



Tales

from the clinic

Personal accounts from
users and providers of
GUM services in England

10 things you probably didn't know about sexual health in the UK

1) In 1997, the Government removed HIV and sexual health from the list of national priorities. Since then, the number of new diagnoses of HIV and sexually transmitted infections (STIs) in the UK have risen dramatically. One in ten sexually active women are now believed to be infected with chlamydia, gonorrhoea rates have doubled and HIV numbers are at an all time high. We now have the worst levels of sexual health since records have been kept.

2) Genito-urinary Medicine (GUM) clinic waiting times are much longer than the proposed national target of 48 hours, with many patients waiting as long as six weeks for an appointment. An estimated one third of patients with symptomatic STIs continue to have sex while they wait.

3) Although the overall workload for GUM clinics has increased by more than 70 per cent since 1997, funding for those clinics over the same period has increased by less than a third. Despite this substantial increase in the number of HIV and STI diagnoses, the number of GUM clinics has not increased since 1997.

4) GUM clinics are reporting increases in the number and proportion of complicated STI cases. This is most likely due to the long wait people are facing when seeking treatment. Failure to treat STIs quickly can lead to serious and long term health problems. This can dramatically increase the cost, both to the individual's health and the public purse.

5) HIV is the fastest growing serious health condition in the UK. There are now an estimated 50,000 people living with HIV in the UK, a third of whom are unaware they have the virus. NHS HIV care costs are increasing by more than £50 million a year, with lifetime treatment costs for the 6,500 new cases diagnosed in 2002 expected to reach £1 billion.

6) Young people are more vulnerable to STIs. They generally have higher numbers of sexual partners, greater numbers of concurrent partners and change partners more often than older age groups. Young women are also more biologically susceptible to some STIs than older women.

7) Untreated chlamydia costs the NHS £50 million per year and is the cause of more than half of all cases of pelvic inflammatory disease. Chlamydia substantially increases the risk of ectopic pregnancy and infertility among those infected.

8) Only half of GUM clinics received their full share of a £5 million special allocation from the Department of Health at the end of 2003 after it had passed through PCTs. In January 2003, when the funding went to them directly from the Department of Health, nearly 90 per cent of clinics received the full amount.

9) Only one in eight GUM clinicians responding to a recent survey believe they have enough resources to manage their current workload and more than two thirds say their ability to provide services is getting worse.

10) A recent ICM poll found that 75 per cent of respondents agree that sexual health should be made an NHS priority again.

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Over the past few months, there have been many media reports of the rise in sexually transmitted infections across the UK and the growth of what the Parliamentary Health Select Committee called "a crisis" in sexual health and "a major public health issue".

Most of these reports have focussed on the statistics of sexual health: the enormous leaps in the numbers of people with gonorrhoea or chlamydia; the spiralling financial costs of rising levels of HIV; the length of waiting lists; the amount of special money allocated by the Government for improvement of GUM facilities that has failed to reach them due to Primary Care Trusts diverting it to other healthcare areas.

Little, if any, of the coverage has looked at the human aspects of the growing UK crisis in sexual health. These infections, and the services provided to diagnose and treat them, are not just about statistics. They are also about human issues: what it is like to attend these services, what it is like to provide them and how people actually feel about the overcrowding, the difficulties and the struggle to provide good services in poor premises and underfunded, often underdeveloped systems.

If we are to win the fight against the growing levels of sexual ill health across the UK, it will be important to understand the human as well as the statistical aspects of the situation. How can we encourage more people to come forward for testing and treatment? How can we make the patient experience the heart of modernised services? How can we provide choice as well as quality?

This publication gives the genuine stories of seven people who use or provide sexual health testing and treatment services within hospitals and in the community. I encourage you to read their experiences in their own words and use these to help us change the direction of the epidemic of sexual ill health in the UK.

These people are the human face of the UK's failure to tackle its poor sexual health. We must work together to ensure that the future is better and that both people in need and those providing care have the services, support and facilities they deserve.

Nick Partridge OBE
Chief Executive - Terrence Higgins Trust

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Perhaps most importantly, we would like to thank the staff and clinicians in the UK's GUM clinics who are doing an excellent job of providing services in the face of increasing pressures, many of whom have supported this endeavour from its outset.

