

DÁIL ÉIREANN

AN COMHCHOISTE UM SHLÁINTE AGUS LEANAÍ

JOINT COMMITTEE ON HEALTH AND CHILDREN

Déardaoin, 27 Samhain 2014

Thursday, 27 November 2014

The Joint Committee met at 9.30 a.m.

MEMBERS PRESENT:

Deputy Catherine Byrne,	Senator Colm Burke,
Deputy Robert Dowds,	Senator John Crown,
Deputy Peter Fitzpatrick,	Senator Jillian van Turnhout.
Deputy Seamus Healy,	
Deputy Sandra McLellan,	
Deputy Dan Neville,	
Deputy Caoimhghín Ó Caoláin,	

DEPUTY JERRY BUTTIMER IN THE CHAIR.

The joint committee met in private session until 10 a.m.

HIV in Ireland: Discussion

Chairman: Apologies have been received from Senator Imelda Henry and Deputy Eamonn Maloney. Deputy Fitzpatrick has to leave us. Deputy Billy Kelleher, who is participating in Leaders' Questions, sends his apologies. Deputy Regina Doherty may be here later. Have there been any other apologies? No.

I remind members, witnesses and people in the Visitors Gallery to ensure their mobile telephones are switched off for the duration of the meeting as they interfere with the broadcasting of the proceedings and with staff.

I welcome everybody to the meeting today. I welcome to the discussion on the topic of HIV in Ireland: Advances in testing opportunities and enhancing engagement with health services Mr. Tiernan Brady, director, gay HIV strategies, Gay and Lesbian Equality Network, GLEN, Ms Deirdre Seery, CEO, Cork Sexual Health Centre, Mr. Peter Foley, *letsgetchecked.com*, and Mr. Jimmy Goulding, Positive Now. They all are welcome. I thank them for being here this morning and to some of them I say, "Welcome back." It is an important issue. I welcome viewers who are watching on the Oireachtas channel.

Witnesses are protected by absolute privilege in respect of their evidence to the committee. However, if witnesses are directed by the committee to cease giving evidence on a particular matter and they continue to do so, they are entitled thereafter only to a qualified privilege in respect of their evidence. Witnesses are directed that only evidence connected with the subject matter of these proceedings is to be given and they are asked to respect the parliamentary practice to the effect that, where possible, they should not criticise or make charges against any person by name or in such a way as to make him or her identifiable. I remind members of the long-standing parliamentary practice to the effect that they should not comment on, criticise or make charges against any person outside the House or entity by name or in such a way as to make him, her or it identifiable.

As members will be aware, Monday next, 1 December, is World AIDS Day. The purpose of the meeting is to hold a piece of work around the issue of advances in HIV testing and of enhancing engagement with the health services on sexual health issues. With that, I thank all of our people for being here this morning and I ask Ms Deirdre Seery to begin.

Ms Deirdre Seery: I thank the Chairman and committee for the invitation.

When I started working in the Cork Sexual Health Centre, then the Cork AIDS Alliance, many years ago, HIV was basically almost a death sentence. Since then, we have witnessed many changes. When I started work there, homosexual acts were illegal and condoms were not freely available. I suppose the context I want to give is that HIV allows us to look at how we need different strategies over the years.

Since we have effective treatments for HIV, people with HIV can lead a healthy life. The treatments also reduce the amount of virus in people's systems and, therefore, they are less likely to pass it on to others. The effect of the treatments means that we can really promote testing and look at the opportunities for testing in community sectors and different types of testing. Essentially, that is what we will talk about today. It gives us the possibility of reducing infections.

The context of HIV is fear and stigma. There is still a huge stigma around HIV and a denial of the risk. I am constantly asked why are there still people getting HIV. There is almost one person per day in Ireland newly infected with HIV. It is preventable. We know how people get it and still the new infections are basically the same. That is why we are focusing on the effectiveness of prevention, both human and financial.

There are three aspects to this that I will outline in my brief contribution: promotion, access and outreach. Promotion has to be targeted at the communities that we feel are most at risk of HIV without losing the focus on the heterosexual population, who still make up a large number of those with HIV. It is a matter of achieving that combination. This is EU testing week. We have got Irish AIDS Day, World AIDS Day and, of course, St. Valentine's week as well. These are all big focal points where the media is interested in promoting testing and we have to ensure that we get as much free publicity as we can out of those.

On access, there are STI clinics in most of the major parts of the country. They offer free and specialist services. They are busy, they have waiting times but they are very good services, and we work hand in hand with those. They give full STI screening.

On top of that, one of the aspects that will be highlighted in the national sexual health strategy is looking at other ways, including community testing. At Cork Sexual Health Centre and the Gender, Orientation, Sexual Health, HIV project, GOSHH, in Limerick, we have rapid HIV testing - a simple finger-prick or saliva test with results in 20 minutes. It is an opportunity to get people to come in and talk. They feel relief when they can come in and talk about their risks, or sometimes they have not been at risk at all and they are just anxious about the fact that they might have put themselves at risk. Then there is the link that we can have in to the STI screening. If people have put themselves at risk, we can refer them to the STI clinic for full screening. Dublin AIDS Alliance works with St. James's Hospital and, therefore, has a different outreach service where St. James's Hospital does it in the Dublin AIDS Alliance's building. Those are examples of community testing. In the United Kingdom, they are exploring the opportunity of testing for migrant communities in churches.

Community testing offers a huge opportunity. We have got out-of-hours services because our research showed that people want out-of-hours services as well as nine-to-five services. It is a safe and non-clinical environment. People can talk. They can get their relief.

It is cost effective. We have to charge for it at present because we had to prove that people would do it. We have to charge €50, on a sliding scale to free. If people need a repeat test, that is always free. We know that the times when we offer it free, we get more people coming for testing and the next stage is how to improve access to free community testing.

It is very simple. There is rapid turnaround and people do not have to wait a week for the results. They know that if they come, they will know within 20 minutes whether they have HIV or not, so long as they are not in the window period.

The other opportunity that it gives us is for early diagnosis. When people are newly infected with HIV, they are more infectious. If we can catch people quite early, they can be referred on. We have very good referral routes onto the specialists in the hospitals and they can go on the treatment route. If they know their status and know they are highly infectious, they are less likely to pass on the infection to other people. It is a win-win situation. Mr. Foley will talk about the home testing.

