
Where's the hope?

Dialogues for Solidarity

28 September 2017



Session 4 - Life experiences

Care providers: Our work today

with guests Prof. J. Anderson, Bernard Kelly and Gary Brough

Where's the Hope?, a year-long series of *dialogues for solidarity*, is coordinated by [ReShape](#), an independent London-based think tank formed to respond to the ongoing crisis in sexual health.

Working together, activists and organisers share their experiences and explore new opportunities to address chronic obstacles to successful organising in HIV, HCV and related sexual and mental health concerns. Emerging advocates and organisers are especially welcome.

Background to the series

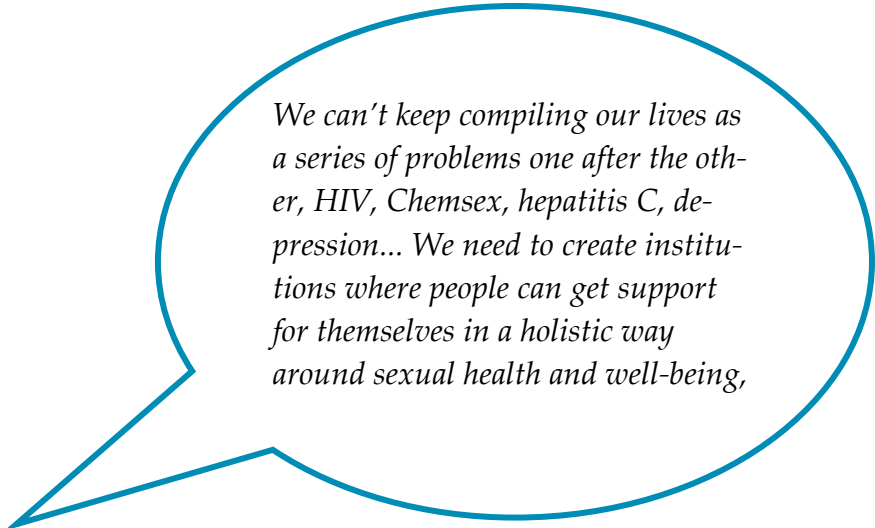
Huge gains have been made in HIV and HCV, related sexual and mental health concerns. We have the science and practice to prevent and treat HIV and HCV; we know more than ever about related sexual and mental health concerns. We are reframing our problems to aim toward sexual health and social well-being.

Yet individuals, organisations, the media and systems continue to stigmatise people living with these diseases and conditions and they often stigmatise themselves. One could also argue that these conditions are less stigmatised within the healthcare system today than they once were - at least HIV - but MORE stigmatised outside of the healthcare system.

Where's the Hope?, the result of extensive dialogue with UK and international activists, is a ReShape series of inter-related community dialogues, in partnership with leading UK HIV/HCV/sexual health and well-being sector organisers, organisations and out-of-country experts. The series will explore the key challenges and gaps of the day, and seeks to promote solidarity, community engagement, organiser mentoring / co-mentoring and effective initiatives.

Where's the hope? intends to be inclusive of people living with HIV (PLHIV), people living with HCV, BAME (Black, Asian, Minority, Ethnic), trans people, elders and young people, as well as social researchers. The ReShape series is designed to assist organisers, activists, advocates and service users impacted by HIV, HCV and related sexual and mental health concerns, with a special focus on emerging advocates and organisers.

All dialogues will be documented, disseminated and posted to contribute to local and international dialogue. The series will run monthly for a year, on the last Thursday of every month.



We can't keep compiling our lives as a series of problems one after the other, HIV, Chemsex, hepatitis C, depression... We need to create institutions where people can get support for themselves in a holistic way around sexual health and well-being,

*Sheena McCormack
European ChemSex Forum, 2015*

Session 4 - Life experiences

The fourth session in the series took place on Thursday 28th September 2017, with Prof. Jane Anderson, Bernard Kelly and Gary Brough.

The session explored current work experiences in HIV care from a specialist point of view and looked at how current conditions impacted related care providers. Reflecting on the changing nature of HIV care and the changing needs of people living with HIV, the session examined the policy implications of a fragmented system and the patients' perspective on HIV care.

The Care Providers session was expected to lay the groundwork for a future session on the failing Health Economy as a leading issue.

Guest Presenters: Prof. Jane Anderson, Bernard Kelly and Gary Brough

Prof. Jane Anderson

Prof Jane Anderson is a consultant physician and the director of the centre for the study of sexual health and HIV at Homerton Hospital. She has a special interest in the treatment and care of women with HIV, of migrant and minority ethnic communities and the psychosocial aspects of HIV care. She is also the chair of National AIDS Trust's Board of Trustees.

Bernard Kelly,

Bernard Kelly is the Senior Health Adviser & Clinical Team Lead, Wandsworth Integrated Sexual Health.