The Consultant's Tale

The woman's legs were shaking uncontrollably as she lay back on the examination couch. The nurse and I exchanged puzzled glances. I began running possible diagnoses through my mind as I reviewed what I knew so far. It was 9.15 on a routine Friday morning at a GUM clinic in mid-January. The woman's legs were still shaking vigorously and uncontrollably – anxiety? She was fully alert, so she was not having seizures. Was it malaria? Septicaemia?

"Are you feeling okay?" I asked her, "Your legs seem to be shaking a lot".

"I'm okay, Doc."

"Has this been happening long?"

"No Doc, just this morning".

"What time did you get here?"

"Seven this morning – I was second in the queue outside".

It was still dark outside, very wet and cold – the winter equinox. She was wearing a knee length skirt, no tights. Images of shivering trekkers flooded into my mind, shivering helplessly in the altitude and cold in my previous year in Nepal.

"Are you feeling cold?" I asked.

"Yes, Doc".

"Well, you've got hypothermia and exposure" I explained. "I've never seen it in a sexual health clinic in England before," I said "but I've seen it in the Himalayas, where you might expect to see it. But you got hypothermia and exposure queuing for a sexual health check-up in the middle of London in the 21st century."

That was the moment I finally decided I could no longer insist on a walk-in policy in our clinic. For years, the pressure had been building. More and more people waited each morning outside the clinic door before it opened. Queues were getting bigger, starting earlier, snaking around the building, exposed to the elements. Members of the Trust Executive had noticed as they passed the queue in the morning on the way to their offices. More and more people were being turned away from the door as the morning quota filled quickly. There were longer waiting times inside the clinic as the staff worked through the patients who had got in. There was more frustration, shorter tempers, shouting and abuse from angry patients. More stress, more staff sickness, more strain all round; burn-out and madness.

None of that had been enough for me to feel that we should end the principle of a walk-in service. The long suffering London public, I felt, had no right to expect anything else. But exposure and hypothermia developing in a member of the queue made me realise that the current situation was dangerous. An uncomplaining woman with a sexual health problem had developed a life threatening complication while queuing up to get her sexual health needs seen to. It was not due to her condition, it was because of the system that was trying to help her. It was demand overwhelming resources; a situation completely out of control.

Two and a half years later and working conditions are ostensibly much better. There are no queues outside the clinic. People make appointments by phone. We give more telephone results, make fewer follow-up appointments, and have made other innovations to allow more patients to be seen with the limited resources available. But it's not enough.

The first two men I saw this morning presented with guilt; what we call "post one-off blow-job" symptoms. One night, or rather a few minutes, of casual, drunken fumbled sex in each case; not with each other, by the way. Both of them in regular relationships, both full of regrets. Then there was a young woman with gonorrhoea and another woman with two partners, unknown to each other. A string of people with pelvic pain, penile soreness; worried adolescents and a new couple wanting a check-up.

"I had real problems getting through on the phone, Doc. It's taken me weeks to get an appointment. I can't get through, or it's booked up," I'm told by one of the patients. But it's a familiar message.

Our new system means appointments must be booked by phone and we only book up to 48 hours ahead. We have a "triage" system to pick up the urgent problems that get to us, but no way of determining who gave up trying to get through. We don't know how many people decide to try elsewhere or go nowhere. Many sexual infections are asymptomatic, or the symptoms settle spontaneously. But the infections remain, perhaps causing more serious damage resulting in infertility, chronic pain, or further transmission to new partners. People with anxieties around sexual health may be the ones who give up trying to get through. Potentially avoidable minor problems may become deep seated, harder and more costly to treat.

We used to feel the pressure of the unmet needs of the public who were turned away from our doors – they passed it on to us directly. Now it's more hidden and less obvious, kept at bay by the phone system. Every now and then our phone queuing system breaks down, so that some patient caller, who has moved slowly up the queue to be the next to talk with the receptionist, is suddenly bounced back to the end of the queue – or even cut off.

The atmosphere for staff and patients actually inside the clinic is much better than it used to be; but we have placed a hidden barrier around our services. Most other clinics have done the same. We know that demand has not gone away, and nor have the infections and distress and suffering – indeed, they have increased. We are doing our best, but more resources are needed.

Schools are where the work of sexual health clinics should start. There needs to be age-appropriate listening, teaching and learning. All it requires is a bit of realism, courage and commitment from policy makers. Sexual health doesn't start at the phone line or at the door of the clinic, or in the raging hormonal and social chaos of adolescence – it must start long before then. Otherwise we will only ever be wondering how to meet the "unmeetable" demands with limited resources.

