



LGBTQ PEOPLES EXPERIENCES OF MEDICINES & PHARMACIES

JULY 2017

BRIGHTON AND HOVE LGBT SWITCHBOARD

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LGBTQ Peoples Experiences of Medicines & Prescriptions

Research Report
July 2017



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, trans and queer people (LGBTQ). 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.

1. INTRODUCTION

This report presents data from an online survey of LGBTQ people in Brighton and Hove and their experiences of obtaining and using medicines in Brighton and Hove. The report also explores LGBTQ people's use of pharmacy services in Brighton & Hove.

1.1 BACKGROUND

A significant area for LGBTQ people regarding medicines and prescriptions is access to hormone treatment for trans people. The Parliamentary Report into Trans Equality¹ highlighted specific issues faced by trans patients in terms of accessing hormone treatment. A key issue was GPs lack of knowledge with regards to the Trans Care Pathway, including the GPs role in prescribing 'bridging' hormones to trans patients, their role in providing continued hormone treatment and their role in referring trans patients to other NHS service including Gender Identity Clinics.

The UK Intercollegiate Good Practice Guidelines for the Assessment and Treatment of Adults with Gender Dysphoria,² advise that hormones can be prescribed 'as part of a holding and harm reduction

¹ House of Commons Women and Equalities Committee (2015) '[Transgender Equality](#)'

² Royal College of Psychiatrists London (2013) "[Good practice guidelines for the assessment and treatment of adults with gender dysphoria](#)'

strategy'. The guidelines request that practitioners consider the risk of harm to the patient by not prescribing hormones where the patient has begun self-medicating.

The NHS Specialised Services Circular³ (2014) states that GPs are responsible for:

- prescribing hormone therapy as recommended by the GICs
- providing patient safety monitoring procedures
- providing basic physical examinations within the usual competences of GPs
- providing blood tests as recommended by GICs

The Parliamentary Report also highlighted poor attitudes towards trans patients amongst some health service providers and cited NHS England as admitting that there was an “unwillingness by some general practitioners to prescribe and monitor hormone therapy”.

These issues are reflected locally in the Brighton & Hove Trans Needs Assessment⁴, where it was reported only 65% of trans patients were satisfied or very satisfied with their GP as opposed to 89% of general population in the 2013 City Tracker Survey.

Another key issue regarding medicines within the LGBTQ community is access to Post Exposure Prophylaxis (PEP) and Pre-Exposure Prophylaxis (PrEP), particularly for gay and bisexual men, other men who have sex with men (MSM), and some trans communities.

In 2014, the Gay Men’s Sex Survey⁵ found that out of 15,360 MSM, 7.2% had taken PEP. This shows an increase from previous years, with 2.4% of men saying that they had taken PEP in 2007. The survey also showed that 39.6% of MSM had not heard of PEP, evidencing a need for increased awareness.

The LGBT HIP⁶ research into Urgent Care (2013) found that a number of gay and bisexual men experienced challenges in accessing PEP following potential exposure to HIV infection. Lack of timeliness and disrespectful treatment were reported. As such, a recommendation for further consultation into the perceptions and experiences of local people who may need PEP was included in the report.

The Proud Study,⁷ researched PrEP mimicking real-world settings as much as possible and found that Truvada reduced the risk of HIV by 86%. PrEP is not currently available on the NHS although the Court of Appeal in 2016 upheld a ruling that NHS England has the legal power to fund treatment. NHS England have announced that they will not be rolling out PrEP as a new specialised service, but will

³ NHS England (2014) '[Primary Care responsibilities in relation to the prescribing and monitoring of hormone therapy for patients undergoing or having undergone Gender dysphoria treatments](#)'

⁴ Brighton & Hove City Council (2015) '[Trans Needs Assessment](#)'

⁵ Hickson et al. (2014) '[State of Play: findings from the England Gay Men’s Sex Survey](#)'

⁶ LGBT HIP (2013) '[Urgent Care and LGBT People Results of an Online Survey](#)'

⁷ S McCormack et al (2015) '[Pre-exposure prophylaxis to prevent the acquisition of HIV-1 infection \(PROUD\): effectiveness results from the pilot phase of a pragmatic open-label randomised trial](#)'

make up to £10 million available to Public Health England to enrol 10,000 participants over the next 3 years in a clinical trial of PrEP.

A recent survey⁸ conducted in July 2017 by PrEP advocacy sites [iwantPrEPnow](#) and [PrEPster](#), with assistance from Public Health England, found that PrEP use has rapidly increased in the last year, with the vast majority (86%) of people buying PrEP online. This survey shows that PrEP use has accelerated rapidly, with only six people saying they'd taken PrEP before 2014, 30 in 2014, 53 in 2015, 252 in 2016 and 425 starting since the beginning of 2017 – more than half of all respondents. The majority of those surveyed said they intend to join the PrEP IMPACT trial when it starts (85% : 651 people), which NHS England says should happen 'by September'.

In 2015, [cliniQ](#)⁹ facilitated a consultation to allow trans people's experiences to feed into the WHO PrEP Implementation Guidelines. The report published following the consultation found that trans communities did not feel that the information on PrEP represented trans people. This is despite evidence that globally transgender people are 49% more likely to be living with HIV than the general population.¹⁰

Another key area raised in previous consultations is access to fertility treatment for LGBTQ people. NICE's guidance from 2013 stipulates that couples must attempt to conceive before being considered for NHS treatment.¹¹ Cisgender/ heterosexual couples are expected to try through unprotected sexual intercourse but this is not appropriate guidance for women in same-sex couples and some trans and non-binary people. NICE guidance therefore stipulates that LGBTQ people accessing fertility treatment must have tried through artificial insemination at least six times to be eligible for NHS fertility treatment, however the funding is still not guaranteed. There is limited information available about LGBTQ people's access to medicines and prescriptions in relation to fertility treatments.¹²

1.2 AIM

The aim of this research exercise was to gather LGBTQ views and experiences of using medicines and prescription services in Brighton and Hove. In particular, LGBT HIP aims to explore access to medicines and treatments with a high prevalence in LGBTQ communities, such as hormone treatment, PEP and PrEP.

⁸ Aidsmap (2017) <http://www.aidsmap.com/PrEP-demand-in-England-is-rapidly-accelerating-and-most-will-want-to-join-the-trial/page/3162707/>

⁹ [cliniQ](#) (2015) 'Report on Public Involvement meetings with trans service users from [cliniQ](#), in the draft stages of the World Health Organisation's PrEP Implementation Guidelines'

¹⁰ UNAIDS (2016) '[Prevention Gap Report](#)'

¹¹ NHS Choices (2013) <http://www.nhs.uk/news/2013/02February/Pages/New-NICE-guidelines-for-NHS-fertility-treatment.aspx>

¹² Stonewall <http://www.stonewall.org.uk/help-advice/parenting-rights/donor-insemination-and-fertility-treatment-0>

1.3 METHOD

Questions were developed in line with questions suggested by the Clinical Commissioning Group (CCG) and adapted to reflect concerns specific to the LGBTQ population. The LGBT HIP Project Manager, Meg Lewis, developed questions on PEP and PrEP in consultation with Terrence Higgins Trust Brighton, and questions on hormone treatment in consultation with the Trans Alliance. The survey was conducted using SurveyMonkey over a period of 3 weeks in June and July 2017. In addition, we also ran another survey using just the questions on PrEP and PEP, in an effort to increase the sample size of respondents to these questions. This survey was conducted using SurveyMonkey and ran over a period of 2 weeks in August.

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. 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 and LGBT Switchboard staff and volunteers.

Responses have been analysed and reviewed by the LGBT HIP Engagement Officer, Scarlett Langdon, and qualitative responses were reviewed to identify key themes and extend quantitative findings.

2. KEY FINDINGS

This report presents data gathered by Brighton and Hove LGBT Switchboard's LGBT Health and Inclusion Project. From July-August 2017 LGBT HIP surveyed 82 people in Brighton and Hove on their experiences of medicines and pharmacies. In particular the survey looked at access to medicines with a high prevalence in LGBTQ communities, such as hormone treatment, PEP and PrEP.

Medicines and Pharmacies

- 9% of those surveyed said they'd experienced challenges as an LGBTQ person accessing services and advice from a pharmacy
- 29% of people had taken prescription drugs outside of the NHS or private healthcare
- Of those who specified what drugs they had taken; 7 were mental health medications (anti-depressants, anti-anxiety), 6 were sleeping tablets/medicines and 3 were hormones. The most frequently mentioned drug was Valium (5)

PrEP and PEP

- 85% of those surveyed had heard of PrEP, and 100% of gay, bisexual or queer men.
- 5 respondents had taken PrEP - two were participating in a study which supplies them with PrEP, two obtained PEP through A&E and only use the Truvada and one was buying generic Truvada online
- 84% of those surveyed had heard of PEP, and 100% of gay, bisexual or queer men
- 54% of people knew where to obtain PEP
- 66% of people knew PEP was only effective if taken within 72 hours after exposure to HIV
- Three people surveyed had taken PEP

Trans Healthcare

- 70% of those who identified as trans, non-binary or gender variant said they had used hormones/blockers
- Over half (52%) had obtained hormones prior to their first appointment with a Gender Identity Clinic (GIC)
- Four out of nine respondents were self-medicating their hormone treatment; buying hormones online (2), or through an unregulated source such as a friend or dealer (2)
- None of those surveyed had received a 'bridging' prescription from their GP
- 27% of those taking hormones outside of the NHS said they had not received any support or tests from their GP about using it safely
- Half of those who use hormones/blockers said their GP does not monitor their hormone levels, offering guidance and adjusting doses accordingly. The other 50% said they do.

3. MEDICINES AND PHARMACIES SURVEY

3.1 DEMOGRAPHICS

Participants were all first presented with an initial screening question, which limited the sample, by self-exclusion of participants who did not meet certain criteria. The screening question limited the sample to 'lesbian, gay, bisexual, transgender and queer people who live, work, study or socialise in Brighton and Hove'. After this question, there were a total of 72 eligible respondents. At the end of the survey, data was collected on participants' age, sexual orientation, gender identity, ethnicity and disability.

Sexual Orientation (63 responses)

Participants were asked to select which of the orientations listed described them and were permitted to select more than one option.

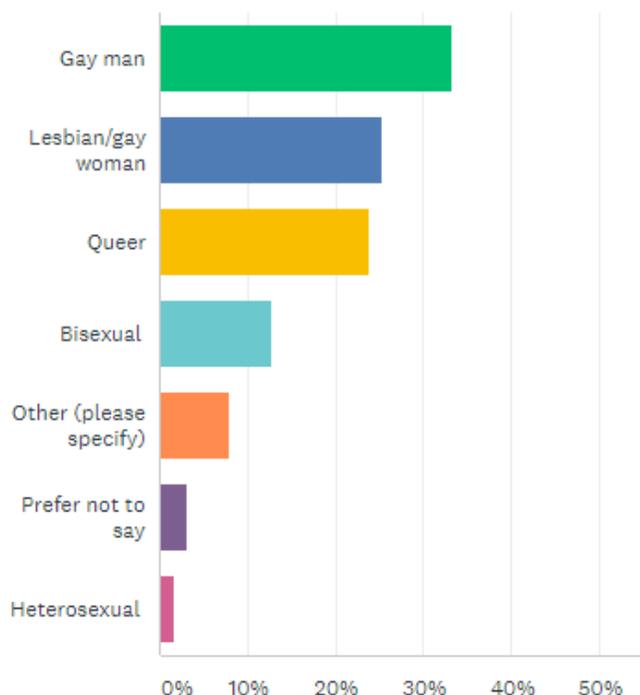
33% (21) indicated that they identified as a gay man

25% (16) indicated that they identified as a lesbian/gay woman

24% (15) indicated that they identified as queer

13% (8) indicated that they identified as bisexual

8% (5) respondents indicated that they identified with an 'other' sexual orientation which was not listed. These included: 'Asexual', 'bisexual lesbian', 'Pan A-sexual',



