



Article

Grit and stigma: Gay men ageing with HIV in regional Queensland

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Abstract

The ageing of the first generation of HIV long-term survivors brings into sharp focus the suffering that activism and the clinical management of HIV has not solved, particularly in regional areas. Although HIV is now usually a manageable chronic condition, it also involves navigating unrelenting social stigma. Quality of life beyond viral suppression is not assured. Despite a history of affected communities demanding equal partnership with health-care providers, an increasingly biomedicalized orientation risks neglecting the psycho-social needs of those with a history of trauma, depression and other co-morbidities often more difficult to manage than HIV itself.

Keywords

ageing, HIV, long-term survivors, quality of life, rural

The children's rhyme is wrong. Just like sticks and stones, words can harm us.

Michael Callen (1990: 52)

Words have always been important in the HIV response. From the early 1980s activists like Callen challenged the defeatism of the label 'victims' and insisted on the empowering designation 'people living with AIDS', then 'living with HIV and AIDS'. The advent of effective treatment from 1996, saw patients 'seemingly rising from the dead', and the discourse shifted firmly from 'AIDS as a death sentence' to 'HIV as a chronic manageable condition' (Siegel and Lekas, 2002: S69). Those accessing effective treatment now rarely meet the criteria to be diagnosed with AIDS, and so the acronym PLHIV (people living with HIV) is standard. UNAIDS, the United Nations HIV agency, and others now promote 'the end of AIDS' but this rhetoric, to celebrate successes and mobilize political will and resources, risks overshadowing the real-life experiences of those living on with HIV.

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Many of the baby boomer generation of Australian gay men did not live long enough to age, and HIV has strongly impacted survivors of the epidemic, despite the country's reputation for one of the most pro-active responses to HIV in the world, near to universal health-care access and a social security safety net. Most PLHIV now survive for decades and are grateful to still be alive well beyond what one participant in this study wryly referred to as his 'dead by date'. However, the success of treatment and conceptualizing HIV as a chronic illness has given rise to the impression on the periphery of the epidemic that treatment has solved everything.

Historical context highlights the potential for this generation to have experienced trauma (Moore, 2001). The American psychologist Halkitis (2014: 162) has asserted that trauma is a defining feature of 'the AIDS Generation - all of us, HIV-positive and negative ... as middle-aged men, we are as a group traumatized and fatigued by 30 years of war'. Despite National HIV Strategies acknowledging key affected populations as essential partners in the response, the inclusion of lesbian, gay, bisexual, transgender and intersex (LGBTI) communities in Queensland has not had consistent bipartisan support.

The Queensland government and media response when four babies died after blood transfusions in 1984, the point at which AIDS entered the mass consciousness of the Australian public (Moore, 2001: 176), laid the foundation of the stigma that still underpins much of the social suffering of PLHIV 30 years later. AIDS and homosexuality were inextricably linked and exploited as a political wedge issue, showing how 'gay identity and HIV identity are forced into connection becoming mutually constitutive' (Flowers and Davis, 2013: 286). Despite both homosexuality and HIV being recently subject to what Flowers and Davis call a 'normalisation' processes, homophobia remains virulent in regional Queensland (Berman and Robinson, 2010: 8) and HIV discrimination still occurs even within the gay community. Stigma is reinforced by the Queensland HIV-specific laws which have not kept pace with scientific advances, and in a recent review of HIV criminalization and public health policy Halkitis and Griffin-Tomas (2017: 4) concluded such laws are 'outlandish' and illegitimate.

Older PLHIV in regional Queensland rarely fit the retiree stereotype of cashed-up white middle-class tree-change/sea-change lifestyle seekers, as living on Disability Support Pension (DSP) for decades and in many respects ageing before their time has rendered most marginal to such social gentrification. Jansson and Wilson (2012: 1) predict that given the impact of improved treatment on survival, by 2020 the population of people living with HIV (PLHIV) in Australia will reach almost 300,000 with significant numbers living outside the capital cities, and the 'expected proportion of PLHIV over 55 years is estimated to increase from 25.3% in 2010 to 44.2% in 2020'. This trend of ageing of the population of PLHIV has serious implications for the planning of future service delivery to meet the psycho-social needs of PLHIV, particularly in Queensland, which has a more decentralized population than the geographically smaller southern states.

