

Finding Our T Spot

**Pushing the Frontiers of Research on Trans Lives, HIV and
Holistic Wellbeing in the UK**

All I can tell anyone for sure about trans people and HIV is my own truth. I have been HIV positive for close to twenty five years, that as a transgender woman who has lived with HIV through most of its cultural and medical-history I have been subjected to horrible discrimination, ignorance and fear and have swallowed most of it without any recourse. I self medicate and self diagnose my interactions because all three of my distinct providers; GP, gender care and HIV care, work separately and claim utter ignorance of the others. There is no data about us and our community within the UK, there is data, speculative data, on a global level that estimates that at least 19% of all transgender women are HIV positive. There is hardly any data about transgender men, and none that references anyone non binary. The data can be reliably honed down to geographical specifics often showing a shameful picture about the treatment of transgender women of colour and transgender sex workers. The intersection of transgender identity and race is still woefully ignored in research, campaigns and funding. But the figure of 19% cannot be picked up and applied to us here in the UK with our greater legislative protections (EA 2010) and our 'free' healthcare system. This isn't the space to debate waiting lists or the NHS, but we have to accept that we have a free healthcare system which many other countries simply don't have and therefore in these countries transgender people have greater challenges in paying for any transition processes they may need or want to have. This lack of localised UK knowledge and data doesn't allow structures to be built systemically for our community, at best we have to use anecdotal evidence and incredibly small sample sizes of data to build a picture which doesn't sustain funding or structural interventions, I know this from my work across the fields of education and sexual healthcare. It frustrates and angers me but worse it means that we do not know how to properly plan to engage, better protect and serve our communities. As I see people using global data to evidence PrEP debates here in the UK I am saddened by the lack of real engagement. Many people utilising global data to produce 'inclusive' campaigns have no real idea about transgender sexual healthcare in this country. Or transgender lives at all.

It is the main driver for the creation of the series of engagements and conversations that I am currently developing and delivering with funding from the Paul Hamlyn Foundation, Finding Our T Spot, the first of which is a film about the

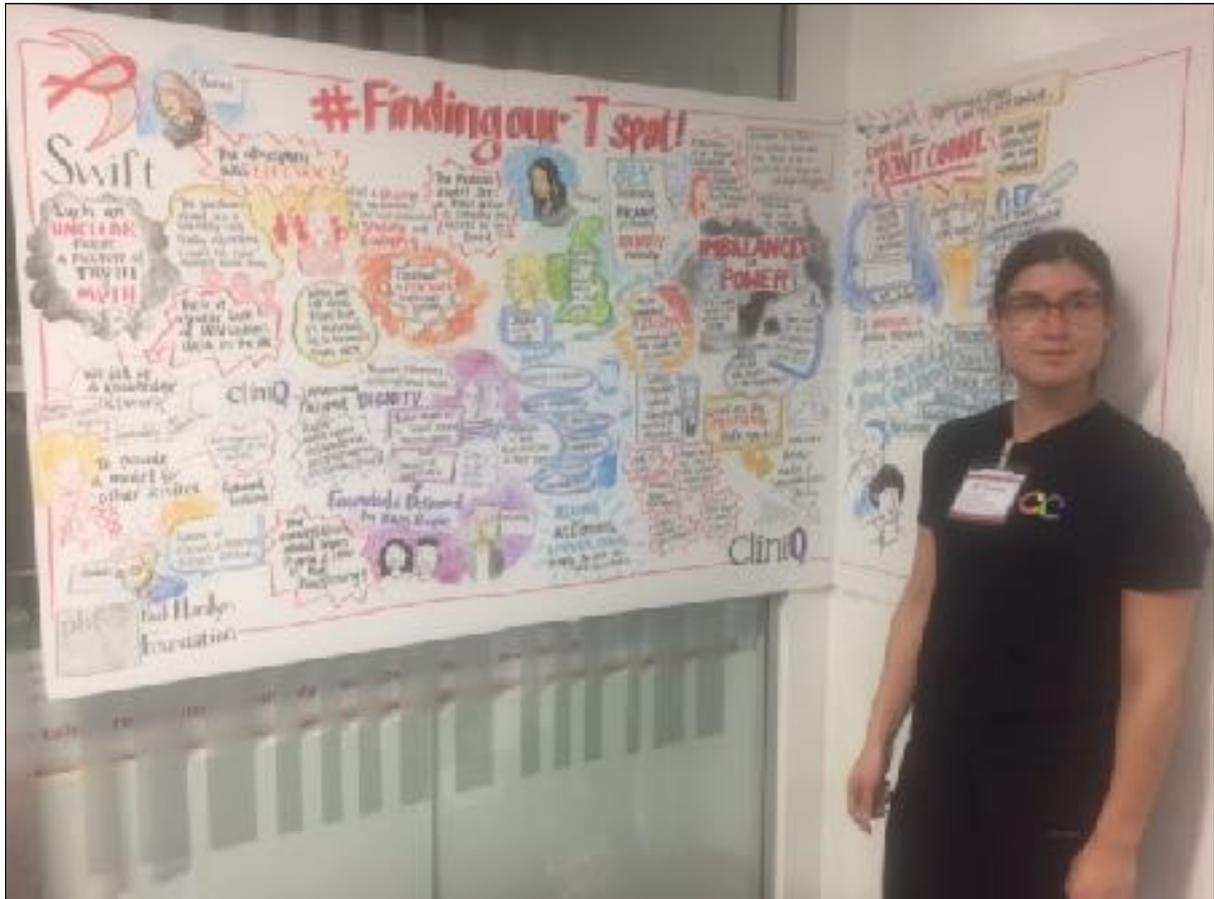
work of cliniQ (<https://www.youtube.com/watch?v=-t1wJ091cvA>) and the second was the recent roundtable event held at Gilead which specifically was designed to examine current research around the transgender community and sexual healthcare and to ask the questions; what research do we need to make viable structural changes to improve sexual healthcare for all the transgender community including non binary and implementations and how and who should carry out the research. There are other events and work planned under the title. The roundtable event was hosted by cliniQ and SWIFT and many of the most important research minds and practitioners within the field were assembled to debate and question current and future thinking and implementation. As well as clinicians and researchers the event also brought together campaigners, activists, media and PHD students to give a wider perspective beyond the purely clinical. It is vital to ensure that research, policy and change is centred on the lives and experiences of real people not preconceived or ill-conceived notions of 'others'. The event was captured by both a visual artist and photographer, the work will eventually be displayed in the home of cliniQ which is one of the long term aims of the project.