Supporting data

"Between 1991 and 2001, new episodes seen at GUM clinics in England, Wales and Northern Ireland rose from 669,291 to 1,332,910. Clinic workload increased by 155% and diagnoses by 61%. Between 2000 and 2001 alone the figures for episodes at clinics rose by over 10%."

Health Select Committee report, 2003

The Royal College of Physicians recommends a ratio of one consultant per 119,000 population. This would require an extra 173 consultants (96% increase) for England. There are currently 274 consultants in England.

- *GUM consultants in South Buckinghamshire reported the ratio in their area was 1:300,000*
- *those in North Cheshire reported the ratio in their area was 1:325,000*
- *those in the North West reported the ratio in their area was 1:400,000*

Health Select Committee report, 2003

Only one in eight GUM clinicians responding to a recent survey believe they have enough resources to manage their current workload and more than two thirds say their ability to provide services is getting worse.

THT/BHIVA survey, 2003

The Man Who Couldn't Wait's Tale

In September 2002, I contracted an STI. I began to suspect I might have something, but a trip to a GU clinic routinely takes three to four hours which really puts you off going for a check-up unless you're sure there's a problem. So it wasn't until the sore throat was really bad that I went to get it looked at. By that time I'd had sex with several other people.

I went to St. Bart's GU walk-in clinic, one of the few places in London you don't need an appointment. I got there in good time to find the doors locked and a sign saying "Due to too many patients, we have closed the clinic early". This, I now know, is not unusual. Trouble was, the next day I had to fly out to Eastern Europe for 10 days, so I couldn't just come back the next day. A few days into the trip the sore throat was unbearable and I took about five day's worth of an antibiotic I had with me. It was Erythromycin, which is used for some STIs. It seemed like a good idea at the time and appeared to solve the problem - if only I'd known.

Two weeks later and back in Britain, I suddenly got ill. The tendons in my knees swelled and my heart was in trouble - chest pains, breathlessness, etc. Doctors kept telling me they didn't think there was anything wrong with me, and I was more or less told I was suffering from anxiety. They prescribed anti-depressants, but I didn't think that was the problem.

A few months later I developed stiffness in my joints. I was told I was too young for arthritis but that they still weren't sure what the cause might be. Fortunately, by then I'd worked out what was going on by doing a bit of research on the Internet: I was having a reaction to the earlier STI.

After insisting on a rheumatologist appointment I was diagnosed with 'reactive arthritis', also known as "Reiters syndrome". This was a full 10 months after first being seen by doctors. Reiters syndrome is untreatable and 18 months on I still have it - and may well always have it. It's a complication of gonorrhoea or chlamydia. My initial raging sore throat pointed to me having had gonorrhoea. I'm left with arthritis, eye problems, heart problems and inflammation affecting my bowel, spine, urethra and tendons.

I'd had gonorrhoea half a dozen times in the past but never any complications. The one time it wasn't diagnosed and treated properly I get Reiters syndrome. No-one will ever convince me that is a coincidence. If I'd been seen by that clinic when I went to them I doubt my health would've been ruined like it has. Incidentally my local GU had a five-week waiting time to be seen - but last time I checked it was even worse - they'd closed their books to new patients.

It'd be interesting to work out the cost to the NHS of what's happened - endless GP consultations, two trips to A&E, a rheumatologist consultation, several cardiologist visits, x-rays, heart tests, eye tests ...

My understanding is that reactive arthritis happens in one out of every 100 cases of gonorrhoea and chlamydia. With the skyrocketing rates of STIs and the NHS GUM service totally ill-equipped I guess quite a lot of people are heading for what I've been through.

Supporting data

Waiting times for GUM clinics are longer than they should be: an estimated 28% of emergencies were not seen within 48 hours and 29% of symptomatic patients waited for more than two weeks for an appointment.

CMO Annual Report, 2003

Studies show that around 30% of individuals waiting to be seen continue to have sexual intercourse despite being symptomatic.

Dr Kevin Fenton, Health Protection Agency, 2003

GUM clinics are reporting increases in the number and proportion of complicated STI cases. This is most likely due to the long wait people are facing when seeking treatment. Failure to treat STIs quickly can lead to serious and long term health problems. This can dramatically increase the cost, both to the individual's health and the public purse.

Health Select Committee report, 2003

The Nurse's Tale

I began working in HIV and sexual health in 1985. At that time, I was based in a Portacabin hidden away in the farthest corner of the hospital. HIV had yet to be named, and we had little information about how it was passed on. I can still remember having heated arguments with ambulance drivers who arrived to collect patients dressed in protective outfits that would have left an astronaut green with envy!