The other aspect we can offer in the NGO sector is outreach work. In our case the outreach work is targeted at men who have sex with men and hidden populations. Many of the men who have sex with men do not identify as gay. So we have to be creative in how we access people who are engaged in risky behaviours. We have to know our populations. We have a very good health intelligence service now from the Health Protection Surveillance Centre. It now has a system whereby it gives us accurate and up-to-date statistics so that we can understand the diversity of populations affected and apply them.

I am also involved in the European Joint Action on Improving Quality in HIV Prevention. That is looking at applying tools so that we are really structured in how we improve quality in HIV prevention. So there are many initiatives going on.

Where do we go from here and how? We still have almost one person a day newly affected with HIV. Over half the people are diagnosed late, which is not good from a health point of view. We have to increase promotion and access. We have the opportunity for leadership. The national sexual health strategy has been sitting in the Department of Health for more than a year. It offers the opportunity to get us all together to work across sectors. It is being modelled on the national HIV strategy committee and we really need to get that out. That is something members of the committee can do. We need to get the national sexual health strategy launched, which will give us the opportunity to work together to develop an implementation plan.

The way HIV has developed is a really good model for responding to a health problem. It involves reflection, focused on continual improvement, strategic work, working across sectors, and effective use of scarce resources. Essentially we focus on doing the right thing at the right time in the right way, constantly reflecting and constantly responding to the needs of HIV prevention.

Chairman: I thank Ms Seery. I call Mr. Brady, director of HIV strategies with GLEN.

Mr. Tiernan Brady: I thank the members of the committee for putting this on the agenda. Unfortunately the trends in HIV diagnosis picture have not changed since last year. Today we are calling for a new approach to this so that we can try to achieve the goals of having zero new infections and zero discrimination against people who are living with HIV in Ireland.

The statistics that have been published clearly show that the trend is not good. In 2005 we had 60 cases of new diagnoses of gay and bisexual men and this had moved up to 159 cases in 2013. This week the figures for the first six months of 2014 were released. Unfortunately they mirror those problems. We have gone from 82 cases in the first six months of 2013 up to 94 in the first six months of 2014. So there is a significant problem here. Especially for gay and bisexual men this is an issue that needs real attention and needs a new set of thinking on how we engage with people and how we get people to engage on their own sexual health. That is one of the key targets here. Ultimately we want to empower people to make the right decisions for themselves.

HIV is an easily preventable condition, as are many sexually transmitted infections. However, we have to be able to equip people with the confidence and awareness they need so that they can engage with their own sexual health. We need to do that, starting from the basis of being honest about sexual health. Nobody looks forward to an encounter with a doctor, an NGO or anybody about their sexual health. Nobody wakes up in the morning with a smile on their face, thinking, "I'm having my syphilis test today"; that is not how the world works. Far too often our services are built on the idea that is how the world works with the notion that if we

provide the service, of course, people will come to it. In reality there are so many significant barriers - social and stigma barriers - to engaging on sexual health for the entire population. A whole additional level goes in on top for LGBT people and in the case of HIV in particular for gay and bisexual men.

In Ireland the most common point of call for people engaging with their health is with their GP at primary care. However, based on the most up-to-date Irish research, 54% of LGBT people are not out to their doctors. If they are not out to their GPs about their sexual orientation, then there is no chance they will be able to get to their next step, which is their sexual health in general and that is important information for their doctors to know.

We have been working with the Irish College of General Practitioners and health-care providers in sexually transmitted infection clinics to build their capacity to understand, first, that they have LGBT patients who look like everybody else and, second, that those patients face significant additional barriers when engaging with health services. Those themes represent a two-step approach. We have to be able to build up the capacity of the service provider before telling the service user it is okay to proceed. We have had a very positive relationship with the Irish College of General Practitioners. We have a new set of guidelines there. We are working with St. James's and the Mater hospitals to help equip doctors through training seminars, increasing their awareness that there are issues and that there are lesbian and gay patients in their clinics.

Once we know of the barriers we need to ask how we can be inventive about trying to create a service that is easy for people to use based on the original principle that we know people would prefer not to use the service at all. We need services that are convenient, accessible, inclusive and understanding of those challenges. Ms Seery's rapid testing service in Cork addresses that fear of the long delay before the result. Mr. Foley's home testing uses new technologies to get people to engage more on their sexual health, while at the same time building up the capacity of primary care to deliver effectively for their lesbian and gay patients and more specifically for their gay and bisexual men patients.

We need strategies that are targeted and tailored, and that recognise that one size does not fit all the population, given that we are dealing with an issue that people are very reluctant to engage in.

Mr. Goulding will talk more about this. We need to get to a point where there is zero discrimination against people living with HIV. It is very real and has not gone away. Stigma still exists. To anyone who believes it does not exist I would ask them, "If you were diagnosed with HIV tomorrow, whom would you tell?" I am pretty sure the answer is "Nobody". Would such people tell their boss, their friends or their family? Why would they not tell them? Regardless of whether we want to concede it, stigma is very real and Mr. Goulding will refer to that.

Some key recommendations arise from this. On testing, we need to develop programmes that are resourced and recognise that we need to make testing accessible in many different ways because of the significant barriers to sexual health engagement for everybody and the additional barriers for gay and bisexual men in particular. As Ms Seery has said, this is important because the vast majority of HIV cases are passed on by people who do not know they have HIV. So we need people to know their status, whether negative or positive. There is peace of mind for those who realise they have a negative status. In addition, the quicker those with a positive status get into treatment the better it is for their long-term health outcomes. So we want to drive in as many people as possible.

There needs to be a new focus on stigma and we need to invest money to raise awareness with the general population. We all remember huge advertising campaigns about HIV when it was in the public consciousness but these no longer exist. We are not unrealistic about budgetary requirements and they will not suddenly start to exist again, but we need to find ways to target messaging to raise awareness that HIV exists, that people live with it and that stigma is unacceptable. The prevention messages must be equally targeted because within the HIV figures we can see the diagnosis age is getting younger and younger. It has gone from 37 years in 2005 to 32 years now. Part of the reason is this generation did not have exposure to the type of information and heavy-duty campaigning that was out there.

We want to sign off on the national sexual health strategy. We know it is nearly completed, or ready to be signed off, but the quicker the better so we can start to implement it. It needs tough implementation guidelines and real targets and goals.

