



**The LGBT Health and
Inclusion Project
Five Ways to Wellbeing
LGBT People's Focus Group**

25 June, 2014.

BETTER CARE: INTEGRATED CARE

Brighton and Hove NHS Clinical Commissioning Group (BH CCG) and Brighton and Hove City Council (BHCC) have commissioned the LGBT Health and Inclusion Project at Brighton and Hove LGBT Switchboard to conduct a series of consultation and engagement activities with local lesbian, gay, bisexual and trans people (LGBT) people. The aim is to use the information gathered to feed into local service commissioning, planning and delivery.

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 Brighton and Hove LGBT Switchboard or of any participating organisation.

Introduction to BETTER CARE: Integrated Care.

BH CCG and BHCC are jointly developing a strategy to integrate health and council services. This will result in a central access point for services including housing, mental health, hospitals, social care, services for carers. This central access point is to be designed to offer more effective support for individuals who have multiple or complex needs and reduce the complexity of accessing multiple services. It aims to reduce hospital admissions and increase care in the community, whilst not requiring new funding. Integration is not new, with several examples already operating in Brighton and Hove. However, this new strategy aims to expand the move away from site-specific services, to a system of integration. The potential impact for LGBT communities is important to consider, especially as anecdotal evidence suggests that local LGBT communities contain a high proportion of people with complex needs. The CCG and BHCC were therefore especially keen to ensure that consultation with LGBT people was undertaken (alongside other groups) as part of the strategic development work, and asked LGBT HIP to carry out this work.

Method.

LGBT HIP convened two focus groups for local LGBT people in order to explore the views and perceptions of LGBT people about the *Better Care: integrated care* plan. To recruit participants, individuals who were registered to receive information about LGBT HIP were informed about the sessions by email. In addition, Brighton and Hove LGBT Switchboard's Twitter and Facebook facilities were used to recruit participants. Local LGBT and other community and voluntary groups were also contacted and requested to pass the recruitment details on to service users and beneficiaries.

Thirteen people attended the groups in total. The groups comprised six women, five men, four people who identify as Trans – or have done in the past – and two participants defining themselves as Other. All participants identified themselves as White, including White English, White Irish and White Other. Four participants identified as Lesbian, five as Gay, one as Bisexual and Three as Other sexual identity. Eight of the thirteen participants considered themselves to have a disability. Ages ranged from twenty two to fifty nine, with an average (mean) age of forty four.

The two focus groups each consisted of a two-hour session, held at Community Base in Brighton. Participants were given a £20 honorarium to attend. They were assured of confidentiality and anonymity and a group working agreement was set to ensure a respectful and open group process. The groups were facilitated by the Temporary LGBT HIP Coordinator. The sessions were recorded and then transcribed by the Temporary LGBT HIP Coordinator.

The primary goals of the focus groups were to:

- Explore participants' previous use of integrated care services (if any);
- Understand how they are currently accessing multiple health and social care services;
- Assess the breadth of services they are accessing that could be combined at a central access point for both council and health services;
- Gauge how participants felt an integrated care model may or may not work for their combined needs;
- Assess the practical applicability of the programme to these particular LGBT individual's care and services requirements

To begin, the group was assured that the focus group meeting was a confidential space and that their contributions would be anonymised in the report. They were assured that the report would be published publicly so that they could view the findings and recommendations themselves. If at any stage in the meeting members felt they needed a break for any reason, they were also encouraged to make their needs known.

A brief outline was given of the proposal to integrate health and council services. Several members of the group felt that it was not clear enough to them how the service would work in reality and raised questions about the specific operation of the service.

Participants were asked to outline their complex needs if they felt comfortable doing so. All participants outlined their needs and shared the range of services they had accessed as a result of their multiple/complex needs.

