



## LGBT Health and Inclusion Project

### Patient Record Sharing Survey Report



### The LGBT Health and Inclusion Project

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

This report presents data from an online survey of LGBT people in Brighton and Hove on the sharing of patient records and particularly the sharing of records through electronic Summary Care Records (SCRs), which can be accessed online by health professionals treating patients.

Current changes to patient record keeping in the NHS include the introduction of centralised patient medical records which can be accessed by clinicians treating a patient where required, including during an emergency and when the patient's GP surgery is closed. This method of patient record sharing will replace older methods of sharing records through email, phone and post.

The introduction of remote access to patient records also means that patients will soon be able to access their own GP health record online and have prescriptions sent electronically from their GP to their pharmacy. Patients will also be asked whether they want information from their GP record to be viewed by people treating them in hospitals, community care and other local services. Other developments for using electronic health records, such as the ability for patients to have their health monitored remotely, are being considered by the CCG.

### Background

Record-sharing is an area of concern for LGBT people, which can both directly and indirectly affect their experiences of the NHS. Key issues include: disclosure, discrimination when accessing healthcare, and experience of healthcare pathways that are directly or indirectly related to protected characteristics of gender identity and sexuality.

Discrimination in healthcare is a problem faced by many LGBT people, in spite of legal protections. Results of national research conducted by Stonewall report that of their respondents 34% of gay and bisexual men and 54% of lesbians and bisexual women who had accessed healthcare services in the past year had negative experience related to their

sexual orientation<sup>1,2</sup>. Whittle et.al found that trans people frequently have bad experiences with healthcare providers. 22% of respondents to the 2007 study felt that being trans affected the way they could access routine services not related to being trans, 29% of trans respondents felt that being trans adversely affected the way they were treated by healthcare professionals in accessing non-trans related routine treatment on the NHS and 17% of respondents had experience of being denied services in the general health sector by doctors or nurses who did not approve of gender reassignment<sup>3</sup>.

Local LGBT research project Count Me In Too (CMIT) reported that LGBT people were more likely to say their health was poor when compared with the general population<sup>4</sup>, and that LGBT people could experience difficulties with their GP in relation to their gender or sexuality. The report identified that LGBT people could have trouble finding LGBT friendly GPs, but that they frequently encountered an imperative to disclose their sexual/gender identities to GPs in order to access treatment. *'trans people, lesbians and bi women, with mental health difficulties and those who are living with HIV are more likely to be 'out' to their GPs. This was often because sexual/gender identities had to be revealed in the course of treatment and no other options were presented.'* (iii-iv) The disclosure of sexual and/or gender identity was especially marked in relation to the experiences of trans people (88%) and those who are diagnosed HIV positive (86%).

We also understand that the NHS currently continues to make use in its record-keeping and clinical coding practices of the ICD 10 Diagnosis Codes F64<sup>5</sup> (gender identity disorders) and F66<sup>6</sup> (sexual development and orientation disorders) for 'diagnoses' related to persons' gender and sexuality. Therefore, LGBT people could feel that record-sharing practices that make use of this clinical coding are yet further institutionalising the medical pathologisation and stigmatisation of LGBT persons within healthcare settings.

## Aim

The aim of this research exercise was to gather LGBT views and experiences of patient record sharing, in the light of changes to ways patient records are shared. This is to make sure that record sharing practices are inclusive and that LGBT people's voices are heard in the process of implementing these changes.

## Method

Questions were developed in line with questions suggested by the CCG, and adapted to reflect concerns specific to the LGBT population. The survey was conducted using SurveyMonkey over a period of one month in September 2014. Paper copies of the survey were also advertised alongside links to the SurveyMonkey online form, and offered to local community organisations for distribution to their clients, but none were requested. The survey was promoted and distributed through a variety of channels including the LGBT HIP members list, LGBT HIP's Social Media presence on Facebook and Twitter, email lists for Community Works, Community Base, LGBT Switchboard staff and volunteers, and via the

---

<sup>1</sup> Guasp, A. (2008) Gay and Bisexual Men's Health Survey. Stonewall: London

<sup>2</sup> Hunt, R. & Fish, J. (2008) Prescription for Change. Lesbian and Bisexual Women's Health Check 20008. Stonewall: London

<sup>3</sup> Whittle, S., Turner, L. & Al-Alami, M. (2007) Engendered Penalties: Transgender and Transsexual People's Experience of Inequality and Discrimination

<sup>4</sup> Browne, K. & Lim, J. (2008) Count Me In Too: General Health additional findings report, University of Brighton: Brighton.