In the current viral suppression era, biomedical narratives tend to put an optimistic spin on living with HIV. Biomedically orientated attempts to 'normalize' HIV incorrectly imply this is an easy way to eliminate the stigma underlying decades of fear and social exclusion (Moyer and Hardon, 2014: 267). As acknowledged by Squires (2013: 14) in response to the 'complicated' stories of PLHIV, the 'recognition of HIV's *particularity*' enables exploration of the range of experiences with stigma and the grit involved in living on, and ageing, with HIV.

Method

Thirty-one older gay men were interviewed via two semi-structured annual interviews across the years 2013–15. Interviews were usually conducted in the participants' home as part of the larger Australian Research Council and Queensland Health Department funded qualitative longitudinal Living Positive in Queensland Study (LPQ). Queensland Positive People (QPP), Positive Directions Anglicare (PD), and the Queensland AIDS Council (QuAC) were the linkage partner organizations of the LPQ Study. The partners were keen to prepare for the projected growth over the next decade of the population of ageing PLHIV in Queensland's tree-change/sea-change areas.

Participants were at least 50 years of age, except Aboriginal men who were included from 40 years of age to reflect the reduced life expectancy of the Aboriginal population in Australia (Australian Institute of Health and Welfare, 2014: 6). Recruitment via historical contact with PD ensured representation of participants like the 'almost one-third of respondents to HIV Futures 7 [who] rated their health as fair or poor (28.6%)' (Grierson et al., 2013: 2), including some who had lost contact with formal support systems. Participants who were coping well, with little or no history of accessing support services beyond routine medical monitoring and treatment, were also recruited via gay community networks. The participants lived in regional centres and hinterland areas of the 1,700-kilometer coastline between Cairns and the Sunshine Coast or in more isolated rural locations. 84% were on Disability Support or Aged Pension, 78% were single and 68% were living alone.

The first round of semi-structured interviews started in 2013 after a newly elected Queensland Government defunded QuAC for gay men's HIV prevention, seriously reducing capacity to address the social determinants of health in the LGBTI communities. The second round of interviews started in 2014 just as PD was also defunded, leaving PLHIV without that assistance to access services. This timing enabled reactions to the changes to be captured. The 90-minute interviews focused on locality, contexts of life, social supports, sex and relationships, health and well-being, ageing and the future, and, in the second interview, changes during the previous year.

Constructivist Grounded Theory (Charmaz, 1990) guided my interaction in the data collection and interpretations. The longitudinal qualitative method drew attention to ordinary everyday experiences and the ways in which people manage their daily routines and relationships. NVivo software was used to organize key themes arising from this data, enabling comparison within and between the themes, and within and across the two points in time.

Results – key themes

Living out of step

The life course perspective has delineated life phases and socially defined transitions like retirement but also enables exploration of inequality and the ways the experiences of ageing change over time (Riley, 1987). Increased life expectancy and good health beyond 60 or 70 years of age for the baby boomer generation have made possible a 'third age', enabling retirement to be a highly creative period before advanced old age, without the usual constraints paid work puts on passion and creativity (Bateson, 2010). However,

facing imminent mortality in early adulthood, and losing partners and entire networks of friends as most participants in this study did, is not the usual life course. The participants had often done remarkable things in their life before their life course was disrupted by AIDS, and often confirmed the finding of Charmaz (1991: 237) that 'living a constricted life for years makes one seem a little 'out of step', if not entirely a relic of the past, even when young'.

I come from the old era ... I see the world from that older perspective. I find that everyone sees it from the new age perspective that you just get on with your life. You get diagnosed positive, you take a pill a day and you live a long life ... it's a wonderful outlook. But we are still here and I feel utterly – like I'm invisible in regards to the way I'm spoken to because I remember from 1992 to 1998, it was just death. We lived – I saw a whole generation of people die. I had a partner of 14 years die. I thought I was going to die. There was no hope, then of course medications came in and it changed. But people like myself, are affected by that time, that have lived through and survived. You could call it PTSD [post-traumatic stress syndrome]. We don't talk about it enough. (50+ yrs, diagnosed 24 yrs)

Illness forced a kind of premature retirement on these participants during the years when most people participate in the workforce and accumulate wealth. The loss of the contribution of regular work to overall well-being of PLHIV was well illustrated by the experience of one participant who, at first interview, had just been made redundant from a part-time job where his team had worked around his periods of sick leave. As well as the loss of intellectual stimulation he lamented the effect of the loss of the routine physical exercise he previously got through commuting. He was volunteering locally and putting time into a seemingly endless project to renovate his home to ultimately finance retirement to a more rural area, but felt he had been reduced to 'an old man shuffle' (53 yrs, diagnosed 23 years) around the house.