Gary Brough,

Garry Brough (Bruff) is London Coordinator of Project 100 at Positively UK and chair of the UK CAB (Community Advisory Board).

Suggested preliminary readings and video:

[HIV in the future NHS - NAT, Dec 2016](#)

[The Future of HIV Services in England - Shaping the response to changing needs - The King's Fund, Apr 2017](#)

A video of Prof. Anderson's presentation on the Future of HIV Services in England can also be viewed [here](#).

Key points from the discussion

- a. The experience of delivering healthcare today is very painful. The things that ought to be done, that are best practice, are not available to do, and doctors who are trained to do 21st century medicine to best standards cannot do that. The number of doctors is plummeting as they feel they cannot deliver professional services as they should. There is a sense of grief and bereavement.
- b. Funding bodies need to look beyond short-termism. The voluntary sector cannot function from one year to the next. Longer funding is needed to be able to efficiently and strategically plan and deliver services. With the lack of resources, value judgements come in, with the so-called deserving against undeserving patient groups fighting for resources.
- c. Collaborative work in the HIV voluntary sector has been problematic. There was a strong feeling in the session that we have lacked the ability to respond as a sector, to changes in services, which had negative impact. It took a court case and mismanagement from NHS England to bring the issue of PrEP access into the collective consciousness, once again pointing to a crisis response and lack of strong leadership rather than a coordinated strategy. This also raises other questions around what we campaign for or not. We campaign for PrEP but not for clinics shutting down. HCV treatment was recognised by NICE as cost-effective, yet for the first time, despite NICE recommendations, it was stopped. This should have been recognised as a crisis point as it set a precedent. However, HCV specialists were left to tell their patients, that although treatment was available, they were not eligible for it.
- d. There is a lack of coordination between services that have been divided and there is no overall well-being strategy. Unfortunately, once something is compartmentalised and priced, it can be outsourced. This extra layer and devolution of services make it very difficult to know who is in charge and how to fight a decision; the shift to local government for prevention and social care services has complicated things with 2 models of bureaucratic organisations. Both of those structures have different priorities and accountability to the system has fallen: It took a court case to decide where the accountability for PrEP rested.
- e. When everything was in the NHS, there was a sense of mutuality between information and expertise sharing rather than the current perceived “need” to compete with external services due to dwindling resources. Today, the expertise sitting in the clinical team is not informing the way money is being spent. The ability of specialists to ask questions to get the overall picture is being lost, leading to repeated infections. This is not a cost-effective system, it’s all about footfall. The connectiveness needed across the system to offer holistic care is not there. At the same time, the biomedicalisation of HIV has changed what “best” care is. The best now is about having less care, which raises questions about how to advocate for gold standard when the gold standard is being seen as less? By moving towards a more generic health system, we might be taking away the ability of someone having complex issues of finding a space where his or her needs can be openly and effectively addressed.

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- f. This is the first time in sexual health where we are trying to keep people out of services, and if they are in services, to keep them out of services as soon as possible. In some areas, people are not able to book sexual health appointments. We try to support people to be proactive but we are taking away the services. There are also discrepancies in access to care in terms of individual demographic groups leading to low diagnosis rates in some community and increased stigma.
 - g. Stigma within the HIV community and the wider community is still problematic. It feeds into individuals' perceptions of themselves and is relevant to issues around knowledge and education. THT is currently working on modernising the curriculum on sexual health in the UK, paying more attention to LGBT issues and sexual health in general. With better education for young people will come a better understanding of HIV and less fear of the virus. Stigma, however, is often already there before people get diagnosed, with wider issues around prejudices. Until marginal communities and the issues that influence their sexual risks are addressed, stigma will continue to affect HIV diagnosis and people's responses to testing and care.

Life experiences

Prof. Jane Anderson

Prof Anderson opened the meeting by stating that everything had changed since the beginning of the epidemic. The HIV care system was, until recently, well designed and unusually fit for purpose. However, the needs of patients have evolved with the advances in treatment and the changes in the epidemiology, and as a result, the system also needs to evolve. There is a sense that the need for care is changing into long-term condition management, which might need to be done elsewhere.

Having worked as an HIV clinician since 1984, a time where almost all the patients died and treatment was mainly about providing palliative care, she noted that her experience had taught her to respect the virus and showed her how much damage it could do, not just physically but also emotionally, financially and socially. Younger colleagues, who had not seen the damages her generation had, perhaps had a different perception of the virus and of what was needed to be done next. However, it was important to remember that HIV today may be a sedated lion in a cage, but it was still a lion and could still kill people.

She remarked that treatment had been successful and we were entering a new era of viral suppression. However, the 90-90-90 target did not mean that everything was fine and questions needed to be raised on how to deliver the next care needs on this evolving spectrum and how to make the right argument for the system to develop so people living with HIV were able to have the life they wanted to have. There was a biomedical intervention that could potentially not only change the epidemic but also improve relationships and social interactions, reduce fear etc, but yet, was it still only preventing death rather than facilitating life? This, she said, was the biomedical switch that needed to be thought about.

