Creating an Agenda for Activism

No Decision About Me, Without Me
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What has Changed?

Mem

Can I take you back to 2004? To the “Changing Tomorrow – Am I Doing Something” conference in Leicester, I had been diagnosed HIV positive in January 2002 and did not know whether I would even be in the UK today writing this article. I told my story to about 400 people in the plenary, still trying to ‘positively’ adjust to living in the UK. I was still afraid of what the future held, uncertain how long my immigration would take and whether I would be allowed to live here. I remember coughing terribly during my talk – just after I had told the audience that the doctor had suspected I had TB – which it turned out not to be. Someone suggested I go and get a second opinion!

The next conference, organised by Positively Women, was in March 2008 – “Positive Action”! I was still waiting for my immigration to be resolved. I spoke in a workshop on influencing services and outlined my experience of being involved with several different user groups. I highlighted the importance of being visible, feeling empowered and influencing services for others. I remember saying, “You need to think, ‘this is MY CARE’ and get involved”; urging other people not to be afraid to ask questions. I suggested that HIV positive people should look out for patient involvement groups, get to know their HIV service commissioners and get involved with local support groups.

What has changed? Well, a lot…

★ I was granted my leave to remain in July 2008 and am now working for HIV i-Base where I co-ordinate the UK Community Advisory Board (UKCAB).

★ A lot has changed in treatment – there are now 30 licensed drugs to treat HIV.

★ Treatment works as prevention – an undetectable viral load reduces the risk of HIV transmission to the negative partner. There is a widening HIV prevention spectrum.

★ There is an “ageing” HIV population.

★ Social networking was probably unheard of (by me at least)…

★ Last but not least, there is research looking at treating HIV sleeping cells, could this lead to a cure or the complete eradication of HIV from the body?

This year at the “No Decision About Me, Without Me” conference I attended three workshops; Networks and Activism, Treatments and Technology and Positive Prevention. The Networks and Activism workshop had three speakers.

It was interesting to see how people living with HIV can influence policy at local borough level. This can be by engaging in the patient and borough consultations on the new GP commissioning. There are opportunities to get engaged in local government; to scrutinise council services and refer any queries to the scrutiny panel. There are area committees; the localism drive will have a bigger voice and building relationships with councillors to get them to know about your organisation. Linking with the Mayor’s office also gets lots of press. Other local networks include LINk and Healthwatch – always challenge the lack HIV and sexual health in their reports to ensure they stay on the agenda.

Another interesting aspect of the workshop was the presentation on digital media campaigns. In today’s modern world, most people use social networking – Facebook, Twitter, to name a few – to communicate and share information. Digital media is an addition to existing traditional campaign tools. This can link your campaign across the world to other activists in a matter of minutes. This medium is safe for those who want to escape government scrutiny in their countries as you can use them anonymously with a made-up username!

In the Positive Prevention workshop, it was interesting to see how treatment is now seen as a prevention tool. Seven years ago, it was difficult for people to admit that they have unprotected sex without worrying about transmission. Evidence from studies shows that people can now have an informed choice on prevention that works for them, especially couples planning to have children in areas where sperm washing is not available, accessible or affordable.

The conference for me was a day to reflect on my own diagnosis, almost 10 years ago and how my understanding of my own care has improved. It was a day of networking with old and new HIV activists. The delegates I spoke to had good things to say about the conference. The feedback was that it wasn’t a heavy conference with too many PowerPoint presentations and everyone felt they were involved and able to participate in the various workshops.

The downside is I am now worrying about ageing but that’s something that I never thought I would live to worry about!

Dear readers,

The clocks have gone back and another year is almost over… Where has the year gone? I keep asking myself!

This magazine issue has stories from the 2011 UK conference of people living with HIV – No Decision About Me, Without Me plus a look at HIV at 30.

It was the third conference organised by Positively UK and over 120 people from the UK attended. The conference was to talk about issues facing people living with HIV – as patient groups and members of society.

During the opening plenary of the conference, it was interesting to hear how treatment has changed – there are more and better drugs with fewer side effects. There is a doctor’s perspective on how treatments have changed over the years. Of course we marked another World AIDS Day, I hope you all wore your red ribbons with pride!

For those who did not make it to the conference, I hope the magazine will give you a full flavour.

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Meanwhile keep warm!

Mem x

Mariella couldn’t quite bring herself to say she is a proper “activist” but rather a vigorous campaigner who just fights for a cause! She would like to get young people involved in HIV campaigns to help fight the stigma surrounding HIV. Stigma in HIV still remains a problem for both young and old people with HIV.

HIV is 30 this year and it is interesting to see how treatment has changed – there are more and better drugs with fewer side effects. There is a doctor’s perspective on how treatments have changed over the years. Of course we marked another World AIDS Day, I hope you all wore your red ribbons with pride!

