The experiences of HIV positive patients when accessing health and social care services in Calderdale and Kirklees.

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Why are we focussing on HIV?

Like other patients, people living with HIV have the right to confidentiality and dignity when accessing healthcare services. Discrimination against people with HIV is unlawful in the UK. There are a number of ways people with HIV are protected from discrimination in UK law.

The Equality Act 2010, which now incorporates the protections of the Disability Discrimination Act (DDA) 2005, defines everyone diagnosed with HIV as disabled and, therefore, entitles them to the same protection against discrimination.

Working in partnership with the Brunswick Centre and Healthwatch Calderdale we have become aware of a number of patients who report feeling that they have been discriminated against, and treated unfairly when accessing Primary and Secondary healthcare services (e.g., Hospital in and out patient appointments, GP and dental appointments) due to their HIV status.

What did we do to investigate?

- We held a discussion group with HIV positive patients at the Brunswick Centre, who shared their experiences when using health and social care services.
- We sent a Freedom of Information (FOI) to the Calderdale and Huddersfield NHS Trust and Mid Yorkshire Hospital Trust requesting that they send through their policies and procedures for providing health care to people who are HIV positive.
- We created a survey to understand the experiences of HIV positive patients living in Calderdale and Kirklees when accessing health and social care services. The link to this survey was made available on the Brunswick Centre website and Healthwatch Kirklees website, and hard copies of the survey were available at the Brunswick Centre.
What did we find?

The following issues were identified:

1. Medical staff

1.1 Attitude of health professionals

Judgemental attitudes and inappropriate questioning about how HIV was acquired by patients.

“The GUM clinic are good. I have had negative experiences with the younger doctors as they don’t seem to understand our needs. The old GPs however are worse as they still assume that it’s our fault for getting HIV.”

(HIV positive patient)

“…the trainee doctor was very nosy about how I got HIV, and said the words “HIV you must be gay”

(HIV positive patient response via Survey Monkey)

“When I had a sprained ankle, I was asked about any medication that I take, and the doctor at infirmary wrote on my notes that "patient with history of HIV"-- I didn’t like that.”

(HIV positive patient response via Survey Monkey)

“Locum GP - Told me my kidneys and liver were like a 60 year old man, I said it’s the medication I’m on- the reply was...“what medication?” , she hadn’t even read my notes, I take 21 tablets a day, which have altered my liver and kidney results.”

(HIV positive patient response via Survey Monkey)

1.2 Privacy and Dignity

Patients’ HIV status mentioned in wards and other public places in front of other patients.

“When I was first diagnosed in March 2004, it was broadcast by the doctor on his ward rounds to the whole ward. I was mortified.”

(HIV positive patient response via Survey Monkey)
“I have heard bad comments discussed about HIV patients soon after they have left the care service. Some health carers think HIV can be passed on in cups and chairs.”

2. Drugs

2.1 Drug interactions

Doctors (excluding Genito-Urinary Medicine doctors) not checking for possible interactions with anti-retroviral medication before prescribing other medication with potentially dangerous consequences.

“I have to get a second opinion when I’m given new drugs, doctors are not checking how they interact with HIV drugs. This is negligent and dangerous. It’s placing the responsibility on the patient.”

(HIV positive patient)

“I was given statins, which were not supposed to be taken with my HIV medication. It should not be the responsibility of the patient to have to get their drugs checked”

(HIV positive patient)

“I was provided with a medication which might suppress the effects of my HIV medication, therefore during further discussions between the doctors it was decided that I cannot take that particular tablet with my HIV tablets... doctors need to cross-check each medication prescribed to a HIV patient, to be on the safe side.”

(HIV positive patient)

“I’ve taken 23 different HIV drugs and now on 7 pills for side effects of old drugs.”

(HIV positive patient)

2.2 Self medication

Anti-retroviral medication not given at the correct times when in-patient at hospital and refusal to do this even when asked. However, some patients were allowed to self-medicate and some weren’t.

“When I was an in-patient I was told that I could not self-medicate, but the nurses were giving medication at incorrect times. Recently when I went to hospital, I was allowed but it’s not consistent”

(HIV positive patient)
“On the whole, treatment is much better than it was. On admission to hospital staff are still reluctant to let you self-medicate. (This is very different important with HIV meds). As the time you need to take them off often doesn’t fit with a drug round.”

(HIV positive patient)

2.3 Routine HIV testing

People not being tested for HIV despite having signs and symptoms of HIV due to value judgements by doctors about their situation based on their outward appearance. (e.g., a white British man in a heterosexual relationship). Patients felt that testing should be routine for all patients to normalise this and reduce undiagnosed infection.

“I was dying in hospital, given two weeks to live, the health advisor talked me out of having the test twice saying "you’ll never get a mortgage or travel insurance", I had the test eventually and I have got a mortgage and have health insurance, so the health advisor was wrong on both, and I could have started treatment sooner."

(HIV positive patient)

“A positive result can be life-changing. However, normalising HIV testing to make available to everyone is essential.”

(HIV positive patient)

“If everyone was tested it would remove all of the stigma associated with HIV/AIDS + treatment can start ASAP..!!”

(HIV positive patient)

“There are still many people who are unaware of their positive status & are continuing to practice unsafe sex due to their ignorance of this. If a routine check was introduced this would surely help to stem the spread of the virus & ensure early treatment.”