<sup>5</sup> <http://apps.who.int/classifications/icd10/browse/2010/en#/F64>

<sup>6</sup> <http://apps.who.int/classifications/icd10/browse/2010/en#/F66>

Trans Alliance. Volunteers were also asked to publicise the survey via social media, community groups and student unions.

Responses have been analysed and reviewed by the LGBT HIP Support Officer, Phoenix Thomas, and qualitative responses were reviewed to identify key themes and extend quantitative findings. Unfortunately the study neglected to capture demographic information alongside responses. Were the study to be taken further, future research would include demographic factors in the collection of data.

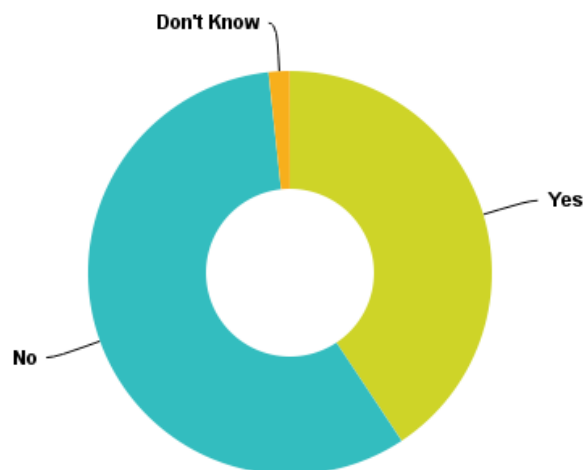
## Results:

### Q1. Awareness of Summary Care Records

The majority of respondents (57%) did not know that most people in Brighton & Hove already have a Summary Care Record that can be shared between health professionals, indicating a poor level of awareness of existing patient record-sharing practices.

#### Q1 Did you already know that most people in Brighton & Hove have a Summary Care Record that can be shared between health professionals?

Answered: 59 Skipped: 0



## Q2. Perceived Benefits of Health Record Sharing

Respondents were asked what benefits they thought might result from the sharing of their health records, given a list of options and asked to tick all of those that they felt applied to them. There was the option for participants to indicate any other perceived benefits which were not included in the list (and a text box where they could supply their thoughts), and also a box provided for participants to check if they could not see any benefits to the sharing of their health records.

Answer Options	Response Percent	Response Count
Better communication between those treating me	84.7%	50
Speeding up my treatment	62.7%	37
Improving my safety as a patient	40.7%	24
More involved in planning my own care	25.4%	15
Being able to see my own record	42.4%	25
Don't have to repeat tests when I see someone new	54.2%	32
Don't have to give the same information each time	66.1%	39
Improved services based on patient information	39.0%	23
Improved trust between myself and health professionals	18.6%	11
I can't see any benefits	8.5%	5
Other (please specify)		2
<b>answered question</b>		<b>59</b>
<b>skipped question</b>		<b>0</b>

The greatest perceived benefit was that of better communication between the various healthcare professionals treating the patient, with 85% of respondents checking this option. Accordingly, there was a high level of perceived benefit in the efficiencies promoted by better communication and sharing of information, with 66% of respondents indicating a perceived benefit in not having to repeatedly offer the same information to health professionals, 54% of respondents indicating a perceived benefit in not having to repeat clinical tests with different consultants and 62% of respondents indicating that they hoped the sharing of health records would result in improvements to their speed of treatment.

A substantial proportion of respondents also perceived that services could be improved with their increased involvement and empowerment as service users. 42% perceived a benefit in being able to access their own record and 19% felt that this would result in improved trust between themselves and health professionals.