Mr. Peter Foley: I thank the committee for the opportunity to speak. I will focus on home testing and how it fits in as another component of making testing in general more accessible. The key differential from other methods is the testing itself is taken away from the clinical setting and is conducted by the user in an environment of his or her choosing. Home testing and remote testing target two areas specifically. In the first instance are people who are asymptomatic who do not present any clinical symptoms, which is quite a large proportion of the population. Before and after seroconversion people with HIV are generally asymptomatic. A total of 80% of women with chlamydia are asymptomatic all of the time. Home testing also removes many of the traditional barriers and encourages people to engage emotionally. People may be afraid of the testing process or going to a clinic in the first instance, or might have geographical restrictions by way of time or where they are located, such as in rural Ireland or various parts of the country. It is about giving them access and ensuring they are provided with a solution.

Letsgetchecked.com is a technology platform that facilitates the dissemination of testing. It sends testing equipment to a person in a secure fashion. It also disseminates results after testing has taken place. I will try to keep my explanation of how the process works as simple as possible. Someone visits the online site and orders a test kit from a laboratory. The laboratory dispatches the kit in discreet packaging to the address designated. The testing or self-sampling is conducted, for HIV it is a finger prick of blood dispensed into a vial, and returned to the laboratory for analysis. The laboratory then runs the test and uploads the results directly to the user's profile. This can all be conducted through a mobile telephone, tablet or desktop device and is accessible and convenient. Anyone can do it at any point in time.

There is an issue with people who test positive for HIV. It is not appropriate that such results are just sent to someone's phone. The project could have gone live much sooner than it did, but we engaged the public health system by way of St. James's Hospital and private health centres. If someone tests positive he or she is contacted by a nurse over the phone. By way of a three-way conference facility the nurse puts the patient directly through to a clinic at either St. James's Hospital or a private clinic in Dublin run by Professor Fiona Mulcahy, at which point our nurse will drop off the phone and the person is directly put into care.

People who are infected also need to be provided with actionable information which allows them make sensible decisions on how they receive treatment or care and how they act socially, whereby they have the knowledge to act responsibly by way of treatment and interaction.

Mr. Jimmy Goulding: I thank the committee for inviting me back to speak about HIV stigma and discrimination. The stigma and discrimination that come along with HIV have a

knock-on effect for those of us living with it. It continues to ensure people living with HIV are marginalised. In June 2006, I took a case to the Equality Authority against a health provider who refused to treat me because of my HIV-positive status. He believed I needed to be treated by a specialist who worked specifically in the HIV area. I won a *prima facie* case in 2009, as the Equality Tribunal believed I had been treated differently from someone who was HIV-negative or someone whose HIV status was unknown.

Along with the decision in my favour recommendations were made at the tribunal, including that universal precautions should always be used when a health provider works with any patient. Universal precautions assume every patient may have an infectious illness. Exercising these precautions ensures every patient is protected and treated equally. Another recommendation was that all health care staff should be educated and trained on HIV transmission. From working with people living with HIV I can say these recommendations have not been put in place. For many of us living with HIV, the places where we experience HIV stigma and discrimination most are with health care providers. We are still given the last appointment of the day, in the belief that this will lessen the chance of cross-infection to other patients. This is the case with my chiropodist at present.

Many people living with HIV have not yet tested. Many do not disclose their HIV status because of the stigma. This needs to be taken into consideration by health care providers, who should use universal precautions. Those of us living with HIV are also aware of nurses and doctors outside of HIV clinics who double-glove when dealing with us. In HIV clinics they do not double-glove as they do not see us as infectious but this still happens today with other health providers.

Many health professionals feel the need to ask people living with HIV how they got it. This question would not be asked of somebody else with a chronic illness. Many health providers feel they have a right to know this personal information. Positive Now works closely with Dublin AIDS Alliance staff, who will say that one of the most frequent questions they hear from those who are newly diagnosed is whether they know of a HIV-friendly dentist or GP. These individuals learned before they became HIV-positive about the stigma which exists. These questions are still being asked in 2014. Why have the Equality Tribunal's recommendations not been implemented? In June 2010 I dropped a case against the HSE asking it to enforce these recommendations. The Government must help tackle HIV stigma and discrimination to improve the lives of people living with HIV.

Chairman: I thank Mr. Goulding for his interesting proposal and testimony. I acknowledge Mr. Patrick Sweeney from the Gay and Lesbian Equality Network and Ms Sandra King from Positive Now who are in the Gallery. They are very welcome. I am aware that Deputy Ó Caoiláin may have to go to the Dáil so I will call him first.

Deputy Caoimhghín Ó Caoláin: I welcome the delegation here this morning. Some members have returned once again and they are welcome back. I have listened to the delegation and have gone through the detail of the GLEN submission in advance. In terms of the immediate actions needed, awareness and testing are the two critical focus points that I have picked up from the messages delivered.

In the table and chart of HIV diagnosis rates over the period 2004 to 2012 there are variations in total numbers. The critical focus of this particular address is on men who have sex with men or MSM. There has been a marked increase in that particular area in comparison with any of the other groups which have been and are at risk of infection. Can Mr. Brady explain

why there has been an increase? There has been real public awareness for many years although it does not have the same public address it once had. Is that a factor in the increase? Has HIV slid off the table in terms of public consciousness? I am anxious to understand why there has been an increase. If the number was to hold at the earlier figures, as had been demonstrated in the table, there would have been a significant overall decrease just like in other areas. There has been a marked rise in the graph depicting MSM.

In terms of media, addressing the most at risk community was mentioned. As I listened to that comment, and having read the report, my thoughts were, and I could be wrong, that the media are a component part of how one addresses the issue. I am only trying to tease out this matter. Are young people coming out more at risk? Is there an analysis of the chart figures in terms of profile? It has been mentioned that the average age of HIV diagnosis has fallen from 37 years to 32 years. Has there been, over the same period, a significant increase in younger males who may not be, for any particular period, heavily exposed to a community of gay men? Does that put them at risk? How do we address the matter if we categorise a group? It is wrong to section off a group but understanding it is a component part. Awareness must be in the round and across the whole of society in order to have the best possible prospect of making an impact. I invite further comments from the delegation on the matter.