The following eight questions were asked of both groups:

1. Do you have experience of having to access multiple health and social care services, and if so, how was that experience for you as a member of the LGBT community?
2. As a member of the LGBT community, how could your experience have been improved?
3. If you could go to just one point of contact to access integrated health services, would you imagine that would be a positive or negative experience for you? Please explain.
4. What do you perceive would be the possible difficulties of integrating multiple services?
5. How do you feel about your GP surgery being a central point of contact for integrated services?
6. Would you like to be more involved in the adaptation of more integration of NHS and council services?
7. How would you like to be involved in the adaptation of more integration of NHS and council services?
8. Have you any more suggestions for promoting integrated services amongst LGBT communities?

The first half of each session was, for the most part, centred around individual needs, developing into group conversation and participation that more broadly addressed 'community' concerns in (roughly) the second half of the session.

FINDINGS.

Overall, there was a great deal of apprehension, and at times scepticism, expressed at the idea of integrating health and council social care services. The key areas of apprehension (and scepticism) can be defined as follows:

- a) *A guise for cutting back services, rather than offering better services.* Pooling funds and potentially cutting services was seen as particular threat to the LGBT community whose members perceived themselves to be a vulnerable group. Furthermore, respondents identified that there were LGBT specific needs that were not presently being met (eg: trans* people and housing). Only one participant felt positive about the changes.
- b) *A lack of knowledge and skill from those who would be responsible for delivering these services.* The majority of the group felt they already took responsibility for self-referral to the services they needed, particularly in regards to LGBT issues, and that on most occasions, had to educate the council workers and health

- practitioners about the solutions they required. They could not see how a single point of contact would be able to hold knowledge of multiple needs and services.
- c) *Waiting times.* Due to previous experience of waiting for what was perceived to be excessive lengths of time for services (such as housing referrals and access to trans* gender reassignment surgery), all but one participant felt there would have to be a negative impact on waiting lists. Rather than streamlining needs, they feared the system would be overburdened.
 - d) *Confidentiality and Privacy.* The majority of participants were concerned about what they perceived would be a requirement to develop a central database giving access to all of their personal data to workers who were not specialists in that field. Furthermore, deep resistance was shown to the idea of having to outline a broad area of needs in a potentially public space. This was coupled with concerns that it could be obvious to users in a public waiting room which services users were waiting for. The idea that referrals would be carried out in commercial contexts (such as Boots chemist) was rejected flatly by all, based on the lack of training and awareness private sector workers were perceived to have on LGBT issues.
 - e) *Thinning of Specialist Services.* A degree of anxiety was expressed concerning participants' inability to understand how this system would be implemented without a de-skilling of specialist workers and a thinning of specialist services available to LGBT people within the broader health and council systems.
 - f) *Representation and Accessibility for Vulnerable Users.* There was a broad consensus that vulnerable users such as those with low technological skills, the elderly, BME, the lesser mobile, and trans* users may experience difficulty coping with the environment/context that would be created to service integrated care. This in turn could lead to delayed treatment and exaggeration of problems that may have otherwise been preventable.
 - g) *Signposting.* Participants who used community group services or were key workers in the third sector expressed doubts as to community groups being able to cope with further, more effective signposting to their organisations without funding or support.
 - h) *Inability of GP surgeries to Cope with New System.* All but one participant felt it would be inappropriate to have the proposed service based at their General Practice. Two specific concerns were raised. Firstly, members of the focus group were already experiencing long waits for, and short appointments with, their GPs. It was general consensus that GP practices could not cope with the extra workload without causing further pressure. Secondly, it was broadly felt that GP staff were currently not skilled in matters relating to LGBT specific issues.

ISSUES RAISED (EVIDENCED BY DIRECT QUOTES).

Synopsis of Positive Responses.

There was a disconnect between what both groups viewed as the theoretical underpinnings of the concept of integrated care (positive), and the inability to visualize how the care would be systematically delivered without resulting in a loss of specialization from both medical and social care workers (negative). Six members of the group briefly voiced support for an integrated model, primarily as a method of minimizing repetition of details of private situations/conditions to multiple medical and council workers. For example:

“The integrated model for me sparks up some kind of hope that there would be a joined-up system, whereby your multiple concerns are raised and they are documented and on file and you don’t just end up repeating yourself over and over dredging up the past. It’s there in seconds. It will reduce the length of consultations and provide for a much more effective service.”