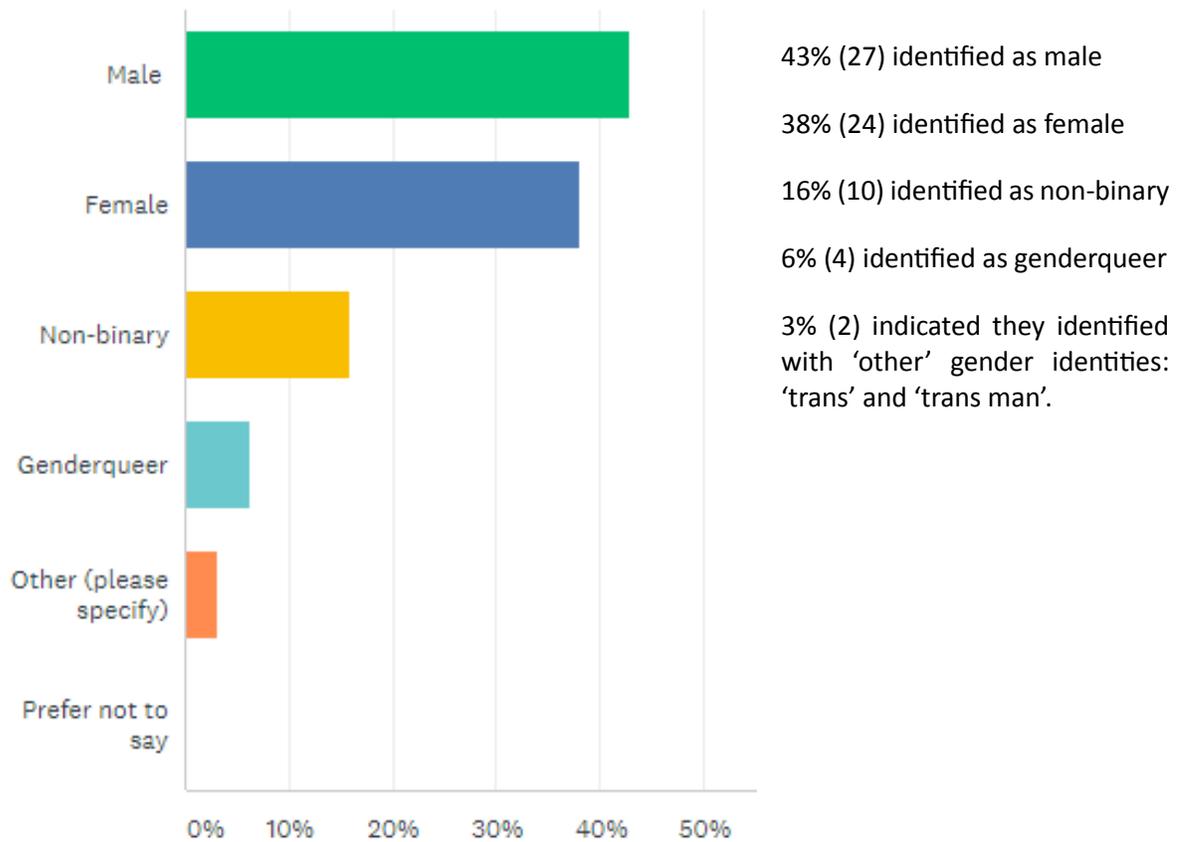
'Femme, bdsm dyke bottom' and 'N/A - I do not use any particular term to specifically describe my sexual orientation'.

3% (2) preferred not to say

1% (1) identified as heterosexual

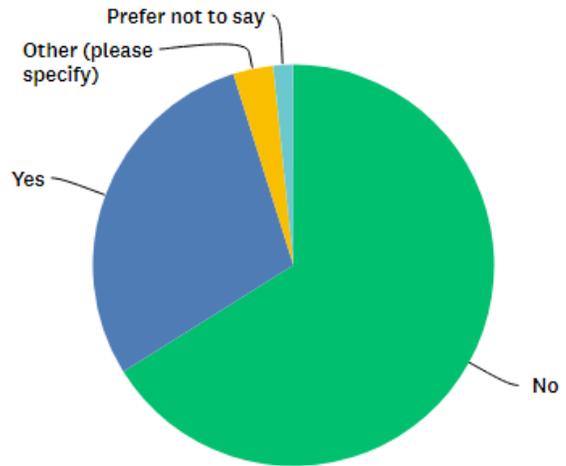
Gender Identity (63 responses)

Participants were asked 'How would you describe your gender identity?', and were asked to select which of the gender identities from the following list best described them: male, female, genderqueer, non-binary, other, or prefer not to say. Respondents could select more than one option and were also presented with an open field in which to describe other gender identities which did not fit into those options.



Transgender Identity (62 responses)

Participants were asked: ‘Do you identify as transgender or trans, or have you in the past?’ 66% (41) of respondents said ‘no’ and 29% (18) of respondents said ‘yes’ they identified as transgender or trans, or had in the past. 3% (2) of respondents marked the ‘other’ field, but didn’t specify, and 1 person preferred not to say.



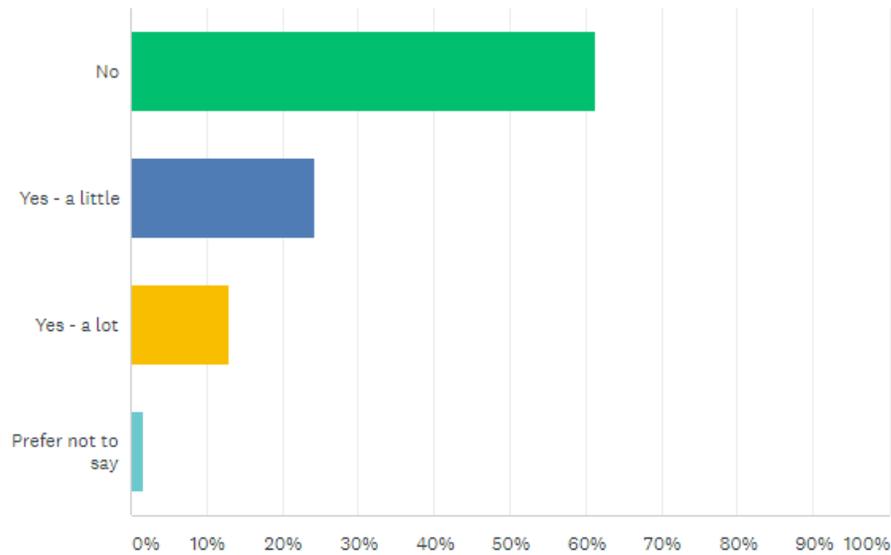
Age (62 responses)

Participants were asked, ‘What was your age at your last birthday?’ and asked to select their age from a range of banded options. The age distribution showed the highest proportion of respondents to be between the ages of 25-34 (17), followed by 45-54 (16), 34-44 (14), 55-64 (7), 18-24 (5) and 65-74 (3).

| ANSWER CHOICES | RESPONSES |
|-------------------|-----------|
| 25-34 | 27.42% 17 |
| 45-54 | 25.81% 16 |
| 35-44 | 22.58% 14 |
| 55-64 | 11.29% 7 |
| 18-24 | 8.06% 5 |
| 65-74 | 4.84% 3 |
| 75+ | 0.00% 0 |
| Prefer not to say | 0.00% 0 |
| Total | 62 |

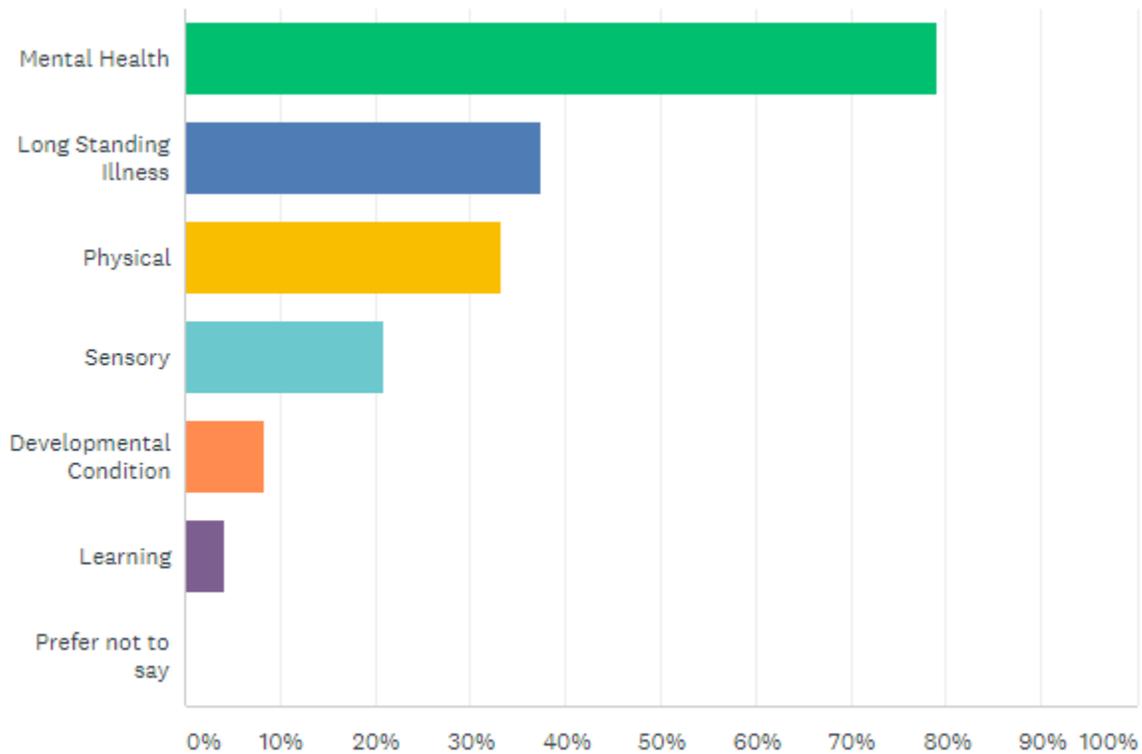
Disability (62 responses)

Participants were asked, ‘Are your day to day activities limited due to being a disabled person?’ In total, 37% (23) of respondents indicated that their day to day activities were limited due to a disability. 24% (15) said their day to day activities were limited a little and 13% (8) said their day to day activities were limited a lot. One person preferred not to say.



Type of Disability (24 responses)

Of those respondents (23) who indicated that their day to day activities were limited due to a disability, 79% (19) indicated they had a mental health condition, 38% (9) a long standing illness, 33% (8) indicated they have a physical disability, 21% (5) a sensory disability, 8% (2) a developmental condition and 1 person indicated they had a learning disability.



Ethnicity (62 responses)

Respondents were asked to select from a list of terms to describe their ethnic background. 76% (45) indicated that they were of White British heritage. 10% (6) of respondents identified as being from any other White background and 8% (5) of White Irish heritage. 6% (4) of respondents indicated they were of mixed heritage and there were two responses left; one wrote 'Latinx' and the other 'mixed white Asian'. 1 respondent indicated they were Asian or British Asian – Indian, 1 respondent indicated they were of 'any other Asian background' and 1 respondent selected 'Other' and wrote 'Iberian'.

The total number of respondents identifying as being of BME heritage was 4.

| | | |
|--|--------|----|
| ▼ White - British | 72.58% | 45 |
| ▼ White - Any other White background | 9.68% | 6 |
| ▼ White - Irish | 8.06% | 5 |
| ▼ Mixed (please specify) | 6.45% | 4 |
| ▼ Asian or British Asian - Indian | 1.61% | 1 |
| ▼ Asian or British Asian - Any other Asian background (please specify) | 1.61% | 1 |
| ▼ Other (please specify) | 1.61% | 1 |
| ▼ Asian or British Asian - Pakistani | 0.00% | 0 |
| ▼ Asian or British Asian - Bangladeshi | 0.00% | 0 |
| ▼ Black or Black British - Caribbean | 0.00% | 0 |
| ▼ Black or Black British - African | 0.00% | 0 |
| ▼ Black or Black British - Any other Black background (please specify) | 0.00% | 0 |
| ▼ White - Traveller of Irish Heritage | 0.00% | 0 |
| ▼ Asian or British Asian - Chinese | 0.00% | 0 |

Neighbourhoods (63 responses)

Respondents were asked to indicate the first four digits of their postcode. 10% (6) indicated that they lived out of Brighton & Hove.

| Answer Choices | Responses | |
|----------------|-----------|---|
| BN1 1 | 4.76% | 3 |
| BN1 2 | 7.94% | 5 |

| | | |
|--------|-------|---|
| BN1 3 | 3.17% | 2 |
| BN1 4 | 4.76% | 3 |
| BN1 5 | 4.76% | 3 |
| BN1 6 | 3.17% | 2 |
| BN1 7 | 6.35% | 4 |
| BN1 8 | 0.00% | 0 |
| BN1 9 | 0.00% | 0 |
| BN2 0 | 4.76% | 3 |
| BN2 1 | 7.94% | 5 |
| BN2 3 | 9.52% | 6 |
| BN2 4 | 3.17% | 2 |
| BN2 5 | 6.35% | 4 |
| BN2 6 | 0.00% | 0 |
| BN2 7 | 0.00% | 0 |
| BN2 8 | 3.17% | 2 |
| BN2 9 | 1.59% | 1 |
| BN3 1 | 6.35% | 4 |
| BN3 2 | 3.17% | 2 |
| BN3 4 | 3.17% | 2 |
| BN3 5 | 3.17% | 2 |
| BN3 6 | 0.00% | 0 |
| BN3 7 | 0.00% | 0 |
| BN3 8 | 0.00% | 0 |
| BN41 1 | 1.59% | 1 |

| | | |
|--------|-------|---|
| BN41 2 | 1.59% | 1 |
| BN41 3 | 0.00% | 0 |
| BN41 4 | 0.00% | 0 |
| BN41 5 | 0.00% | 0 |
| BN41 6 | 0.00% | 0 |
| BN41 7 | 0.00% | 0 |
| BN41 8 | 0.00% | 0 |
| BN41 9 | 0.00% | 0 |

3.2 FINDINGS

Pharmacies Usage (68 respondents)

Participants were asked 'What are the main things you go to a pharmacy for?' (please select all that apply). Overwhelmingly the responses were around picking up prescriptions and buying over-the-counter medicines. The responses were as follows:

Pick up repeat prescriptions: 72% (49)

Pick up prescriptions: 71% (48)

Buying over-the-counter medicines: 62% (42)

Advice on treatment of minor conditions and healthy living: 29% (20)

