

## The LGBT Health and Inclusion Project

NHS Sussex and Brighton and Hove City Council (BHCC), have commissioned a consortium of organisations providing services to lesbian, gay, bisexual and transgendered (LGBT) people in the city to conduct a series of consultations with local LGBT people. The aim is to use the information gathered to feed into local service commissioning, planning and delivery.

The partner agencies are: Brighton and Hove LGBT Switchboard, THT South, MindOut, Allsorts Youth Project, Brighton Bothways and the Clare Project. The consortium has employed a worker to coordinate the project, known as the LGBT Health and Inclusion Project (LGBT HIP).

## Please note, the following report presents information about the consultation and engagement work conducted by LGBT HIP and should not be taken as a position statement of any of LGBT HIPs Consortium partners.

### Background

A local LGBT action-research project (Count Me In Too) presented a number of important findings in relation to sexual health and trans people. The research indicated that trans people were less likely than non-trans people to say that they needed a sexual health check-up, were less likely to have had one in last six months and more likely to have never had one. Trans respondents were also more likely to say that they would not know where to find help around sex and relationships and were more likely to regard sexual health resources as not relevant to their sexual practices or gender identity.<sup>1</sup>

The LGBT HIP consortium therefore identified initiatives to engage trans people in consultation around ways to improve access to sexual health services as a priority. The consortium agreed to develop a pilot initiative to progress this. The aims of the initiative were:

- 1. To pilot a session to enable trans people to learn more about the primary sexual health clinic in Brighton and Hove and to feel more confident about using sexual health services independently in future.
- 2. To provide an opportunity for the primary sexual health clinic in Brighton and Hove to consult with trans people about ways to make clinic services more accessible.

The objectives were:

- 1. To engage the sexual health team at the Claude Nicol Centre (CNC) and cancer prevention team (cervical screening advisor) to work in partnership on the initiative.<sup>2</sup>
- 2. To facilitate a training intervention on 'trans awareness' for all CNC staff.
- 3. To engage 10-15 local trans people in the clinic familiarisation session.
- 4. To evaluate the impact of the pilot for trans participants and staff using pre and post intervention questionnaires and brief, 'vox-pop' interviews.
- 5. To provide a briefing paper detailing key learning and recommendations from the pilot.

<sup>&</sup>lt;sup>1</sup> Browne, K. & Spectrum (2008) Count Me In Too: Trans People (Academic Report). Brighton: Spectrum.

<sup>&</sup>lt;sup>2</sup> The initiative included cancer prevention input to address issues concerning trans men's need for cervical screening and trans women's need for prostate care.

## **Pre - Intervention Preparation**

Before the intervention with trans people could begin, it was important to ensure that all staff potentially involved were trained in trans awareness. The LGBT HIP Coordinator worked with the trans awareness trainers at the Terrence Higgins Trust to develop and deliver a two-hour training session with CNC staff. This covered aspects concerning terminology and trans identities, transition pathways, hormonal and surgical procedures, interaction between hormones and HIV medication and anti-discrimination legislation. The methods included talks, small group work and case studies. Over 40 staff participated and 32 completed evaluation forms. The key finding from the forms was that the training was very well-received but was felt to be too brief, with longer than two-hours requested.

## The Intervention

The LGBT HIP Coordinator worked collaboratively with two sexual health advisors and a cancer prevention health trainer to design the intervention. The intervention was planned as a two-hour session, hosted on a Friday evening when the clinic was closed to all other service users. The team delivering the intervention was: the LGBT HIP Coordinator, two sexual health advisors, a sexual health doctor, a sexual health nurse, a health trainer and a clinic receptionist. Participants were recruited through two trans support groups operating in Brighton (FTM Brighton and the Clare Project) and the LGBT HIP members database. An article was also published in the local LGBT magazine GScene to publicise the session.