(HIV positive patient)

“this would hopefully reduce the stigma attached to HIV.” (on routine HIV testing)

(HIV positive patient)
3. Dignity and discrimination

3.1 Unnecessary Delays

Being put at the end of the list for medical procedures, e.g., tooth extraction, dental surgery, and endoscopy. This causes patients problems such as:

- Patients have told us that they are often left waiting indefinitely for their turn which means they are unable to eat at the right time which can impact their medication.
- Not knowing when they will be seen means that patients are often having to take more time off work than needed.
- Not knowing how much parking time they will require. Also the longer they wait the more they have to pay in parking charges.
- Patients reported feelings of embarrassment, frustration and anger at being made to arrive at the same time as all the other patients but then being made to wait till the end, just because they are HIV patient.

“I have had bad experiences, whenever I attend my appointments at Calderdale conception unit I have to wait for longer periods, or be spoken to in way that I’m not a human being.”

(HIV positive patient response via Survey Monkey)

“I was made to wait till the end, because of my HIV status. The nurse told me that they would have to operate on me last as they will need to wash the operating table and theatre thoroughly after me. Surely this should happen after every patient not just those who are aware of their HIV status.”

(HIV positive patient response during a meeting)

“Left till the end of clinic for minor surgery told by a doctor, HIV you must be gay. Refused dental treatment.”

(HIV positive patient)

3.2 Gowning

- Inappropriate gowning and “covering up” for medical procedures.
- Patients also reported that they were being put in isolation and barrier nursed unnecessarily.
- “Danger of infection” notices on doors in hospital.

“I was put in a room with a notice outside it that said “Danger of Infection”.

(HIV positive patient)
“Most places will make HIV positive patients wait till last as they say that the equipment needs to be cleaned thoroughly. If they’re only cleaning because a person is aware of their HIV status, then they are putting others (patients who are not aware of their HIV status) at risk”

(HIV positive patient)

“Dentist when I had my implants, the doctors were in space suits. And treated me as if I was diseased. Whilst the nurse was dressed normally. This occasion was only to take a tooth out.”

(HIV positive patient)

“Just last week I had to disclose at the eye clinic (Halifax), no problems, just the doctor then put on gloves/ shouldn’t they always use gloves, not just when they find a HIV patient.”

(HIV positive patient)

3.4 Discrimination

Patients not feeling able to disclose their HIV status for fear of discrimination.

“As I have been discriminated against before and have seen it myself as a health professional, I do not tell any health professional unless it is directly relevant.”

(HIV positive patient)

“Moved to side ward to get me away from patients, my father can no longer give blood. Given plastic knives and forks on ward.”

(HIV positive patient)

“I have had to complain for discriminatory service in secondary care and occupational health due to my status in the past. On every occasion I have received an apology on the grounds that they did discriminate against me due to my HIV status.”

(HIV positive patient response via Survey Monkey)

“Being from Africa there is stigma attached with disease. So coming out or even testing was a challenge until my health deteriorated and was forced to visit a clinic.”

(HIV positive patient response via Survey Monkey)
4. Policies and Training

4.1 The Mid Yorkshire Hospitals NHS Trust

The Trust follows and adheres to the British HIV Association “Standards of care for people living with HIV, 2013”. Refer to: Standard 3 in this instance. The Mid Yorks hospitals does not have a policy of placing HIV positive patients to the end of the list for surgical and anaesthetic procedures on a particular day.

4.2 Calderdale and Huddersfield NHS Foundation Trust

The policy CHFT have for HIV patients is in relation to operating theatres process for patients with a blood borne virus, which states that patients known as “infection risk” should be operated on at the end of the list. The trust does not have a policy for outpatient clinics or other healthcare appointments.

“There needs to be a policy for HIV positive patients that states how we should be treated and what to expect”

(HIV positive patient)

“We would be happy to speak to doctors, on how to work better with HIV positive patients. If we could help in training them to be better, then that would be a win-win situation for all”

(HIV positive patient)

“There appears there is still stigma towards being diagnosed in certain circles or places. Maybe people still need a lot of education on how HIV is transmitted and the after care and treatments when diagnosed.”

(HIV patient response via Survey Monkey)
5. What do HIV positive patients want?

Drugs
- Patients want doctors to check the medication they prescribe and how it will interact with anti-retroviral medication.
- To explain any side effects of new drugs that are prescribed.

Self-medication
- Patients should be allowed to self-medicate when they are staying in hospital. If this is not possible, then the hospital staff should ensure that anti-retroviral medication is given at the correct times.

HIV Routine Testing
- Not all patients who are HIV positive are aware of their status. Those who are unaware may still be engaging in unsafe sex, consequently placing other people at risk.
- Patients want HIV testing to become routine, as this can prevent unnecessary deaths through early diagnosis and treatment.
- HIV positive patients feel that routine testing would help remove the stigma associated with HIV.

Unnecessary Delays
- If patients are to be placed at the end of the list, then they should be given the last appointment available rather than being made to wait the whole morning or afternoon. A set time will help patients to make any travel arrangements, book the correct time off work and plan their medication.

Gowning
- Patients staying over in hospital want to be treated with dignity and respect-therefore they do not want notices such as “Danger of Infection” to be placed outside their door.
- If double gowning is practiced then it should be applied for all patients not just those who declare that they are HIV positive. What about those patients who are not aware of their HIV status?

Hospital policies
- Patients want clear communication, transparent and fair hospital policies that address their concerns.
- Patients want to know why Calderdale and Huddersfield NHS Trust places HIV positive patients to the end of the list for procedures such as endoscopy and camera test etc.