HIV prevention in a complex world: critical reflections on community mobilisation and engagement with gay, bisexual and other MSM

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Communities

A group of people living in the same place or having a particular characteristic in common
Social & sexual networks and health
Varied research examining the role of sexual networks in disease transmission

Density: 11%
Mean node degree: 1
2-Cores: 1 involving 5 nodes

Density: 11%
Mean node degree: 1
2-Cores: none

Density: 22%
Mean node degree: 2
2-Cores: 1 involving 5 nodes
Community mobilisation

- ‘Community’ responses to HIV have long been linked to successful HIV prevention among gay, bisexual and other men who have sex with men (MSM)

- Creation of ‘safer sex’ among gay men in the 1980s as a response to HIV, largely credited to gay communities, represents the best recorded evidence of population level behaviour change

- Extensive evidence of the success of peer and community engagement in facilitating sexual health improvement and HIV prevention
CDC ‘HIV prevention that works’ website includes a range of effective community-level interventions.
Research has questioned the role of ‘gay community’ – changes to its role in HIV prevention

What do we mean by gay communities?
How are communities defined?
How we measure and evaluate impact on these?
Changing communities?

• Changes to:
  o the structure of ‘gay communities’
  o patterns of socialisation
  o ways of connecting socially and sexually

• Role of shifting social attitudes to same-sex relationships has been linked to changes in men’s sense of connection to ‘gay communities’

• The proliferation of novel sexual health technologies, self testing and pharmaceutical HIV prevention, present new opportunities and challenges
AIM

- Building on the community mobilisation approach that was successful during the early HIV epidemic, how can we understand, measure and capitalise on ‘new’ community responses to improve holistic health and reduce multiple and interrelated health inequalities among gay men?

- Explore what community mobilisation might look like in the dynamic and changing context of our world and facilitate a wider discussion about how we - researchers, practitioners and communities - can take this forward
Session outline

- Young gay and bisexual men’s ‘personal communities’ (Nicola Boydell)
- Digitisation of gay communities and implications for HIV prevention (Paul Flowers)
- Biomedical HIV prevention and emerging, new community responses (Ingrid Young)
- ‘New’ community participative approaches and the implications for developing and evaluating public health interventions (Lisa McDaid)
- Discussion
Young gay and bisexual men’s ‘personal communities’
World stands in solidarity with Orlando's LGBT community as a city weeps

Obama to Orlando gay community: 'You are not alone'

US President Barack Obama on Tuesday voiced solidarity with the LGBT community after the shooting rampage at a Orlando gay nightclub, calling the gunman an "angry, disturbed, unstable young man who became radicalized."
Gay men and ambivalence about ‘gay community’: from gay community attachment to personal communities

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The concept of ‘gay community’, and gay men’s attachment to and involvement in gay community activities, has held both a symbolic and practical role in understanding and guiding responses to HIV in developed world contexts. In the West, the HIV epidemic has disproportionately affected gay men. Being involved in and connected to gay community activities (what, in Australia, is described as ‘gay community attachment’) predicted the adoption of safe sex practices. However, the meaning of gay community is changing. This presents a challenge to those working in HIV prevention. With reference to previous research, the meaning of gay community is analysed in qualitative interviews conducted with Australian gay men. The interview data indicate that gay men are often ambivalent about gay communities, suggesting a need for subtlety in the ways we think about and address gay men in HIV education and health promotion. The concept of ‘personal communities’ may better reflect the ways in which gay men engage with each other and their social networks.

Keywords: ambivalence; gay community; gay men; HIV prevention; personal communities

Introduction
Community is a notoriously fluid term in the social sciences. It refers to a group of people that has a shared characteristic, but the range of shared characteristics that can form the basis of a community is dizzyingly broad. Sources of community can include where people live, shared languages, identities, mutual values or beliefs and collective practices. When a group of people exhibit shared characteristics, particularly when they live in the same area and associate with each other, it is easy to think of these people as forming a community. However, there are many examples where people’s sense of community is imagined as a shared bond rather than demonstrated by geography, co-presence or shared action (Anderson 1991). The complexity of the term, and the variety of ways in which it is used and abused, has led many to conclude that community as a social and political concept is deeply problematic and perhaps unusable (Alman 1994; Frazer 1999; Nancy 1991; Young 1986).