The intervention consisted of the following:

- Welcome participants were greeted as they arrived and buffet refreshments provided.
- Participants were introduced and a group working agreement was set concerning confidentiality, respectful treatment etc.
- Participants were given a tour in two groups of the clinic facilities, with an opportunity to ask questions as the tour progressed. This included an introduction to the waiting area, reception, examination rooms and testing facilities.
- One of the sexual health advisors and a doctor role-played a consultation to portray the process.
- The health trainer conducted a cancer prevention quiz.
- A brief discussion was then conducted with participants about ways to make the clinic more 'trans-friendly'. This part of the session was recorded with participants' permission.
- The session was then closed.

### Analysis and Evaluation

As the project was a pilot, it was important to gather information about its impact. The following mechanisms were used to gather data.

- Staff training evaluation forms were collected (=32).
- Pre and post intervention surveys were collected from participants (pre=15, post=17).
- A one-hour staff team debrief was conducted to review the development and implementation of the initiative. This included the LGBT HIP Coordinator, two sexual health advisors and one health trainer.
- Data from the pre and post intervention surveys was analysed using Excel. As the number of participants was small, simple frequencies of responses to questions are presented.

The staff debrief and participant group discussion were audio recorded with permission. Recordings were transcribed verbatim. An inductive approach was taken to analysis, with themes emerging through a process of studying the transcripts. Themes were allocated codes and a code frame was created for each transcript. The code frames were then applied to each transcript in full to generate the findings.

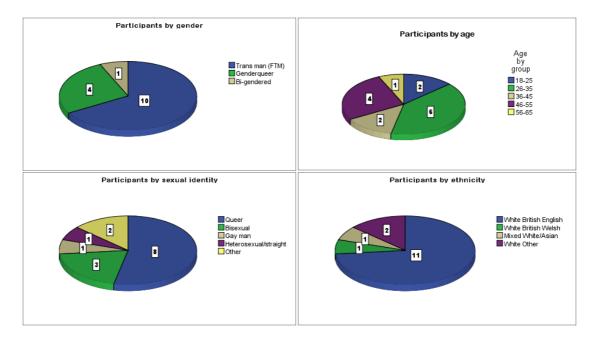
# **About This Report**

Part one of the report summarises the quantitative findings from the pre and post intervention surveys that were conducted with participants. Part two presents the qualitative findings. The final sections outline conclusions and recommend actions.

# **Part One: Quantitative Findings**

## Demographic Characteristics

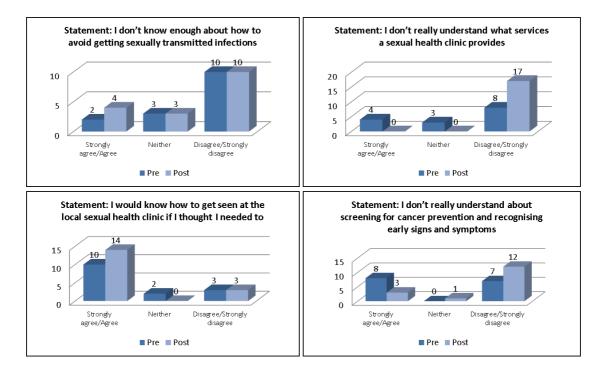
In total, fifteen participants completed a pre-intervention survey. Seventeen people attended the event and also completed a post-intervention survey. All but two of the participants were female-to-male trans people, with 'trans man' being the most common gender identity reported. The age range was fairly wide but most participants were in the 20s - 30s range. 'Queer' was the most commonly reported sexual identity, followed by 'bisexual'. Almost all participants were from the White ethnic group.



### Knowledge

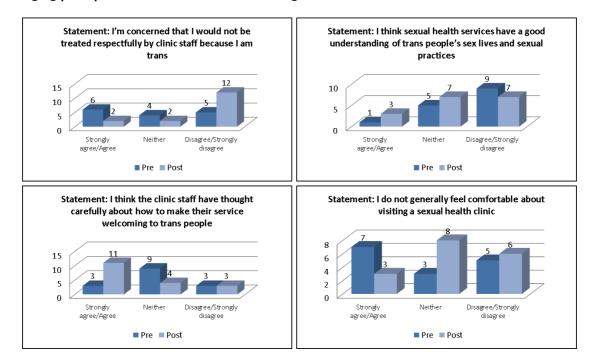
The questionnaires contained a series of knowledge-related questions and asked participants to what extent they agreed or disagreed with the statements. In the tables that follow, positive and negative response categories have been collapsed for purposes of reporting (e.g. strongly agree and agree have been combined). The darker bars represent pre-intervention responses and the lighter bars represent post-intervention responses.