Disposing unwanted or out-of-date medicines: 9% (6)

Flu vaccination service: 7% (5)

Medicines Use Reviews: 4% (3)

Minor ailment service: 4% (3)

Emergency supply of prescription medicines: 3% (2)

Needle and syringe exchange service: 3% (2)

Stop smoking service: 3% (2)

Supervised consumption of prescribed medicines: 1% (1)

NHS Health Check (blood pressure, cholesterol or blood glucose testing): 1% (1)

Chlamydia screening and treatment service: 1% (1)

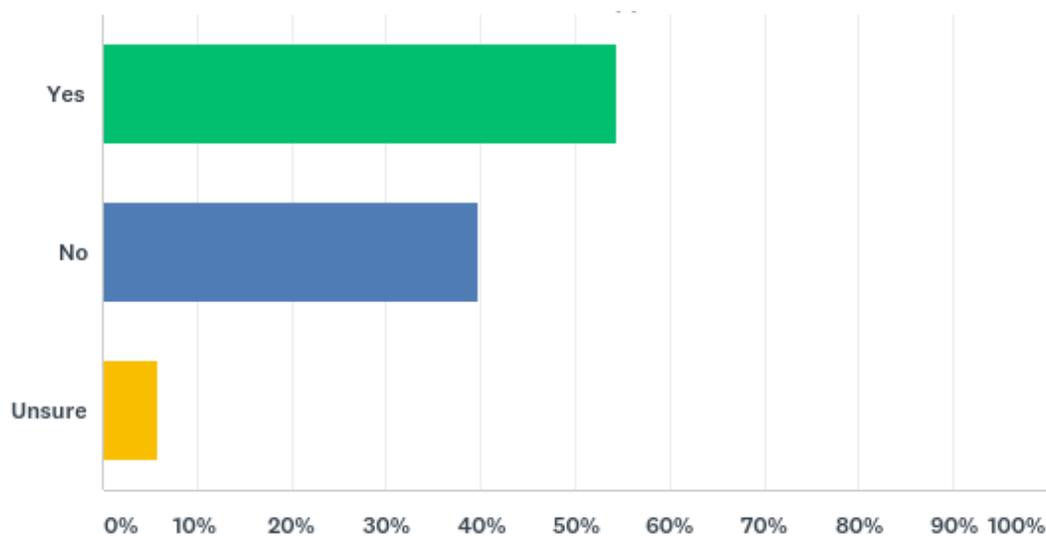
Condom supply service: 1% (1)

The other options included; New Medicine Service, Advice on alcohol consumption, Pregnancy testing, Carer support, Stop smoking voucher service, Weight management service, Emergency hormonal contraception (EHC) service and Independent prescribing by pharmacist. None of these options were selected by participants.

| ANSWER CHOICES | RESPONSES |
|---|-----------|
| ▼ Pick up repeat prescriptions | 72.06% 49 |
| ▼ Pick up prescriptions | 70.59% 48 |
| ▼ Buying over-the-counter medicines | 61.76% 42 |
| ▼ Advice on treatment of minor conditions and healthy living | 29.41% 20 |
| ▼ Disposing unwanted or out-of-date medicines | 8.82% 6 |
| ▼ Flu vaccination service | 7.35% 5 |
| ▼ Medicines Use Reviews | 4.41% 3 |
| ▼ Minor ailment service | 4.41% 3 |
| ▼ Emergency supply of prescription medicines | 2.94% 2 |
| ▼ Needle and syringe exchange service | 2.94% 2 |
| ▼ Stop smoking service | 2.94% 2 |
| ▼ Supervised consumption of prescribed medicines | 1.47% 1 |
| ▼ NHS Health Check (blood pressure, cholesterol or blood glucose testing) | 1.47% 1 |
| ▼ Chlamydia screening and treatment service | 1.47% 1 |
| ▼ Condom supply service | 1.47% 1 |

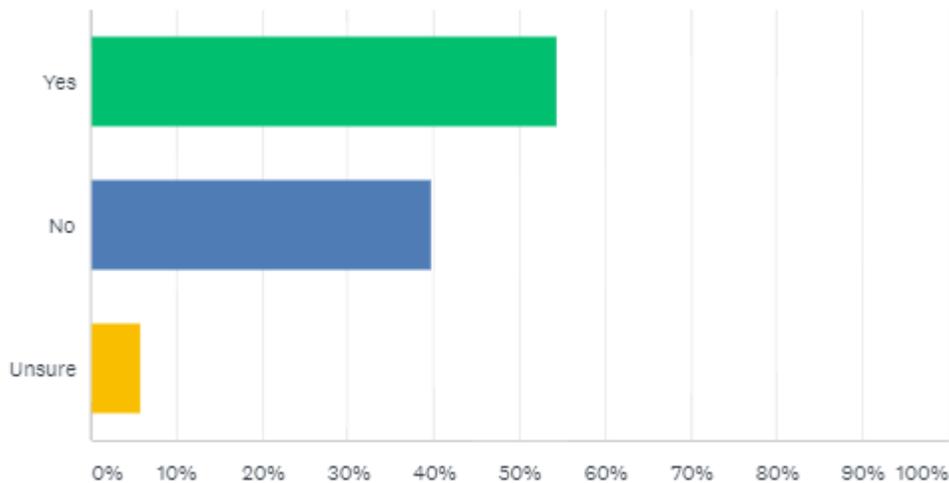
Pharmacist – reviewing and managing medicines (68 responses)

Participants were asked 'Did you know you can ask the pharmacist to review your medicines and help you manage them?' 56% (38) of respondents answered 'yes', with 40% (27) answering 'no' and 4% (3) being unsure.



Pharmacy check ups (68 responses)

Participants were asked “Did you know you can have certain checks at your pharmacy – e.g. diabetes?” 54% (37) answered ‘yes’, with 40% (27) answering ‘no’ and 6% (4) ‘unsure’.



Challenges to accessing services or advice from pharmacies as an LGBTQ person (68 responses)

Participants were asked ‘Have you ever experienced challenges as an LGBTQ person accessing services or advice from a pharmacy?’ 91% (62) said they hadn’t, 9% (6) said they had.

Given the opportunity to comment on the challenges they’d faced six people left comments which can be broadly grouped into a lack of understanding from staff, and a lack of competent care in relation to their LGBTQ identity.

One trans respondent answered ‘Being misgendered’, and another wrote ‘People pointing out that I’m trans while I pick up medication’.

Two people commented on a lack of understanding from staff in relation to their LGBTQ identity:

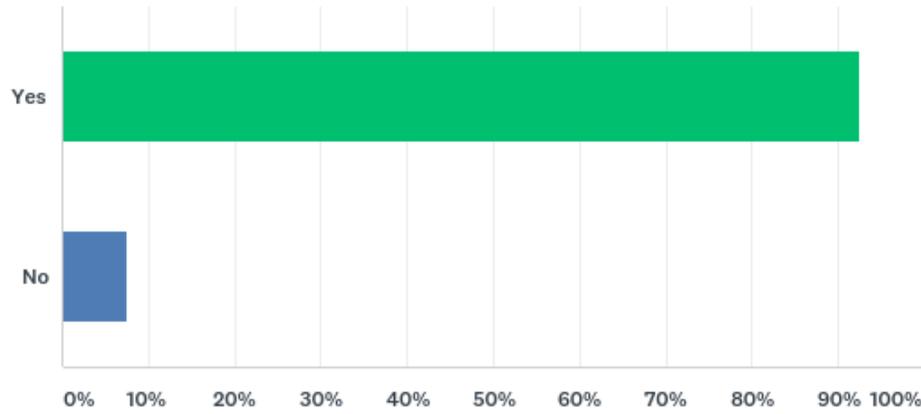
‘People asking if I was ‘heterosexual’ to ask if I had had sex with a person with a penis, people referring to me as ‘female’ when talking about menstruation’ (Non-Binary, Bisexual)

‘having been to a sex clinic they repeated questionnaire from beginning once I disclosed I was bi. that was unnecessary and cumbersome.’ (Female/Non-Binary, Bisexual)

And another commented on a lack of competent care from the pharmacist in regards to their HIV medication; ‘I did ask Boots Pharmacy pharmacist (North Street) recently for advice on taking hayfever medication with HIV antiretrovirals... she wasn’t able to give advice and referred me back to the Lawson Unit. Not sure whether this advice on potential contraindications should reasonably have been within the scope of practice/service?’ (Male, Cisgender, Gay)

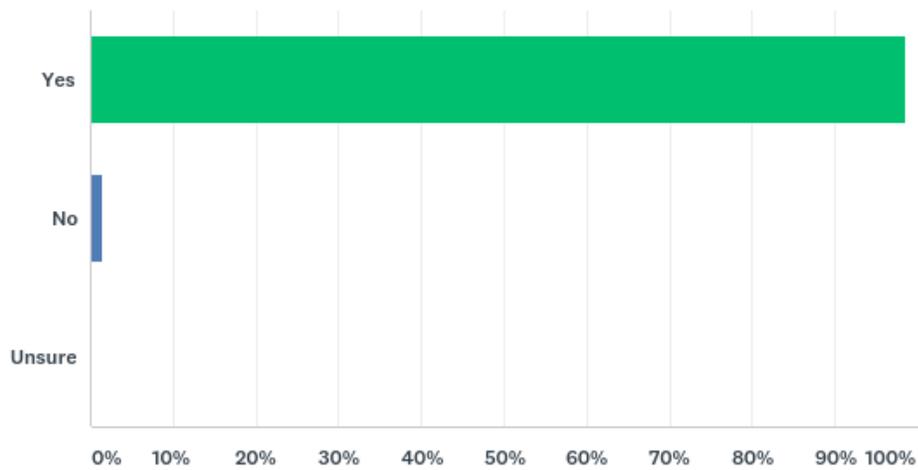
Medicines (40 responses)

Participants were asked 'Do you take medicines?' 93% (37) answered 'yes' and 7% (3) answered 'no'.



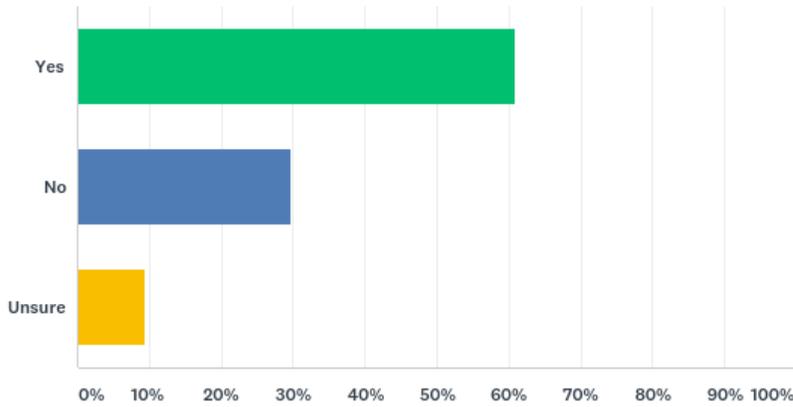
Medicines (64 responses)

Participants were asked 'Do you know what your medicines are for and what they do?' 98% (63) answered 'yes' and one person answered 'no'.



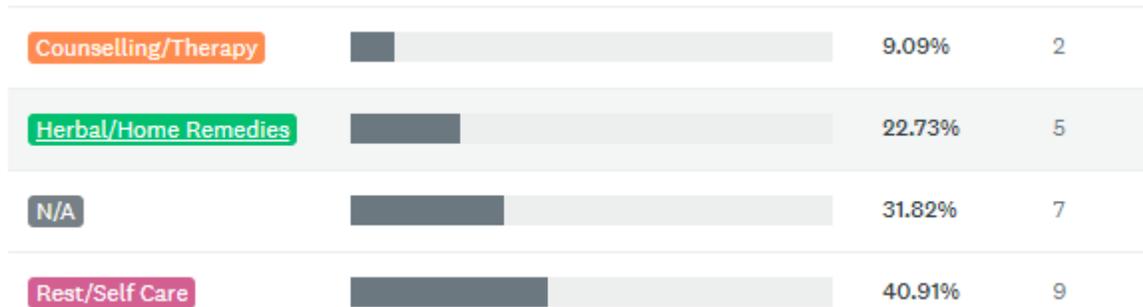
Medicines: Side Effects (64 responses)

Participants were asked, 'Did you have the side effects explained to you?', 61% (39) answered 'yes', 30% (19) answered 'no' and 9% (6) said they were 'unsure'.