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Dealing with the NVQs

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On a bright summer morning in 1985 I joined a small group of people with HIV gathering on the edge of Hyde Park at Speaker’s Corner: the starting point for that year’s Gay Pride march. I was surprised to find myself there. I had never seen myself as an “activist” or the sort of person who goes on protest marches. Gay Pride marches in the 1980’s were not the carnivals they are now; they were serious political protests against the rampant homophobia and discrimination of the time. I was nervous too, partly because I didn’t know what to expect – the police were out in force – could there be violence? But we were all nervous, mainly because we were going to march under a Body Positive banner. Body Positive had been founded earlier that year as the first “peer support” organisation of and for people with HIV. We would be “coming out”, in a very public way, as HIV positive; it would be the first ever act of public protest by a group of HIV positive people in the UK. What had driven us to it? This was when newspapers were full of stories about AIDS as an unstoppable killer disease, a “gay plague” spreading inexorably and threatening everyone. It was before any public education campaigns telling people about the very limited ways HIV and AIDS could be caught. Because no one knew where AIDS had come from, it was widely perceived as a penalty for immorality: people who got AIDS deserved to die. The prevailing attitude to people with AIDS and “AIDS carriers” was fear and disgust. The public wanted to be protected and there were demands in the press and by MPs that people with AIDS or HIV should be forcibly detained and kept away from the rest of the population.

There was no public understanding of the distinction between an AIDS diagnosis and HIV positive test result. There was no treatment. Anyone with HIV was assumed, like someone with AIDS, to be dying. We were marching to try and claim, in the face of all that prejudice and ignorance, the possibility of, and the right to, a better existence than that of condemned pariahs. None of us knew what reaction we would get. Although other people on the march probably knew what Body Positive was, it was so new that few, if any, members of the public along the route would understand what the name on the banner meant. But if they stopped one of us and asked us to explain, we would have to say what we were and what Body Positive stood for. Few of us thought the reaction would be sympathetic.

What drove me personally? If, because it was untreatable, I couldn’t do anything about the HIV inside me, I had to do something about the HIV outside me. If my time was limited, I wanted to be able to say, when it ran out, that I’d used it well. I could try and make sure other people finding out they had HIV didn’t feel as isolated and terrified as I had felt. I couldn’t tolerate the thought that people who knew nothing about me could judge me morally, decide that I was a threat to public health, take away my rights and even “detain” me. I felt betrayed by having been brought up to believe that society was fundamentally compassionate and finding that, in reality, people – my friends – who had acquired a terrible and fatal disease, and who were dying horribly, could, despite meaning no harm to anyone, be met with revulsion and refusal to care. I was very angry.

Other people with HIV might define what drove them differently, but, over time, this need to be “doing something” about the HIV inside and outside us came to be expressed in different but complementary ways. In helping and supporting each other; in campaigning for effective treatment; in empowering ourselves with the knowledge we needed to maximise our health and shape services to meet our needs; in demanding involvement in decisions about our treatment and care; in asserting our human rights and in challenging stigma.

Now, 26 years later, we have effective treatment; we are probably one of the most educated and empowered groups of people with a medical condition in history; the principal of involvement in decisions about treatment and care – “no decision about me, without me” – is claimed by the Government to be the cornerstone of its reforms of the NHS; our right to freedom from some of the worst forms of discrimination is protected in law, and the general public is better educated about HIV so there is less fear of people with HIV and, consequently, less stigma.

With all this progress, do we still need “activism”? The 150 people attending Positively UK’s activists’ conference would have answered with an emphatic, “Yes!”

The need to help and support each other is as strong as ever. Join the online forums at myHIVorg.uk and you’ll find, especially for the newly diagnosed, an outpouring of mutual advice and support.

Although we have drugs to keep us alive, HIV can still damage our health and, it seems, age us prematurely. We’re vulnerable to mental health problems. Co-infections and drug resistance complicate treatment. We need drugs with fewer side effects. We need a cure.

The growing numbers of people with HIV, estimated to be 100,000 by next year, and Government spending cuts mean that decisions about care and treatment are increasingly influenced by the need to save money, making it all the more important that people with HIV are involved and consulted to minimise adverse effects on our well-being.

Although we are legally protected from some forms of discrimination, the old urge to protect public health by penalising people with HIV keeps surfacing in, for example, attempts to extend criminalisation of HIV transmission.

And as for stigma: in some communities it still feels like 1985. Of all the things that were wrong about society’s response to AIDS and HIV, it was the stigmatisation – the abuse and lack of compassion for people suffering and dying – that I found most difficult to accept. I simply didn’t think it possible that anyone who really understood what it was like to get an HIV or an AIDS diagnosis could react with anything but sympathy. And after 26 years of talking in public about what it’s like to have HIV, I know that’s true. Nothing is more effective in dealing with stigma, in widening the circle of empathy, than talking with absolute honesty about what having HIV is like and how other people’s reactions affect us.