The findings suggest that there was little change evident in influencing perceptions of how knowledgeable participants were about avoiding sexually transmitted infections (STIs). However, this was expected as the intervention did not cover this to a significant degree, concentrating mostly on content about sexual health clinics or cancer prevention. A considerably greater impact was evident in terms of raising awareness about the functions of a sexual health clinic. There was also more modest improvement in raising awareness about how to get seen at a sexual health clinic. Improvement was also shown in raising awareness about screening for cancer prevention and recognising early signs and symptoms.



#### **Attitudes and Beliefs**

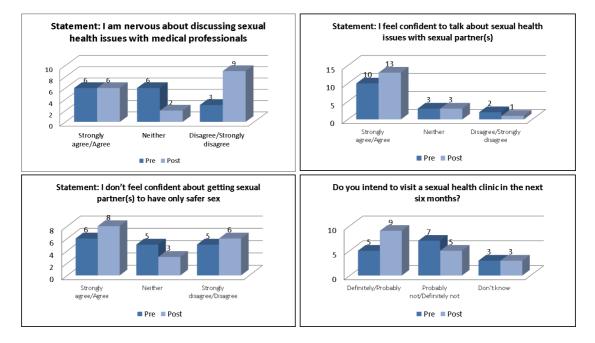
The surveys also contained a series of statements concerning beliefs and perceptions about sexual health clinics. There was a noticeable reduction in concerns that participants would be treated disrespectfully by staff because of being trans. However, the effect was less noticeable in relation to perceptions that clinic staff have a good understanding of trans people's sex lives and sexual practices. However, there were considerable improvements in perceptions that staff have made efforts to make their services welcoming for trans people. More modest improvements were seen in changing perceptions of discomfort about visiting a sexual health clinic.



### Intended Behaviour

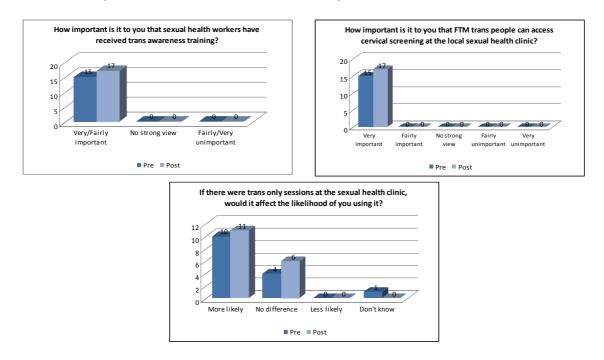
A series of statements were contained in the questionnaires about behavioural intentions. There was evidence of reduced nervousness reported about discussing sexual health issues with medical professionals and a small increase in confidence in discussing sexual health issues with partners (although this was not a primary feature of the intervention). It appears that more participants felt a lack of confidence in getting a partner to have only safer sex after the intervention than before but this effect is due to the impact of the two extra participants who completed a post-

intervention survey. The intervention had greater impact on increasing intentions to visit a sexual health clinic in the next six months.



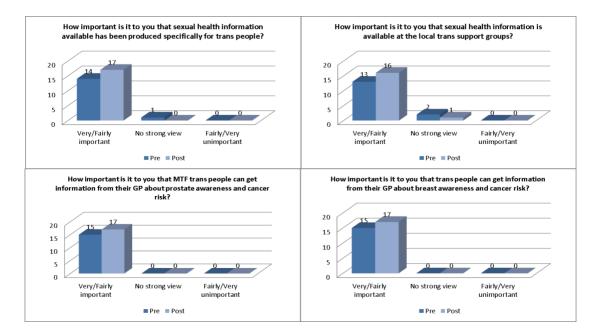
#### Services Provided

We asked a series of questions about sexual health services. Participants overwhelmingly agreed that training on trans awareness for staff was very or fairly important. They were also strongly in favour of trans men being able to access cervical screening at the clinic. Opinion was somewhat more divided about whether trans-only sessions at the clinic would make them more likely to use it. However, both before and after the intervention, around double the number of people said that trans-only sessions would make them more likely to use the clinic.