Medicines (22 responses)

Participants were asked, 'If you don't take medicines and rely on other things to help when you feel ill, what are these?'. There were 22 responses left which can be broadly categorised as follows:



Comments included:

'Self regulation, e.g. breathing, meditation, stretching, gentle exercise Being in nature Hot shower helps with one of my conditions'

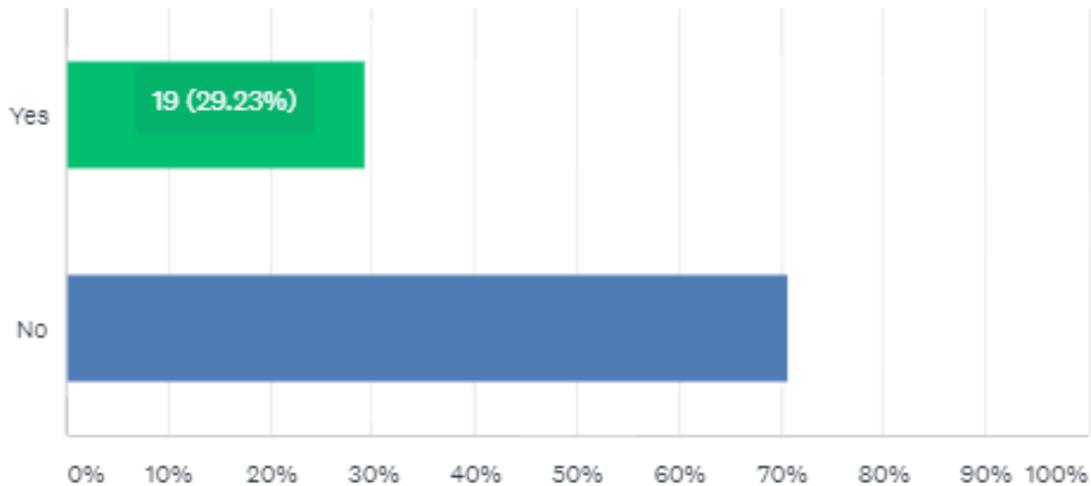
'When I am unwell, I drink lots of water or hot drinks (hot chocolate and green tea work for me), use a hot water bottle, etc. I rarely take medication for passing illnesses (like cold, flu, stomach bugs), only my ongoing repeated medications.'

'Social support and self-care for mental health issues, go to counselling when possible'

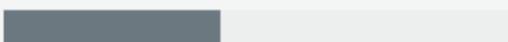
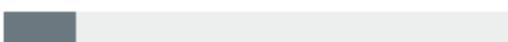
'Herbal teas, a good diet, lots of water'

Obtaining drugs outside of the NHS and private healthcare (65 responses)

Participants were asked, 'Have you ever obtained prescription drugs outside of the NHS or private healthcare?' 29% (19) said 'yes' and 71% (46) said 'no'.

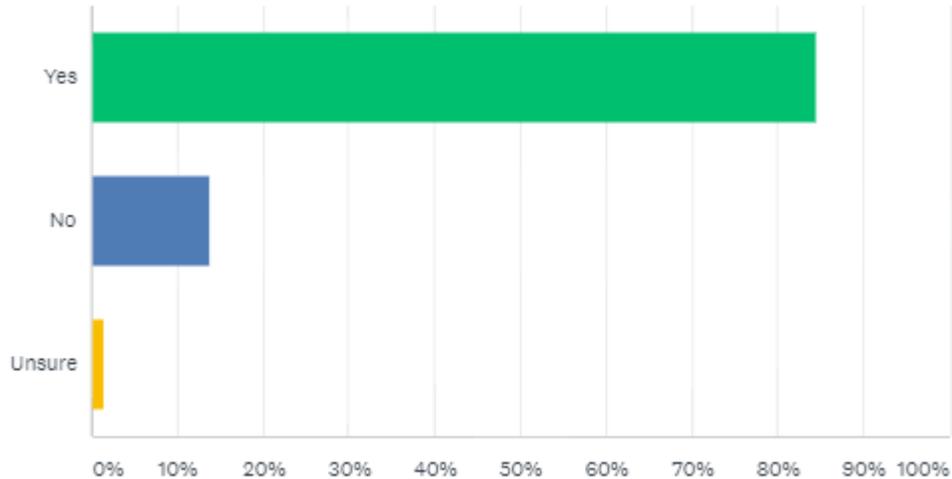


For those who responded 'yes', 14 left comments, which can be categorised into the following; mental health medications (anti-depressants/anti-anxiety) (7), sleeping medicines/tablets (6), and hormones (3). The most frequently mentioned drug was Valium (5).

| | | | |
|---------------------------|--|--------|---|
| Hormones |  | 21.43% | 3 |
| Mental Health Meds |  | 50% | 7 |
| Sleeping Meds |  | 42.86% | 6 |
| Uncategorized |  | 14.29% | 2 |

PrEP (65 responses)

Participants were asked 'Had you heard of PrEP before this consultation?', 85% (55) answered 'yes', 14% (9) answered 'no' and 1 'unsure'.



Of those who identify as a gay, bisexual or queer man 100% (27) had, and for those who identified as transgender 81% (17) had, and 19% (4) had not.

PrEP (65 responses)

Participants were asked 'Do you currently take PrEP, or have you taken PrEP in the past?', one respondent said 'yes', 64 said 'no'.

How you obtained PrEP (1 response)

Participants were asked 'How have you obtained PrEP', the one respondent who said they had taken PrEP responded 'I get PEP from A&E departments and only use the Truvada', which was one of 6 options available.

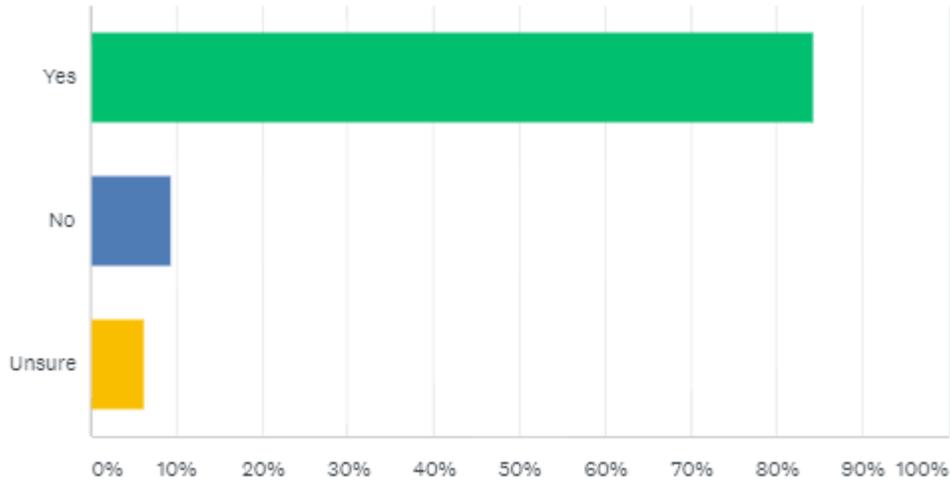
| ANSWER CHOICES | RESPONSES |
|--|-------------------|
| I am participating in a study which supplies me with PrEP (such as Proud) | 0.00% 0 |
| I buy generic Truvada online | 0.00% 0 |
| I get PEP from A&E departments and only use the Truvada | 100.00% 1 |
| Through a paid-for prescription from an NHS GP or private health care | 0.00% 0 |
| I buy/ share from an unregulated source (Such as a friend, partners or dealer) | 0.00% 0 |
| Other (please specify) | Responses 0.00% 0 |

PrEP: Support and Safety (1 response)

Participants were asked, 'If you are taking PrEP outside the NHS, do you receive support from local sexual health service SHAC about using it safely?' the same respondent answered 'Yes' to this question.

PEP (64 responses)

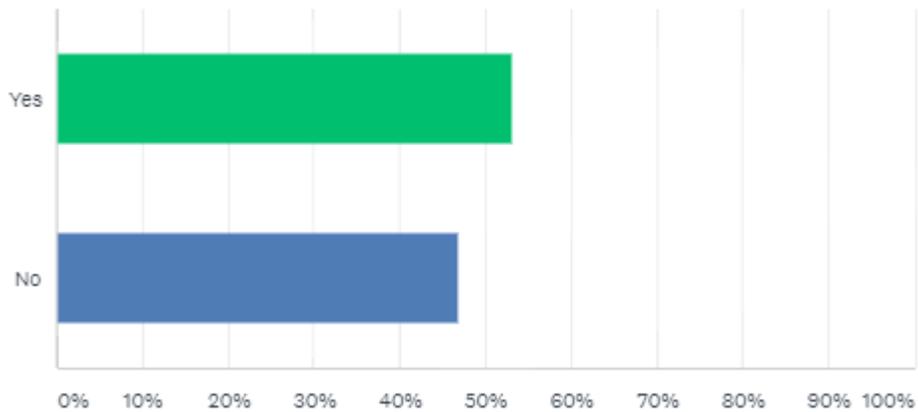
Participants were asked, 'Had you heard of PEP before this consultation?' 84% (54) had, 9% (6) hadn't and 6% (4) were unsure.



Of those who identify as a gay, bisexual or queer man 100% (27) had, and for those who identify as transgender 86% (18) had, two hadn't, and one was unsure.

PEP (64 responses)

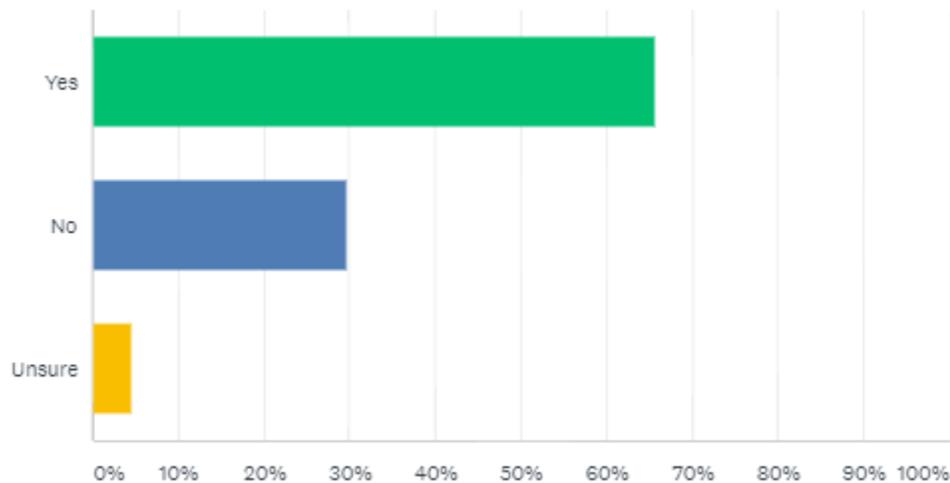
Participants were asked, 'Do you know where you can get PEP from?' 53% (34) answered 'yes' and 46% (30) answered 'no'.



This figure rises to 74% (20) when it comes to gay, bisexual and queer men, with only 7 (26%) saying they did not know where to obtain PEP. For those who identify as transgender 52% (11) answered 'yes', and 48% (10) answered 'no'.

PEP Effectiveness (64 responses)

Participants were asked, 'Did you know that PEP is only effective if taken within 72 hours after exposure to HIV?' 66% (42) answered 'yes', 30% (19) answered 'no', and 3 were unsure.



Have you taken PEP (64 responses)

Participants were asked, 'Have you ever taken PEP?', 63 said 'no' and 1 said 'yes'.

The respondent who answered 'yes' was the same respondent who had answered yes to say they had taken PrEP. In the comments they wrote: 'work related injury from high risk patient which required me to take a course of pep'

PEP/PrEP – Further comments (6 responses)

Participants were asked, 'Is there anything else you would like to tell us regarding PEP or PrEP?'. Two of the responses said 'no', one said 'I am interested in taking prep', and the other comments included:

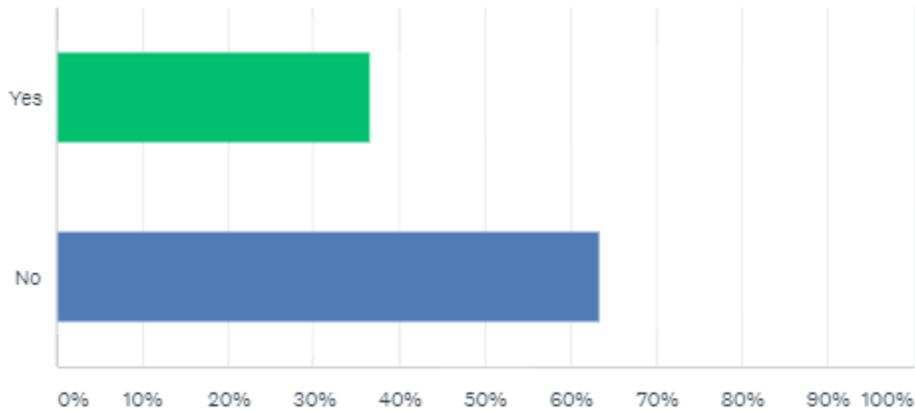
'The only people I know who have been informed by the pharmacy about PEP and PrEP have been cisgender gay men.' (Respondent identified as bisexual, non-binary)

'It is extremely concerning that PrEP is not available on the NHS. This is a game-changer in terms of HIV prevention'. (Respondent identified as gay, cisgender, male)

'I am disappointed to realise that I had not heard of either of these medications, and wish they were more widely promoted'. (Respondent identified as bisexual, cisgender, female)

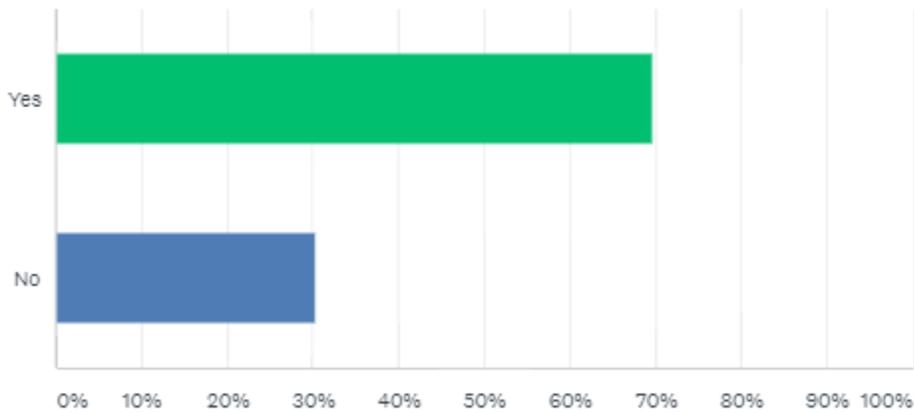
Trans-related Health Care (63 responses)

Participants were asked, 'For the purposes of these questions, do you identify as trans, non-binary, or gender variant?' 37% (23) answered 'yes', 63% (40) answered 'no'. 11 people skipped the question.