Life-saving treatment for HIV has freed HIV activism, in the UK at least, from having to be about life and death. It means that, now, a conference of HIV positive activists involves a rich mixture of teenagers and pensioners, men and women, gay people and straight, black and white. I’m sure this diversity is one of the reasons why, compared with the last conference of people with HIV I went to in 2001, there was at the 2011 conference, a very different tone: less strident, less confrontational, more constructive; a greater appreciation, perhaps, that the complex issues we face about treatment and care, social disadvantage and stigma will be solved more by engagement and attention to detail than passionate rhetoric.
Networking, Youth and “Positive Prevention”

Alice Welbourn

It is always a great thrill for me to meet together with a large group of “activists” living with HIV in the UK especially. Since I live in a very rural part of England and since my work is largely focused outside the UK, I normally attend gatherings of positive people in far-flung corners of the world, be it Mexico, Vienna or, most recently, Rome. This might sound quite exotic to some – and if it weren’t for the jet lag, the extremely long intensive hours there and the weeks of exhaustion involved beforehand, I guess it is. One thing for sure is that all such events are always very emotional – reconnecting with old, dear friends, mourning together the loss of those who have passed on and wondering where we will all be in a year’s time.

The conference in London in September – the first national conference in the UK for several years – was no less emotional and rather more poignant for me, given that it was in Britain, full of people with HIV in this country, addressing issues just facing us here – no matter how similar these issues might still be to the global issues facing many others also. There were the “dinosaur” moments where several of us who had last met together on an advisory panel in the mid-1990s were glad to find one another, still alive, and still very much involved. There was the thrill of the new, with the terrific presentations of a new fresh, young and female generation in the open and closing plenary, questioning the meaning of the identity label “activist”; and there was the sense of apprehension hanging heavy in the air over us all as the new NHS “reforms” are set to challenge, yet further, our rights to high quality, equitable, judgment-free services.

I took part in three particular sessions which interest me. The first, on networking, included two valuable presentations. One was from Simon Mitchell, Head of Well-being and Involvement, London Borough of Hounslow, who presented a useful guide to lobbying MPs, health and local authorities to ensure that existing services are not cut. The other was from Agnes Hall, Digital Campaigner from ActionAid UK, about the power of social networking sites such as Twitter, Facebook, Hollerback and others, to hold governments to account, to spread the word about issues and to reach out to a younger, newer generation of the public on the issues we all face. (Both presentations are available on the Positively UK website.)

The latter presentation in particular raised valid concerns about privacy and confidentiality – issues we have all faced at one stage or another along the line, which are increasingly challenged by photo-tagging in Facebook, mobile phone videos and the power of internet search engines. In this regard, I know a number of young women globally who have been powerful public activists whilst single, who have then chosen to withdraw from the public gaze once deciding to have children. This step back into anonymity, whilst entirely understandable in the context of wishing to protect our children from the stigma which we all still face, is increasingly challenged by IT.

Another session I took part in was led by young delegates, including two useful guides to lobbying MPs, health and local authorities to ensure that existing services are not cut. The other was from Agnes Hall, Digital Campaigner from ActionAid UK, about the power of social networking sites such as Twitter, Facebook, Hollerback and others, to hold governments to account, to spread the word about issues and to reach out to a younger, newer generation of the public on the issues we all face. (Both presentations are available on the Positively UK website.)

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Talking about the issues they have faced in growing up with HIV from birth here in the UK. As usual I was bowled over by their strength, their humanity, their determination to turn things round for their own generation and the challenges which they continue to face with dignity and courage in their own lives. All this sounds so clichéd, but anyone who knows whom I am talking about will know just how much they personify this description.

Last but not least, the session on “positive prevention” – or “positive health, dignity and prevention” as we, thankfully, prefer it to be known. In the light of the new wonderful findings that those of us with a stable CD4 count and undetectable viral load are virtually unable to share our virus with anyone else, even if we tried to conform to Red-Top

and the public’s thinking about what HIV means in all our lives. Policy makers like to say, “Oh, HIV is now just a long-term condition, like diabetes”, in order to justify their funding cuts to our services. I am not trying to suggest that diabetes is an easy ride for anyone. Nonetheless, I look forward to the day when people newly diagnosed with diabetes can feel comfortable if they are told, “Oh diabetes is now just a long-term condition, like HIV.” Maybe then we will all have something to celebrate together and we can all hang up our activist cloaks for good.

Nonetheless, I look forward to the day when people newly diagnosed with diabetes can feel comforted if they are told, “Oh diabetes is now just a long-term condition, like HIV.” Maybe then we will all have something to celebrate together and we can all hang up our activist cloaks for good.
Outraged from Yorkshire

Julie Reynolds

I attended the “No Decision About Me, Without Me” conference wanting to get a better understanding about the changing landscape of health and social care, its impact on the HIV sector and how best I can take action to influence change. The conference gave me some food for thought. Jonathan Grimshaw remains inspirational as a man and a campaigner and took me back to times when there were no treatments and we lived in uncertain times. We now have treatments but, the NHS and welfare state are going through times where their survival is uncertain. The conference left me wondering if I would have to compromise my beliefs and values to fit in where fierce debate, protest and outrage seem to have no place and indeed if I should make that compromise.