Sharing of patient information was also perceived by around two-fifths of respondents to lead to an improvement in the quality of care and patient safety; 39% anticipated an improvement in services based on patient information and 41% felt that the sharing of information would lead to an improvement of their safety as a patient. One qualitative response also indicated

that the sharing of patient information between health professionals could be beneficial to safeguarding, as it could prevent an over-dependence on the role of third parties in the care of vulnerable people:

*“I have mental health problems and I like the idea of health professionals having access to plenty of information about me in case I can't tell them my self. Also, I have been abused by my next of kin so I want health staff to have my records rather than rely on my NOK.”*

9% of respondents stated that they couldn't see any benefits to the sharing of their health records. This could be interpreted as suggesting a disengagement with the health service, and/or a low level of dependency in some parts of the community.

### Q3. What do you want to know about the way your health information is used?

Respondents were asked what they would like to know about the way in which the information on their patient records were going to be used. This was asked in the form of a checklist of questions around the use of patient information, as well as one open-field text box for respondents to volunteer alternative questions which were not listed, and a final box which indicated that the respondent did not want to know anything about the way their information was used.

Answer Options	Response Percent	Response Count
Who holds information about me?	81.4%	48
What information is held?	83.1%	49
Who will have permission to access my record?	83.1%	49
How do I give/remove consent for information to be shared?	67.8%	40
Will my record state that I am LGBT?	67.8%	40
How can I see my record?	83.1%	49
How can I amend my information if it's wrong?	78.0%	46
Can I add my own notes to my record?	52.5%	31
Have those accessing my record had LGBT awareness training?	59.3%	35
How do I complain if I think my information has been misused?	69.5%	41
Is my record used for planning or improving services?	55.9%	33
I don't want to know anything about the way my information is used	5.1%	3
Other (please specify)		2
<b>answered question</b>		<b>59</b>
<b>skipped question</b>		<b>0</b>

95% of respondents indicated that they would like to know about how their information was going to be used, with only 5% stating that they did not want to know anything about the way their information is used.

There was a relatively even spread of responses to these various questions around how patient information might be used, with at least a 50% response to each of the questions given. Of all of these questions, however, those which attracted the highest percentage of positive responses were those relating to the ownership, integrity and governance of patient information.

A high percentage of respondents indicated a desire to oversee the data held about them, with 83% wanting to know how to see their own record, 78% wanting to know how to amend information if it is wrong and 52% wanting to know if they would be able to add their own notes to their record.

Information governance was a strong concern. Over 80% of respondents indicated a desire to know: who held information about them (81%), who would have permission to access their record (83%), and what information would be held (83%). 67% of respondents wanted to know how they could give/remove consent for information to be shared and 69% wanted to know how to complain if they thought their information had been misused. Regarding questions explicitly related to respondent's LGBT status, 68% wanted to know whether their record would state that they were LGBT and 59% wanted to know if those accessing their record had had LGBT awareness training.

Regarding the practice of patient record sharing for purposes not directly related to individual patient care, 56% of respondents wanted to know if their record would be used for planning or improving services. 'Other' questions submitted via the survey were also concerned with the sharing of information for commercial/research purposes:

*"I don't think my record should be used for planning or improving services without asking me each time and explaining what the project is. My record should be shared with people treating me."*

*"Will any information be sold on, even anonymously?"*

**Q4. If you have any concerns about the sharing of your health information, please tell us about these concerns in the box below.**

The qualitative responses to this question continued to echo concerns around the ownership, integrity and governance of patient information.

Confidentiality was a central concern, with many respondents citing examples of perceived risk in the sharing of information between numerous parties. The adherence to standards of confidentiality and information governance by staff working at various levels in different health and social care organisations was identified as a key area of concern, with a number of respondents indicating apprehension around the inclusion of sensitive or personal information, including that around people's gender identity or sexual orientation:

*"Just that any privileged information is used with sensitivity and not disclosed to 3<sup>rd</sup> parties or gossiped about"*

*"How confidentiality is handled and the criteria for how it is decided who needs access to which records."*

*"I expect there to be rigid access controls so that the information is only available on a genuine need to know basis"*

A number of respondents were worried about experiencing discrimination as a result of their data being shared with healthcare professionals with personal prejudices against LGBT people and their sexual practices and/or a limited understanding of LGBT issues:

*"I wouldn't want details of sexual health check ups to be included on the SCR"*

*"I worry about being pre-judged and also confidentiality"*

*"that being LGBT is not shared as a pathology, that GPs are trained in understanding the issues so they don't see us as somehow abnormal..."*

These responses were part of a significant wider trend in the data which indicated that respondents' apprehensions around the sharing of patient information were often characterised by some notable lack of confidence in healthcare professionals. Some other responses also suggested concerns that a perceived lack of integrity on the part of healthcare professionals could compromise the accuracy of the data shared.