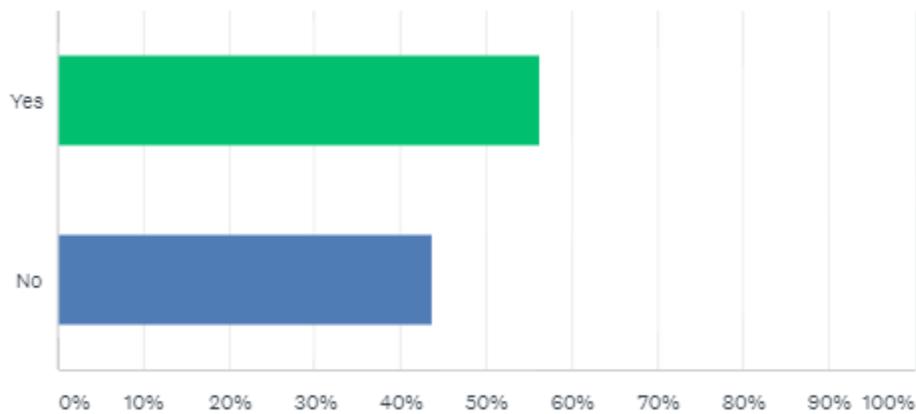
Trans Health Care – Hormones (23 responses)

Participants were asked, 'Do you use hormones/ blockers, or have you used them in the past?' 70% (16) answered 'yes', and 30% (7) answered 'no'.



Trans Health Care – Hormones (16 responses)

Participants were asked 'Have you obtained hormones prior to your first appointment with a gender identity clinic?' 56% (9) said 'yes' and 44% (7) said 'no'.



Trans Health Care – Hormones (10 responses)

Participants were asked 'If yes, how did you obtain the hormones?' They were then asked to select from the following options, and their responses were as follows.

Prescription from NHS GP following a letter of recommendation from a private consultant: (3)

I bought it over the internet: (2)

I bought it from an unregulated source (Such as a friend or dealer): (2)

With a prescription from private healthcare: (1)

With a 'bridging prescription' from an NHS GP: (0)

There was also the option to select 'Other', which two people selected and left the following comments:

'I first used a private provider, then received a bridging prescription from my GP.'

'Two of above options - with a prescription from private healthcare AND prescription from NHS GP following a letter of recommendation from a private consultant'

Trans Health Care – Hormone Safety & Support (15 responses)

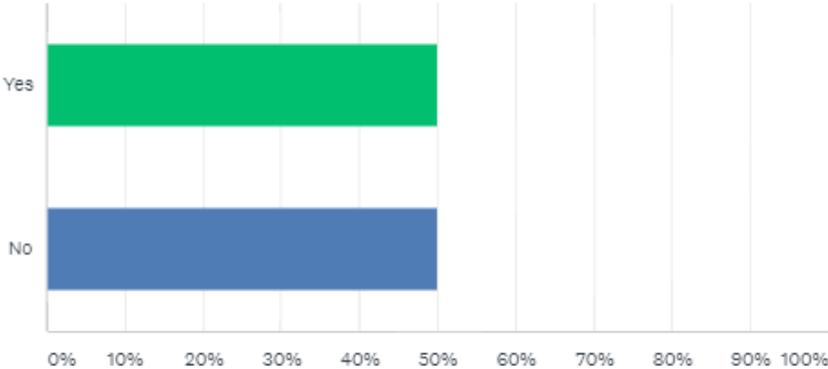
Participants were asked 'If you are taking/ have taken hormones outside the NHS, have you received support and tests from your GP about using it safely?', 40% (6) said they had received support, 33% (5) said they hadn't taken hormones outside of the NHS and 27% (4) said they hadn't received support about using it safely.

| ANSWER CHOICES | RESPONSES |
|---|-----------|
| I do/ have taken hormones outside of the NHS and have received support from my GP about using it safely | 40.00% 6 |
| I do not/ have not taken hormones outside of the NHS | 33.33% 5 |
| I do/ have taken hormones outside of the NHS and have not received support from my GP about using it safely | 26.67% 4 |
| TOTAL | 15 |

Of the four that hadn't received support, two of those had bought hormones from an unregulated source (such as a friend or dealer), one had bought through private healthcare, and the other did not specify.

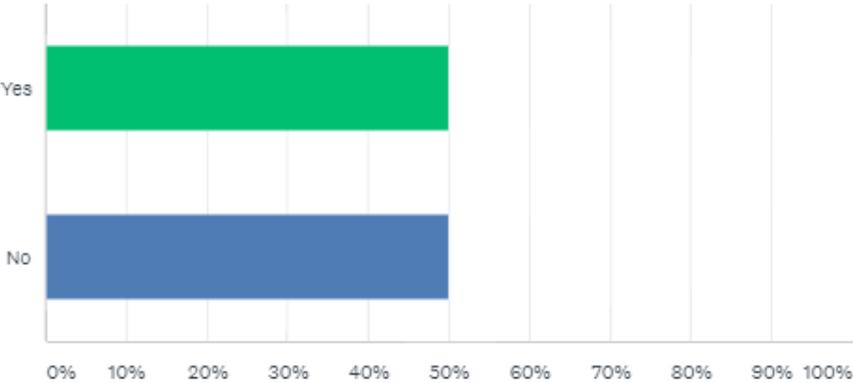
Trans Health Care – Hormone Monitoring (16 responses)

Participants were asked 'If you use hormones/ blockers (from any source), or have done in the past, does your GP monitor your hormone levels, offering you guidance or adjusting your doses accordingly?' 50% (8) answered 'yes' and 50% answered 'no'.



Trans Health Care - Hormones (16 responses)

Participants were asked 'Do you, or have you in the past, received hormones through a regular injection?' 50% (8) answered 'yes' and 50% answered 'no'.



Trans Health Care - Hormones (8 responses)

Participants were asked *'If yes, does your GP'*, and then asked to select from the following options:

Order it into the practice for your injection: 3

Give you a prescription for you to pick up the hormones from the pharmacy prior to your injection: 3

Other: 2

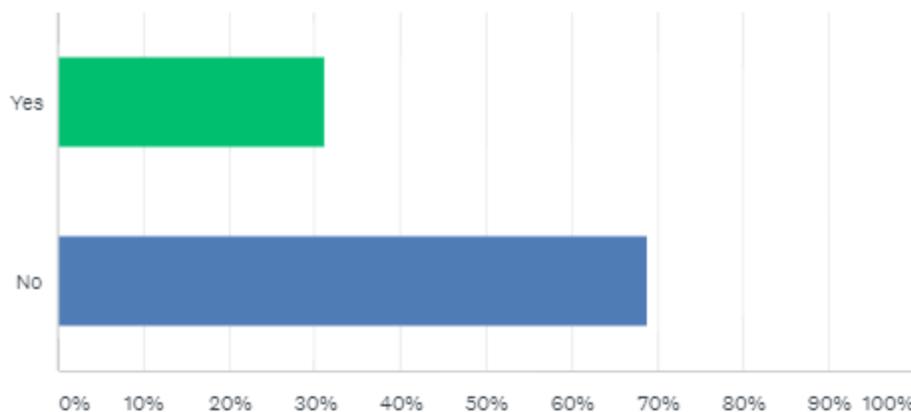
Of the two that selected 'other', the following responses were left:

'Ordered over the internet, did my own injections. Also I used to have regular GNRH inhibitor injections via the gp'

'I do my own injections by picking up needles from a pharmacy'

Trans Health Care – Self Administered Hormones (16 responses)

Participants were asked *'Do you, or have you in the past, self-administered your hormones with injections?'* 31% (5) answered 'yes' and 69% (11) answered 'no'.



There were six comments left on this question. Four of those said yes/no, and the following two responses were left:

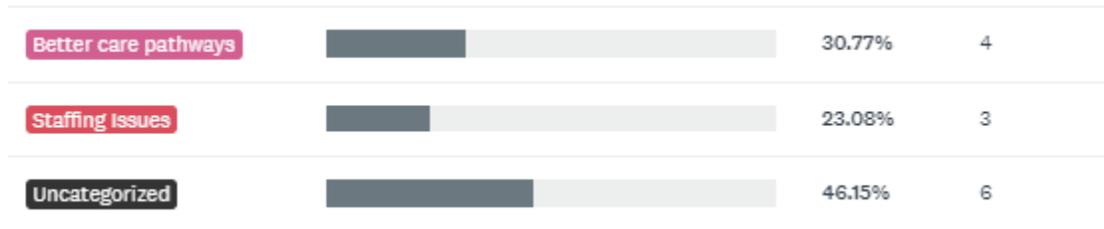
'No. I use gel.'

'Yes but my GP will not switch me to injectable testosterone'

Trans Health Care – Additional Comments (13 responses)

Participants were asked *'Is there anything else you would like to tell us regarding trans-related medicines or prescriptions?'*

There were 12 responses to this question which can be broadly categorised into two themes; one on better long term support and care pathways for trans people, and one around staff and a lack of understanding, and occasional transphobia from medical staff



'There should be more follow up once you've been discharged from the gender clinic. Medicines change over time and the ones you take need reviewing form time to time.'

'some pharmacies are questioning why people have cross-sex hormone prescriptions others are overtly transphobic'

'I would like to see more information for trans women on the effects of taking Decapeptyl (possibly other anti androgens but this is the only one I have experience of). The advice and info I received from the NHS did not adequately describe how this drug affected my emotional well being and I did not feel properly prepared.'

'I have both received support & advice, and NOT received support & advice from my GP - different GPs and practices, some have been willing to help with blood tests etc and some have been extremely unhelpful. I've also had many GPs at different practices refuse to issue NHS prescriptions under a shared care agreement with a private doctor (and often be very rude or dismissive) before my current GP agreed to take over my prescription.'

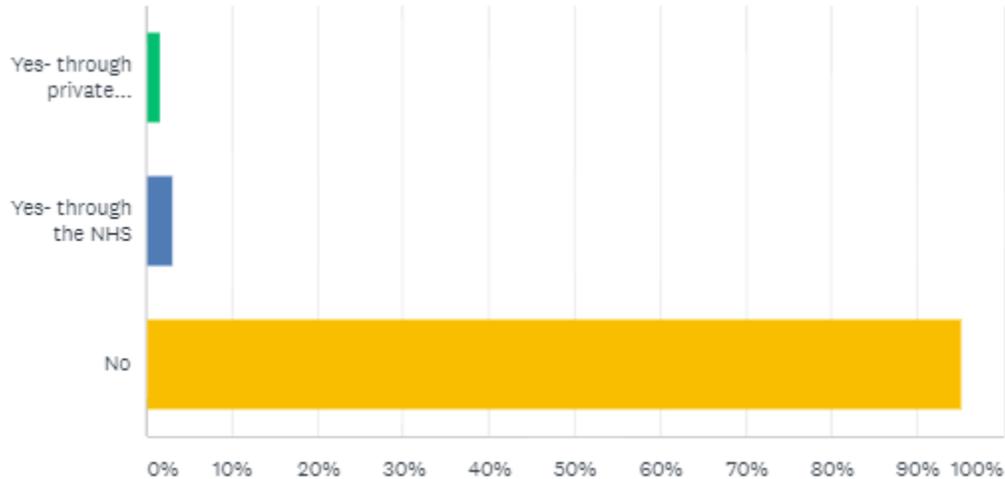
'The GIC waiting list is so long that it drives trans people to suicide, and it needs reform. I lost a close friend because the waiting list was too long for them to handle.'

'my gp said she'd help me in regards to working with my private doctor, but then backed out. i had to pay a private gp lots of money u til i found a new gp who was willing to work with my private doctor, because of this my consumption of hormones was dramatically delayed, causing a lot of distress to myself and my mother'

'I would rather my surgery ordered in my hormones as they inject them. This service was available in my last GP.'

Fertility Treatment (63 responses)

Participants were asked, 'Have you ever accessed fertility treatment?' 95% (60) hadn't, 3% (2) had through the NHS, and 1 had through private healthcare.



Fertility Treatment – Prescriptions and Medicines (7 responses)

Participants were asked, 'Is there anything that you would like to share with us regarding prescriptions and medicines in relation to fertility treatment?' All but one of the responses left said 'no' or 'N/A', the one comment left was:

'shop around as prices vary greatly and only certain places will issue meds from an overseas fertility clinic script. You can also Fed Ex drugs fr clinics overseas'

Additional Comments (13 responses)

Participants were asked, 'Please use the space below to tell us any other experiences or views you would like to share about medicines and prescriptions'. There were 13 responses to this question which were too varied to be categorised by theme but included the following:

'Pharmacies and GPs tend to be nice, understanding, helpful and kind - Pyschiatric services in Brighton and Hove to get the initial prescription tend to be difficult, unpleasant and dismissive and judgemental of LGBT issues and people.'

