. In regard to the latter point, it may be the case that the struggle against HIV and AIDS led by marginalised communities lacks the glamour of the various democratising movements of the 'Arab Spring'. The crucial point, however, is that changes in digital media access, meaning and consumption now provide—more than ever before—new modes and platforms for refining, rethinking and redesigning localised struggles at scale by strategically aligning them with national, regional and global movements. Perhaps now that the totalising paranoia over getting everyone on ARTs seems to be gradually being replaced by a new rhetorical zeal for a 'democratised AIDS response' (Sidibé, 2011), The HIVe can step outside the exigencies and the threats of playing the game everyone else is playing. The HIVe thus re-presents and re-searches the arrhythmia of a forthcoming 'HIV Spring', where the game of prevention as a solution is not wholly subsumed under the biomedical game of 'treatment as prevention'.

A new game

The localised, community-based, long-term approaches advocated by frontline workers, activists, researchers and practitioners in this Special Issue provide examples of new ways of playing public health. While breaking the rules by using digital media innovatively, they also show how to make tangible impacts. These practical foresights allow policy makers and programmers to not simply adjust to the new digital era, as they have kept adjusting to every other technological and methodological change that has come knocking on the door of the house of AIDS over the last 40 years. They allow all involved in the ruthless game of AIDS to launch fast and furious into a future ecstasy while present in the moment.

The proliferation of free, easily accessible person-to-person and one-to-many platforms for communication and education, and the relative everydayness of these platforms in the context of people's media use, make them desirable objects for supplementing the 'feel' for the game of HIV in the lives of young people and communities of gay men, other MSM and transgenders. Used critically to game the status quo, these technologies hold the possibilities for disrupting traditional biomedical discourses, norms and practices that continue to perpetuate stigma and discrimination and even deny pleasure and intimacy (Walsh and Singh, 2012).

Digital technologies also offer frontline workers, researchers and practitioners working with young people, gay men, other MSM and transgenders new ways of conceiving of and connecting to these communities. Whereas local factors and normative scientific practices and instruments may influence how groups that are particularly at risk are categorised by those who know how to play the game to acquire profit and distinction, digital media could be developed by communities for the sharing of resources between, as well as within, such groups. This resource sharing creates the opportunity to develop interlocking projects on a variety of scales (Bennett, 2003). An example is the collaboration between practitioners and researchers to co-develop an open access HIV and AIDS portal on Wiki Educator that can be viewed here[1]. These innovations embrace complementary yet differentially targeted localised approaches to opposing the biomedical modulations of the game to build AIDS resilient communities.

The HIVe has a particular point of view on this new game. Because it provides examples and an open access education and research platform (www.hiv-e.org) for grassroots—and larger—movements, it can establish wider connections: both with similar movements in other locations, or that are targeted at other vulnerable groups; and with government and non-government aid and development organisations at the national, regional and global levels. These horizontal and vertical connections can contribute reflexive attention to fostering dynamic modes of apprehending AIDS resilience and competence among communities. As examples, the HIVe has produced a digital flyer and digital video advocating HIV prevention as a solution that are now being disseminated widely through social media and can be viewed at http://www.facebook.com/TheHIVers.

Free of the unthinking automata and determinism of biomedical and typological social sciences, this new game can be conceptualised as a community engagement game that offers opportunities for collective agency to manipulate vulnerability and risk. It provokes the possibility of 'moding' the public health system by directing and reshaping previously top-down implementations. The HIVe embraces this gaming approach and ethos. It connects 'n00bs' (a term for an inexperienced digital game player) with 'l33ts' (a term used to designate a digital game player) to promote capacity building online

mentorships. It adopts an approach to HIV discourse and pedagogy that does not end with an understanding and acceptance of HIV that is entirely defined by the 'official' positions. Through the disruption and modification of reified rules and routines, The HIVe aims to share new and evolving practical realistic interventions that play public health productively and ask crucial questions about designing prevention as a solution that the essence of biomedical treatment games exclude.