In this paper I would like to consider one particular form of community and its discontents – gay community (Woolwine 2000). In particular, I want to consider how gay community is used in HIV prevention research and how particular members of the...
‘Personal communities’

“... personal communities represent people’s significant personal relationships and include bonds which give both structure and meaning to their lives... personal communities provide a kind of continuity through shared memories and can help to develop a person’s sense of identity and belonging”

They go on to say:

“...these personal communities are more ‘communities in the mind’ than communities on the ground. People relate to each other in personal communities on a range of different levels... but the framework of belonging may not always be as visible.” (2006, p. 45)
‘Mapping’ and analysing men’s ‘personal communities’
‘Personal communities’ in relation to wider ‘gay communities’

- Personal communities complex and diverse - partner(s), friends, family, ‘professionals’, groups and colleagues

- Many of the young men have highly ‘mixed’ groups of friends, both in terms of sexual orientation, and gender

- Men articulated their understandings of ‘gay community/ies’, BUT, not framed as a central organising factor in terms of their ‘personal communities’

- Men’s understandings of safer sex shaped by social norms, particularly within their personal communities and wider ‘gay communities’
I think modern society has forgotten the AIDS struggle, has forgotten even gay rights struggle, and such so yeah we, we're, how fortunate are we that we're fighting for equality in marriage, not all gays want that... I, even I am one generation, or two generations removed of the society of free-sex, where you just had sex, and maybe you just had to worry about gonorrhoea, and syphilis, and then all of a sudden seventy per-cent of your friends vanish because of a mysterious illness. And, I think all history is important, but even I - at my age - am too old when talking to seventeen and eighteen year olds" (Kalen, 29)

"I mean there's lots of little subgroups within what would be called a wider gay community..." (Harry, 23)

"So as well as just identifying as gay, you also have to identify if you're a twinky, if you're a bear, if you're a top or a bottom or versatile, if you're into kink stuff, if you're not into kink stuff, if you want to dress up in drag, that kind of, like, there's so many little groups within the big community that people then get into, and then a lot of people run with it" (Deid, 27)

"...there's sub-cultures in the gay community that have maybe fetish for bare back and sex and stuff and group sex and whanot and like dark rooms and sex and whanot" (Eddie, 21)

"Ok, to me it's [the scene community] just... very centred on bars and clubs and I guess that'd be in Edinburgh, but when I think of Manchester the whole gay village, I guess, with the shops and bars, restaurants, nightclubs, all of that is just where it's centred and then people go there because it is a gay place" (Theo, 23)

The gay community... I don't know I'd say just the gay scene, like in a, like a city say because there's not really one in like towns mostly." (Gary, 20)

"...on the scene people make friendships with each other on the scene because of how they look, and that's generally it. Or not necessarily how they look but how a person fancies them or says "oh", like blah, blah, blah, insert dirty talk here. And that's generally it." (Eddie, 21)

"...the scene is rife with gossip, you know, so and so's doing this with so and so, and so and so has been doing this, so and so's slept with this person, someone's trying to, you know, they're now going out and they're breaking up and this, that and the other. That aspect of the gay community I don't like very much." (Tom, 26)

"I wouldn't really feel comfortable, like walking just walking down the street holding hands with a partner, but when I'm in, like, the scene, or the gay community, or, I would see that as a safe space, where I could do that. So yeah, I see that as a comfortable space." (Kyle, 26)

"...and I think there's a sort of culture as well that's within that around like, so like if I go to London there's a gay bookshop in London and I'll go and buy, you know, gay books from that or I'll watch, you know, gay interest films or documentaries or whatever and that sort of gives you more information and knowledge about the community you're in and are part of." (Max, 25)

"I'd say bigger places like cities are more gay community places than smaller places, but if you are in a smaller place and you're part of the community it's maybe online I would say, it would be an online community." (Quinn, 19)

"Having an online community in terms of Gaydar, Grindr, that kind of thing, makes it easier. I mean, a lot of people go on about how, "oh, it makes people just go and have sex." They're going to have sex anyway, really, it's just it's a tool of using how to get it. But I think for some people they can make friends through that." (Deid, 27)

"Fit Lads, you know what Fit... Yeah... Yeah. And I think the thing with websites like that is there's the assumption you're on there for sex and like sex just doesn't interest me...[goes on to say] and basically you can be on these websites and you can be there for friends, you don't have to be there for a quickie." (Eochan, 27)

"I think in general I do identify as homosexual or gay, and so I also try to find friends who are like-minded...and I think it's also because I already know that we're going to have something in common, and that is that we like boys." (Kalen, 29)

"...gay community where like-minded people are able to meet up to give each other the support, and basically even for socialising, fun and everything, where they can go to the same places and find people with the same interests and whatever. I think that's what kind of I classify kind of gay community, kind of togetherness of people with shared interests and... but support. I think support is the one that kind of came into it for me the most, that's what I think of when I think gay community." (Tiernan, 25)
Thinking through implications for community-level interventions

- Who is ‘imagined’ as belonging to ‘communit(ies)’?