Participants on DSP had faced the challenge of finding a non-work-related purpose early in life, and this quest tends to intensify with age as questions of legacy arise (Bateson, 2010: 182). Most were proud of their contributions to the HIV response in the first decades, and were even nostalgic about the camaraderie they felt in those years when the community was mobilized and better funded. For example, most of the Sunshine Coast participants referred to the halcyon days of Grimwood House, a once thriving community centre that housed QuAC and QPP in Nambour until 2004. This was a classic 'enabling place' (Duff, 2011) where they contributed time and skills, but dwindling government funding and community mobilization now rarely enabled such opportunities in regional areas.

Premature ageing

Participants were troubled by reports that long-term survivors (L-TS) face a premature ageing with a disability profile 10–15 years in advance of their HIV negative peers, despite the evidence for this being contested (Rasmussen et al, 2015). Their lived experience suggested to them that their ageing process was at least accentuated. Those with sufficient stamina had resisted the DSP path; for example, a younger participant frustrated by the struggle to find employment feared that living on a pension would

prematurely age him and rejected the potential ‘structured dependency’ of welfare (Townsend, 1981).

I know a lot of HIV positive guys who are on the pension who become ageing, there’s effective ageing earlier than their prime ... they’re pensioned off, there’s a surrender that goes on there. (45 yrs, Indigenous, diagnosed 29 yrs)

However, older participants often had little choice:

I was of the generation where you were diagnosed and they organized to put you on the DSP. You were told to cash in your super and if you wanted to go overseas, go overseas now while you could and then you stuffed it all up and stayed alive. (52 yrs, diagnosed 25 yrs)

Most appreciated the breathing space that improved treatment had provided, for example enabling PLHIV who were previously putting considerable energy into staying up to date with the scientific literature, to relax into relying on their HIV doctor to stay on top of the technical side of their HIV care.

I no longer am quite as obsessive about reading everything.... I no longer feel the need – it’s not the number one show in my life. (57 yrs, diagnosed 17 yrs)

Little turnover in the state-funded sexual health centres workforce had enabled long-term partnerships to develop between PLHIV and their HIV doctors and nurses. Addressing the range of psycho-social and financial issues intersecting with disability and HIV co-morbidities was often much less straightforward. Care of co-morbidities, including diabetes, neurological decline, cancer, peripheral neuropathy, acquired brain injury and so on, involved many specialists, so most participants took on their own care coordination.

I see that as my primary job. I’m the CEO and my health is the bottom line of my company. (50+ yrs, diagnosed 28 yrs)

Ageing on our own terms

Most participants felt that the complexities of their lived experiences had given them wisdom that could be applied to the process of ageing.

I think the wisest people are perhaps those who have gone off the track a little and they’ve got a broader landscape to choose from. (57 yrs, probably living with HIV 13+ years, diagnosed 5 yrs)

As in the above case, even those diagnosed after effective treatment became available had often grappled with challenging life experiences, including coming out as gay and separation from wife and children, decades of problem drug use, and then life-threatening illnesses such as cancer, and loss of capacity to continue in a very physical occupation.

The need to maintain a positive mental attitude was often asserted, but this included not dwelling on what ageing could mean as it would raise anxiety levels for no tangible benefit.

I knew people who were diagnosed early anyway saying 'I won't see my 30th birthday', so a month before they're 30 they died. So that's the power of negative thinking as far as I'm concerned. So it's not something I dwell upon ... (52 yrs, diagnosed 25 yrs)

However, the participants were determined to age on their own terms. Those participants who cared for their ageing parents or other relatives had clear ideas about their own advanced ageing. This produced both pragmatism and insight into getting the best out of the system, and for many a determination to exit before suffering reached unacceptable levels. There was almost universal and adamant rejection of nursing home care as a future option, in part due to not trusting institutions to be LGBTI culturally competent and the fear of abuse arising from homophobia. Federal government efforts to address LGBTI cultural competence in the aged care sector, including recognition of LGBTI elders as a special needs group, had not changed the perceptions of participants.