In terms of home testing, I note that the text given to us states, “[W]orking with GLEN and healthcare providers to develop good practice models for the delivery of home testing services”. The term “working to develop” sounds very complicated but testing should be a straightforward and simple practice. It should be part of life and a regular routine for any male involved in sex with males. It is for their own personal good health and that of their friends. I ask the delegation to develop what is meant by developing good practice. What more needs to be done in terms of the use of the word develop? Home testing strikes me as preferable to some other options and is the least personally challenging. In addition, one has personal control of the situation, one has full knowledge and one then is informed as to how to proceed. It does not necessarily mean the information belongs to somebody else, who may not have anything other than a relatively distant professional relationship, that is, a practitioner or whatever is the case. Home testing means one has control and is in charge.

I understand the case for targeted information and awareness. However, there is a whole new generation and generations who were not exposed to the same wow factor and bombardment of awareness that people of my age experienced so many years ago. Perhaps society needs that again. Go raibh maith agat.

Senator Jillian van Turnhout: I shall pick up on the Deputy’s last point and state that awareness raising is overdue. Mr. Goulding spoke about the matter and I was saddened to hear his experience. We need a targeted awareness programme but we also need a broader awareness raising piece. There is a generation that knows about HIV but there is another generation that is awakening which does not necessarily know about it.

Today’s presentation reminded me of another presentation here a few years ago by Comhairle na nÓg on the difficulty accessing sexual health services for young people generally, particularly for people who lived outside a city environment. Comhairle na nÓg wanted to know where one could access very basic information about sexual health services and today’s presentation feeds into a wider discussion on the matter.

I was also surprised to read reports today that were published in the Irish Medical Journal. It surveyed 1,112 of 14 to 16-year olds of which approximately 5% or 58 of them had worries

about sexual orientation. That number was broken down into 35 boys and 23 girls. Let us remember that these are 14 to 17 year olds. I was alarmed to read that findings of the survey which talked about higher levels of mental health difficulties, an increased prevalence of attempted suicide, physical assault, sexual assault and substance misuse. The survey is on today's Ireland and not 30 years ago when we had campaigns and awareness. It is almost 1 December 2014 but this cohort of 14 to 17 year olds still face immense challenges and there is no reason this should be the case. I would welcome the views from the delegation on how to reduce victimisation. How do we ensure, when raising awareness, that we do not contribute or add to preconceived notions? Those of us who are aware understand what the message is behind an advertisement or an awareness raising campaign. For those who are not aware a campaign can sometimes feed a preconception or notion. I am interested in hearing what the delegation has to say on the matter. As the Chairman knows, I must chair a meeting and so must leave shortly but I shall stay as long as I can.

Senator Colm Burke: I thank members of the panel for their very detailed presentations and all the information they have given this morning.

I wish to touch on a few items that were raised. Ms Seery stated that over half of HIV-positive people are diagnosed late. What is meant by “diagnosed late”? It is important that we get clarification on the matter.

Mr. Brady referred to the need for a campaign. How, in the delegates' view, should one be conducted, taking current financial restrictions into account? Is there a particular cohort at whom a campaign should be targeted and how should the campaign be managed? For example, should it be conducted through third level colleges, social media or particular organisations? I am interested in hearing the delegates' views in this regard, given that they are the ones with experience of dealing with this issue.

It was stated that, according to *LetsGetChecked.com*, there were approximately 100,000 people living in Ireland with the infection, 25% of whom did not know they had it. How can the organisations encourage greater awareness? An Oireachtas colleague told me yesterday that he had received a telephone call from a person complaining about the number of non-Irish people living in Ireland, suggesting they were the cause of all our infection problems. The tendency of Irish people to blame everybody else for their problems is amazing. Based on the figures available, is it possible to provide a breakdown of the socioeconomic make-up of those with the infection, the number of Irish people who have travelled abroad and are infected and the number of people who have come here from abroad and are infected? Are details available in that regard? In terms of our tendency to blame everybody else for our problems, it is important that the correct information is placed in the public domain.

Deputy Catherine Byrne: I apologise for my late attendance, but I was listening to the discussion on the monitor in my office.

I was once asked what was my favourite film, to which I replied without hesitation “Philadelphia”, which starred Tom Hanks. It was the first film I had seen that dealt with the issue of AIDS. It brought home to me the reality of the rejection of people not alone in their employment but often also in their neighbourhoods and by their families. For me, the film depicted how the human body broke down when people were infected and how because of this their bodies became offensive to others.

Mr. Brady asked whom we would tell if we were diagnosed with HIV tomorrow. The same

question arises in regard to mental health issues. Whether we like it, there is a stigma attached to mental illness. I recall the impact of Princess Diana touching, hugging and kissing people infected with HIV, while others were running away from them fearing they would become infected by them. This brought home to ordinary people the reality of how much we stigmatised others.

These days young people are well educated. They are not stupid, yet they continue to take huge chances and risks in their sexual activity. This applies across the board, not only to gay men and lesbians. Will the delegates explain the reason for this? It has been stated it is estimated that one in four people infected with HIV remains unaware of his or her condition, yet we have great services in place to deal with breast, bowel and prostate cancer. How do the organisations fund their awareness programmes? What funding, if any, is provided by the Government? If there was one recommendation the delegates would wish the committee to take on board, what would it be? The committee meets many groups and makes many promises, half of which we do not get to keep. When I leave the meeting, what is the one thing I, as a member of the committee, can do to help? What is the main issue with which the delegates would task the committee which I hope we will be able to achieve? In this regard, they should not ask for a couple of million euro because they have no chance in the world of getting it.

I thank the delegates for their presentations, in particular the presentation made by Mr. Goulding whom I think I have met previously.

Deputy Dan Neville: I welcome the delegates. I found the presentation on stigma very interesting. It is a live issue in the area of mental health which has been a particular focus of mine for many years. It is a difficult one in which to make inroads. However, inroads are being made, although there is a long way to go.

There are many who say it is not possible to destigmatise a particular illness. I refer to TB and how it was destigmatised, as also happened in the case of cancer which was known as the big "C". Why cannot mental illness and HIV be destigmatised? Have the organisations looked at the Government's plan, See Change, and considered addressing the destigmatising of HIV in a similar manner? The former Minister of State, Mr. John Moloney, did a great deal of good work in this regard. Destigmatisation of HIV is key.

I found Mr. Foley's presentation very interesting. To be honest, I was unaware that home testing was available, even though I had been reading information from GLEN for many years. If I was unaware of it, many of the people who should be aware of it - as we all should be - are not aware of it. There is perhaps a need for greater promotion of the availability of home testing kits.