#### **Getting Information**

There was strong support both before and after the intervention for sexual health information to be produced specifically for trans people and to be made available at the local trans support groups. Participants also strongly supported being able to access information for trans women about prostate health and cancer risk and for both trans men and women about breast health and cancer risk.



## **Part Two: Qualitative Findings**

This section presents findings from two audio recorded discussions concerning the Clued Up intervention. The first was a brief group discussion with trans participants conducted as part of the Clued Up Intervention. The second was a debrief session facilitated by the LGBT HIP Coordinator with the staff team that developed the Clued Up intervention.

This analysis focuses on barriers reported by participants in accessing and providing sexual health care in order to inform identification of appropriate interventions to reduce those barriers. Discussions with staff focussed on the development of the Clued Up intervention to review and inform future initiatives.

### Interactions Between Staff and Service-Users

Participants recalled having had difficult experiences of sexual health clinic visits in the past, leading to the impression that accessing sexual health services was stressful and something to be feared or dreaded. Such accounts were not confined to the clinic participating in this pilot and included experiences of clinics elsewhere.

"Coming to the sexual health clinic is a very stressful experience." (Participant)

"I find it very stressful." (Participant)

"I could tell you horror stories." (Participant)

"It's always been a complete nightmare coming here." (Participant)

Many of the barriers that emerged centred on social interaction and communication between clinic staff and service-users. This was related to perceived staff discomfort and disrespectful treatment.

"[The doctor] was clearly mortified to be dealing with me and he was bright purple the whole time and he kept talking about 'um, down there'." (Participant)

"He had such a horrendous experience with the junior doctor. He's clearly male, no one in the world would ever think he wasn't male and the junior doctor's called him she." (Participant)

One staff member commented:

"It kind of echoes exactly what happens in clinic – you really want to get it right, and then you find yourself falling at the first hurdle because you've used the wrong term, or, yeah, you presume something." (Staff Member)

This comment illustrated the strong desire of staff to 'get it right' but that communication difficulties were often at the heart of those occasions when they felt they had inadvertently 'got it wrong'. The fear of causing offence appeared to stem from a lack of understanding of trans issues and lack of confidence and experience in working with trans service-users. For participants, the perceived lack of awareness was one of the major barriers they faced in relation to sexual health care.

"They [the clinic staff] were really shocked there wasn't a penis there, and it was like, God [it] caused so many problems!" (Participant)

"Being aware is going to make a huge difference as to whether or not I feel comfortable getting um screening... you can't underestimate the importance of it... that is one of the most uncomfortable things, um, and that's the sort of thing that scares me from coming." (Participant)

However, there were also examples where participants reported positive interactions with sexual health services. These were explored to identify those aspects that contributed to a positive evaluation.

"Once I went in, I said I'm a trans guy this is my situation; there was a sensitivity with the staff... the willingness to say: am I getting this right, have I, you know, is this an OK way to approach this? And it's not necessarily knowing all the answers it's being willing to ask for guidance and to say I'm not too sure of my ground, please bear with me." (Participant)

The quality of interaction with clinic staff therefore emerged as the most prominent factor in perceptions about the quality of the clinic experience. Being trans aware (culturally competent), sensitive and able to be open about gaps in knowledge were important factors informing positive views.

#### Forms and Administration

Participants also gave feedback on aspects of the way in which the clinic was set up and run that they felt acted as barriers. These focussed on the ways in which the administration of the clinic was perceived to be based upon binary notions of gender that excluded some participants.

"Yeah, it's all very geared ... male or female." (Participant)

"An awareness of people not necessarily identifying gender-wise in the binary – female or male – is trans friendly." (Participant)

Participants perceived that staff needed to be aware of the fact that trans people may present with varied gender presentations that may not be limited to binary notions of gender, and be able to work with trans people without making assumptions.