'It may not be relevant, but I would like to share difficulties I, and other queer female friends of mine, have had in relation to the experiencing of having a cervical screening test. There still seems to be a huge lack of understanding of the different needs before, during and after a screening consultation that lesbian or bisexual women may have.'

'I learned via Assert Autism Support Group that people with ASC have lower tolerance to medicine side effects. ie do better with lower doses, and that fits my experience. I think that should have been

information that I gleaned from the GP, not information that I had to relay to medical practitioners myself.'

'I always struggled with the Pill when I was taking that, as it was prescribed for serious menstrual cramps and I wasn't having sex that could lead to pregnancy at the time. It was frustrating having to re-iterate that every time I saw the doctor to renew the prescription. I never had an issue collecting it from pharmacies though. It's worth noting I'm not so visibly queer, so my experiences will differ I imagine from those who are more easily identified as Other.'

'I'd like to have greater control over my hormones and mirror normal women's values as much as possible.'

'As a monogamous bisexual person I appear straight, which means I am not supported and feel as an outsider in the very community which I identify with.'

'This may not be within the scope of the survey. I recently went to the Dean Street Express STI clinic in London with a friend. Online booking, self-service swabs, and results text'd within 6 hours. By contrast, the standard turnaround time at Morley Street/Claude Nichol appears to be 2 weeks. This must be delaying treatment/medication when required, and impacting infection rates. Why such a difference in service, for what is (presumably?) the same laboratory test.'

'Wasn't warned about side-effects of meds.'

4. PREP/PEP SURVEY

This survey followed the same format as the previous survey, but limited the questions to just those on PrEP and PEP.

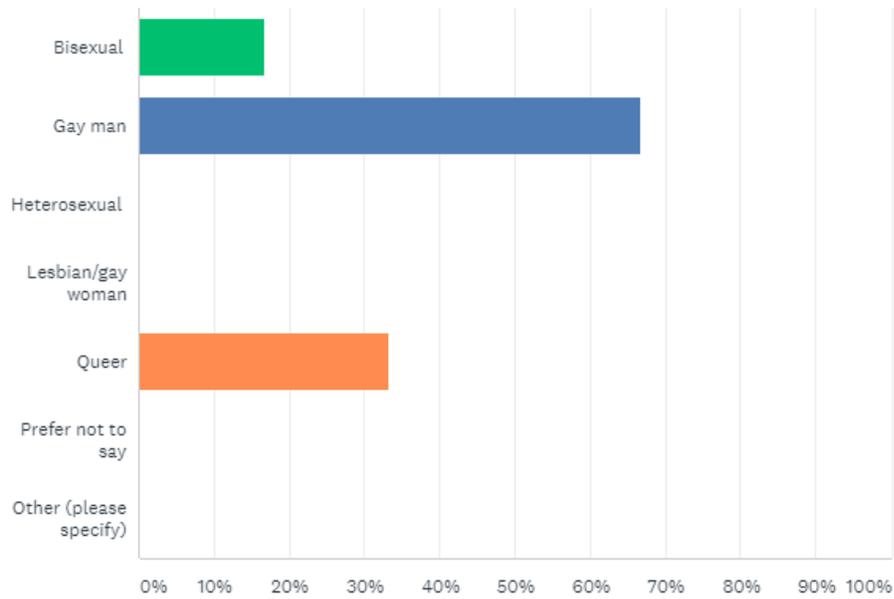
There were 8 responses to this survey, 7 of which were eligible after the initial screening question - *'lesbian, gay, bisexual, transgender and queer people who live, work, study or socialise in Brighton and Hove'*. At the end of the survey data was collected on participants' age, sexual orientation, gender identity, ethnicity and disability.

4.1 DEMOGRAPHICS

Sexual Orientation (6 responses)

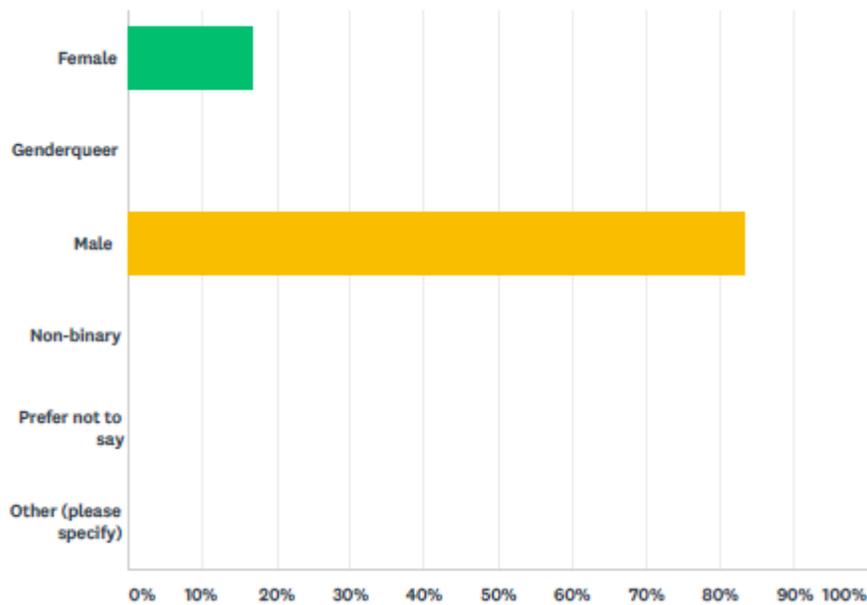
Participants were asked to select which of the orientations listed described them and were permitted to select more than one option.

67% (4) identified as a gay man, 33% (2) identified as queer and 1 as bisexual.



Gender Identity (6 responses)

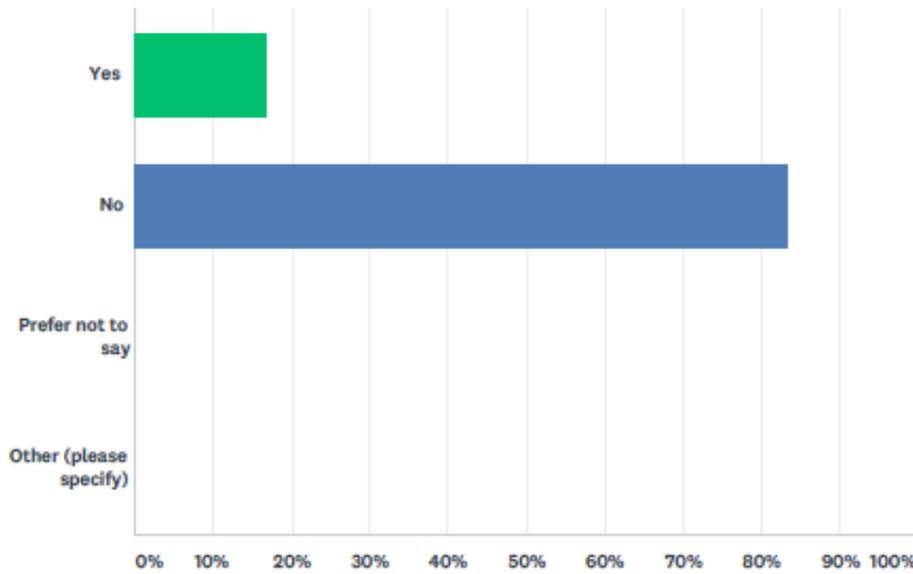
Participants were asked ‘How would you describe your gender identity?’, and were asked to select which of the gender identities from the following list best described them: male, female, genderqueer, non-binary, other, or prefer not to say. Respondents could select more than one option and were also presented with an open field in which to describe other gender identities which did not fit into those options.



83% (5) identified as male, and 1 identified as female.

Transgender Identity (6 responses)

Participants were asked: 'Do you identify as transgender or trans, or have you in the past?' 5 said 'no' and 1 said 'yes'.



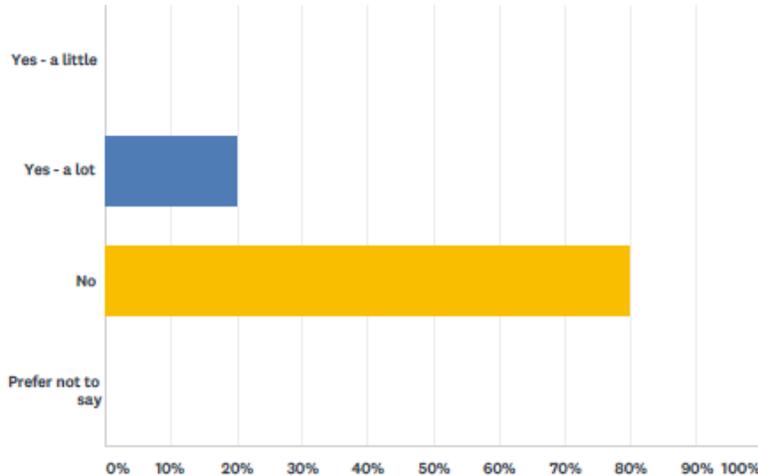
Age (6 responses)

Participants were asked, 'What was your age at your last birthday?' and asked to select their age from a range of banded options. The age distribution showed the highest proportion of respondents to be between the ages of 35-44 (3) followed by 45-54 (2) and 25-34 (1).

| ANSWER CHOICES | RESPONSES |
|-------------------|-----------|
| 18-24 | 0.00% 0 |
| 25-34 | 16.67% 1 |
| 35-44 | 50.00% 3 |
| 45-54 | 33.33% 2 |
| 55-64 | 0.00% 0 |
| 65-74 | 0.00% 0 |
| 75+ | 0.00% 0 |
| Prefer not to say | 0.00% 0 |
| TOTAL | 6 |

Disability (5 responses)

Participants were asked, 'Are your day to day activities limited due to being a disabled person?' 4 respondents answered 'no' and one answered 'yes- a lot'.



Disability: Type of Disability (2 responses)

Participants were then invited to state their type of impairment from a list of options, and could select as many as applied.

Two respondent's indicated that they had a mental health condition, and one respondent indicated they

| ANSWER CHOICES | RESPONSES | |
|-------------------------|-----------|---|
| Physical | 50.00% | 1 |
| Sensory | 50.00% | 1 |
| Learning | 0.00% | 0 |
| Mental Health | 100.00% | 2 |
| Long Standing Illness | 50.00% | 1 |
| Developmental Condition | 0.00% | 0 |
| Prefer not to say | 0.00% | 0 |
| Total Respondents: 2 | | |

also had a long standing illness, as well as physical and sensory disabilities.

Ethnicity (5 responses)

Respondents were asked to select from a list of terms to describe their ethnic background. 60% (3) indicated that they were of White British heritage. 1 person indicated that they were of 'Any other White background', and 1 person indicated that they were 'Asian or British Asian - Any other Asian background'.

The total number of respondents of BME heritage was 1.

Neighbourhoods (6 responses)

Respondents were asked to indicate the first four digits of their postcode. One person indicated that they lived out of Brighton & Hove.

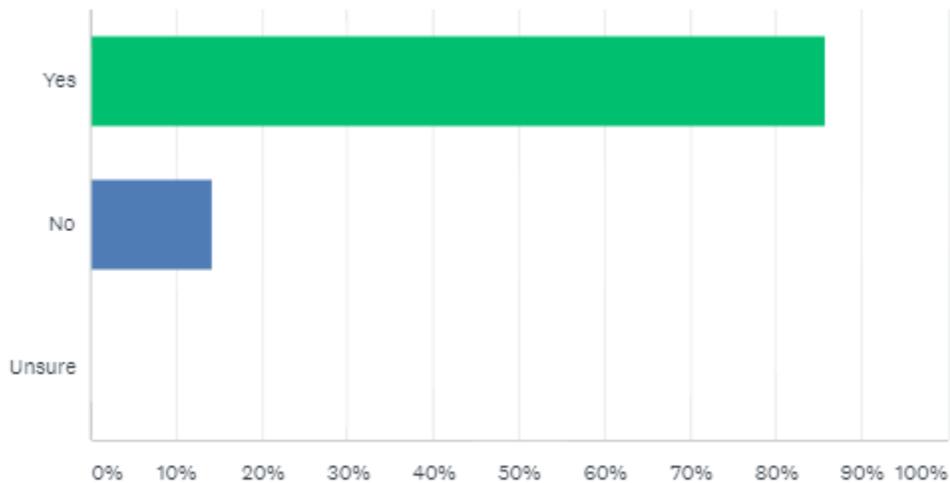
The responses were as follows:

| ANSWER CHOICES | RESPONSES |
|-------------------------------------|-----------|
| ▼ BN1 1 | 16.67% 1 |
| ▼ I live outside of Brighton & Hove | 16.67% 1 |
| ▼ BN1 3 | 16.67% 1 |
| ▼ BN3 4 | 16.67% 1 |
| ▼ BN2 4 | 16.67% 1 |
| ▼ BN2 1 | 16.67% 1 |

4.2. FINDINGS

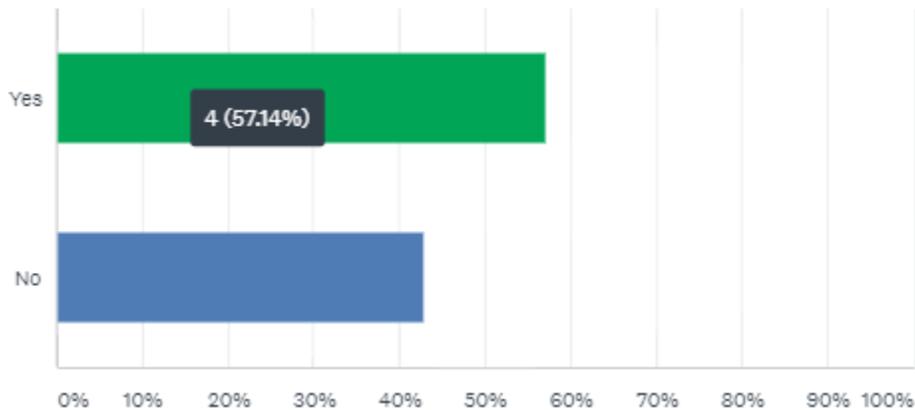
PrEP (7 responses)

Participants were asked 'Had you heard of PrEP before this consultation?' 6 had, and 1 hadn't. 100% of those who identified as male answered 'yes'.