On the 5 July 1948, Bevan’s National Health Service Act of 1946 came into force its champion Nye Bevan proclaimed, “No longer will wealth be an advantage nor poverty a disadvantage. Healthcare will be provided free of charge based on clinical need and not on ability to pay.” Or so Nye Bevan believed. The creation of the NHS was a radical and hard fought ideological battle and these reforms were not achieved in times of affluence and prosperity; they were achieved in the face of great financial difficulty following World War II. These reforms were about equality for all.

I was a little surprised when the negative implications of the NHS and welfare state “reforms” were skated over at the conference with no real opinion one way or the other expressed. I find it difficult to believe that people didn’t hold strong opinions about something that will impact on the poor and vulnerable the most, or maybe a conference about the changing landscape of health and social care was not the place to express it. When I raised concerns about this another participant said, “Well it’s happening, there is nothing we can do we just have to work with it.”

I am sure there are many similarities and parallels between these reforms and the current ones, to think that the NHS and welfare state are going through times where their survival is uncertain. The conference left me wondering if I would have to compromise my beliefs and values to fit in where fierce debate, protest and outrage seem to have no place and indeed if I should make that compromise.

Under the new plans, by 2014 NHS hospitals will no longer beanswerable to the taxpayers who have paid for them over the years and they will no longer have the overriding aim of providing the best possible healthcare for the local community. Businesses will be competing with private hospitals and clinics for NHS patient income. These are generally large, multinational companies. They are attracted to providing NHS patient care because they see it as being profitable for them! Therefore there will be a focus on profitable treatments and neglect or even abandon high-cost and unrewarding ones in order to match the for-profit sector.

Is no-one thinking all this may leave us with health services that are less accountable, less responsive to the needs of clinicians and patients and, ironically as a result, less efficient? In the 1980’s the cleaning of hospitals was “outsourced” to the private sector and given to the lowest bidder, the cost of cleaning was cheaper but, surprise, surprise hospitals became dirtier and as this was not done in-house more difficult to resolve quickly. This in turn led to super bugs like MRSA, which guess what? Not only cost people their lives but also cost the NHS millions.

“Efficiency”, “savings”, “restructuring”, “reforms” are just another euphemism for the “C” word – Cuts. The NHS is already cutting costs as they try to reduce their spending by 33% or £20 billion. To stay afloat financially they will have to cut costs further, reduce staff (54,000 NHS jobs so far and still counting), lower the “skill mix” (“limit or remove” mandatory staffing ratios which stipulate the number of registered nurses to patients a ward should have) and reduce levels of pay (re-apply for jobs at a lower band and lower rate of pay). These cuts impact doctors (and consultants) who have to pick up the administration and support work themselves. This means less patient time. Patient Involvement initiatives are not immune from the cuts either. On a personal level I don’t mind giving up my time to help a public NHS, to offer my expertise as a patient representative or be part of a forum, but I am not willing to see private companies profiting from me giving my free time or spinning opinions to suit their own, using “Patient Choice” as a tool to manoeuvre private businesses in. A number of leading health charities agencies such as Alzheimer’s Society, Asthma UK, Breast Cancer Care, Diabetes UK, National Voices, Rethink, the British Heart Foundation and the Stroke Association all think that patient power could be weakened by the radical changes and cuts. Strangely no national HIV organisation seemed to agree – at least not publicly anyway.

The aim of all of this “restructuring” is to take chronic care out of hospitals and deal with it in non-hospital settings – “super-surgeries” or clinics, largely owned and run by private companies. Expertise and capacity for research within NHS settings could also suffer as private companies “cherry-pick” the more profitable but clinically less important work. Already, large elements of the health service are falling into private hands. Last September, Serco, the multinational services company with an empire stretching from railways to maintaining ballistic missiles, became the UK’s largest provider of pathology services, a market worth £2.5 billion, with the takeover of King’s Hospital laboratories in London.

Let’s not forget a private company’s first obligation is to its shareholders, not to the NHS, not to the doctors within it and definitely not to the patient. The patient cannot come first under this system. We are rapidly moving towards a healthcare market, very like that in the United States. The US system is not equitable, it does not work for those who are the poorest and it is costly.

The US spends more per capita than any other nation in the world on this public/private health care system and more money per person is spent on health care than in any other nation in the world, but is one of the few industrialised countries that lacks some form of universal health care. Health insurance in the US is expensive, rapidly rising costs are affecting employers and consumers as well as the government, and a study in Health Affairs concluded that half of personal bankruptcies involved medical bills. Poor people have lower life expectancies, higher prevalence of chronic illnesses and health conditions, and more unmet health care needs. Health insurance in the US is expensive, rapidly rising costs are affecting employers and consumers as well as the government, and a study in Health Affairs concluded that half of personal bankruptcies involved medical bills. Poor people have lower life expectancies, higher prevalence of chronic illnesses and health conditions, and more unmet health care needs.

Under the new plans, by 2014 NHS hospitals will no longer be answerable to the taxpayers who have paid for them over the years and they will no longer have the overriding aim of providing the best possible healthcare for the their local community.
People with HIV in the UK may feel under attack from a number of directions. Specialist social care for people with HIV is being cut. So are mental health resources. Prevention for people with HIV – how not to pass it on to our partners – is conspicuous by its absence from the public eye, except when HIV MONSTER headlines hit the nationals. In London, the ever-expanding HIV drugs budget has led to tighter control over which HIV drugs are prescribed; this is likely to happen elsewhere.