HIV was eventually identified, but it would be some years before there was any treatment. By then, I was working with a hospice for people with HIV. It was a challenging time, when we were looking after people the same age or younger than ourselves who had a very poor prognosis. Without effective treatments, they knew they would die. When the first antiretroviral treatments came on the market, people were understandably very excited. But it would be some years before triple therapy, when people would really begin to benefit from treatment.

I moved to London – and out of the Portacabin – in the early 90's. The patient population was, by then, very different. In Scotland, our clients had been predominantly gay men and injecting drug users, but increasingly now it was heterosexuals from sub-Saharan Africa. It became apparent that although the patients may have had HIV, the virus was not top of their priorities.

Many had come from war torn areas and were trying to regain some stability in their lives. Others had been diagnosed in the UK and had left families back at home. For them there was a conflict between remaining in the UK, where they could get treatment, or returning home to their loved ones. To come to the clinic for the first time must have been, and still is, very daunting.

For most people, finding us is the first challenge. It seems that "keeping the clinic confidential" translates somehow into "locate the clinic in the most difficult to find place in the hospital". Once the clinic has been found, there is the challenge of trying to get an appointment. Over the past few years, clinics have become increasingly busy and, as a result, it is very difficult to get a same day appointment. For individuals who may not have English as a first language, it can be hard to understand the system. Many don't make their appointments on time, and many need extra support of one kind or another.

My role as HIV Nurse Practitioner began to expand to take into account these varied needs of clinic attendees. Engaging patients and encouraging them to use support services was a real challenge. Patients were reluctant to go to services because they were afraid of stigma and discrimination from within their own communities. It became apparent that we could not work in isolation and needed to link the clinic in with the African communities.

We began by offering workshops in the clinic, where patients could meet workers from support groups in a safe setting. From this, the voluntary groups suggested that the clinic run education events. They would supply the food, we would supply the speakers. These were very well received, and have been a monthly feature now for some years.

Then came the dreadful news. Due to modernisation, we would be temporarily moving – back into a Portacabin! This, like everything, brings its own unique challenges. Patients have to queue outside, as there is limited space in the reception area. This is not at all good for maintaining confidentiality, and I'm not sure if I would want to attend a clinic where I might be recognised by neighbours while I was waiting in a queue.

In the clinic, the walls are paper thin, so consultations have to be done in very low voices. I sometimes suspect that patients think that we talk quietly to save our voices. Portacabins, or "temporary buildings" as we have been asked to call them, tend to be hot in the summer, cold in the winter and when it rains, very wet. All we want is somewhere to see patients that is clean, comfortable and private. It shouldn't be too much to ask.

Looking back, what has really changed? Twenty years on, I am still working from a Portacabin! The number of patients has continued to rise. While there are now very effective treatments for HIV that can keep people well and working, changes in the NHS regulations mean that some of our patients will no longer be eligible for them. Recent amendments, originally meant to target so-called "treatment tourists", mean that patients who have been refused asylum will no longer be able to get any further NHS services, including antiretroviral therapy, unless they pay privately.

Most of our patients in this situation don't even have enough money to feed themselves, so it is extremely unlikely that they will be able to raise enough funds to pay for treatment. They will be living in the UK with HIV, but will only be able to get free short term emergency treatment when they are gravely ill – as they will be, over and over again, costing far more than the antiretroviral treatments that would keep them well and lower their infectiousness.

I really don't want to go back to 1985 when I lost so many people, both personally and professionally. Apart from the effect of this policy on individual and public health, it undermines recent initiatives to encourage people to have an HIV test, because people ask why they should test if they will not get treatment.

Looking over it all, I have found the last twenty years challenging, exasperating and very rewarding. I have had the privilege to work with some great colleagues, and to share in the lives of many of my patients. But I still don't like working in Portacabins, and I think our patients deserve better after all this time.

Supporting data

The total cost for carrying out necessary work to improve GUM facilities is estimated at £152-248 million

- 20% of clinics were located in Portacabins
- 80% of clinics need refurbishment and extensions

Specialist Societies for Genito-urinary Medicine to Health Select Committee, 2003

"[STIs] are preventable infections and it is a cause for considerable concern that we are still seeing increases in new diagnoses of STIs across the UK and unsafe sex is undoubtedly a main contributor to this".