Having faced mortality very early in life, participants were universally quite matter of fact about death. Having taken control by putting in place a plan to end their life if necessary, they were freed up to manage complex treatment and care routines and make the most of daily life. Those who talked most about suicide or euthanasia were putting enormous effort into a kind of pharmaceutically mediated truce with suffering.

Financial precarity limits options

As many of the participants missed the opportunity to accumulate wealth in their early and middle-adult years, they approached ageing acutely aware that their precarious financial circumstances limited their ability to fully utilize the positive aspects of ageing. While participants who were still working all talked of plans to retire early, most participants had been relying on DSP since their HIV diagnosis and cut living expenses by moving from the city. Most participants remained motivated to be actively involved in community and give back, but opportunities were limited by location, fear of discrimination, and lack of finances for transport.

Those who were coping best had found a way to supplement the DSP, and this extra income and social involvement enhanced quality of life. Strategies such as never working two days in a row and working from home with no firm deadlines, made it possible to sustain this very part-time work without causing health problems. However, these kinds of arrangements are unusual and those with them dreaded the possibility it could trigger a DSP eligibility review. A small amount of income above DSP enabled travel to take a break from the pressures inherent in day-to-day life and the location, adding to overall contentment and the maintenance of support networks beyond their immediate locale.

The defunding of PD had left some participants alarmed about the added costs of accessing services, especially dentistry.

whenever I needed dental work done they [PD] used to fund it in a way and that ... now I've got to try and get into a hospital ... when they folded they sort of sent this letter out saying blah, blah, blah; so that was a bit of a tail spinner. (50+ yrs, diagnosed 30 years)

This participant also had no idea where to turn for advocacy support upon receipt of a letter from the real estate agent denying permission to live with and care for his ailing HIV+ partner. He just put the letter away and hoped to avoid detection.

Mental health challenges

The most significant longitudinal finding was that, with cuts to services, the most vulnerable PLHIV in regional areas were feeling abandoned to cope in isolation with the cumulative impacts of the epidemic on their well-being, provoking a strong sense of injustice given they put their bodies and lives on the line for the drug trials that enabled effective treatments to be found. Some participants had moved out of the city to lessen inputs by constricting activities and withdrawing from social contact, consistent with Charmaz (1991: 95), who found people with chronic illness ‘pull in to manage their illness’. The sense of being overwhelmed by events was exacerbated by depression and HIV-related neurological decline affecting response times and memory.

Every day was just an Everest in a way and so the less there was, the better. Then I could manage it. And that’s what it’s been like ... the only way to manage was to do this, a very circumscribed life. (50+ yrs, diagnosed 19 yrs)

For some the isolation was so complete that meaningful conversation was rare.

Just the psychiatrist. I don’t talk to anyone about anything ... they don’t want to hear, they don’t care ... all they want is to talk about the weather and the grandkids. (60+ yrs, diagnosed 30+ yrs)

The impact of the QuAC Community Visitor’s Scheme was dramatic between interviews one and two for the oldest participant in the study, as he rediscovered the art of conversation at 76 years of age.

Trauma was common in the life experience of the participants and most were on anti-depressants long term, but did not have a mental health plan beyond the exercise programme that PD helped them set up in the past. Their complex circumstances included acquired brain injury and other disabilities, homophobic and race violence and minority stress, self-harm and eating disorders, sexual abuse in childhood, post-traumatic stress disorder, episodes of homelessness, and problem alcohol and drug use and gambling.

Trauma was strongly connected with place for some participants, motivating them to relocate and make a new start so they are not constantly pulled back into the past.

Which is one of the hard things now because I don’t like being in [regional town] because, I talk to my partner about it all the time that ... I don’t like being here because ... I know the spot that it all happened ... and I hate going past ... (40 yrs, Indigenous, diagnosed 14 yrs)

Relocation was one of the few opportunities available to reset circumstances, and the participants were highly mobile with diffuse support networks. Relocation enabled regaining control over who knew their HIV status to avoid the stress of being treated by

everyone as 'the person with HIV'. Those with local ties had usually lived elsewhere to come out as gay and develop a career, and had mixed feelings about 'going back' as an expression of the way HIV curtailed their life trajectory.