PrEP (7 responses)

Participants were asked 'Do you currently take PrEP, or have you taken PrEP in the past?', 57% (4) respondents had and 43% (3) had not.



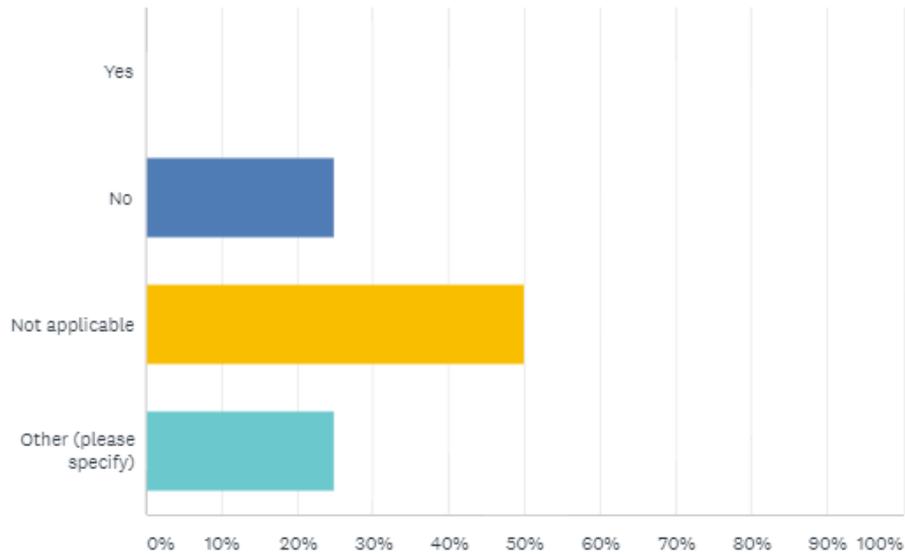
How you obtained PrEP (4 responses)

Participants were then asked 'How have you obtained PrEP' and asked to select from six options, including 'Other'. The responses were as follows.

| ANSWER CHOICES | RESPONSES | |
|--|-----------|----------|
| I am participating in a study which supplies me with PrEP (such as Proud) | 50.00% | 2 |
| I buy generic Truvada online | 25.00% | 1 |
| I get PEP from A&E departments and only use the Truvada | 25.00% | 1 |
| Through a paid-for prescription from an NHS GP or private health care | 0.00% | 0 |
| I buy/ share from an unregulated source (Such as a friend, partners or dealer) | 0.00% | 0 |
| Other (please specify) | 0.00% | 0 |
| TOTAL | | 4 |

PrEP: Support and Safety (4 responses)

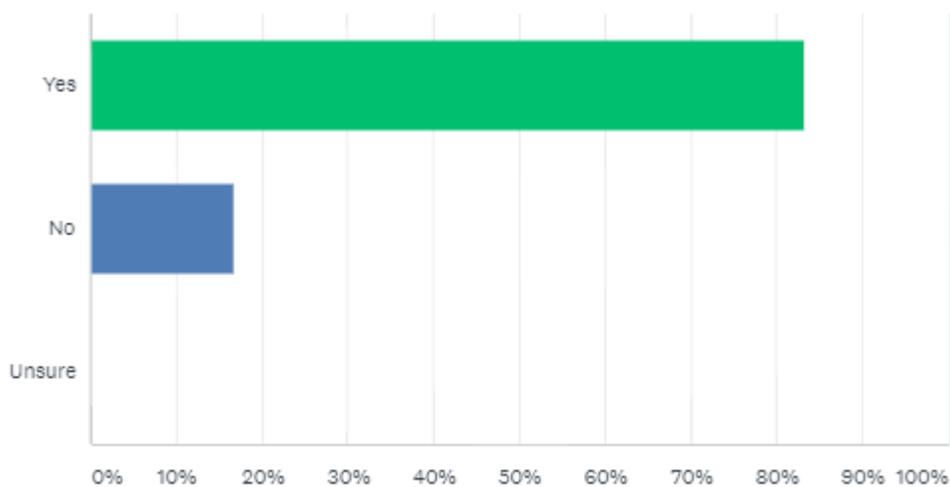
Participants were asked, 'If you are taking PrEP outside the NHS, do you receive support from local sexual health service SHAC about using it safely?'



One respondent answered 'no', this person indicated they obtained PrEP 'from A&E departments and only use the Truvada'. Two answered 'N/A', who both indicated that they were 'participating in a study which supplies me with PrEP' and one selected 'Other' and wrote 'Dean Street in london'. This is the same respondent who said they 'buy generic Truvada online'.

PEP: Awareness (6 responses)

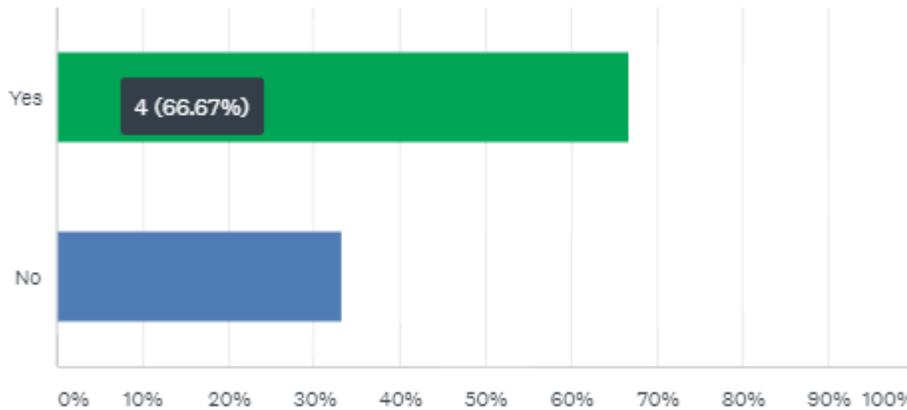
Participants were asked, 'Had you heard of PEP before this consultation?' 5 answered 'yes', 1 answered 'no'.



Of those who identify as a gay, bisexual or queer man 100% (5) had. The respondent who answered 'no' identified as female, cisgender, and bisexual/queer.

PEP (6 responses)

Participants were asked, 'Do you know where you can get PEP from?' 4 answered 'yes', two answered 'no'.



Of those who answered 'no', one was female, cisgender and bisexual/queer, and the other a cisgender, gay man.

PEP Effectiveness (6 responses)

Participants were asked, 'Did you know that PEP is only effective if taken within 72 hours after exposure to HIV?' 5 answered 'yes', 1 answered 'no'. Again 100% of gay, bisexual or queer men answered 'yes'.

Have you taken PEP (5 responses)

Participants were asked, 'Have you ever taken PEP?' 2 answered 'yes' and 3 answered 'no'.

Of the two who answered 'yes' they were asked to comment on their experiences of getting PEP.

One respondent wrote, 'The A&E staff were really unfriendly and I felt judged. Furthermore some of the doctors and nurses did not understand the urgency of taking PEP and I had to insist to get the medication as quickly as possible' (Male, Cisgender, Gay)

The other respondent said 'I got it from Claude Nichols after exposure' (Male, Transgender, Gay)

PEP/PrEP – Further comments (1 response)

Finally, participants were asked 'Is there anything else you would like to tell us regarding PEP or PrEP?'

There was one response left to this question which said 'PrEP is awesome - taking PEP would make me quite anxious' (Male, Cisgender, Gay)

5. ANALYSIS: KEY FINDINGS

5. 1. PREP AND PEP

PrEP – Awareness

In both the Medicines and Pharmacies survey and the PrEP and PEP specific survey there was a high level of awareness of PrEP from the LGBTQ community, in particular by gay, bisexual and queer men. In both surveys 100% of participants who identified as gay, bisexual or queer and male, answered ‘yes’ to the question ‘**Had you heard of PrEP before this consultation?**’ The majority of transgender respondents had also heard of PrEP, with 81% (17) answering ‘yes’. PrEP awareness was lowest amongst lesbian/gay, bisexual and queer cisgender women with 70% (14) saying they’d heard of PrEP before this consultation.

PEP – Awareness

Similarly, there was a high awareness of PEP with 100% of gay, bisexual or queer men having heard of PEP in both surveys. For those who identify as transgender 86% (18) answered ‘yes’ which is a slight increase in awareness to PrEP, and 65% (13) of lesbian/gay, bisexual and queer cisgender women.

In terms of where to obtain PEP, participants were asked ‘**Do you know where you can get PEP from?**’ The awareness of where to obtain PEP was far less with 53% (34) answering ‘yes’ and 46% (30) answering ‘no’. This figure increased to 74% amongst gay, bisexual and queer men.

Worryingly for those who identify as transgender just over half 52% (11) answered ‘yes’, with 48% (10) indicating that they did not know where to obtain PEP. This is concerning considering that globally transgender people are nearly double more likely to be living with HIV than the general population¹³. Again, amongst LGBQ women there was far less awareness, with only 35% (7) knowing where to obtain PEP from.

We also asked participants ‘**Did you know that PEP is only effective if taken within 72 hours after exposure to HIV?**’, amongst gay, bisexual, queer men almost all answered ‘yes’ (31) with only one respondent saying ‘no’. Again with trans respondents this figure dropped to 62% (14) answering ‘yes’ and 33% (7) answering ‘no’ with one person saying they were ‘unsure’. Again, for LGBQ women only 35% (7) answered ‘yes’, with 60% (12) answering ‘no’ and one person who was ‘unsure’.

PrEP – Access

The majority of respondents surveyed had not taken PrEP, with only 1 respondent from our initial survey indicating they had taken PrEP. In our PrEP and PEP survey there were 4 respondents who said they had, giving us a sample size of 5.

In terms of access to PrEP due to the limited sample size it was difficult to draw any conclusions from this data. Of the five that had taken PrEP two respondents checked ‘I get PEP from A&E departments

¹³ UNAIDS (2016) [‘Prevention Gap Report’](#)

and only use the Truvada', one respondent said 'I buy generic Truvada online', and another two respondents said 'I am participating in a study which supplies me with PrEP (such as ProuD)'.

It is perhaps not surprising that the numbers are low considering the overall response rate to the survey and that PrEP is not currently available on the NHS. A recent national survey¹⁴ however gives us some useful data on PrEP both nationally and locally. This survey which was conducted by PrEP advocacy sites iwantPrEPnow and PrEPster, with assistance from Public Health England, ran for ten days in July 2017 and had 766 responses. It was limited to those who were currently, or had at some point, taken PrEP, and were living in England.

The survey found that the vast majority (86%) of people using PrEP are currently buying it online. The minority who were not sourcing PrEP online were getting it via repeated post-exposure prophylaxis (PEP) prescriptions (10%), friends (8%), via a private doctors' prescription (3%) or from an informal contact (2%).

When asked where the survey respondents would want to get their PrEP from Brighton was the third most popular location after London and Greater Manchester. Considering the size of Brighton in comparison to these two cities this shows a very high demand for PrEP in Brighton, and the South East in particular which was the second highest geographical area after London.

PEP - Access

Similarly the majority of respondents had not taken PEP with only one respondent from the Medicines and Pharmacies survey answering 'yes', and two from the PrEP/PEP survey.

One respondent wrote '*work related injury from high risk patient which required me to take a course of PEP*'. Another said '*I got it from Claude Nichols after exposure*'.

The other comment left from the third person who said they'd taken PEP and was more around their experience. They wrote '*The A&E staff were really unfriendly and I felt judged. Furthermore some of the doctors and nurses did not understand the urgency of taking PEP and I had to insist to get the medication as quickly as possible*'. This is a concerning comment which echoes the LGBT HIP research into Urgent Care¹⁵ in 2013 which found that a number of gay and bisexual men experienced challenges in accessing PEP including a lack of timeliness and disrespectful treatment.