Deputy Sandra McLellan: I thank the delegates for their detailed presentations which included information on the services people could contact if they wished to talk about their condition. This is not an issue that is raised with us daily in our constituency offices. As such, the information provided in the presentations is welcome. A lack of awareness and education has been highlighted as the main cause of stigma. A lack of education causes fear which, in turn, causes stigma. In times past there was a fear of other diseases. The fear and stigma now attached to HIV are due to a lack of awareness and education.

I thank the delegates for the information on the rapid test and the availability of home testing kits. I know that if I needed to take a test, I would be afraid to go to my GP. The availability of the rapid test or a home testing kit is important.

On the question of who campaigns should be targeted at, as young people believe nothing will ever happen to them, it is important any campaign conducted is aimed at them first.

I again thank the delegates for their presentations.

Senator John Crown: I apologise for coming and going, but I am also dealing with another matter this morning. I am in the grip of double jobbing, for which I apologise.

This has been one of the most extraordinary stories in modern medicine. People forget this, but it is simply amazing. If anyone had predicted, even in 1989, that treatments routinely available within 15 years would be so good that, as far as we know, most patients with HIV infection would be actuarially restored to a normal life expectancy curve, rather than facing the uniform death sentence which applied heretofore, it would have been regarded as science fiction because medicine does not work like that. This was an extraordinary achievement which involved brilliant science and good medicine. The various activist groups had a lot to do with it and deserve great credit for pushing hard for increased investment in research at a time when it was regarded as a lower priority research undertaking. People who have this virus need to know they have it because the treatment available is really good. Not knowing that they have it poses substantial risks to their health. One message that needs to go out is that testing is good. People need to know their status not, as was the case in the 1980s, because of some societal warning that they should not be taking risks for somebody else's sake, although that is important, but for their own health. There will be further advances and, obviously, it is hoped a vaccine will be found.

Key issues that will arise in the coming years include the right to confidentiality and insurance. These are complicated issues which have to be dealt with differently now that we know people will survive with the disease. All of the concerns about issues such as life insurance, mortgage protection insurance and health insurance need to be seen in a totally different light. In the past somebody with an incurable disease such as Crohn's disease would not have faced the same strictures in respect of insurance and confidentiality compared to somebody with this disease. We need to normalise our understanding of it. It is another chronic illness such as rheumatoid arthritis, epilepsy, diabetes or, increasingly, many forms of cancer. It can be treated and people will live with it. We need to develop structures in the health system, insurance market and our general attitudes to reflect this reality.

Somebody needs to sit down to write the wonderful story about how this disease was contained in a totally different way from what had been expected. The original notion was that it would never be treatable and that a vaccine would instead have to be developed. The outcome has been exactly the opposite. It involved extraordinary work in the area of molecular biology.

Mr. Tiernan Brady: Deputy Caoimhghín Ó Caoláin asked about the age profile of those affected. There are multiple reasons the age profile is dropping - there is no single reason. One explanation is that it is a generational issue. There is no doubt that people of a certain age who did not grow up in the 1980s or 1990s simply do not have access to the massive public awareness campaigns pursued during those decades. Issues also arise around education. We need to teach a sexual health programme in schools in an honest and inclusive way for everybody in the classroom.

Chairman: Does Mr. Brady think the SPHE programme is not inclusive?

Mr. Tiernan Brady: The TRUST programme is very good, but it is not being taught. We advised on its development and also prepared a document with the Department of Education

and Skills specifically aimed at helping teachers to provide a sexual education and the SPHE programme for lesbian, gay, bisexual and transgender people. However, we know that it is not being taught universally, even though everybody who is 17 years old is in a classroom. If we are discussing marketing and targeting awareness subject to budgetary constraints, we know where a lot of people are at any one moment. We have a curriculum and have to have it taught.

We repeatedly come back to the issue of stigmatisation of sexual health. People do not want to teach this subject for the same reason a person does not want to go to a doctor to discuss his or her sexual health. I agree that mental health and sexual health are twins in terms of the stigma attached to them. People are embarrassed to engage and this has a detrimental impact. As Senator John Crown rightly noted, engaging is the best thing for individual health outcomes, as well as the other issues that arise from people not knowing their own status. Education is key in building awareness. Sexual health education is about giving people the capacity to assess their sexual health. Once they have confidence, knowledge and capacity, that is the biggest step. It should not be the case that they have to go to a doctor every couple of months. They should know how to take care of themselves and be able to make the best decisions for themselves.

On risk, there is a process which we call “othering”. People underestimate their risk exposure. HIV is a good example. Everybody thinks it happens to somebody else. Some think it happens to people from Africa. Straight people think it happens to gay people and gay people think it happens to straight people. The result is that nobody thinks it happens to anybody. Younger people form one of the groups most at risk. When it come to the nationality breakdown, the single largest group is Irish people and, within that cohort, young Irish men. However, these are also the ones who think they are not exposed to risk because they consider themselves to be invincible. They take the attitude that they know what somebody with HIV looks like. They make the same presumptions about someone their own age as they make about themselves and, instantly, that othering process increases their exposure to risk.

To respond to Senator Jillian van Turnhout’s question, we know from Irish research that most people become aware of their sexual orientation by the age of 11 or 12 years. The average age when someone comes out is 21 years. In the intervening ten years people keep to themselves one of the most important things about who they are. When we say “coming out”, we are referring to the first time a person tells a close friend not to inform his or her entire class. This is an area in which people are incredibly susceptible. There is a good chance that a person under the age of 21 years who presents to a doctor is not out to anybody. We have to ensure health care professionals understand they may be the first to be informed by the patient. What can they do to create an environment that makes it easier and more likely to happen?

On the issue of rapid and home testing, one of the reasons we have only started into this process is there has been considerable worry during the years about home testing and, for example, the circumstances in which a person might be if he or she was to test positive. The safeguards being put in place are very good. Our goal is to persuade people to normalise testing and engagement. Sometimes we devise services for others instead of asking ourselves basic questions about what we would do. Would I prefer to sit in a hospital for several hours or have a home testing kit? When we ask ourselves that question, the answer is so obvious that we can design a system flowing from it. Similarly, in respect of rapid testing, do I want to have to wait for ten days for a result when I can have it in 20 minutes? We should be using all of the technologies available to us to build the widest array of services and break down the barriers in order that people will have pathways for engaging.