Many participants were improving their home environment as a refuge. Moran and Skeggs (2004: 86) concluded that for gay men it is common that 'home is comfort as a located experience of safety and security', a response to the outside world as threatening. Thus place can ameliorate or exacerbate uncertainty and fear.

I do worry about the future, yeah.... Where will I end up? ... Well I'd hate to lose this apartment.... You never know what's around the corner do we? You never know what's around the corner. But I'd flip out completely if I wasn't here. (50+ yrs, disabled by a gay hate crime, diagnosed 10 yrs)

The early 'death sentence' HIV diagnosis had also permanently altered attitudes to time, even as the language had shifted to living with a 'condition' rather than an 'illness', possibly offering some psychological relief (Corbin, 2003: 257). Most participants were still living very much in the present with little planning for the future, a mode adopted when they were given a short time to live. This mode was also evident in those participants diagnosed after the 'death sentence' narrative was replaced by the 'chronic illness' discourse (Siegel and Lekas, 2002).

I don't really have any [plans]. No. That's another thing about my life is I tend to just live day by day.... But yeah I don't really have any plans for the year, and that's – that can sometimes be a bit de-motivating. But if I make a plan I get anxious about it. (67 yrs, diagnosed 14 yrs)

While mental health issues including stigma are commonly associated with living with chronic illnesses, the combination of HIV stigma and homophobia were experienced as exceptionally corrosive on well-being across the decades, despite attempts to 'normalize' HIV as 'like any other' condition (Moyer and Hardon, 2014: 263).

I frame myself, I get up in the morning and I look at myself in the mirror and I just see AIDS infected poofter, that's the three words. (45 yrs, Indigenous, living with HIV 29 yrs)

Discussion

The early response to HIV involved an impressive community mobilization (Power, 2011: 27), but this solidarity has waned since more effective treatment became available from 1996 and government funding was targeted elsewhere. For the first study of L-TS Callen (1990: 241), resisted 'the temptation to exaggerate the good news or to censor the grim realities' and that approach is still necessary, despite the recent successes of the medicalized response to HIV. Likewise, Settersten and Gunhild (2015: 45) cautioned that the unbalanced emphasis in gerontology on successful and active ageing has neglected 'an obligation to make visible the full spectrum of aging experiences'. The PLHIV empowerment movement has always cultivated the resilience necessary to live with HIV, but ageing brings into sharp focus the suffering that activism and the clinical management of HIV has not solved.

A lot has changed since Callen (1990: 22) defined L-TS as surviving ‘twice the current median survival time’, which in 1987 was just three years. Although Halkitis (2014) asserts that a whole generation of gay men has been traumatized by AIDS regardless of class or HIV status, in the literature the term ‘long-term survivor’ is usually reserved for those diagnosed pre-1996, but time and ageing are probably rendering this cut-off less relevant, particularly for those diagnosed after 1996 who delayed treatment. Despite the biomedical progress, uncertainty was still impinging on the daily lives of the longest-term survivors in this study, plus those diagnosed more recently who were also experiencing a cumulative impact of many years living at the heart of the epidemic, an extended period of untreated HIV, co-morbidities, treatment side-effects and now ageing.

The participants were still coming to terms with ageing and often did not want to dwell on the implications. The need to ‘keep optimism alive’ was still the foundation of the ‘grit’ Callen (1990: 183) identified as a key characteristic of survival. Although dealing with more health issues than most people their age, consistent with Atchley’s (1999) Continuity Theory of Ageing, most approached ageing as a continuation of their current circumstance of managing a chronic illness and co-morbidities. They were learning to live within the body’s limitations (Corbin, 2003: 257) but anticipating that over time ageing would just mean more complications to deal with than HIV negative peers would face, at least until advanced old age. Claiming a right to euthanasia was the common response when participants anticipated lack of support or opportunities to contribute socially, and multiple co-morbidities, amounting to ‘no good days any more’.

The youth-orientation of the commercialized gay culture reinforces assumptions that ageing brings only negatives, but this generation of gay men has achieved significant reform of their social standing during their lifetimes, and will likely approach ageing in creative ways that disrupt heteronormative assumptions. The complexity of living with multiple co-morbidities highlighted the limitations of neoliberal notions of individual responsibility (Squires, 2013: 152), particularly when participants struggled with logistics due to depression and cognitive decline. The defunding of PD particularly impacted these participants. GPs are formally supposed to take on care coordination but receive little remuneration for the dedication involved, and most participants missed the support of a well-informed PD worker to occasionally discuss their situation and support necessary advocacy.