In some other ways, however, the opportunities for HIV activism may be better than they’ve been for a while. This is partly because of an increasingly restless body politic generally ranging from cuts protests to riots. But the NHS reforms and parliamentary concern at the increasing burden of HIV in the UK and an apparent failure to rein in the epidemic may lead to new opportunities for campaigning and getting involved.

Keith Alcorn writes:

The British response to HIV has been left to slide in recent years. Although we have one of the best standards of treatment and care in the world, our record on prevention is unimpressive to say the least.

However politicians are waking up to the extent of this mistake, and at the end of 2010 the House of Lords decided to establish a special committee to investigate the state of the HIV response in the United Kingdom. It was set up at the urging of Lord Fowler, responsible for the “tombstone” HIV prevention campaign of the 1980s and for the relatively pragmatic way in which a Conservative government set about dealing with thorny issues such as talking about sex in public.

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When a committee is led by a high-profile peer, the recommendations will attract attention, especially at a time when health policy and getting value for money on health are at the centre of national politics.

I was invited to give evidence to the committee. Though Parliamentary Select Committees often look like the Spanish Inquisition, this one was less interested in scoring points and more interested in hearing from a wide range of people living with HIV, HIV specialists, NHS commissioners and prevention experts.

Where the committee wanted to know, could treatment be delivered most effectively? It had just been announced that commissioning of HIV would stay with a strategic commissioning body, rather than being devolved to GPs. But there was still interest in the extent to which HIV care could be delivered locally.

I felt it was particularly important to get across two points. The first was to help the committee to understand that the needs of people with HIV in the UK continue to be complex; it would be a mistake to assume that everyone will eventually be cared for through GPs. Most of us have access to a standard of HIV care that is amongst the best in the world, so ripping up the current system without recognising its strengths would be a disaster.

Management of patients with stable HIV infection may eventually be suitable for general practice or polyclinic-type centres with clinical nurse specialists. Better monitoring technologies, greater durability of HIV treatment and home delivery of medication may mean that people stabilised on HIV treatment might only have to attend a hospital, say, annually.

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As the HIV positive population ages, there will also be a growing need for collaborative working between HIV services and other specialisms such as cardiovascular medicine, oncology, hepatology and geriatric medicine.

Effective commissioning will require the recognition that the long-term needs of the HIV positive population will remain complex and possibly get more so.

**Prevention**

The committee has also heard clear evidence from the Health Protection Agency (HPA) about continuing rises in diagnosis amongst gay men in the UK, and heterosexuals infected here.

“We are advocating a substantial increase in the intensity of testing in the gay community”, Professor Noel Gill of the HPA told the Committee, insisting that the continuing high rate of new infections among gay men needed to be tackled by intensified combination prevention built around the GUM clinic network.

There was considerable disagreement in the evidence given to the Committee regarding the current state of HIV prevention in the UK. A minority of witnesses and submissions to the Committee, including David Bridle, owner of Boys magazine, were highly critical of current HIV prevention messages, criticising them for appearing to condone sex without condoms.

The majority of witnesses were keener to stress another problem with HIV prevention in the UK: the sheer lack of scale. The government spends £750 million a year on treatment but only £3 million on prevention campaigns. The Committee returned again and again to this problem when questioning witnesses, and it ended up making a strong recommendation that more money be devoted to HIV prevention in the UK.

**Recommendations**

It was clear that one thing which excited the Committee was the idea of another national HIV prevention campaign, and no-one was surprised when it turned out to be a headline recommendation. Health Minister Anne Milton expressed scepticism about this approach, saying it might be a diversion of attention away from the bigger issue of how we increase the scale and effectiveness of prevention, but at the very least, the committee argued, if there is no national prevention campaign, HIV must be integrated into future sexual health campaigns.

“In particular”, Lord Fowler said, “We want to see a new emphasis on people getting tested,” and an expansion of testing – outside GUM clinics, as routine upon registering with a GP, to all hospital in-patients, to all patients with TB, and on treatment, the Committee wanted procurement of HIV drugs to be conducted on a national (English) basis. On the one hand, this would enable the NHS to drive a tremendously high brand with the pharmaceutical industry. On the other, it runs the risk of HIV care being standardised to a lowest common denominator and individual physician/patient choices being squeezed out.

**No Decision About Me, Without Me**

Gus Cairns writes:

With the political push for HIV reforms stronger than it has been for some time, I attended “No Decision About Me, Without Me”, the first conference of people living with HIV in the UK since Positive Action 2008 three and a half years ago.

It’s interesting comparing the discussions at this conference with the one back in 2008 and realising how much our world has changed.

The two issues that stood out at the 2011 conference weren’t even seen coming in 2008: the wholesale reform of the NHS and of public health and the related subject of cuts to HIV health, social care and prevention.