Education is key not only at second level but also throughout life. Not everybody is in

secondary school. However, we have a good curriculum and need to ensure it is taught in an inclusive way for all students in the classroom. That would be one of my key asks. I am sure everybody else would have a key ask as well. I hope that answers some questions.

Ms Deirdre Seery: I will respond to the question on the reason people still get HIV. Contracting HIV is associated with risk. People still have unplanned crisis pregnancies. People have sex with others under the influence of alcohol and may not even remember whether they have had sex, let alone with whom they had it. It is associated with the culture.

For the person with HIV, there are issues around telling a sexual partner. Does one tell him on the first date or at what stage does one tell him? This is one of the issues that our counsellors deal with all the time. For a person with HIV in the gay community, at what stage in a relationship does one tell the other person? If one divulges one's secret and the relationship does not go anywhere, will he tell other people? There is a significant issue around disclosure, whether people divulge their status or not. All of this impacts on whether people have risky or safe sex.

On the question of targeted information for men having sex with men, MSM, there is no one type of MSM. Many men who have sex with men are in an almost married civil partnership or monogamous relationship and are not on the scene. There are different scenes and what we in the Sexual Health Centre are doing to promote our rapid HIV testing is training advocates to be in all of the different scenes in order that wherever men are having sex, they will have access to somebody who will say to them that for their own health would it not be a good idea to go along and have a test. We have to get people out there to interact with others.

We published a very nice leaflet and distributed it all over the place. Of the 520 people who have come to the Sexual Health Centre for their rapid HIV testing in the past two years, not a single person came because of the leaflet. Although we spent a little bit of money on it and though it was a good thing, nobody came because of that leaflet. We have to analyse continually how people are hearing about our services. It is by word of mouth and the Internet.

Chairman: Do social media represent the new forum?

Ms Deirdre Seery: Yes. We advertise on Grindr. It is very expensive to advertise on Grindr but it gave us a discount. We took a risk and tried it out and it is very effective. For European Testing Week, running from 21 to 28 November 2014 we advertised on Grindr. As a result of European Testing Week, we as well as GOSHH in Limerick will have people coming in for testing all week.

Advertising on the sites that gay men use works. Next year they might be using different sites, so we have to have a feedback loop from all the different types of sexually active gay men. We could be advertising on Grindr next year but everybody could have moved to a different site in the same way that many people do not get their information from Facebook now. One has to keep up with the trends and one does that from the feedback loops with people who are engaged with all the different sectors of the community.

That is what is exciting about our work. People in hospitals do not do that kind of work normally. We, the NGOs, can do it and we have the energy and the connections to do it. That is why it is a really good partnership between the State and the NGO sectors in terms of HIV prevention.

Chairman: Will Ms Seery comment on the health promotion unit of the HSE, in terms of its communications, visibility and output in raising this issue and addressing the barriers to ac-

cessing services?

Ms Deirdre Seery: The HSE does a different kind of work. The work it does is not uniform throughout the country.

The crisis pregnancy programme has done amazing work on highlighting the issue of pregnancy and will be taking the lead role in the sexual health strategy. I hope that some of the expertise it has developed can target the general population, which in turn will support us in our work of targeting the particular populations. One has to be on the ground to know the nuances. One does not get it if one is working in an office in the HSE. That is not to be critical of the HSE but to recommend a partnership approach.

I do not know all the places that men have sex with men in Cork, because I am also in an office, but I know people who do. That is the key.

The Sexual Health Centre was the first organisation in the country to become a sexual health centre as opposed to a HIV service. Sex and health were not words that were normally at the same time. Now it is normalised. Senator Crown talked about writing the story. I love that idea. That is my retirement plan. I have been involved in this field for 24 years. It has been fascinating to see how it evolved. We are involved in outreach work with disadvantaged communities in Cork but we also are involved in schools. The implementation of the SPHE programme in schools is patchy but I think there is a real role for organisations like ourselves to work in schools. We would work in partnership with teachers. Teachers are not necessarily the most appropriate people to talk to children about the risks associated with oral sex and how to have an orgasm. These are the type of questions that people ask us. That is what people want to know. They need to know the biological facts but they have other questions. The major concept that we need to promote is that it is quite easy to talk about sex. If one cannot talk about sex, one cannot talk about risk, sexual pleasure and how to have healthy sexual relationships. Our schools programmes focus on these issues. BeLonGTo has school programmes which focus on sexual orientation and we, together with GOSH in Limerick, work on those as well.

The HSE trains the professionals who are working in these organisation. We all have different roles.

Chairman: Will Ms Seery comment on the point made by Mr. Brady in respect of the 11 to 21 age cohort, who are introvert rather than extrovert about certain things? How do we bridge that gap to bring more openness to and better communications on the issue of sexuality? As Deputy Neville said, mental health and sexual identity are twin issues.

Ms Deirdre Seery: They are absolute twins. We often say, if it was only HIV. One of our new services - we are constantly evolving - is sexual issues counselling. Much of that is around people not feeling good about themselves or good about their relationships. Sexual and mental health are intertwined.

I was discussing suicide prevention yesterday. Many people commit suicide as a result of sexual orientation issues that are unresolved, with people not feeling comfortable with their peers and not feeling that they can get out there and develop healthy relationships. These are intertwined issues.

The Chairman asked about the support for those in the 11 to 21 age cohort. We have different interventions for different ages. We have a school programme that is geared towards second year students, a different programme for transition year students and other programmes

for others up to 21 years.

Our booklet, *The Sexual Times*, will be made available nationally, but we have no funding to do it yet. One can never wait for the funding. One has to do things and then hope that the funding comes. We give out *The Sexual Times* to pupils in every school. The booklet looks at issues such as mental health and same-sex relations, and we hope it will become available nationally. We have been distributing *The Sexual Times* in schools in Cork city and county for the past four years. The sky has not fallen down and we have not had a single complaint from a parent. Speaking of parents, the crisis pregnancy programme has very good programmes for parents.

I will now concentrate on all the positive things that are happening, but they are all over the place and everybody does not necessarily know about them. On the question of late diagnosis for HIV, a person who is diagnosed with a CD4 count of less than 350 cells/mm³ is a late diagnosis. Some 49% of our clients were diagnosed at that stage. A very late diagnosis is when the CD4 count is less than 200 cells/mm³. We need to ensure that we get people into treatment before their CD4 falls to those levels. Half of the people are still being diagnosed when the treatment is - while I will not say too late because it is not - not at its most effective.