Sir William Stewart, Chairman, Health Protection Agency, July 2004

"Unless sexual health is given higher priority within the health service we see no immediate prospects of widespread improvement"

Health Select Committee, 2003

"Ministers are ignoring the problem because they can. If a similar crisis were to strike cancer care, MPs' postbags would be bursting. But the enduring stigma of STIs mean that patients suffer in silence".

The Times, July 2004

The Long Term HIV Patient's Tale

I have been using GUM services at my local hospital's HIV clinics for the past five years. Over the last two, I have seen a deterioration in the level of services offered at the clinic that I attribute to the increased number of patients being seen. I have especially noticed the difference in the individual attention that was given when I first attended the HIV clinic in 1999 and the attention I get now.

When I began attending the HIV clinic, the environment at the clinic was very warm, and welcoming. I always looked forward to my next clinic appointment. Most of the front line staff – the receptionists, nurses and health advisers – knew my name. They were all very helpful and caring. They would offer me a cup of tea or water as I waited to see the consultant. They asked me how I had been, how I had been coping with my medication and about my general well being. If I missed an appointment, someone from the clinic could call me to make sure I was alright.

In a way, my HIV clinic was like my second home. I enjoyed the welcoming and caring environment. I had one consultant at the clinic that I saw every time I went. I was free to discuss my sexual health issues with my consultant without worries or fears because I had known him for more than three years.

The waiting time to see the consultant or nurse when I had an appointment was less than 10 minutes. Sometimes, I could ring up the clinic for a same day appointment if I was not feeling well. On two occasions, and I remember them well, I just walked into the clinic because I was not feeling well and wanted to sort out my medical concerns. I was welcomed and attended to almost immediately.

That welcoming and caring HIV clinic is now long gone. The general service in my clinic is deteriorating and individual attention at the clinic is not good enough, because of the large number of patients using the services. At my last appointment, I was surprised (and I must admit, a little bit hurt) that one of the health advisers who had known me for more than three years had even forgotten my name. When I reminded her, she told me that she was sorry, saying she now sees so many people she can't remember all of their names.

The clinic's reception area is always crowded, and I now find myself praying to finish as soon as possible so I can go home. The nurses and health advisers are usually very busy and have no time to discuss other social issues. Even if you wanted to discuss your issues, the reception is too crowded to allow any privacy. Furthermore, some of the staff are neither welcoming nor approachable, due to stress as a result of their workload.

If I miss my GUM appointment, I have to re-schedule, which can take up to six weeks. There are now some "walk-in clinic" days, which have been introduced to reduce waiting times. However, these clinics are usually so crowded that I have to wait an hour or two before being seen. In fact, most of the times I have gone to the walk-in service I have been unable to see the consultant because there has not been enough time for him to attend to everyone. It's better to wait for a scheduled appointment, especially if you are a student or in full-time paid employment, to avoid the inconvenience.

One of the biggest changes I've noticed is that I no longer know my consultant. Every time I go, I wind up being seen by a different consultant. As a result, I have to tell them my medical and social background and they have to refer to my notes to check my prognosis. This takes a lot longer since I have to go through my background and other medical history each time. Also, I sometimes feel I can't talk about developments in my health because I haven't established the necessary level of trust with the new consultant.

There are many ways in which GUM clinics can improve their services and at the same time accommodate the increasing number of patients without services deteriorating. Community HIV testing could be contracted to voluntary HIV organisations and other agencies to reduce workload at GUM clinics. The clinics themselves could be upgraded to provide a more pleasant environment and could be open in the evenings to better accommodate working people. Perhaps most importantly, patients could be included in the planning process to help develop solutions that work for them, not just the NHS.

In spite of it all, I still like my clinic. It has really helped me to cope with living with HIV. The staff at the clinic are wonderful and are doing their best to manage despite the decreasing financial resources and increasing patient numbers and workloads. I hope that something can be done soon. My HIV clinic is not very bad, but it's going to be very bad if things do not improve soon.

Supporting data

Although the overall workload for GUM clinics has increased by more than 70 per cent since 1997, funding for those clinics over the same period has increased by less than a third.

House of Commons written answers, 2004

In 2003, the Department of Health allocated £18 million to improve GUM clinic services. When the money went directly to the clinics, 86% of the clinics received the full amount. When the money was routed through Primary Care Trusts, however, increasing amounts of the allocation disappeared into other services deemed to be a higher priority. Only 35% of GUM clinics received their full share of the £5 million allocation in the December 2003 dispersal of money.