The Chair of the All-Party Parliamentary Group on AIDS, Pamela Nash MP, opened the conference. She said that late diagnosis remained one of the greatest challenges to HIV healthcare and as a gesture against stigma, was about to take an HIV test herself and would announce the result on World AIDS Day.

Jonathan Grimshaw MBE, one of the first people diagnosed in the UK in 1984, said that the biggest challenge to the continuing empowerment of people with HIV was that the current model of HIV care was unsustainable, “because treatments are successful, there are now 100,000 of us … and we are seeing some social care and even some treatments withdrawn or restricted. Stigma and poverty blight the lives of too many”, Jonathan also pointed out the ageing of the HIV positive population and how to resource their future medical and social care needs was also problematic.

Neil Beasley, a Terrence Higgins Trust director, mapped out the health and social care landscape we will inhabit in the next few years. One challenge is money: HTF had a 25% cut in statutory income this year, they expect next year to be worse, and they have fared better than some other organisations.

HIV services will be commissioned by two very different ends of the health spectrum. HIV treatment will be commissioned by the NHS Commissioning Board; on the other hand HIV testing, STI services and HIV prevention services will not be run by the NHS at all but by local authorities as part of an expanded public health remit.

The dangers of fragmentation are obvious, as is the striking lack of Primary Care and GP involvement – an opposite pattern to other chronic health conditions such as diabetes.

**Opportunities for Participation**

The workshop on health and social care that followed uncovered a number of opportunities for patient power within the new structure. Local authority prevention and testing services are now being overseen by local Health and Wellbeing Boards whose job is to co-ordinate services. They will include councillors, GPs and the local Directors of Public health and Social Work but must also have patient representatives on them.

Another opportunity to get involved in through Health Watch, local authority “consumer forums” that are part of the Care Quality Commission and replace the previous LINKs (Local Involvement Networks).

How to get involved at the “top end” and influence the NHS Commissioning Board is more problematic, but one opportunity may be provided by NICE, the National Institute for Health and Clinical Excellence. NICE has to involve patients in its consultations and is increasingly getting involved in guidelines, not only on HIV testing and prevention, but also on the quality of evidence and rigour of the next set of BHIVA Treatment Guidelines.

On the local level, Forum Link, up till now an ad-hoc federation of clinic patient groups, is seeking voluntary organisation status and may provide a more co-ordinated patient voice in the future alongside the UK Community Advisory Board (UKCAB).

At the end of the day Jonathan Grimshaw remarked on the constructive and engaged atmosphere at the conference and the lack of over-strict demands. Although people with HIV may face a strained existence in the future in terms of benefits and treatments, the system is not automatically loaded against us and the opportunities to have your voice heard are, if anything, better than ever.


NHS and Social Care Reforms - How Can We Influence Our Services?

Susan Cole

After four years of baby production and children’s television viewing I’m back at work, this time for NAT. I assumed I’d be eased gently into my role, certainly not expecting to have to present at the conference on changes to the NHS and social care. If it was on changes to the social network of Peppa Pig there would be no issue. Somehow I managed to muddle through and have apparently assimilated some of the information.

We may not like it but NHS and social care reforms are heading our way and we need to be prepared.

So how will things change? A new national body “The NHS Commissioning Board” will be responsible for primary care (such as GP services) as well as authorising the newly created groups of GP practices “Clinical Commissioning Groups” who’ll be responsible for most secondary care (such as hospitals). There has been some concern about HIV care being under the responsibility of GPs, but this will now not happen. The central NHS Commissioning Board will also commission HIV treatment and care.

What about new social care arrangements? Social care will continue to be commissioned by local authorities, and although there will still be continued “HIV/AIDS support” in a financial grant from central government; this funding is not ring-fenced.

The theme of the conference was “No Decision About Me, Without Me” This theme is particularly pertinent in relation to the NHS changes, so we need to consider what we can do to influence our services. There are a number of possibilities. Clinical Commissioning Groups and the NHS Commissioning Board will have a legal obligation to involve and consult on their plans. These plans will give details of how services are delivered. So this should give us a key chance to have our say. For example, do we want HIV clinics to provide better mental health support or safer sex support? We can try to get the commissioning plans to include it.

An important body that will be set up when the changes come into effect is The Health and Well Being Board (HWB). Their main purpose is to ensure NHS services, social care and health improvements all join up and support each other. This may be important for many people living with HIV who need social care support as well as NHS services. Every local authority will have a HWB. They have a legal obligation to involve the public in their work and meetings are meant to be in public. Hopefully we can assert some influence here. The HWB are meant to ensure they get input and advice from community organisations. We can ask the Board to hear from HIV voluntary groups as well as gay and migrant organisations.

The two key documents for local services produced by the HWB will be the Joint Strategic Needs Assessment and the Joint Health and Well Being Strategy. All local services should be planned on the basis of these documents. If we manage to influence these documents effectively we should ensure our services reflect the wishes of people living with HIV.