There were also some responses concerning the use of patient data in terms of its use in the planning and delivery of future services. While a couple of respondents indicated a desire for data to be collected and used to identify and address the health inequalities of LGBT people, one of these also suggested that a *current* lack of awareness among health professionals and commissioners was a contributing factor to a lack of engagement from the LGBT community. It was implied that such a lack of engagement could result in data being incomplete, which could potentially further minimise and marginalise the specific health needs of LGBT people such as those around mental health and substance abuse. The undesirable prospect of marginalisation was also raised by two further respondents, both of whom suggested that they were concerned about data being used to support any economically-motivated stratification and/or fragmentation of services – with the implication being that these could potentially result in inequalities of provision.



### Q5. How could the Clinical Commissioning Group help you to understand the choices you have about your own health record?

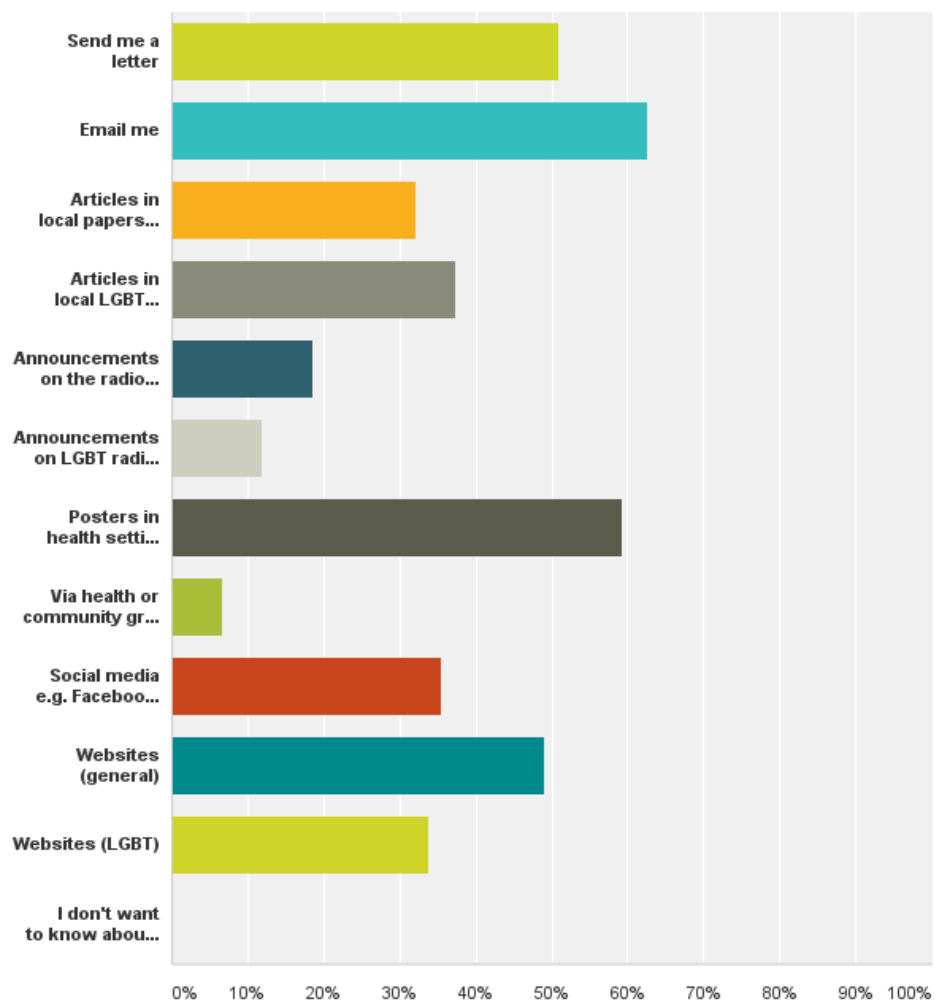
Respondents were offered a series of suggestions concerning how they would like the Clinical Commissioning Group to help them understand choices around their health record. There was also an option for respondents to check if they did not want to know about the choices available to them, but 100% of respondents indicated that they would like the CCG to support them in understanding their choices.