BHIVA conference, April 2004

"I have never seen the extraordinary intensity of patient numbers as witnessed in the last month or so. The Department feels like a war zone or Accident & Emergency; there is a queue of patients up to 40 deep most mornings"

Dr Sarah Gill, GUM physician at Paddington, to Health Select Committee, 2003

"Other sick people club together to lobby parliament, but no one wants to join a gonorrhoea action group".

The Times, July 2004

The Receptionist's Tale

Ive worked on the reception desk of the community HIV testing clinic at Lighthouse in West London since it opened early last year. It's a rewarding job because you feel like you're really able to make a difference, to help people cope a little better during what is often a really difficult time. I think everyone involved in the testing programme knows we're making a difference to the lives of the people we see, but it's also frustrating because it's obvious we're only able to see a fraction of the number of people who would like to be tested.

The clinic is run by the Chelsea and Westminster Healthcare NHS and Terrence Higgins Trust. It's one of only three NHS clinics in London that provides a one-hour testing service. A fast turn around is important because some people never come back for their test results at clinics that take a week or so to do the same thing. There's a whole list of reasons for why they don't come back – they're scared or too upset or they decide they don't want to know – but by being able to find out fast, they're more likely to follow through and to know whether or not they have HIV. It sounds like a simple way to solve the problem, and it is, if only there were more of us.

The testing clinic is part of a special new initiative, but it's pretty clear to me that it's not nearly enough to meet the demand that's out there. We need to help people get tested, but there's so many people that we're turning away; as many as we're able to see. We'd like to be able to do more, but we just don't have the resources.

Testing takes place on a Monday evening only, and we're limited in number as to how many tests can be carried out each session. The clinic is intended to be a walk-in service. It's conducted on a first come, first served basis. We don't take appointments. Although the clinic is open to everyone, its main aim is to attract members of London's African and Asian communities who are more likely to have undiagnosed HIV.

There's a real need for this type of testing. Some of the people we're seeing say they've been trying to get into the ordinary hospital clinics for weeks, but that there's just no room. It's a big problem; one that seems to be getting worse all the time. A third of the people infected with HIV in this country don't know it because they haven't been tested. And yet there aren't enough places for them to be tested. It's a vicious circle.

From the reactions of our clients, I know the benefits the clinic offers. The fact that a person can come in for a test and have the results within an hour and not have to wait a week has got to be the way forward.

The big problem we have to deal with is the number of tests that can be carried out in any one evening. Ten is the magic number, and it is not very pleasant to have to explain to late-comers that they can't be tested and turn them away. They have, after all, worked up enough courage to have the test in the first place and made the effort to get to the clinic. I can't imagine what they must feel having walked into the front door to be met by me and told, "Sorry you're too late, come back next week".

You know, it's quite unexpected in a way, the reactions you can get when you tell them they won't be able to be seen. Some smile and you can see the relief in their faces at not being able to test and others can have a real go at you. On balance, most people appreciate the service we offer and you would be surprised at the wide cross section of people coming in to be tested. I certainly am.

On some nights we don't reach our target of ten tests, but most of the time we have to turn away as many as we're able to see, and it ain't funny. This is even more frustrating when you think how few clinics there are in London offering a "results-within-an-hour" service. There's just no place for a lot of these people to go. Everyone's talking about how people need to be tested, and people want to know whether or not they've been exposed to HIV, but without the money, without a real commitment, it's just not going to be enough.

When I first started on Reception I had a theory that if the weather was good and it was a pleasant evening, people tended not to come in for a test because they didn't want unpleasant thoughts to break the spell of the moment. And if the weather was lousy the number coming through the front door was higher because it reflected how they were feeling.

Of late it would look as though I've got it well and truly wrong. It's not really down to the weather, or the traffic, or any other cause. For quite a while now we have exceeded our allotted number each night. I can only hope that the powers that be can see their way clear to securing the means to increase the number of people who can be tested. God knows there is a need for it.

Supporting data

More than half (54%) of the 256 GUM clinics across the UK advertised opening times of less than 21 hours per week and just two new GUM clinics have opened since 2002.

fpa survey, July 2004

Research should evaluate the feasibility and acceptability of HIV testing in settings outside the genitourinary medicine clinics.

CMO Annual Report, 2003

An estimated 31% of people with HIV infection in England remain undiagnosed.