Represented on the HWB will be an organisation called Health Watch. Set up in every local area to promote patient and public involvement and seek views on local services. They will be replacing Local Involvement Networks (LINks) and will be funded by the local authority. Health Watch should also seek views on local health and social care services which can be fed back into commissioning. Health Watch will have a very important voice at the local level so we need to consider how the opinions of people living with HIV are heard by them and ensure they are effectively representing our needs.

Another opportunity for us to influence healthcare services is through the three new Outcomes Frameworks on the NHS, public health and social care, as emphasis will now be on assessing outcomes rather than activities. Local authorities and the NHS will be obliged to look at these when evaluating their own performance and it will give us a chance to see how they are doing. The public health outcomes framework hasn’t yet been finalised but we are hopeful that there will be an indicator on late HIV diagnosis in the final version. The other two have been published and includes an outcome indicator on employment of people with long term conditions (including HIV) and how many people with a long term condition feel supported in managing their condition. We have the potential to look at these indicators and if we find our local authority isn’t doing well point it out to them and try to get them to improve.

Participants at the workshop on NHS and social care reforms identified a number of challenges we could face in trying to influence HIV services. There were concerns about the HWBs and how the diverse voices of people living with HIV could be heard, particularly in rural areas and with the fear of stigma and discrimination. However the HWB was regarded as a key opportunity to influence our services. A number of people said there were already problems as people with HIV are often “ping-ponged” between their HIV clinic and GP, each saying the other is responsible for a particular aspect of care. Will the new system make things even worse? It was pointed out that the NHS Commissioning Board will be commissioning both HIV clinics and GP services, so it is well placed to “bang their heads together” and get this problem sorted out. We need to alert them to this problem.

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To see so many people attend a workshop whose very subject matter would have been unthinkable only ten years ago is itself a great vindication of the success of combination therapy. Recent studies show that someone diagnosed with HIV today who starts treatment with a healthy CD4 count can expect to live well into their 70s—an age broadly comparable to the general population of the UK.

This is borne out by the increasing numbers of older adults who are living with HIV—one in five people living with HIV in the UK are over the age of 50, a figure that will continue to rise as we all live longer and as higher numbers of older adults are diagnosed. New diagnoses in the over-50s age group doubled over the last decade, and two-thirds of those were diagnosed late, begging the question – where is the safer sex information for older adults, and who is providing it?

So, whilst longer lives are undoubtedly a cause for celebration, for many of us with HIV, long-term survival will bring its own set of challenges. The focus of the workshops at the ‘No Decision About Me, Without Me’ conference was to explore these challenges, with lively discussion following on from a presentation on the 50Plus research that was carried out by Terrence Higgins Trust in collaboration with Age UK, for background reading the full 50Plus report including recommendations, an executive summary and a resource written by and for people living with HIV over 50, are all available at www.tht.org.uk/50Plus.

A large proportion of both sessions focused on health-related matters, not least the oft-quoted possibility of us developing a range of age-related health problems (cardiovascular, bone density, renal, neurocognitive, cancer, diabetes, frailty) and at an earlier age than usual. It is worth noting that much of the clinical research on this topic has been done in America, where the HIV population and healthcare system are very different to the UK, and which is therefore not always a reliable comparison.

Professor Jane Anderson (who was present for the morning session) reinforced the For example, a 50% increase in the risk of developing a cancer sounds horrendous until you consider that if your initial risk is 1%, the additional increase means that your new risk is only 1.5%. better health outcomes that we have in the UK and that fact that despite the increased risks of developing some conditions, the statistics often sound scarier than the reality. For example, a 50% increase in the risk of developing a cancer sounds horrendous until you consider that if your initial risk is 1%, the additional increase means that your new risk is only 1.5%.

There was also great emphasis placed on the ‘No Decision About Me, Without Me’ theme, there were a number of workshops on HIV and Ageing to provide an excellent solution to both problems, and could be easily set up with the peer communications network that we now have in place.

In short, with longer life comes a need for greater forward-planning on all our parts to ensure that our health and well being needs are identified and catered for in a sensitive and appropriate manner. Some of this work can be done on an individual basis, but we will need to work together to have an influence on the NHS and the services that are dedicated to taking care of us in our old age, but which are currently, in all likelihood, unfit for purpose.
What really stood out for me was the development that has taken place in treatment over the years. There is now in total 30 drugs to treat one illness. Current drugs may not be perfect but in general treatment is safer than people believe and benefits people beyond keeping us well, it also reduces transmission across the board. Those with a long-term undetectable viral load, now have the same life expectancy as someone who is HIV negative. Sounds too good to be true given that I was written off in 1992 with only 18 months to live and now, nearly 20 years later, I have the hope of twenty and more years to come.

The belief that treatment is toxic in not supported by evidence; the Strategies for Management of Antiretroviral Therapy (SMART) study changed this view. SMART was a large international study designed to examine the effects of intermittent treatment in HIV positive people. The study recruited 6,000 patients, all with CD4 cell counts of 350 cells/mm³ or greater. They were randomised to receive continuous anti-HIV treatment, or to receive intermittent treatment on the basis of their CD4 cell count. Surprisingly, the study found that patients on intermittent treatment were more likely to experience serious complications usually associated with HIV treatment. Going on and off treatment is not a safe option and treatment interruption is not a good idea. If and when you experience side effects talk to your doctor about managing them, having a good relationship with your doctor can be helpful. Try and see the same doctor where possible and bear in mind the better you are as an advocate for yourself the better the outcome.