"I'm not sure how somebody who identifies as genderqueer or non binary gendered...would, that still cause a lot of trouble?" (Participant)

"I think people see 'trans' and they see 'surgery' and then a lot of confusion happens... it's really important [to be aware] that someone might be looking a certain way and be at any stage and may have never had surgery." (Participant)

The imposition of binary notions of gender was particularly exemplified by clinic forms. Participants expressed the view that clinic forms ought to be flexible and allow space for individuals to describe themselves, their bodies and their needs in their own words.

"So if there were either space at the bottom or on the flip side of the form to just say any other information that we need to [let them] know. So that if you tick 'male' or you tick 'other' under gender and blah blah blah and then you get to the bottom and you say these are the 'bits' that I have and these are the things that you need to know. There could just be an empty box to put it in your own words." (Participant)

## Disclosure

For participants, issues of disclosure emerged as a key theme. A particular concern was the point at which disclosure of trans status to clinic staff was necessary. Participants perceived that clinic staff needed to be aware of their trans status but wanted to have control about when and how the disclosure was made. They wanted this information disclosed only to staff who needed to know and at a timing and method of their choosing.

"I'd have a problem with reception dealing with that part of the form. I would want for my own privacy, I would want as few people to know about whatever's working 'downstairs'." (Participant)

"Well if you've got the form that says 'male', 'female' or 'trans' or 'other'... then you've not disclosed what's in your pants to the reception but the doctors are going in knowing, right, we need to be asking these questions because this is not 'standard kit'." (Participant)

### Clinic Code Words

The clinic had a procedure where service users could use a special code word to indicate to the receptionist, either on the phone or on their arrival, that they had specific needs to ensure ease of access to the clinic (e.g. that set up for sex workers). The discussion considered whether such a process would be useful in relation to a code to denote trans status. Perceptions about this were mixed. Some participants perceived that it would be helpful in alerting staff to the fact that the service user was trans. Others, though supportive, perceived that it didn't really help the clinic staff to know what to expect in terms of the type of genitals the person had, which was felt to be a central question that staff would be interested in from a clinical point of view.

"Well maybe it just gives people a bit of warning really." (Participant)

"Maybe if you've got a code word, if you come in and you say, right, basically whatever the trans code word is, maybe they're less likely to put you in with the junior doctor who's doing the first day on their rotation." (Participant)

"We might not necessarily need a code word because, like the trans tick box on the form, which is a good start, [it] might not, um, might not actually indicate what 'bits' we have, and really it's the 'bits' that we're going to be here for." (Participant)

### Marketing

One of the ways in which the sexual health clinic could make itself more accessible to trans people was to market its services in a way that would enable trans service-users to feel confident that they would receive a trans aware and accessible service.

"If I was going to a sexual health clinic for the first time I would probably look it up online, to see where it is and to see what time it opens and all that kind of thing. And if it said somewhere on there, a little bit, on the hospital page, we have had trans awareness training, we understand that some people may have this and that, here is a code word if you need it, here is what to ask for if you want to have a particular doctor to have special training, let us know at this stage if you've had this surgery or that, I know going in that they are clued up and I know when I'm supposed to say stuff so I don't just get nervous." (Participant)

### Intervention Development

The following section explores staff perceptions of the Clued Up intervention to consider what worked well and what could be improved. Overall, the session received very positive feedback from the clinic staff; it reportedly ran smoothly and the atmosphere was perceived to be conducive to open and frank discussion.

"The process just went very smoothly and the uptake was brilliant." (Staff Member)

"I was really taken aback by how many people attended, and how receptive and positive the whole feeling was of the whole evening." (Staff Member)

Staff members perceived that it was important that the whole sexual health staff team was represented in the session but that the staff presence was also proportionate. The role-play was considered to be particularly successful and mirrored well scenarios in the clinic. Staff also observed that the session had represented a learning opportunity for them as well as participants.