Funded support services for L-TS in Queensland are now narrowly focused on maintaining treatment adherence to meet the United Nations 90-90-90 target (State of Queensland, 2016: Outcome 4), but with ageing, psycho-social needs will be accentuated. Montaigner and his British Columbia team have also observed a ‘compression’ of illness towards the end of life for PLHIV and that ‘it remains imperative to address the challenges this population faces in achieving a healthy state to improve quality of life over the life course’ (Hogg et al., 2017: e275).

For some, moving away from the city meant leaving behind a PLHIV identity; a distancing to live beside rather than within HIV, but stigma and discrimination persisted even though most PLHIV now on treatment have an undetectable viral load. Despite the evidence that ‘undetectable = uninfected’ (U=U) (Prevention Access Campaign, 2017), a key mental health challenge remained overcoming internalized stigma and residual fear of passing on the virus. Most participants reacted to HIV stigma and homophobia by adopting a low profile to remain socially undetectable, which limited their

ability to build mutually supportive social networks. Campaigns displaying role models of successfully living with HIV and successful ageing were insufficient to address existing mental health needs, nor were they a replacement for actual social solidarity. Isolated individuals will continue to struggle, so collective advocacy is essential to deal with the range of issues involved in ageing with HIV. This requires a more sustained solidarity than the synthetic community of anti-stigma advertising and social media campaigns.

The literature on long-term survival with HIV commonly engages with notions of resilience (Lyons and Heywood, 2016), and the defunded programmes of PD and QuAC did build resilience. However, such resilience remains vulnerable to erosion by social isolation and unrelenting HIV stigma and homophobia in regional Queensland. Overly optimistic biomedical and normalisation narratives can effectively silence the suffering of L-TS, subtly aided by the empowerment approach that has otherwise served PLHIV so well. A similar dilemma has been critiqued by Stringer (2014) in relation to survivors of abuse and rape. She argued that feminist empowerment has dovetailed with neoliberal individual responsibility so that suffering is only conceptualized as victimhood. That critique could inform re-authoring L-TS' empowerment narratives to better reveal 'how social and psychological factors synergistically interact with physical health' (Mendenhall, 2012: 22).

Conclusions

In this study the L-TS, and those diagnosed after 1996 who were advised to delay starting treatment, have evidenced considerable grit to not succumb to a daunting array of physical, financial, psychological and social challenges. They were living with the legacy of the first 30 years of the epidemic and had mixed feelings about an exclusively positive spin on living with HIV, particularly as they faced ageing with an increased burden of morbidity and no discernible decrease in social stigma. Ideally stigma will reduce as more people become aware that 'HIV is different now' (*QPP Alive*, 2013), but this is unlikely while Queensland's out-of-date HIV-specific laws imply that stigma is justified.

The lived experiences of those participants in this study who struggled with the social determinants of health before HIV was even acquired, challenge the emerging biomedical narrative that in the future HIV will have minimal impact on life trajectory and identity as early treatment will enable PLHIV to remain in good health and work. The call of Stephenson and Kippax (2016) for 'socialising the biomedical turn in prevention' is also applicable to treatment and care as PLHIV age.

Improved access to flexible part-time work for PLHIV could enable those with the necessary stamina to escape isolation and maintain social connections. It would also alleviate financial precarity, create options, and ameliorate the uncertainty around ageing. For most, flexible access to DSP would need to continue, so the workers can remain responsive to signals of fatigue, and not join the ranks of the working poor with no health-care benefits card.

Mental health plans and services, and social solidarity, are essential to address poor quality of life beyond viral suppression. To assure the voices of PLHIV are heard, a quality of life target (Lazarus et al., 2016) needs to be incorporated into Australia's next National HIV Strategy.

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Author biography

Bernard Gardiner has been involved in the HIV response for over 30 years. He is the past Global HIV Programme Manager of the International Federation of Red Cross and Red Crescent Societies, and has served as a volunteer, governing board member and staff member of both the Queensland and Victorian AIDS Councils.