Answer Options	Response Percent	Response Count
Send me a letter	50.8%	30
Email me	62.7%	37
Articles in local papers or magazines (general)	32.2%	19
Articles in local LGBT magazines	37.3%	22
Announcements on the radio or television (general)	18.6%	11
Announcements on LGBT radio programmes	11.9%	7
Posters in health settings e.g. hospitals and GP Surgeries	59.3%	35
Via health or community group meetings I already attend	6.8%	4
Social media e.g. Facebook adverts	35.6%	21
Websites (general)	49.2%	29
Websites (LGBT)	33.9%	20
I don't want to know about the choices available to me	0.0%	0
Other (please specify)		5
<b>answered question</b>		<b>59</b>
<b>skipped question</b>		<b>0</b>

The most popular options were for the CCG to disseminate information via email (63%) in the form of a letter (51%) through posters in health settings such as hospitals and GP surgeries (59%) and through non LGBT-specific websites (49%), suggesting that there was some slight preference for information to be presented directly and comprehensively via a 'formal' platform, as opposed to being presented via channels in which the information might be limited in scope by conventions of the medium, and/or presented alongside unrelated content.

### Q5 How could the Clinical Commissioning Group help you to understand the choices you have about your own health record?

Answered: 59 Skipped: 0



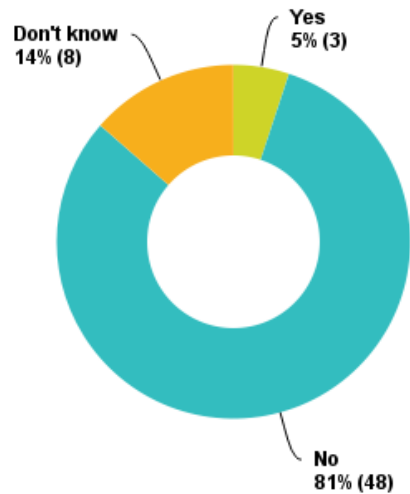
Nonetheless there remained considerable percentages of respondents who said that they would like to be informed via alternative platforms such as social media (36%), LGBT websites (34%) and articles in local papers or magazines; both those targeted towards the LGBT community (37%) and the general population (32%).

Information presented via the radio and television was less popular, with only 19% saying that they would like to receive information via general radio and television, and only 12% saying that they would like to receive information via LGBT radio programmes. Even less popular was engagement via health or community group meetings already attended (7%) These options could be less popular because of the declining popularity of traditional broadcast television and radio, and limited community engagement with health and community groups, but could also be less popular because of their ephemeral nature – meaning that information presented there might not be as easily accessible or retainable, and might be less readily recalled in future.

**Q6. Would you need support to get online and access your own health record?**

**Q6 Would you need support to get online and access your record?**

Answered: 59 Skipped: 0



The majority of respondents stated that they would not need support to get online and access their own health record (81%), however there is a demonstrable need to make support available given that 19% of respondents stated either that they would need support (5%) or that they were unsure whether they would need support (14%).

**Q7. What are the implications for LGBT people of more health information and services going online?**

Respondents were asked what implications for LGBT people they thought might result from more health information and services going online, given a list of options and asked to tick all of those that they felt applied to them. There was a further check box attached to an open text field for participants to indicate any other perceived implications which were not included in the given list, and also a box provided for participants to check if they could not see any implications for LGBT people of more health information and services going online.