“I seem to be passed from pillar to post mostly, so [like] the idea of having a care coordinator in a central place because there wouldn’t be gaps because the buck’s being passed to another service...”

“One good example [of integrated services] for LGBT, particularly for the ‘T’, is Clinic T.”

“I think it would relieve a lot of the stress or the anxieties around about seeing a lot of health care professionals who you don’t necessarily know that well... It’s not that easy to sit in a room and tell a professional your life story.”

Issues of Privacy and Confidentiality.

The process of centralizing an individual’s data and then giving a non-specialist (such as a general council worker or private service provider such as a chemist) access to that data came under question. This appeared to have specific resonance for LGBT users who felt there was not enough education, training and understanding amongst medical professionals or council workers at large about LGBT issues:

“I have grave hesitations about someone having access to all my information.”

“The local chemist model is something that would be easy to farm out and privatize. Most chemists don’t have a private consulting room or anyone who can do the consulting.”

The public space in which users would have to wait for services they required access to was also questioned. Participants felt it unsafe to have a generic waiting space, that other users

would be able to identify what services they were accessing, and that this could potentially cause fear, embarrassment, a hesitation to access services they required and potential situations of discrimination. The term “outing” was repeated by several members of the group.

“Effectively you are outing yourself by going to see that person in a room full of people there for different things. The example I had was at a GP surgery in Hastings and she had a mental health service they did counselling and everyone knew what she did so everyone knew why you were there. Most counseling services are in a safe or secure area not a public area. I think confidentiality is going to be a huge problem.”

“Does this mean I have to tell someone I’m trans who isn’t part of the health system and has never received any training on trans issues? You have got to be joking. How on earth is that safe? It’s forced ‘outing’ to unskilled workers and will be an absolute field day for exposure to abuse, discrimination and backhanded jibes. It’s hard enough dealing with the receptionists at my GP, let alone at a faceless centre mobbed with people scrabbling to have their needs met- or ignored more like. It makes me feel incredibly anxious. I can imagine not wanting to go and putting off treatment, which is maybe what the government wants to save money. Except that is so shortsighted. Treating health at the last stages is much more expensive than dealing with minor conditions- unless it’s left to be the next government’s problem I suppose.”

“I think there is definitely a need to make both Council and NHS services more accessible to the LGBTQI communities because a lot of people may not come to their GP about these kind of issues if it has something to do with their sexual orientation. Say if they want to talk about mental health issues that may relate to their sexuality and they may not be willing to divulge that.”

De-specialization and Levels of Staff Training/Qualifications/Knowledge.

Participants questioned how effectively LGBT people with complex needs would be supported under the new model being proposed. Much of their inquiry was focused on not being able to envisage the workings of the new model. Whilst many supported the concept of “whole person care”, few could envisage how it would be delivered.

“How can someone know how to do this?”

“You’re never going to get anyone who is knowledgeable about every condition known to man.”

“I’m very concerned that you will lose specialization. Even with CRI with my alcohol issues I have a specialist LGBT worker there, and sexual health is LGBT focused for me. I’m worried losing specialists workers and making it generic will dilute services.”

“How qualified are they going to be to make the assessment in the first place? How long are they going to spend assessing?”

Several identified that they were their own integrated care workers, fulfilling the role of identifying the services they needed, and were best placed to refer themselves onto the services including sexual health, alcohol and drug counselling, as well as individual medical conditions requiring medication and monitoring. LGBT specific issues such as recognition of partners and gender identity were used as examples of the necessity to guide the process in a system from which they described as feeling largely disenfranchised.

“I’m the person who has self-referred myself to the care that I get because I know what I need for my specialist needs. I’m concerned that there wouldn’t be the specialism needed. There are big differences between my trans issues, my [health] issues, my needs for counselling...”

“I think if you try and look at more than one problem at a time it creates more problems. Yes you might have mental health problems because you live in bad housing but do you deal with the mental health officer or the housing person?”

“I haven’t had a problem accessing the services I need. I’ve had more problems with not having the services there.”