HPA data, 2004

Waiting times for genitourinary medicine clinics are longer than they should be: an estimated 28% of emergencies were not seen within 48 hours and 29% of symptomatic patients waited for more than two weeks for an appointment.

CMO Annual Report, 2003

The New Patient's Tale

It took me five years and a boyfriend I loved to actually face my fears and go and get a full STI screening. I hadn't had a particular history of risky sexual behaviour, but the fear still lurked in my mind that I had taken risks that might have far-reaching consequences I had not considered at the time. I, like a lot of people, felt that I would "rather not know" if I had anything because I feared that STIs were untreatable. I am an educated person with two degrees and yet I knew very little about testing, diagnosis or treatment and so chose to bury my head in the sand. This meant that I had a number of sleepless nights over the years, worrying that I was infected with something and infecting other people. And yet I did nothing about it.

A month ago my boyfriend of seven months tackled me about this and forced me to face up to the huge denial I was living in. He had been tested recently and advised me to do the same. It was the first time that anyone had confronted me about this; even though my friends and I talk about sex openly we never discuss the less "sexy" side of it – contraceptives, clinics, testing, infections. It's all very taboo and makes it all the easier for us to live in our own private worlds of denial.

After a long period of consideration, I finally made the appointment. I shook as I rang the number of my local hospital and didn't appreciate it when the receptionist made a joke about me using a false name. The name I gave really was my name and her tactlessness in such a sensitive situation was troubling. The fact that she made this joke also made me think that maybe I was doing something shameful that I should lie about – it had never occurred to me before.

My first impression of the GUM clinic was when I arrived at the reception desk to find a young girl in front of me tearfully pleading for an appointment. When the receptionist asked her if she had symptoms, she said she didn't (I would argue that tears are a symptom). She was told she couldn't see anyone then but that she should come back in three days. She said she couldn't do this and became even more upset, finally leaving in tears.

Next I was seen by a doctor. She rattled through a list of questions like we were discussing the health of my car and offered me no counselling or advice about what would happen next. After we were finished she left me alone in a corridor without explaining what to expect.

The two nurses I saw next answered my questions with care. However, I was so distressed by this stage that I just wanted to leave. To make matters worse, one nurse made a mistake and told me that they would call me if I tested "negative" for anything. She should have said "positive". If she had, it would have saved me two weeks of torment every day the phone didn't ring. I was afraid I would phone up and have tested positive for everything! A simple mistake made the next two weeks hell for me.

I was shocked to be told that I had to collect my results on the phone without having any preparation or counselling for this. They told me that even if I were HIV positive they would tell me over the phone. This made the waiting period ten times worse. The thought of hearing this alone and without any preparation was terrifying.

Those two weeks were the loneliest and most frightening of my life with plenty of time to think about the potential consequences of my actions. I'm sure that if more people were encouraged to go through the process they would think a lot more carefully about taking risks. Thinking back, I am only sorry I waited so long.

As time went by I was unable to take the strain of waiting so I rang the clinic's health advice line to clarify what I could expect to hear on the phone. When they discovered the nurse's error and realised how stressed the waiting was for me, they gave me my results two days early. I am thankful for that and the fact that all my tests were clear but regret that the process was so impersonal and insensitive. I can imagine that a lot of people would never go back to a GUM clinic if they were treated the same way.

In the future, I'd like to be treated in a more humane way and to be given better information about what to expect. I'd also like to be made to feel like I'd done the right, brave thing and not made a mistake for trusting a health service that seems to view STI patients as a nuisance and a bother.

Supporting data

"Another year, another set of figures and yet more predictions of an impending public health crisis. Well, I've got news for the Government, the crisis is here. Despite showing a slowing down of the rate of increase for some STIs, the 2003 figures still make very depressing reading indeed. It is a scandal that the service we offer patients today is worse than it was 90 years ago."

James Johnson, Chairman, British Medical Association, July 2004

The long term costs of leaving the current epidemic of sexual infections in the UK untreated are incalculable for fertility, cancer, GUM, neurological and mental health services and general practice.

"Why the Government should make sexual health and HIV an NHS priority", THT briefing paper, 2002

At a time at which access has improved for other services such as A&E, primary care, and major specialities, access to GUM services has worsened.

"Sexual Health and HIV", Brook, fpa, MedFASH, NAT and THT briefing paper, 2004

"Prompt treatment of STIs is critical to their control, yet NHS care seems designed to discourage this. Funding for this unglamorous field of medicine has failed to match spiralling demand, and clinics are dilapidated and overrun".