Answer Options	Response Percent	Response Count
Health professionals are more informed about LGBT people's health needs	44.1%	26
Health information and services are more transparent and accountable	44.1%	26
LGBT people have more ability to challenge and change information held	52.5%	31
Possibility of discrimination if health professionals know LGBT status	69.5%	41
Possibility of being 'outed' by health professionals to other people	61.0%	36
Need for guidelines on how sexuality and gender are recorded	72.9%	43
I don't see any implications	1.7%	1
Other (please specify)	10.2%	6
<b>answered question</b>		<b>59</b>
<b>skipped question</b>		<b>0</b>

A reasonable percentage of respondents agreed with the suggested positive implications of more health and information services going online. Over 40% of respondents believed that health professionals would be better informed about LGBT people's health needs (44%) and that there would be greater transparency and accountability for health information and services (44%). 53% of respondents felt that LGBT people would have more ability to challenge and change the information held about themselves, which indicates a moderate degree of confidence that LGBT people could potentially benefit from the empowerment of having access to their own medical records, but by the same token an acknowledgement of existing inequalities and inadequacies in current record-keeping practices which may need to be directly addressed in the development and implementation of proposed changes.

A substantially greater percentage of respondents agreed with the suggested negative implications. 70% of respondents believed that there was a possibility of discrimination if health professionals were made aware of a person's LGBT status, 60% agreed that there was a possibility of being 'outed' through that information being shared with 3<sup>rd</sup> parties and a further two respondents also indicated that they felt there could be implications around breach of confidence and misuse of information:

*“In my experience the concept of patient confidentiality is not understood within the NHS. They seem to think that anyone employed by the NHS has the right to access confidential personal information”*

Questions around information governance were broadly felt to extend beyond confidentiality to the need for guidelines on *how* gender and sexuality were recorded in the first instance; which could refer to a) the structural safeguarding of sensitive personal information within the recording process, b) the need for clarification on policy and procedure around the collection of data on gender and sexuality to maintain standards of quality, consistency and accountability c) the need for a review of the standardised NHS clinical coding of ‘diagnoses’ related to people’s gender and sexuality under the WHO’s ICD 10 Diagnosis Codes F64 and F66 which serve to pathologise and yet further stigmatise LGBT people’s gender and/or sexuality.

**Q8. Have you ever had any particularly negative or positive experiences as a result of having your health record shared? If so, please tell us about your experience here if you feel able to.**

The response rate to this question was about 1/3 of the total participants. Of those who responded to this question, approximately half stated that they had not (knowingly) had any particularly negative or positive experiences. One respondent indicated that they had benefitted from record-sharing between healthcare professionals providing services for health problems crossing several disciplines. The other half of question respondents (1/6 of total) indicated that they had had particularly negative experiences as a result of having their health record shared.

Negative experiences spanned a range of issues. Four respondents had had poor experiences around the inadequately confidential handling of their or someone else's data., where they felt that too much had been disclosed, or that information had been shared or accessed which was not relevant to that aspect of their care:

*"My records were confused with those of someone else of my name and in the process the other person was outed to me as HIV+"*

*"NHS Employee disclosed my HIV status to his friends."*

*"One nurse asked me about a mental health condition. I was upset that she could see my record and made a comment on it when I was speaking to her about an entirely different matter."*

There were also accounts of various misuses or misinterpretations of data which had had a negative impact upon access to or standards of care:

*"Yes – between health trusts in the same hospital[...] Only the summary was passed on with the result that my situation was not understood & the care I received worse than it would otherwise have been."*

One respondent also expressed frustration that although various health professionals had access to their records, this resource did not appear to be properly utilised, resulting in additional unnecessary stress and labour where receiving treatment for various conditions.

### **Q9. Do you have any other comments to make about the sharing of patient health records?**

Approximately 1/3 of total respondents provided additional comment and, while the majority of these returned to the same key issues which had emerged over previous questions, it is notable that respondents wanted to consolidate or expand upon these at the conclusion of the survey.

The most prominent concerns were around issues of confidentiality and information governance, as indicated over trends in responses to earlier questions. Informed consent was described by several as being imperative:

*“It needs to be on a need to know basis, with very secure settings to avoid hacking, or prevent adjust any person from a service accessing the details to maintain confidentiality. Information sharing agreement also needs to be written to give service user the choice to opt out.”*

A central, more generalised point around the question of information governance (i.e. a prominent concern not ostensibly linked to people’s LGBT status) emerged more strongly here than it had in previous, targeted questions, however; which was the specific concerns around the ethics of sharing patients’ personal data with private companies.