Prof Anderson also stated the need to reconsider the state of the health economics at present, as it is difficult to argue for more resources. The use of generic antiviral drugs, which are cheaper, is rising, but there is valid concern that these savings are not being reinvested in HIV services. The fear is for these to disappear into a black hole rather than being recycled to pay for PrEP or some other bit of the system that is evolving.

Prof. Anderson also noted that the change in the relationship between activism and medicine was very important. She recounted the story in her early days when, as a clinician at Barts Hospital, a patient, who was also an Act-Up activist, shocked by the lack of facilities, declared that he would chain himself to the hospital to get her a working space if one had not materialised in the next 6 weeks. She expressed how this had made her feel hugely supported. Today, as services were closing and resources dwindling, with a huge impact on the system, questions as to whether we still needed this kind of activism, and how to get it, were crucial.

She also expressed how important peer support was for care providers, especially when the care they hope to deliver was impossible. Compassionate care required us all to be kind to each other's as well as to patients.

Bernard Kelly

Bernard Kelly remarked that HIV had come into the culture in a very shocking way and shocking events help create spaces. It took a world war to create the NHS. He also noted that people used to go on marches, not just for HIV but for a lot of other issues as well. This activism had been behind all of us, informing us and propelling us forward.

Bernard read an extract from Sean Strub's book, *Body Count*, quoting Stephen Gendin last column before he died in 2000. Stephen had come to the conclusion that AIDS activism as we knew it was over: *"These days, my friends and I often mourn the loss of activism. Everyone we know is still doing AIDS work, but our involvement has become institutionalised. We aren't volunteers anymore: we're professionals. AIDS is a 9 to 5 job. It disgusts me to see what I've become. Ten years ago we would have never such gifts and graft from drug companies. Now we've come to count on it. But nothing is free, and whether we know it or not, we're paying the price with our lives."* A system that was very cooperative, with HIV, sexual health networks and other services all working together, bore fruits, but now we are all competitors in this new economy. The NHS itself has become a corporate entity looking at how to survive. In the old days, individual survival was *the* concern; today organisational surviving has supplemented it. Saying there is no money has become the end of the conversation, and no one is saying: there is a lot of money, just not everyone has it. The question should be: Do we always have to be faced with a shocking catastrophe before we act, or do we act when we see it coming?

Sexual health is being contracted out, services are being fragmented and some are simply disappearing. Patients are being turned away, safe spaces for gay men are disappearing leading to many isolated and unhappy gay men in London. Problems have not been solved and are being replaced by even more complex problems. When cuts come, support services tend to be the first to go.

Gary Brough

Gary, using the analogy of the frog placed in cool water that is slowly heated up to boiling point and cooked to death without noticing, felt that the urgency was lacking. The health care system is being fragmented and there has been a slow shift from HIV specialist care towards joint primary and secondary care and from three monthly to yearly appointments. This slow shift has resulted in the chipping away of a gold standard service, where rather than being maintained at that level, it is being brought to the level of a normal NHS service. In this new NHS business model, clinicians have become managers and services are open to competitive tenders, making caring for people much more difficult.

The reality, however, is that patients are quite happy with yearly appointment and do not recognise the slow fragmentation of services. As Bernard stated, a crisis is what spurs people into action, and people, in general, are not proactive health seekers. The focus now should be on how to help people live healthily without them having access to support services to complement the medical care they receive. We know from experience that medical care is not enough for HIV, the help and social care package, the whole person ethos, the well-being are paramount and without addressing reasons leading to diagnosis, gains will not be made. While the individual medical care is being taken care of, other issues are coming to the fore and politically, the agenda has been to distract us while the whole system of caring is being dismantled in front of us. Staying up to date with what is happening is a constant struggle and the steps of engagement are constantly changing. New activists need to figure out where are the pressure points that would allow them to exert influence. Gary also noted that issues around long-term management of HIV are not necessarily about HIV, they can be about kidneys, heart etc. and the actions we take need to happen in collaboration with other patients groups instead of fighting each other.

Going Forward

What can care providers and community activists do in a fragmented, complex and under-resourced system?

- ⇒ Care providers need to acknowledge they are struggling and state clearly that there are issues and problems
- ⇒ Articulate to people what the risks to the service are and how they could help.
- ⇒ Recognise quality, keep advocating for it, and maximise demands
- ⇒ Work more collaboratively with the community and the voluntary sector to generate a joint system response.
- ⇒ After the session, a quick meeting of speakers with ReShape brought forward a proposal for a day-long session expanding on this Where's the Hope? session that involves key HIV stakeholders and organisations but also other stakeholders at threat from NHS fragmentation with sexual health service providers and experts.