Winning the game?

Winning the game will require activists, researchers and practitioners knowing how to play the game without being aware of the ambiguous and uncertain rules of the ever-changing game of HIV prevention and education.

For a start, digital media offers access to community, education and health without necessarily compromising anonymity (Henry, Yomb, Fugon and Spire, this issue). This is an especially valuable social action for marginalised groups where social stigma and/or taboos play an influential role in structuring HIV vulnerability, as is often the case with gay men, other MSM and transgenders (Walsh, Lasky, Morrish, Chaiyajit, 2011). Anonymity is an asset that allows members of these groups digital access to information and services without putting them at further risk of the violation of social taboos when playing the sex game. It also empowers individuals living with HIV to play actively, and who, in public health paradigms, are often conceived of as 'sufferers' who need to be identified, treated, regulated and controlled (Schenk and Singh, this issue). Digital media further provides members of these groups a meaningful space to participate in games that rethink the design, delivery and evaluation of digital public health interventions which, rather than focusing on body counts and numbers, seek to mobilise and empower AIDS resilient communities (Beck, Catanes, Hebert and Ayala, this issue).

Anonymity, of course, produces its own risk, that of exposure, but also that of winning the game. For frontline workers, activists, practitioners and researchers, this means that extra care must be taken to ensure the anonymity of communities that they are involved with. As social networks become increasingly important for day-to-day communications and everyday public health and commercial operations, they also become increasingly vulnerable to misuse. Over the past few years a number of high-profile media stories have dealt with the issue of the 'digital footprint'—that is the portrayals and records of oneself left online (Weaver and Gahegan, 2007). It is incredibly easy to retrieve such data even if it is dispersed around a number of sites, and this data is often used in identity theft and account hacking. Members of anonymous online communities also face the risk of having themselves exposed, and this risk must be attended to consciously.

Another avenue for playing public health to win the game against HIV, as a result of the two-way flow of information facilitated by social, participatory media, is imagining new modes of evaluating the long-term effectiveness of programmes and other interventions that are not solely biomedical. The number of people living with HIV can now be identified and treated. But these statistics can also be supplemented by a detailed understanding of how to support communities, grow, develop and respond to change and crisis caused by globalisation and the Internet. Importantly this opens the possibility of evaluating the success of a program or intervention in relation to 'large picture' agendas, opening up such programs to deep political and philosophical questioning beyond their numerical effectiveness. This shift is a necessity to win the game ethically.

At the extreme end of the data-gathering processes that can take place using digital media are new possibilities for the representation of the pandemic. The aggregation of

large-scale data on communities with varying 'levels' of AIDS resilience, combined with software-driven modes of data analytics specifically designed for handling so-called 'big data', opens scholars and practitioners to new ways of perceiving the context and complexity of long-term approaches to the AIDS pandemic and promise to drive methodological innovation in HIV and AIDS interventions.

All these intersectional innovations brought about by the digital era require critical consideration by public and global health authorities seeking to reduce HIV vulnerability and mobilise young people, gay men, other MSM and transgender communities effectively. In turn, whether community-based and led theoretical innovations in using digital media will influence policy and practice will rest on their ability to harness the power of digital culture to design practical models and develop an evidence base for useful and usable digital HIV prevention and education.

By playing the game to win against HIV, there needs to be a commitment to developing 'middle-range theory' (Merton, 1967) to balance and overcome the science/community and biomedical/social sciences dualisms. Only a strategic digression in theory building and methodologies will enable current and as yet unimagined digital spaces to make a material difference to communities in the fight against HIV. Winning the game also requires considerations for new rhetorical and discursive policies and practices. Playing the discursive game inclines researchers to overcome the logicism inherent in the objectivist/positivist methodological viewpoint, and the relativism of the subjectivists/post-positivists. Only by forcibly changing the nature of practice by playing pubic health differently will we be in a position to uncover the underlying principles of social practices that hamper efforts to improve access to equity and justice for marginalised communities.