"We were able to sort of you know represent everybody that works within a clinic and I think our numbers were just right, I think if we'd have had more staff, it could have felt quite threatening." (Staff Member)

"Yeah, it felt like quite um, a dual thing, there were as many questions I think from our side as there were from the people that came and it felt – it felt like we were all learning." (Staff Member)

As a result, clinic staff came away from the session feeling that they had a greater awareness and understanding of the issues faced by trans people.

"I don't think that I'd maybe fully appreciated people's vulnerability, you know in the community, you know outside of the clinic and what people have faced and what they've been through." (Staff Member)

"The psychological impact of being in that transition and what people have to go through. It's not easy and we need to be mindful of that." (Staff Member)

Clinic staff perceived that as a result of the intervention, communication with trans patients would be more relaxed, making interaction easier.

"I think also from my own perspective, I will be less hung up about trying to get the words right and just being, you know, up front, honest and asking if I don't know something. Asking them, asking that person rather than worrying so much about getting it wrong." (Staff Member)

"It was good practice just to remember the realness of it all ... it's just people isn't it? It's just talking to people and that is actually a lot easier than you might think it is." (Staff Member)

#### **Modification**s

Potential modifications to the session were explored by staff. It was noted that two hours was insufficient and that three hours would have been a better allocation of time. From the staff perspective, greater utilisation of the opportunity presented was an important area for development. A number of ideas were generated concerning how the opportunity could be further capitalised upon. This included:

- Booking follow-up clinic appointments with participants at the session.
- Delivering some forms of screening and testing during the session (i.e. minimally invasive tests requiring only urine samples or self swabs).
- Retaining cancer prevention as a discussion topic, which was a novel feature of this intervention.

In addition, staff would have liked more time during the session for one-to-one conversations with participants, as staff felt that this would facilitate constructive two-way interaction.

"Maybe having the opportunity to have a one to one kind of chat with people if that's, if that was what people felt they would like. And perhaps I would have liked that too, you know for me, to be able to ask more, more questions perhaps." (Staff Member)

#### **Conclusions**

The primary conclusion from this analysis was that this was a successful pilot intervention. The preintervention staff trans awareness training was well received and there were important positive outcomes for both participants and staff. According to the pre and post intervention data, there were positive gains for participants in terms of:

- Improving knowledge about the services sexual health clinics provide.
- Improving knowledge of how to be seen at a sexual health clinic.
- Improving knowledge about cancer prevention.
- Increasing confidence that staff have thought about how to make services welcoming.
- Increasing confidence in respectful treatment by clinic staff.
- Increasing confidence to discuss sexual health matters with medical professionals.
- Increasing intention to visit a sexual health clinic in the next six months.

More modest but important gains were made in terms of:

- Raising awareness about how to avoid STIs.
- Increasing confidence about clinic staff awareness of trans people's sex lives and sexual practices.
- Increasing confidence in visiting a sexual health clinic.

However, it was notable that increasing confidence to negotiate safer sex with partners was not improved. This was expected as this was not a significant feature of the intervention but it does suggest that there is scope to develop interventions for trans people to respond to this need.

The intervention was also able to identify important new information about participants' preferences to access cervical screening for trans men at the sexual health clinic and to have trans-specific sexual health information available at local trans support groups.

The staff debrief also indicated that there were positive gains for staff in terms of:

- Increasing awareness of the issues and barriers faced by trans people.
- Increasing knowledge and confidence in working with trans people as service users.

#### Limitation;

Although this intervention has been effective in meeting its objectives, there are two important limitations to be noted. Firstly, that this was only a first pilot exercise including a small number of participants (n=17). Secondly, that despite efforts to involve a diverse group of trans people, most participants were drawn from a trans-masculine group (i.e. female-to-male trans). Almost all participants were White so that the ethnic composition of the group was not diverse. These are important limitations and findings should not be generalised beyond this group. Bearing these limitations in mind, the following recommendations are offered to support the development of the Clued Up intervention and improve access to sexual health services for local trans people.