Senator Colm Burke: Will Ms Seery clarify the levels about which she is talking? Members of the public who are listening to these proceedings may not be aware of this issue and she might clarify the specific CD4 levels.

Ms Deirdre Seery: I am not a medical person and always have avoided medical details because I would not wish to give the wrong information. The virus attacks one's system, so a simple way to say this, because I am simple when it comes to science, is that as it attacks one's system, one's viral load rises and one's CD4 count falls. When one's CD4 count gets to a certain level, one gets treatment. If it falls below that level, the treatment is not quite as effective and one may have developed symptoms. Some people are picked up and are diagnosed by the time they already have developed symptoms. The reason we must get people to test early is because the treatment is much more effective at that point. In respect of where people are born, 41% were born in Ireland and 50% were born abroad. We now have an international environment and it is important to reach out to all populations in Ireland in this regard.

As for one thing that could be done, I could list loads of things but were the national sexual health strategy to be launched, it would pull us together. A strategy sounds like an abstract thing and it has no targets and no timeframe but it is a high-level strategy. One could say it lacks teeth and while I acknowledge it does not have enough teeth, they will come at the implementation stage. We need to put people around the same table to discuss matters, as used to be done with HIV prevention. The national HIV committee no longer meets and is suspended while we wait for the national sexual health strategy committee to be set up. There are wonderful people in Ireland doing wonderful work and if we all gather around the same table to talk to one another, to communicate, to solve problems as they arise and to look at health intelligence-----

Chairman: Is there a pending date for the strategy or is it out in the ether?

Ms Deirdre Seery: I have written to various people and have been told the date would be before the end of last year and that it would be before the end of this year. It is there, it is in the Department and it has passed through various stages. If it is launched, we will then assess constantly the health intelligence information and the gaps therein and will look at the behavioural changes as they change. We will look at the schools programmes and all the issues raised here,

including stigma, discrimination, the services and the gaps in the services. This is all in the strategy and if we all are sitting around the same tables, communication will improve and we will all work together. It really is a no-brainer; we simply must have a strategy.

Chairman: I propose that the joint committee should take up this issue with the Department of Health and the Health Service Executive.

Mr. Peter Foley: In response to Deputy Neville on why home testing has not come to the fore until now, basically, when I embarked on putting together the system, I tried to emulate the national chlamydia screening programme that operates in the United Kingdom. There, they have targeted chlamydia as an area, with much success, and have tried to provide women under the age of 25 with home test kits. Using that as a benchmark, as well as their best practice models, I tried to create a more holistic approach that covered the various infections. However, approximately six months ago, I reached a point at which I realised their system, in which results were delivered via text message, was not suitable, in particular with regard to infections such as HIV. Obviously, there are massive privacy, confidentiality and even emotional issues and there is a responsibility on me or the company relaying these messages that they would not come in such a format. It was at that point it became clear that it would be necessary to integrate existing systems and processes such as hospital infrastructure and whatnot to provide clear pathways to care in order that someone who tested positive would be put straight into the right environment and would not be left to deal with this alone. In addition, the fact that this is an online entity meant that while it started off operating solely within Ireland, there has also been uptake in the United Kingdom. For that reason, I was obliged to find similar pathways by way of the Terence Higgins Trust, which is the main HIV and AIDS charity in the United Kingdom, and Chelsea and Westminster Hospital, which is the number one foundation hospital in London, to try to emulate the work we are doing here in St. James's Hospital. This pretty much is what slowed down the entire process and it is only now that we are really at a point to make noise about it and bring it to people's attention.

In response to Senator Colm Burke, the reference to Ireland and 100,000 people is a misprint. It should have stated the number of people in Ireland and the United Kingdom was 100,000.

Senator Colm Burke: I apologise; I was wondering.

Chairman: Does Mr. Goulding wish to make a couple of concluding comments?

Mr. Jimmy Goulding: I have just one comment. While Deputy Catherine Byrne observed that young people are very aware of their sexuality, I do not believe young people are sufficiently educated in that they go out and have unprotected sex while thinking there now is a treatment for HIV. This is the perspective that young people to whom I talk have. A 27 year old who had been diagnosed with HIV approached me last month. He did not know what HIV was and actually told me that while it was a death sentence years ago, he thought it now was a life sentence because he would be obliged to alter his life and all that. Consequently, I believe that young people are not being educated sufficiently about HIV.

Chairman: From your group's perspective, in terms of visiting schools, for argument's sake-----

Mr. Jimmy Goulding: While we would do that, if they will not allow us, we are not allowed to conduct a sex education programme.

Deputy Catherine Byrne: Mr. Goulding may have misunderstood what I said. I stated that I believe young people are better educated and there are more young people in school than ever was the case previously. My point was that I could not understand why this was happening, but obviously the reason is the system in school does not work. I have raised the programme that is being run in schools at this joint committee. Teachers must teach their own classes sex education and it does not work. I have spoken to many teachers and it does not work. It is very difficult for young teachers to be asked to conduct an SPHE session in which they are talking to those children to whom they probably taught maths or English an hour earlier. The feedback I have been getting from teachers is that this is a real difficulty for them. While I have raised this issue here, I have spoken to a few teachers about it and there should be a system within the education system whereby teachers are specifically identified who are not obliged to teach the programme within their own schools but can teach it in neighbouring areas or communities. Consequently, they would not be facing the young people they know, because Mr. Goulding is correct and I agree with him. I have two teenagers at home and this is not a taboo subject in our house. We talk about it freely enough but the point is that when one is in a classroom and one is a young teacher and one is being asked to talk about people's private experience, it is very difficult for young people to open up. One of the biggest problems is the need to consider a system that allows teachers or specific people to travel around schools and teach this programme.

A long time ago, I raised at this joint committee the possibility of having a mobile bus that would travel to all schools - similar to a mobile library, although one could not borrow a book - aboard which people's sexuality and other health issues would be discussed. While people laughed at that suggestion, one of the best innovations in the country has been the introduction of mobile clinics. When they were introduced, they were great for helping people who had drug addictions. Similarly, while I am unsure whether it is there every evening, I frequently pass a mobile clinic on St. Stephen's Green that deals with those who are homeless. They can step onto the bus from time to time if they have a complaint. It is a great facility to have and I reiterate young people should be allowed the opportunity to be able to express themselves in the classroom, albeit not necessarily with Mr. Brady or Mr. Foley, because they had taught those pupils maths ten minutes earlier.