cliniQ (cliniq.org.uk) currently operates as a three hour clinic on a Wednesday evening within the rather wonderful 56 Dean Street. It is a vibrant, totally inclusive and diverse space which transgender people utilise as a vital part of their healthcare. But it is underfunded and overcrowded. We need a specific transgender sexual holistic healthcare centre and we need it urgently as funding is cut across the board and hopes of embedded transgender training modules float off down the river of austerity. we do have funding to deliver some outreach work through cliniQ but this is finite. One of the clear things to come out of the event was the paucity of quality in healthcare across the board for the transgender community, we know that trans people are slipping between ever growing cracks and that there is an a real inequality both in the delivery of healthcare and the quality of healthcare. A centre of excellence has never been more vital.

Over the course of an afternoon charity heads and researchers from right across the sexual healthcare sector addressed needs, gaps and reforms as individuals and in groups that infrequently come together. This afternoon the transgender

community didn't have a mere place at the table they were the table and all of its participants.

Juno Roche - Writer, campaigner, Patron of cliniQ and member of SWIFT



SWIFT is a knowledge network focused on promoting research on HIV and women (www.swift-women.co.uk). We aim to bring together clinicians, academics (from a variety of disciplines), activists, and women living with HIV. The needs of trans women has been, until recently, a noticeable lacuna in our work. We were delighted to be able to collaborate with Juno (who also sits on our Steering Group) and CliniQ, and to support this innovative and landmark roundtable event. The participatory and multidisciplinary ethos behind the roundtable mirrors the values of SWIFT. We are excited to see the outputs of the day, and look forward to working together to put the research needs of trans men and women firmly on the agenda.

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UK

The event was opened by the facilitator Razia Aziz from the Equality Academy. In her opening - after briefing on housekeeping and introducing the two artists present, she talked about the full extent of the facts, details and factors to be addressed within the scope of research. What became clear from her introduction was the range of structures and systems entwined that currently prevent good, systemic practice and how we might consider unpicking these in order to identify clear, concise strands of research. After a brief session to ignite thinking and to introduce all participants we moved onto addressing the first set of questions:

- **What does/can holistic sexual healthcare look like for trans people?**
- **What are the barriers?**
- **How can we research and address them?**

We were asked to look widely and address; communication and information language, attitudes, environments and institutional structures. We addressed these questions in smaller groups.

1) What does/can holistic sexual healthcare look like for trans people?

Person should be treated as more than sum of parts, keep person centre

Integration - should be able to access all services in one space as it cuts down on the risk of discrimination and quality

Listening to people and finding out what they really need rather than presuming

Trans clinics that could disseminate good practice nationally -educating others

Available across the country not just London or city-centric

Safe spaces providing good quality services

Must be holistic and able to address a multiplicity of needs

2) What are the barriers to or in research?