- Development of future community-level interventions take into account changing patterns of sociality
  - Recent Consultation with young MSM - not gay identity

- Diversity of experience in terms of ‘connection’ to community (Keogh et al., 2004; Formby, 2012)

- Consider how different people within men’s personal communities could contribute to HIV prevention interventions; partners, family, friends
Digitisation of gay communities and implications for HIV prevention
Digitisation of gay communities and implications for HIV prevention
The changing ecology of community

- Rhetoric of digitalisation often focuses upon radical and polarised differences between the old physical world and newly developing digital worlds.

- Digital ‘revolution’ discourse doesn’t capture the commonalities and constants that remain foundational in considering recent digital developments.

- These include the bread and butter of HIV social science: Safety, risk, cultures, subjectivities, communication, pleasure and HIV transmission.

- Ecological considerations avoid techno-determinism and bring systemic understandings that capture complexity and interactions between actors and their environments (e.g., Gay men and HIV).

- They provide a means to consider the affordances within changing systems and illuminate the means of transferring good practice (HIV prevention) into new and changing niches.
What are some of the systemic changes in community ecology?

• Speed of innovation (gay.com; gaydar; Grindr)

• Temporal aspects (Open access 24-7)

• Geographical aspects – global reach but micro-spatial (GPS)

• Population segmentation (e.g., bears, BBRT)

• Modes of communication (e.g., twitter)
Speed of digital innovation

- Harnessing rapid pace of change presents both opportunities and challenges

- For HIV prevention –balancing usefulness of traditional cumulative knowledge with an often acute need for implementation science presents one key example- as the transferability of interventions are considered

- For practitioners, theorists and methodologists the pace of change demands lifelong learning, flexibility in our practice and on-going CPD for all

- How can we transfer best practice across into digital platforms and then across digital platforms

- Opportunities for industry collaboration and social responsibility –flash point for activism
Temporal aspects of community digitalisation

- The rhythm of gay life used to be regimented by the opening hours of venues and the diurnal cycle that changed public parks to cruising places at different times of day.

- This enabled us to think about targeting HIV prevention resources to captive audiences.

- Bounded physical spaces provided concentrated access to dense populations of MSM and access to processes of social influence – enabling time efficient use of limited resources.

- Now we have 24-7 access to each other, MSM and their communities are dispersed in time and space and normative communication and social processes can be asynchronous.
Spatial aspects of community digitalisation

- The infrastructure that supports communities now has global reach
- This facilitates communities and sexual mixing in new ways and in diverse places (at every spatial level)
- Diminishing pressures of gay urbanisation. GPS technology enables safe spaces and places to be constructed anywhere with 3G
- Social isolation, exposure to HIV prevention, gay rural de-population are all moderated by the reconfiguration of gay communities within space
- Digital platforms provide a ready made means of communicating with MSM and delivering interventions
- GPS technology enables spatial targeting of HIV prevention and message blasts with particular accuracy

Steve: I think being part of the minority, people have always wanted the reassurance of knowing that they're part of a larger group, and that's something that this technology has definitely provided that wasn't there before. There's hard evidence in these phone things that there's one [another gay man] 100 meters away, 400 meters away, all that kind of stuff.
Community segmentation and digitalisation

- In the past only large cities such as London or Amsterdam could host specialist venues that facilitated sexual mixing according to particular sexual or demographic tastes.

- Digitalisation has enabled the democratisation and proliferation of ‘spaces’ that facilitate new types of communities and associated sexual and other social identities.

- Mirroring the dense networks that facilitate LGV or Shigella transmission, new opportunities exist to harness the amplification of social processes and influence to further HIV prevention.
Modes of communication and digitalisation

- Digitalisation often means interactions are staggered and staged across time and place (from profiles meeting to eventual sex)

- This differs significantly to the embodiment interaction of a face to face encounter

- This social distance can shape interactions – less of a social contract (e.g. blocking/blanking)

- The staging of interactions often begins with profiles – making sexual and other social mixing possibilities explicit (e.g., serosorting etc.)

- There is a sense of communication within communities becoming more textual and visual aligning itself to commodification

basically when the profiles meet I think you’re both projecting big time. It’s a construct in your head and it’s not the real person. You’re filling in all kinds of gaps. Even more than that, I think you’re just constructing a whole other person actually, and then very often the reality of course is wildly different. But I think we all do it. I mean we’re doing it on both sides, and therefore the mismatch is sometimes just too big to have a kind of meaningful meet very often. So one of the things I learned early on as well, don’t chat to somebody for weeks and weeks before you meet them because then their kind of construct becomes so big that I think the meet can’t really survive it, so try and meet relatively quickly, within a few days, before you start imagining a whole other person.
Digitalising HIV prevention

- An ecological model of gay communities stresses how the environments in which we interact with each other and HIV are changing but not so dramatically.