The Times, July 2004

The Pharmaceutical Rep's Tale

Pharmaceutical representatives are the day-to-day link between the industry and the medical profession. I gained an insight into just how well the relationship functioned on my first day as an HIV Therapy Adviser. It was 1996, and my company had just doubled the number of its UK HIV Field Team members because of new HIV treatments.

That summer, my first port of call was the Kobler. I was overwhelmed by the reception. Everyone I met was so helpful. By the end of the afternoon I had enough reading for a month – a stack of clinical papers, plus literature from the Crusaid and Star Information Exchange, Terrence Higgins Trust and Body Positive. I had also booked a place on the excellent Chelsea and Westminster two-day HIV Course for Healthcare Professionals.

One thing I learned quickly was that HIV positive people were far more knowledgeable about their illness than was the case for other branches of medicine in which I had worked. This level of understanding was encouraged by their physicians. As a pharmaceutical rep, I found it stimulating to be involved in this partnership.

With the introduction of antiretroviral medications, there was a new optimism for the long term outcome for HIV-positive individuals. Everyone was encouraged to help develop new ideas, including the reps.

My own contribution, based on a suggestion from the Senior HIV Pharmacist at St Mary's, was to encourage my company to produce the "Lifestyle Booklet" – a series of individual cards that were based on the Chelsea and Westminster A4 Fact Sheets. These pocket-sized cards included photographs of the various tablets and capsules used in treatments to help patients identify the proper medication. This was a useful tool, given the many complex combinations and multiple therapies used in HIV treatment. Producing it was hard work, outside my daily role, and I am delighted that the cards gained widespread acceptance.

Over the years, HIV has been a roller-coaster; not only for patients, but also for those involved in treatment and support. The improvement in outcome for HIV-positive individuals since the very early days is well-documented; there was increased awareness that HIV could become a controllable lifelong illness, more like diabetes.

Development continues with new drugs, which hopefully will be more effective, easier to take and with fewer side effects. Meanwhile, the number of people living with HIV in the UK continues to grow, and they're finding they face new obstacles: longer waiting times at clinics, the elimination of specific funding for HIV programmes and continuing stigma and discrimination. It's a worrisome situation. I think the increased demand on the existing health care system is probably the most troubling.

I was recently at a clinic where a patient had been given a prescription to collect at the pharmacy when it opened. For various reasons the prescription could not be dispensed immediately; the patient was kept waiting for several hours, but he had an urgent meeting at work and could not wait any longer.

He said he had enough tablets for the day and would return later for his new supply. But what a waste of time and energy! And would he really be able to get back before the medication ran out? Sounded to me like a major threat to his adherence. Easier surely to have the drugs delivered to the patient's home? I'm currently working as consultant to a company who specialise in just that – home delivery for drugs and other services in order to help alleviate this type of situation. One patient used to bring a suitcase to the clinic to collect his massive supply of pills! He is now happily on home delivery and the problem has been solved.

Over the years, I have gained knowledge and experience. I have met talented, dedicated and brave individuals – doctors, pharmacists, nurses, health advisers – many of whom have dedicated their careers to helping people with HIV; some have become my personal friends. But perhaps most important of all, from dealing with patient groups, I have seen for myself some of the hardships of people living with HIV. I want to carry on helping to make the system easier for people to manage.

Supporting data

"Persistent under-funding, combined with spiralling drug costs and the emergence of many new drugs on to the market, means that clinicians struggle to prescribe the appropriate therapies for their patients and that funds needed for other sexual health services may be diverted to pay for HIV drugs".

Health Select Committee report, 2003

"The whole point of an effective health care system must be to reduce the numbers of people who have to go to hospital..."

Secretary of State for Health, John Reid, August 2004

"Nobody wants to end up in the 'clap clinic' let alone when you have to wait up to four hours to discuss your most intimate of problems, with a harassed doctor who is still worrying about the last patient hurried out of the room in a bid to try to relieve the already heaving waiting room."

Dr Sarah Gill, GUM physician at Paddington, to Health Select Committee, 2003

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Websites

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British Association of Sexual Health and HIV
www.bashh.org

British HIV Association
www.bhiva.org

Department of Health
www.dh.gov.uk

fpa
www.fpa.org.uk

Health Protection Agency
www.hpa.org.uk

National HIV Nurses Association
www.nhivna.org.uk

Terrence Higgins Trust
www.tht.org.uk

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