The assumption that cis people will be researching trans people rather than employing trans researchers to work alongside or to lead projects

Stigma re HIV within the trans community and towards the trans community

Expectation of an asexual narrative or a pre conceived narrative that doesn't really fit

Poor and harsh gate keeping that turns trans people away from engaging in research

Lack of baseline data to build new more detailed research - for example numbers of trans people who are HIV

Anxiety about drug interactions have impacted trans people engaging with say PrEP research, much more information needed here

Internalised Transphobia because of incredibly negative interactions with the NHS 'I survived the process', means a reluctance to engage

Fear around sexual health - as with any other community

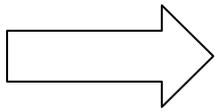
Fear of poor engagement from researchers - often trans people are asked inappropriate and '101' questions

Trans research is often underfunded as it is seen as marginal

Funders like big number studies, we are a small community

3) How can we address these barriers?

Map what services already exist



numerator: Trans people with HIV

denominator: Number of trans people

What is the most useful definition of trans for what we want to achieve?

Basic lack of awareness of trans meaning

We need to know about the prevalence of HIV within the trans community (cliniQ '2 step' data collection rolled out)

More international collaboration to increase scale and to share expertise

Look at our terms - often 'trans and transgender' are examples of Western language

World Cafe activity

The group then divided and looked at different set questions that had come out of the previous discussions, the following questions were addressed:

1) What are the most important priorities for UK-based research into trans lives and HIV?

Some responses -

- *defining populations of interest*
- *mapping exercise of services and needs*
- *what are minimum standards of care?*
- *intervention trial, comparing a holistic model of care with outcomes in the usual disconnected care*
- *are there different risk factors for trans people if so how can we develop sexual healthcare messages which are relevant?*
- *identify prevalence for the widest range including trans men and non binary*
- *can we use international data?*
- *look at 2-step data collection as a must as so many trans people are wrongly recorded*

2) How can we create the best combination between trans-specific and mainstream research?

Some responses -

- *we need to articulate and demonstrate that inclusion of trans people improves the basic quality of research*
- *encourage researchers to include trans researchers*
- *look again for hidden findings in published work that may be of use*
- *share funding*
- *address sexism within current research to allow others in*
- *standardise gender questioning across the board*

3) What are the real sexual healthcare needs of trans bodies and what are the relevant research questions?

Some responses -

- *promote pleasure and sexual satisfaction for trans people - not just preventing disease*
- *assumption that 'post transition' everything is taken care of*
- *how does transition change sexual practice and sexual health care needs?*
- *poor surgical results can = poor mental health and low self esteem = risk taking potential*
- *poor surgical results can = psychosexual problems*
- *negotiating condom use difficult in communities that just don't use condoms*
- *what do we need to grow as a community?*
- *look beyond cis-normative bodies - exploration*

- *how can we ensure that healthcare professionals understand trans bodies and risks?*
- *understand social factors such as transactional sex*
- *trans people need to speak more about their bodies, include partners in this*
- *we need experts to have expertise*
- *we need to discuss openly our bodies, our genitals and our pleasure and inform others - trans women don't need cervical smears but we do have prostates*

4) How do we research the emotional, psychological and spiritual needs of trans people, including aspirations?

Some responses -

- *this question is far too wide, perhaps begin with slimming down*
- *outreach work and community groups, perhaps begin to centralise data*
- *embed research ethically within therapeutic services that are inclusive*
- *we especially need much more qualitative research on emotional aspects of marginalised lives*

5) What is happening now in services to trans people and research on, by and for the trans community - in relation to sexual health?

Some responses -

- *most services that exist are horribly underfunded, volunteer run*
- *community led research*

- *but communities can set the agenda and questions, we just need to empower with access and funding*
- *create more partnerships - DMU?*
- *many trans researchers are completing PHDs but lack the funding or opportunity to produce research*
- *form a network of trans researchers producing, sharing and collating work*
- *trans people are still misgendered and inappropriately handled when they go to sexual healthcare centres*
- *long waiting times*

Closing Space comments

Juno: *Create a centralised archive within cliniQ and form a small cross-organisation working party which has the specific remit to build our knowledge of the Trans community in the UK and HIV. Ensure that trans people are fully included within wider debates around HIV and sexual healthcare*

Alastair: *What currently happens is tokenising. We need to be careful about the way we use the word 'community' - what does that really mean in its widest sense?*

Mags: *What can we do as a group to influence what is already happening in the wider context?*

Shema: *Develop standards of care through mandatory training for all healthcare professionals*

Lee: *Not just medical professionals who need training but also community workers, work to create truly safe spaces within the field.*

Kate: *All About Trans work building links between professionals and teams and encourage them to share and learn from each other, for example GPs.*

Nick: *Combination of personal experience and professionals is very powerful, enable trans people to demonstrate this through research with trans researchers leading or being central to teams*

Shema: *Academics could give time to support others to develop research skills*

Victoria: *Our research should always be shared internationally as it could have an incredibly positive influence.*

Valerie: *PHE - there is a real opportunity here to create a platform for this discussion about research.*

Juno: *It seems vital that we create a small working group.*

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