“I feel that my role is not as a user, more as a Professor... The mental health team don’t know about my medical problems, let alone knowing about what it means to be genderqueer or what my relationship with my partner means to me.”

“Who says what is the right signposting?”

Transparency, Implementation and Logistics of Delivery.

It was highly apparent that focus group participants were confused about how *Better Care: integrated care* would be delivered, which created levels of distrust about the proposed changes as each session progressed. Whilst members of the group understood the theory behind integrating services, they could not envisage how the theory would translate into practice. This led to anxiety overriding any expectations of positive change:

“What I see is one person will be sitting in front of a computer asking a lot of questions and then eventually the computer will tell you “You need to see such and such services... Because they won’t spend the money on the training for an expert to be able to go here’s your housing needs, here are your mental health needs.”

“How would it work? The mental health team don’t know about medical problems, the medical team don’t know about mental health problems... And to throw into the mix, my LGBT needs aren’t met at all- my partner isn’t recognized as my partner even

though she's at home pretty much most of the time for me and she's not given the ability to make contact for me."

"There's not enough information about how they're going to achieve these idealistic outcomes. How are they going to empower the individual? Some seem a bit too idealistic, for example, providing services 24-7. Is one person going to be their phone 24-7 for several people at once?"

"I am my own coordinated integrated care person. I'm feeling very anxious about what's on offer with this integrated care. I cannot see how this is ever going to work."

"I don't have any understanding of the logistics of how on earth this can work."

"It's totally impractical that one person would be this super care worker for complex people. There will just be a signpost really."

"I cannot see how one person can ever have all the knowledge to deal with all of this."

"You would need a nominated lead person to coordinate a person's care. Where's that budget going to come from? Think about it- one person would only be able to cope with ten people!"

"As an LGBT person with Asperger's I find it very difficult to see the bigger picture."

"For me I'm still unsure what role this person will play and that's something I think they need to spell out clearer. It's still very unclear to us how this will pan out and what's the role of these individuals."

This inability to envisage how the service would be provided was further clouded by predictions that there would be a loss of funding streams for LGBT specific services:

"I find mergers are a cloak for cuts- who's funding what- it's difficult to track the funding streams when it merges and is all put in a pot and the pot just shrinks and shrinks and shrinks and there are turf wars about priorities about what is important and usually it's minority groups who get left as the poor relations. That is my big, big worry around, in inverted commas, integrated services."

"How is allocating of funding of services going to be made clear?"

"It'll be a feeding trough with the needy scrabbling around for a place to stick in their snouts by pushing someone else's out. And the people who will be pushed out won't be heterosexual, CIS, white males, that's for sure."

“We have a huge sector of the population here in Brighton that’s LGBT- more than anywhere else in the country. Is this generic national system going to be adapted to represent that higher proportion per capita here?”

“Are these people going to have targets?”

Signposting.

Further hesitation was expressed about the possibility of individuals being lost in a system that was delivered through signposting.

“I predict that it will be signposting, not caring or assessment in any real form... Which adds another layer to the mix instead of taking one out- it’s fundamentally flawed.”

“My concern is that it becomes a signposting service instead of care on any difficult level, you’re led off to five or six different services and no-one is there checking back on you.”

“Where do you go and deal with it if it all breaks down?”

Overloading of Charities via Increased Connectivity.

Workers and users of the third sector identified the struggle that LGBT charities have in coping with increased referrals through signposting, without extra funding and support. They predicted the consequences of effective integrated care could be users being better networked to find groups that previously had not had similar levels of exposure. Furthermore, these groups were identified to be lacking the infrastructure required to cater to a higher numbers of users.

“My other worry is if people are signposted, who decides where they get signposted to? Is it going to be that people get signposted to this group because people have paid the most money for that contract? Or they get signposted to a charity because it’s cheaper but then that charity gets overloaded and it crashes. But what works for one person doesn’t work for others.”