### **Recommendations**

#### To further develop the Clued Up intervention:

- 1. *Experiment with intervention adaptation* Staff had important and useful suggestions as to how to further develop Clued Up, which should be explored (e.g. booking follow-up appointments, enabling self-screening testing). In addition, the time allocated to the intervention needs to be at least three hours.
- 2. Retain the cancer prevention content This was a novel aspect of the intervention demonstrating effective NHS partnership working that should be retained and developed. The cancer prevention content was a valuable aspect of the pilot in its own right. However, because participants strongly wanted cervical cancer screening to be available at the sexual health clinic, this provided enhanced opportunities to develop cancer prevention awareness work.

- 3. Conduct further research The intervention was an important 'proof of concept' study, which showed that a clinic familiarisation session could be developed and run with trans people, leading to important gains in the development of knowledge and attitudes about sexual health services. However, more research is needed to examine the extent to which this leads to behavioural outcomes (i.e. increased use of clinic services by trans people).
- 4. *Experiment with different forms of recruitment* The pilot was effective in recruiting a group of trans-masculine people to take part. However, it is important to involve a range of trans people, to include trans women. Therefore, additional forms of recruitment should be explored. Peer and community-led approaches are likely to be most useful.
- 5. *Explore adaptation for other underserved groups* As a successful 'proof of concept' pilot, there is scope to investigate whether the intervention could be adapted to meet the needs of other underserved groups (e.g. lesbian and bisexual women).
- 6. Disseminate the intervention The staff at the CNC and Cancer Prevention Team have developed a pioneering intervention to develop a novel approach to enhancing sexual health clinic access for an underserved community. This achievement should be recognised and opportunities made available for staff to disseminate information to wider professional networks so that further development and piloting might potentially be replicated elsewhere.

#### To further develop local sexual health services:

- 1. *Provide on-going trans awareness staff training* It was essential to the success of the intervention that staff were equipped and confident to work effectively with trans people attending Clued Up, and with those who might attend subsequently. It is therefore essential to ensure that trans awareness training is repeated at appropriate intervals to ensure that all staff can benefit.
- 2. *Pilot trans only clinic sessions* In order to explore whether knowledge and attitudinal gains can be further capitalised upon, pilot trans only sexual health sessions at the clinic to identify whether this leads to increased service uptake.
- 3. *Review clinic administrative processes and systems* Clinic administrative systems that operated with a binary notion of gender (e.g. clinic forms, clinic signage, administrative processes) represented a barrier to accessing clinic services, which could be removed to enable better access for trans people. Piloting the use of a code word to denote trans status discretely to clinic reception staff would also be useful.
- 4. Develop complementary educational sexual health interventions for trans people This intervention was focussed on sexual health clinic services. Its impact was understandably less marked in relation to enhancing sexual negotiation skills. However, there is no known local intervention for trans people to enable development of such skills. Attention should therefore be paid to the feasibility of developing such an intervention. In addition, trans people wanted tailored sexual health information available at local support groups. This should be provided.
- 5. Involve and engage trans people in service development Staff commented that they learned a lot as a result of the intervention and that there was an aspect of knowledge-exchange, which they wanted more opportunities to engage in. Trans people should therefore be involved in the further development of Clued Up and any other related activities to facilitate knowledge exchange and ensure that services are relevant, culturally informed and respond to trans people's expressed sexual health needs.

# Acknowledgement;

This report was written by Nick Douglas and Bridie Phillips (LGBT HIP). The Clued Up intervention was developed by Nick Douglas, Clare McEwan (Sussex Community NHS Trust), Jonathan Roberts and Jules Davies (Claude Nicol Clinic). LGBT HIP would like to thank all of the staff at the CNC and the participants who took part in Clued Up. In addition, we would like to thank Michelle Ross (THT) for providing staff trans awareness training. Many thanks also to GScene for helping us to publicise the project.

# **Key Contacts**

LGBT HIP Project Coordinator

Nick Douglas Email: <u>nicolas.douglas@tht.org.uk</u>.

LGBT HIP Project Commissioners

Phil Seddon, Equality and Diversity Manager, NHS Sussex Email: p.seddon@nhs.net.

Nicky Cambridge, People and Place Coordinator, Equalities & Communities Team, Brighton and Hove City Council Email: nicky.cambridge@brighton-hove.gov.uk