Mr. Tiernan Brady: That is a good point. We know that education works and equips people to make the best decisions for their lives and sexual health. We also now know there is a barrier to delivering that education for multiple reasons, including some of the ones the committee has correctly pointed out. A proper strategic response is required that accepts that we have a problem and need to deliver education. We need to determine the layers and approaches that can be used to make sure we can deliver it everywhere. The approach in one school might be different from that in another. An NGO presence might visit some schools. Teachers who are trained might travel. There is a requirement to recognise that there needs to be a strategic response to the problem. That is the most important thing, in terms of strategy, to come from this side.

I wish to refer to some figures. Some 41% of people who are diagnosed with HIV are not Irish, but the majority of gay and bisexual men diagnosed are Irish.

Chairman: Can you repeat that?

Mr. Tiernan Brady: I referred to 41% of the total. Well over 50% are Irish, a figure which has decreased. It was over 60% two years ago. One of the groups in which we are seeing a growth in diagnosis rates in Ireland for gay and bisexual men is the Brazilian population. That is something to which there needs to be a strategic response as a group which can be targeted

for messaging.

Chairman: How receptive are people of different nationalities to testing, awareness programmes and sexual health?

Mr. Tiernan Brady: It varies greatly depending on the culture from which they come. Ireland is a great success story. In 21 years we have moved from decriminalisation to being on the verge of a referendum on equal status in the Constitution for couples in terms of marriage. That is not mirrored everywhere in the world. Many people who come from other parts of the world come from places where there is the death sentence, life imprisonment and social ostracisation. Their experience and the barriers they face in engaging with sexual health are increased because of their cultural background. Each area is different and one size does not fit all.

It comes back to the point that while there is a need for a national awareness response, groups have to be targeted and the messages tailored because they face different barriers. We need to make sure we are addressing those barriers with each intervention and are getting to the people we need to reach. On CD4 counts, gay and bisexual men are much more likely to be diagnosed early because they have higher rates of engagement on sexual health.

Chairman: Reference to that was made in the presentation. What about the heterosexual community? How do we raise awareness in that community?

Mr. Tiernan Brady: Again, there are a multitude of responses, whether in schools, targeted at specific groups or at-risk groups or general awareness. There is no one-size-fits-all approach, rather it is about understanding that everybody has different barriers to why they engage on this issue and different levels of awareness. We need to take the resources we have and box clever with them.

Senator Colm Burke: On the 100,000 HIV cases, are there figures on Ireland? It is important that we have the correct information. What, in real terms, are the figures in Ireland?

Ms Deirdre Seery: It is just over 7,000. I have not added in the last quarter's statistics.

Senator Colm Burke: Do those figures refer to HIV?

Ms Deirdre Seery: The figures refer to people diagnosed with HIV. There were 344 people diagnosed last year.

Senator Colm Burke: On the figure of 7,000, is Ms Seery saying that technically there are another 2,000 or 2,500 people who have not been diagnosed but who may very well have HIV?

Mr. Peter Foley: Yes.

Senator Colm Burke: That is the figure we are discussing, that is, approximately 2,000 to 2,500 people.

Mr. Peter Foley: At least.

Chairman: I ask that the witnesses give a copy of their presentation to the committee secretariat in order that it can distribute it to members.

Ms Deirdre Seery: I can guarantee they will not be able to read it. I will type it up when I return to Cork and circulate it.

Chairman: We would like to have it as a resource, in particular the figures. Are there any final comments?

Ms Deirdre Seery: I had a dream regarding mobile testing, but it did not work out. In terms of our sexual health education, we travel all over Cork. We used to travel all over Cork and Kerry but we did not have the resources for Kerry. We have a car which travels to schools and it is very effective. We are not precious. I constantly hear people say they cannot take what we do in Cork into account because it does not happen all over the country. I wonder why they cannot learn what we do in Cork. We will make our programmes available all over the country. We can train people. We are making our Sexual Times available all over the country because people think it is a good resource. We have to share information.

In regard to the education of young people, one does not have to be a teacher. Some of our staff have backgrounds in nursing or teaching and some do not. The most important things are the ability to connect with young people and being comfortable talking about sex. Education does not just take place in school; it also takes place in the home and the broader community and on the Internet. Many young people now think that nobody has pubic hair - I apologise for mentioning pubic hair in the Oireachtas but it is important that we know this - because they are getting their education from porn.

We have to be able to talk to people. It does not matter how much one knows about sex. The actual information one gets about sex is not rocket science. The ability to talk is what is important. Transition year is wonderful for giving people confidence and competence in terms of understanding where they are coming from. The biggest bonus for sexual health education is developing good self-esteem and confidence. One will not let anybody lead one astray if one values oneself. Young people need good general health education and specific sexual health education so that nobody can say if one has sex standing up, one is all right, which is one of the myths out there. They are important in enabling people to stand up for themselves and determine what information is correct or incorrect.

We are a small country. We all know each other. We work well together. We have made major changes over the years. I have every confidence that we will continue to do so. In answer to the question about the heterosexual population, it is the most difficult one in some ways. We do not know who they are. We have people who get a late diagnosis, some of whom are from different countries and are terrified of taking a test because they are afraid they will be sent back to their own country. It is a very diverse population and that is why we need very good health intelligence to break down the populations and be constantly alert about where we can go to make sure people get information about testing. Rapid HIV testing uses home testing in an organisation so that it is coupled with counselling. We are operating from the same page. I have every hope that if we were to come before the committee in five years' time, a lot of what we have said would be history and we would have made even further progress in the field of sexual health.

Chairman: Are there any final comments?

Mr. Jimmy Goulding: We could consider looking at the recommendations of the Equality Tribunal. They are needed for people living with HIV to be treated equally. I thank the Chairman.

Chairman: I thank the witnesses for coming before the committee. I congratulate them on their work they are doing and the very important advocacy role they play in terms of challeng-

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ing the organs of the State and raising awareness among the population. A communication will be sent to members regarding our visit to the national children's hospital site at 12.30 p.m. on Tuesday. On Tuesday afternoon at 4.15 p.m., the joint committee will have a discussion with HIQA on the report on ambulance services. With that, we stand adjourned.

The joint committee adjourned at 11.30 a.m. until 4.15 p.m. on Tuesday, 2 December 2014.