“Most charities don’t have the funding to do the work they do. If somebody trans was to come along and be signposted to the Clare project because we do a drop-in that’s good, but if a hundred people were signposted the Clare project would crash. And then you wouldn’t have places where people are being signposted to services they need that people who are like them know about. The third sector is the best for providing that information but if you overload the third sector it quickly grinds to a halt.”

“By using a system of better care if it is working properly then it means a lot more people are going to be better connected and that may result in an overwhelming number of people being directed to a particular service which will evidence need. But will the Council or the CCG respond to that by saying we need to put more money into this service and we need to provide more support to these organizations that are doing the work. I don’t know how they’ll manage to fob that off.”

Threats to Vulnerable Voices Being Heard.

Both groups identified (through their own independent discussion) the issue of vulnerable people having their “voices heard” and thus, their needs met: a target aim of the *Better Care: integrated care* scheme. Vulnerable groups were non-exclusively identified as elderly and BME members of the LGBT communities (not represented in either focus group), depression sufferers, those needing advocacy, as well as those with disabilities:

“One of the major concerns that I’d mention is that people who shout the loudest get the help. If you’re depressed then that will influence your ability to get there in the first place and if you’re given an email [address] and then expect that person to do it themselves, it doesn’t seem to be very caring. You have to be well to be able to follow up being signposted.”

“It’s ideally great- like so-called “Care in the Community”... But we all know what happens: no-one owns any individual cases and as such and it becomes a free-for-all where only the fittest survive.”

“My main concern is the advocacy issue. I don’t know what would have happened to me if I wasn’t able to contact the advocacy services and I’m really worried about the people who can’t speak up for themselves getting lost.”

“I am very aware there are no older people in the group or BME and that they are key users of multiple services. How are they going to be heard? Can they be heard?”

“If you’re talking about an elderly population who aren’t familiar with technology what will happen to them?”

“I would be very concerned about people who can’t actually get out. God knows you can’t ring your doctor, they are already notoriously overworked and understaffed. I would be very people who don’t have a voice- people who can’t even get there in the first place.”

“I think it’s important that whatever the involvement of the LGBT is not tacked on at the end.”

“My concern is that the people who go in shouting and screaming and causing the most chaos would get most of the time... The people who were less confident or too polite would get lost.”

Concerns about the GP Model.

The group explored the possibility of an integrated service being made available in their General Practice. It became evident that the participants broadly felt that GPs and other staff based in the practice did not meet their LGBT needs, lacked training on the issues surrounding these communities and in some instances, did not wish to address their lack of knowledge in the field. Comments included:

“I feel most GPs are not understanding of our community at large.”

“If a GP is a central point of contact that’s ok- but it depends how good your GP is. I’ve had some horrific experiences with GPs and they’re not all interested in learning about what services I need as a lesbian.”

“I was made aware earlier this year my GP attended HIV health training for the first time ever. Again, the problem is specialization. Some GPs have more knowledge than others, but because of the catchment area system you can’t get to the best doctor for treatment.”

These concerns were coupled with a broad consensus that GP services currently appeared to be overstretched in the Brighton and Hove area, and would be unable to cope with a remit to offer further services:

“The last place I would want to go is to a GP for ten minutes under immense pressure because there is no chance or time to integrate my own needs as it is!”

“The physical buildings aren’t big enough in most GP surgeries- people are going to be queuing down the street.”

Furthermore, the independence and impartiality the group felt would be required by an integrated worker may be compromised if that worker were connected with the GP, as this participant relates:

“What if you have a problem with your GP? How are you going to work with someone in that practice? That was my firsthand experience. My GP was not referring us on to the place that we needed to go, would not take us seriously, would not look at the LGBT context which was very, very relevant and we got stuck. If somebody was in that practice- who are they working for? Are they working for the GP’s? Is the GP likely to be one of their bosses?”

Future Progression & LGBT Involvement.

The focus groups identified a need for not only future consultation with the LGBT communities on this matter, but for active involvement with the development, design and implementation of the *Better Care: integrated care* scheme. This involvement was seen as vital to the process of protecting existing services (and funding), voicing and identifying LGBT needs that participants felt were unlikely to be recognized by the broader community and developing training for front-line professionals who were to be responsible for delivering this service:

“I definitely feel that LGBTQI need to be involved in more focus groups. There’s a huge gap in the recognition of different people in this acronym (LGBT) as a trans intersex person I’m not even considered to be here!”