PrEP – Support

In response to the question '***If you are taking PrEP outside the NHS, do you receive support from local sexual health service SHAC about using it safely?***' one person answered 'yes', one answered 'no', and one 'other'. Of the person who replied 'Other' they said they were receiving support from Dean Street clinic in London. This was the same respondent who said they were buying generic Truvada online. For

¹⁴ Aidsmap (2017) <http://www.aidsmap.com/PrEP-demand-in-England-is-rapidly-accelerating-and-most-will-want-to-join-the-trial/page/3162707/>

¹⁵ LGBT HIP, Urgent Care Report (2013) <http://www.switchboard.org.uk/wp-content/uploads/2013/09/LGBT-HIP-Urgent-Care-Report-Final-Draft.pdf>

the person who answered 'no', they indicated that they obtained PrEP through A&E departments and only use the Truvada.

Again due to the small sample size it is difficult to draw any conclusions as to the support received by people taking PrEP outside the NHS. Anecdotally, Terence Higgins Trust Brighton said they have seen people at their clinic who're buying PrEP online but aren't being checked regularly by a clinic. It would be reasonable to suggest that as we know nationally the majority of people are buying PrEP online that there are also many people who are not receiving any support.

PrEP and PEP – Additional Comments

The last question to this section asked ***'Is there anything else you would like to tell us regarding PEP or PrEP?'*** There were seven responses to this question, one in particular which stood out. They wrote; *'The only people I know who have been informed by the pharmacy about PEP and PrEP have been cisgender gay men.'* (Respondent identified as bisexual, non-binary). This comment again echoes some of the national research conducted by CliniQ¹⁶ which suggests trans communities do not feel that the information on PrEP represents them.

5.2. TRANS HEALTHCARE

Hormones

Of those who identified as trans, non-binary or gender variant 70% (16) indicated that they had used hormones/blockers. Just over half of those 56% (9) said they had obtained hormones prior to their first appointment with a gender identity clinic, and 44% (7) hadn't. When asked how they obtained the hormones 2 people indicated they had bought them over the internet, and 2 people had bought them from an unregulated source (such as a friend or dealer). Due to the limited sample size these numbers are quite small, however it is worrying that 4 out of 9 are self-medicating hormone treatment. Usually people self-medicate as a last resort due to experiencing long waiting times or difficulty obtaining hormones. Considering that waiting times for an appointment at a gender identity clinic (GIC) are about nine months on average¹⁷, and one in six wait more than a year; many people will have to wait between 12-18 months before they are even prescribed hormones. Therefore it is not surprising that people choose to self-medicate, despite the health risks. It is also unsurprising that many people are turning to private consultants (3) and private healthcare (1) to obtain hormones as this dramatically speeds up the process. However for those who are unable to afford this they are faced with the option of a year or more wait, or self-medicating and the potential health risks associated with that.

It is also concerning that no one indicated they had been prescribed a 'bridging' prescription from their NHS GP. This is where a GP may decide that the risk of harm to the patient by self-medicating is greater than the risk of initiating hormone therapy before being assessed by a specialist. In The Parliamentary

¹⁶ cliniQ (2015) ['Report on Public Involvement meetings with trans service users from cliniQ, in the draft stages of the World Health Organisation's PrEP Implementation Guidelines'](#)

¹⁷ The Guardian (2016) <https://www.theguardian.com/society/2016/jul/10/transgender-clinic-waiting-times-patient-numbers-soar-gender-identity-services>

Report into Trans Equality (2013) a key issue which was highlighted was GPs lack of knowledge with regards to the Trans Care Pathway, and their role in prescribing 'bridging' hormones.

Hormones: Support

For those who are taking/had taken hormones outside of the NHS, 40% (6) said they had received support and tests from their GP about using it safely, 33% (5) hadn't taken hormones outside of the NHS and 27% (4) said they had not received support. Two out of the four indicated previously that they obtained hormones from an unregulated source (such as a friend or dealer).

Participants were also asked **'If you use hormones/ blockers (from any source), or have done in**

the past, does your GP monitor your hormone levels, offering you guidance or adjusting your doses accordingly? Worryingly only 50% (8) of those taking hormones/blockers answered 'yes', with the other 50% answering 'no'. The NHS Specialist Services Circular (2014) states that GPs are responsible for providing patient safety monitoring procedures and basic physical examinations, however it is clear that there is not consistency of care across the board.

Trans Healthcare: Additional Comments

The final question to this section asked **'Is there anything else you would like to tell us regarding trans-related medicines or prescriptions?'** There were 12 responses to this question which could be broadly categorised into two themes; one on long term support and care pathways for trans people, and one around staff and a lack of understanding from GPs and pharmacists.

5.3. SELF-MEDICATION

Participants were asked, **'Have you ever obtained prescription drugs outside of the NHS or private healthcare?'** 29% (19) said 'yes' and 71% (46) said 'no'.

For those who responded 'yes', 14 left comments, which can be categorised into the following: mental health medications (anti-depressants/anti-anxiety) (7), sleeping medicines/tablets (6), and hormones (3). The most frequently mentioned drug was Valium (5).

It is worrying that over a quarter of respondents are taking non-prescription drugs, especially as the vast majority are medicines which can be obtained through your GP. This suggests that there are barriers to obtaining prescriptions which should be investigated in more detail. This could be due to stigma, and patients not feeling comfortable talking to their GP (in particular as the most common medications were for mental health difficulties), a negative past experience with a GP, a distrust of GPs and/or pharmacists, not having a permanent/fixed address and being unable to register with a doctors surgery or an unwillingness to prescribe medication by GPs.

5.4. CHALLENGES TO ACCESSING SERVICES OR ADVICE AS AN LGBTQ PERSON

Whilst it's reassuring that only a small number of people (6) said they had experienced challenges to accessing services or advice as an LGBTQ person, this does suggest that there is still more work to be done around staff training and a lack of understanding when it comes to LGBTQ people and their health

needs. There was also a disparity identified between different groups of the LGBTQ community and their experiences, for instance many of those who commented on their negative experiences were transgender and/or bisexual. Typically these are groups of the LGBTQ community where there is less awareness and understanding generally, and this mirrors both national and local research which shows transgender and bisexual people are less satisfied with their GP than the rest of the LGBTQ community. In national research conducted by Stonewall on bisexual people's health they found that 51% of bisexual women have had negative experiences of healthcare in the past year¹⁸, and in the Brighton & Hove Trans Needs Assessment¹⁹ they found only 65% of trans patients were satisfied with their GP as opposed to 89% of the general population.

Some of the comments left when asked ***'Have you ever experienced challenges as an LGBTQ person accessing services or advice from a pharmacy?'*** included:

'People asking if I was 'heterosexual' to ask if I had had sex with a person with a penis, people referring to me as 'female' when talking about menstruation' (Non-Binary, Bisexual)

'having been to a sex clinic they repeated questionnaire from beginning once I disclosed I was bi. that was unnecessary and cumbersome.' (Female/Non-Binary, Bisexual)

'Being misgendered' (Genderqueer, Queer)

Looking at the open text comments left across the survey, there are other examples which display a lack of understanding from healthcare staff, and a lack of competent care in relation to the patients LGBTQ identity; again with the majority of the negative experiences coming from transgender and non-binary people, and queer and/or bisexual people.

'I always struggled with the Pill when I was taking that, as it was prescribed for serious menstrual cramps and I wasn't having sex that could lead to pregnancy at the time. It was frustrating having to re-iterate that every time I saw the doctor to renew the prescription.' (Female, Cisgender, Bisexual/Queer)

'some pharmacies are questioning why people have cross-sex hormone prescriptions others are overtly transphobic' (Male, Transgender, Bisexual)

'I have both received support & advice, and NOT received support & advice from my GP - different GPs and practices, some have been willing to help with blood tests etc and some have been extremely unhelpful. I've also had many GPs at different practices refuse to issue NHS prescriptions under a shared care agreement with a private doctor (and often be very rude or dismissive) before my current GP agreed to take over my prescription.' (Non-Binary)

'I would like to share difficulties I, and other queer female friends of mine, have had in relation to the experiencing of having a cervical screening test. There still seems to be a huge lack of understanding of the different needs before, during and after a screening consultation that lesbian or bisexual women may have.' (Female, Cisgender, Bisexual)

¹⁸ Stonewall, Bisexuality: Stonewall Health Briefing (2012)

http://www.stonewall.org.uk/sites/default/files/Bisexuality_Stonewall_Health_Briefing_2012_.pdf

¹⁹ Brighton & Hove City Council (2015) '[Trans Needs Assessment](#)'

‘There should be more follow up once you've been discharged from the gender clinic. Medicines change over time and the ones you take need reviewing from time to time.’ (Female, Transgender, Bisexual/Queer)

‘I would like to see more information for trans women on the effects of taking Decapeptyl (possibly other anti androgens but this is the only one I have experience of). The advice and info I received from the NHS did not adequately describe how this drug affected my emotional well being and I did not feel properly prepared.’ (Female, Transgender)

‘my gp said she'd help me in regards to working with my private doctor, but then backed out. i had to pay a private gp lots of money u til i found a new gp who was willing to work with my private doctor, because of this my consumption of hormones was dramatically delayed, causing a lot of distress to myself and my mother’ (Male/Non-Binary, Transgender, Queer/Gay Man)

‘The A&E staff were really unfriendly and I felt judged. Furthermore some of the doctors and nurses did not understand the urgency of taking PEP and I had to insist to get the medication as quickly as possible’ (Male, Cisgender, Gay)

6. CONCLUSIONS

PrEP and PEP

It is positive that there is generally a very high awareness of PrEP and PEP from the LGBTQ community, and in particular by gay, bisexual and queer men where 100% of those surveyed had heard of PrEP and PEP. However, there is more work to be done on ensuring that the work done to promote PrEP and PEP is representative of the entire LGBTQ community – and specifically targeting transgender people where the data shows there's less awareness, but a higher likelihood of HIV²⁰. In particular, more work needs to be done to ensure people know where to obtain PEP, and its effectiveness (i.e. only 72 hours after exposure). Furthermore, we should not forget that LGBTQ women are also at risk of HIV, in particular those who are trans, sex workers, IV drug users, or subject to sexual violence.

Trans Healthcare

Access to hormones for trans, non-binary and gender variant people was highlighted as a particular concern. With just over half (56%) of respondents obtaining hormones prior to their first appointment at a gender identity clinic, and 4 out of 9 choosing to self-medicate by buying hormones online or through a unregulated source. This is most likely due to long waiting times, and the damaging effect this has on someone's mental health. What was most concerning about this was that no one who filled out the survey had been prescribed 'bridging' hormones by their GP. This is an area that needs further research and consultation with GPs and health professionals to investigate what the barriers are to prescribing bridging hormones.

In addition, the support received by trans patients from their GPs was not consistent with only 50% of those taking hormones/blockers having their hormones levels monitored and GPs offering guidance and

²⁰ UNAIDS (2016) ['Prevention Gap Report'](#)

adjusting doses accordingly. Again this is something which needs to be looked into further as many of the open text comments left from trans people talked about a lack of long term care and support after being discharged from the GIC. As this is within the remit of what GPs are responsible for it could be that further training is needed for GPs to best support trans patients.

LGBTQ Awareness & Understanding

Overall it's positive that the number of people who said they'd experienced challenges accessing services and advice as an LGBTQ person was low. However, whilst there were only few instances that displayed outright LGBTQ-phobia, there were several comments left which displayed a lack of understanding when it comes to LGBTQ people's health needs, in particular by transgender and bisexual people. There appears to be a disparity in the satisfaction of transgender and/or bisexual people, who made up the majority of the negative experiences that were left in the open text comments. This suggests that work has been done to improve healthcare staff's understanding of gay and lesbian people – but that more work needs to be done on the needs of transgender and bisexual people – who tend to be the most marginalised groups within the LGBTQ community.

7. RECOMMENDATIONS

These recommendations have been developed out of the findings of the online survey. It is hoped that the following recommendations may act as a guide for the CCG:

1. Further consultation with GPs and health professionals on trans related healthcare - in particular to investigate what the barriers are to prescribing 'bridging' hormones, and to providing long term care for trans patients such as monitoring hormones
2. LGBTQ awareness training should be undertaken by all GPs and healthcare staff by 2020, with a particular focus on the needs of transgender, non-binary and bisexual people.
3. A refreshed PEP campaign should be undertaken, with a focus on where you can obtain PEP, and it's effectiveness
4. An awareness raising campaign on PrEP and PEP – in particular targeting the trans community and ensuring they're represented and consulted in any work on this going forward
5. Lobby NHS England to increase the number of people in Brighton who can participate in the IMPACT PrEP trial due to high demand
6. Evidence from this survey should be used to support discussions around the need for a gender identity clinic in Brighton and Hove, in particular highlighting the long waiting times and number of people self-medicating

7. The Inclusion Award to be developed as a mechanism for measuring quality and for promoting best practice when working with LGBTQ people and in providing an inclusive experience.
8. Further consultation and engagement work to be undertaken with the trans community in partnership with Clinic T and Clare Project to identify what changes people would like to see in terms of monitoring and self-administering hormones. This should include a joint focus group between trans community representatives and local doctors/pharmacists.
9. Further research to be undertaken on self-medicating to better understand the barriers. Possibility of collaboration with MindOut and destigmatising disclosure of help for mental health difficulties.
10. Further research to be commissioned around access to fertility treatment for LGBTQ people.

Key Contacts

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