*“My concern is about the NHS’s ability to control patient information because NHS services are also delivered by third sector and private sector organisations (who may also be a subsidiary of an insurance company). If such a contracted-out organisation ceased to provide a service who would the data controller be?”*

*“I insist that my records are not used by people making money out of them”*

*“I do not want my records or data extracted from my records to be sold to other bodies for any reason at all.”*

*“I’m in favour of sharing information if it benefits the patient or is used to better meet the needs of patients in the local area. But since data is increasingly being used by private companies for their own commercial interests I have deep concerns about the sharing of patient records.”*

There was also some cautiously optimistic positive feedback volunteered here which indicated that a number of respondents anticipated the conditional potential for some positive impact on their experiences as LGBT people within the health service, and *could* be happy for records to be shared under the right conditions:

*“I want to be asked before sharing happens. I don’t naturally trust health professionals per se.”*

*“I’m all for sharing these records BUT medical professionals need to actually read and use them.”*

*“Could be helpful to prevent people being misgendered, but only if good gender-options are available (ie, outside the binary constructs)”*

*“Everyone involved needs good training and they need to be able to map LGBT issues and fund accordingly.”*

## Conclusions

This survey of 59 people who identify as either Lesbian, Gay, Bisexual or Transgender, explored attitudes of the LGBT community towards current and prospective practices in sharing patient information within the NHS in order to examine how proposed changes to record sharing practices might specifically impact upon LGBT people in Brighton and Hove.

Patterns which repeatedly emerged from the data collected indicate that direct and indirect discrimination continue to be an unfortunate but very real fact of life for many LGBT people, and this impacts profoundly upon their experiences within the healthcare system as invoked through the use, misuse and abuse of their personal information. The result being that there is a marked apprehension towards any proposed changes in the sharing of patient information which might compromise their human right to privacy, and place them at risk by rendering them more exposed to the potential ignorance, prejudice or insensitivity of others, especially those healthcare professionals upon whom they depend to access services.

This apprehension appears to be representative of a broader wariness around the perceived inconsistencies in attitude, awareness and professional integrity of health professionals within the National Health Service around LGBT issues. This is perhaps as much indicative of the high risk factors and potential trauma involved for this already marginalised demographic, as it is of the prevalence of such shortcomings (though existing national research suggests that this is still high, as established in the 'background' section of this report). The resulting lack of trust and engagement appears to compound existing barriers to healthcare and expedite a sense of disenfranchisement from one's medical care and associated patient record – as indicated by the strong responses stating a desire to oversee one's record, the repeatedly reported perception of a need to be able to challenge and change the information held about oneself and the aspiration towards greater transparency and accountability. This ideally projected transparency and accountability also seems to correspond with cautions aspirations toward better standards of consistency and awareness among health professionals.

**In conclusion, the broad consensus of those polled appears to be one of caution, with considerable apprehension around the serious risks associated with the sharing of patient information, but there is also some limited optimism that, carefully managed and regulated by strict standards of information governance, shared access to patient information could deliver real benefits in addressing some of the health inequalities faced by the LGBT community.**



## Recommendations

This consultation has identified concerns around information governance, confidentiality and a lack of LGBT awareness amongst professionals. It is hoped that the following recommendations may act as a guide for action.

1. *Information Governance*: Clear and transparent standards of information governance must be in place to ensure confidentiality of patients. These standards should be made readily available to members of the public.
2. *Training*: Professionals who can access Summary Care Records should receive LGBT awareness training to ensure they are able to respond sensitively to LGBT people's needs.
3. *LGBT Specific Guidelines*: Clear information should be given to patients with Summary Care Records as to which information will be made available, to whom, and whether there are opt-out options for HIV status, sexual orientation or gender-identity information to be shared.
4. *Sharing Information*: The CCG should consider producing a leaflet for LGBT people about Summary Care Records and responses to specific LGBT concerns and disseminate electronically and hard-copy via LGBT services.

## Key Contacts

*LGBT HIP Project Manager:*

Meg Lewis  
[meg.lewis@switchboard.org.uk](mailto:meg.lewis@switchboard.org.uk)

*LGBT Switchboard Director:*

Maria Antoniou  
[maria.antoniou@switchboard.org.uk](mailto:maria.antoniou@switchboard.org.uk)