“Eight people here cannot reflect the city. There needs to be further contact and consultation and an opportunity to give feedback if a pilot is run.”

Specific suggestions were proffered in regards to the role LGBT HIP could take in taking forward participants’ concerns and delivering accountable recommendations. These included expanding the service’s remit to include advocacy work and lobbying on behalf of LGBT people in Brighton.

“I think it’s fundamental if we are reshaping a service then we need to be part of reshaping that service. Not an add-on, but a very involved central part. We must help reshape these services. I think that- for want of a better phrase- communities of interest should have a standing advisory group so that as the blue print is put out there we then help design the new services and that they are inclusive and responsive and that we are very clear about funding so we need to be at the table so that we know what our views are and there are clear transparencies and funding pathways and they are clearly accountable and not in some huge integrated fog.”

“We should be involved in the design, implementation and development of these services.”

“I know that there is a perception out there that [LGBT] HIP is a mechanism of the Council and that it doesn’t represent the community. But there is no better way to undermine a voice than to tear itself apart. I think it’s important that it’s not just a bit of consultation that happens here and there along the way, because you can consult and then ignore! There needs to be some sort of facility to be a lobbying group.”

“There needs to be an LGBTQ standing advisory group that needs to be fully involved with the process and developing the blueprint and the services so that if we are having integrated services we are not only consulted but fully involved in designing that integrated service. And we must not lose specialism around LGBT issues in this race for integration services nirvana which are great on paper in theory but in reality are

all about resources. We must design and implement these services as an advisory group of LGBT people so this isn't a one week process."

"There is definitely a need for more training amongst health care professionals in general on how best to engage and develop that level of trust."

Participants in these two focus groups proved to be thoughtful, informed and eloquent. They displayed a great deal of foresight that allowed them to raise issues of concern that were shared amongst the group and qualified by personal experience. The groups both expressed concern that whilst the issues they have raised may be recorded, they may not be addressed or actioned. Similarly, several members requested access to the report to be published by LGBT HIP, inferring that they intended to remain informed and would be monitoring the joint responses from the CCG and Local Authority.

RECOMMENDATIONS.

The follow recommendations are made for BH CCG and BHCC

1. A clearer model of how *Better Care: integrated care* will be practically implemented needs to be communicated to Brighton's LGBT communities to clarify confusion as to how integrated care services are to be delivered and alleviate anxiety surrounding issues of confidentiality and privacy;
2. That all personnel responsible for delivering *Better Care: integrated care* (including GPs) receive LGBT awareness training delivered by LGBT trainers;
3. Waiting rooms and queues for the service must be organised so as not disclose confidential information to other users also waiting about which service individuals are accessing (e.g.: all users must share the same waiting number ticketing system, there must not be separate queues for housing, HIV services, mental health services etc in the one room and counters must be far away enough from both queues and each other so as to avoid overhearing other users' requirements);
4. That further planning of *Better Care: integrated care* is developed in consultation with Brighton's LGBT communities, and that this consultation results in actions that are formulated in consultation with LGBT HIP;
5. That the needs of vulnerable members of the LGBT communities are assessed in further consultations in order to ensure that referral routes are designed to meet these needs;

6. The changes to access to funding for services that will affect LGBT communities must be made transparent (through publication) in order that the LGBT communities in Brighton feel that the services currently being provided are still offered to the same extent as they are currently, and to disqualify the existing notion held that this integration will result in increased lack of representation and decreased access to services;
7. That key LGBT third sector workers are consulted about their services and their abilities to meet increased demands, if referrals are made to them, and that this information is collated and produced as a reference pack for *Better Care: integrated care workers*.

Recommendations for LGBT HIP and its funders:

1. That LGBT HIP considers widening its remit to include a lobbying service in order to ensure that recommendations from the community consultations become actions.

Acknowledgements

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