Playing public health is a game changing strategy wake-up call for bridging the knowledge-practice gap, harnessing transnational flows of knowledge, inculcating a culture of digital community-based and led research, and diffusing innovation and enterprise to incorporate a critical understanding of the unexpected and significant changes caused by mundane and incipient digital media. These changes now reveal not just the highly constructed nature of our object of inquiry, HIV prevention and education, but also the narrow way that we have framed that object. This historic opportunity to turn the tide on the AIDS response by playing public health differently is essentially what building the HIVe was about in the first place.

What is needed to win the game now are further transcendental frameworks for collaborative inquiry and strategic alignment between biomedical, social, cultural and political sciences, education and digital media activists, practitioners and researchers. Really playing public health to realist lofty visions of healthcare and human rights for all requires funding and policy support to build The HIVe, so the question remains, "who is willing and able to pay and play?"

References

Adams, B. (2012). Epistemic fault lines in biomedial and social approaches to HIV prevention. *Journal of the International AIDS Society*, 14(Suppl 2), 1-9.

Auerbach J, Parkhurst J, & Cáceres C. (2011). Addressing social drivers of HIV/AIDSfor the long-term response: conceptual and methodological considerations. *Global Public Health*, 6 (suppl 3), 293-309.

Bennett, W. (2003). Communicating global activism. *Information, Culture & Society*, 6(2), 143-168.

Bourdieu, P. (1990). *The logic of practice*. Stanford: Stanford University Press.

Kippax, S. & Holt, M. (2009). *The State of Social and Political Science Research Related to HIV*. Geneva: International AIDS Society.

Johanssen, T. & Hammarén, N (2007). Hegemonic masculinity and pornography:Young people's attitudes toward and relations to pornography. *The Journal of Men's Studies*, 15(1), 57–70.

Larson, H.J, Bertozi, S. & Piot, P. (2011). Redesigning the AIDS response for long term impact. *Bulletin World Health Organization*, 89, 846–852.

Merton R. (1967). *On theoretical sociology. Five essays, old and new*. New York, NY: Free Press.

Ogden, J., Gupta, G.R., Fisher, W. & Warner. A. (2011): Looking back, moving forward: Towards a game-changing response to AIDS. Global Public Health: An *International Journal for Research, Policy and Practice*, 6(Sup3), S285-S292

Salen, K. (2007). Gaming literacies: A game design study in action. *Journal of Educational Multimedia and Hypermedia*, 16(3), 301-322.

Salen, K. (2008). Toward an ecology of gaming. In K. Salen (Ed.). *The ecology of games: Connecting youths, games, and learning* (pp. 1-20). Cambridge: MIT Press.

Sidibé, M. (2011). Letter to partners. Geneva: UNAIDS.

UNAIDS (June 1, 2011). 2 500 young people newly infected with HIV every day, according to Opportunity in Crisis. Retrieved from http://www.unaids.org/en/resources/presscentre/featurestories/2011/june/20110601aunicef/

Walsh, C. & Singh, G. (2012). Building the HIVe: Disrupting Biomedical HIV/AIDS Research with Gay Men, Other MSM and Transgenders. *AERA 2012*.

Weaver, D. & Gahegan, M. (2007). Constructing, visualizing and analysing a digital footprint. *Geographical Review*, 93(3), 324-350.

Walsh, C. S., & Singh, G. (2012, April 16).Building the HIVe: Disrupting Biomedical HIV and AIDS Research with Gay Men, other men who have sex with men (MSM) and Transgenders. *Paper presented at the annual meeting of the American Educational Research Association (AERA)*. Retrieved, from: http://www.aera.net/repository/

Walsh, C. S. (2009). Mobile phones as high impact, low cost tools in the fight against HIV/AIDS with men that have sex with men and male sex workers in Thailand. *IADIS Multi Conference on Computer Science and Information Systems 2009*, Algarve, Portugal. June, 2009.

Acknowledgements

Biographical Statements

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1 See http://wikieducator.org/HIVAIDS_Portal