- It avoids technological determinism and highlights the similarities in what we have done with meeting the challenges of what we will do.

- Many of the biological and social determinants of HIV infection remain identical to previous decades.

- Many of our interventions rely on social determinants and social influence to change communities and culture and should be relatively straightforward to translate.
Digitalising HIV prevention

• A sustained focus upon how to grasp the new opportunities and overcome new challenges is required

• How can we use the changes in community segmentation to maximise effectiveness of social marketing, how can we use changes in communication (e.g., durable profiles to facilitate partner notification), how can we use changes in time and space to overcome barriers to HIV testing (e.g., direct to MSM self-testing in rural areas)

• How do we adapt our research methods to capture complexity, systems and digitalisation?

• Who gets left behind – material resources and issues such as digital literacy amplify existing inequalities
Biomedical HIV prevention and emerging, new community responses
Imagining PrEP, imagining PrEP communities?
Translating PrEP
Online community spaces, peer sharing

- Online opportunities for sharing PrEP experiences
  - Blogs (e.g. My PrEP experience)
  - Selfies

- Facebook forum: PrEP Facts: Rethinking HIV Prevention and Sex
  - Closed group with moderators
  - Not only for gay men

- Hegemonic PrEP narrative (Crath & Rangel)
  - PrEP works
  - Mobilizing research/science to support arguments
  - Sex positive approach – PrEP use framed as part of responsible sexual practice
  - Often a rejection of dissenting voices

- What PrEP community is imagined (or) inscribed here?
Community action to access PrEP in UK (?)
Is PrEP activism reimagining community engagement?

- Complexity of ‘community’
  - Coalition of actors demanding PrEP
  - Research, health practitioner and gay community collaborations
  - At the same time:
    - More than about identity politics or sexual practices
    - but still very much about identity and sexual practices

- Translating PrEP
  - How does this inscribe/imagine a particular PrEP community?
  - What are the implications for implementation, for community engagement and for HIV prevention?
‘New’ community participative approaches and the implications for developing and evaluating public health interventions
Gay men experience a disproportionate burden of ill health in relation to sexual health, mental health and substance use.

46% of gay MSM reported 2+ health inequalities with 10% of gay MSM reporting all 3.

Mercer, C. BMC Public Health, in press.
Promoting the health and wellbeing of gay, bisexual and other men who have sex with men

Initial findings

Report is only able to set out interventions that address sexual health, mental health and substance use separately
Knowledge gaps...

- Few studies have addressed the co-occurrence of psychosocial problems, substance use, and sexual and mental ill health.

- None of the available evidence considers the delivery of multiple ‘tried and tested’ interventions in tandem.

- Inequalities experienced by gay men are complex and their health improvement will require complex interventions.

- These could be more efficient and synergistic than multiple, separate, uncoordinated efforts that may duplicate effort or be competitive and even counterproductive.

- ‘New’ problems = ‘new’ approaches?
Syndemics theory suggests the co-occurrence of multiple, interrelated disease epidemics at the individual- and population-level, sustained by harmful social contexts.
"HIV prevention work would be more efficacious if it were designed to incorporate naturally occurring resiliencies that manifest among gay male communities rather than primarily using interventions that address vulnerabilities among men who continue to reside in high risk contexts."

(Herrick et al, AIDS Behav, 2014)
Current UK health improvement model

Current efforts characterised by disjointed health services and single outcome interventions

Interventions are unable to counter the pathogenic context that exacerbates health inequalities, resulting in no sustained impact on sexual and mental health and substance use outcomes.
An alternative?

**Asset based model of public health**

- Assets are the collective resources available to individuals for the promotion of health and wellbeing.

- Interventions focus on enabling salutogenic, protective factors and resources of individuals and communities, rather than deficits and needs.

- Underpinned by values of and principles, that enable strengths, capacities and abilities to be identified and developed for positive outcomes, and sustained through people’s actions, connections and participation.

- Evidence of effectiveness is still limited, centred on ‘physical’ communities’ and largely absent from health improvement efforts with MSM so far.
Could understanding ‘new’ community responses, and capitalising on these, be key to reducing health inequalities among gay men?
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Discussion

• Is community mobilisation still important?

• Who are the communities and networks to work with?

• What might the barriers/facilitators to engagement be?

• How might we operationalise assets and measure impact?
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