These are some of the interesting points that came up during the workshop:

- There are new guidelines for starting treatment when viral load is high regardless of CD4 count.
- Interesting studies looking at the difference and benefits of starting treatment with CD4 count between 500 and 350 copies.
- Last but not least there is also exciting developments that is looking at the long eradication of HIV. The case study is exploring how to activate latent cells as current treatment does not work on infected sleeping cells. That’s why a cure is difficult.

For a more detailed account and more information of current studies and treatment contacts www.i-Base.info.org.uk and info@nam.org.uk and remember “No Decision About You, Without You” where your HIV care is concerned.
"Nothing About Us Without Us"

Silvia Petretti

I firstly heard the expression "nothing about us without us" at a meeting of the International Community of Women Living with HIV (ICW), and if you go to the ICW Global website it still runs as a banner in capital letters on the home page. This expression ticks all the right boxes. It uses a "us" language, stressing the importance of collective action, it expresses values of participation and inclusion which are fundamental to real democracy. It is about power being shared equally. It is about voice and control.

With a little bit of research, and a few mouse clicks, I discovered that this expression has its roots in the Disability Rights Movement (DRM). It was the title of a famous book by the disability activist James Charlton. The author first heard it from South African activists from the DRM, who claimed it came from activists in Eastern Europe. So it originates at least partially from South African activists from the DRM, who claimed it came from activists in Eastern Europe. It was the title of a famous book by the disability activist James Charlton. The author first heard it from South African activists from the DRM, who claimed it came from activists in Eastern Europe. So it originates at least partially from South African activists from the DRM, who claimed it came from activists in Eastern Europe.

It all sounds very familiar, doesn’t it? Obviously there are many affinities between the disability movement and the movement of people living with HIV. Many of the barriers we face are not imposed by the virus or physical limitations but by society. The enormous advances of medical care mean that many of us have, from a narrow medical point of view, healthy lives. However society’s attitudes and prejudices towards HIV still prevent many of us to live our lives fully, or at the same standard as anybody else. To give some examples, in the past few months I attended a support group where young beautiful women were isolated and terrorised to disclose their status to anybody, and hadn’t had a relationship in years. I met a mother who had her children separate cutlery and plates because of the fear of HIV. A few weeks ago a colleague who is also openly living with HIV and has often spoken publicly about stigma, had eggs thrown at her. This is happening in the UK in 2011. The virus may be undetectable in our blood, but stigma is around us: often reinforced by other social factors, such as poverty, gender inequality and racism. Reclaiming our voice, reclaiming our visibility, is part of our struggle.

“Nothing about us without us” has recently moved from being the slogan of those at the margin, fighting against oppression, to being integrated in the mainstream and absorbed in the language of those in power. The current UK Government used “nothing about me, without me” as the mantra of their plans to restructure the NHS. This time they stressed the individual, “Me” instead then “Us”. After much debate the NHS reform bill was passed in Parliament. The bill includes much more localised health boards in which patients, including people with HIV, and other stakeholders, such as healthcare providers, and elected decision makers, will have a place to influence how health services are delivered. So far so good, it is difficult to argue about 'shared decision making', and there is a wealth of evidence that shows that when ‘patients’ are involved in all decisions and planning of their health the outcomes are better. However it implies that there is a level playing field for all people who access health care. Sadly the reality is that we live in a very unequal world, and I am doubtful that people with HIV, and especially those who are poor and isolated, will be able to seat on those decision making bodies.

At the International AIDS Society conference in Rome last July, Louise Binder, an HIV positive woman and advocate from Canada said, “At school I learnt that if A equals B and B equals C then A equals C. We keep hearing Knowledge is Power. And I know that Power equals Money, so therefore Knowledge equals Money”. Louise’s point was: how can we know our rights and our interests do we represent? We are a very diverse group and this is our richness as well as our weakness. Questions of how we can better represent our diverse communities and also how we can be accountable also belong to us at the grassroots as much as to those at the top.

The hard questions we need to ask ourselves as advocates are about who is the “US” in “nothing about us without us”...

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Dictionary

An activist: the policy or action of using vigorous campaigning to bring about political or social change.

I am Mariella a 19 year old girl who’s finding it difficult to define my position in the “HIV world”. The term activist has never sat right with me, yet is a term that has been used many times to define me. If people consider me to be a HIV activist when did I begin? Will I ever lose this title? And what do people assume of me as an “activist”?

The recent Positively UK “No Decision about Me, Without Me” conference gave me a chance to seek a definition I was comfortable with. I went to the networking and activism workshop in hope of enlightening my role within this world. I was slightly disappointed as I hoped to come out with a clear definition of what activism was but I left with yet more questions. Networking was quite dominating in the session and a key point was highlighted regarding identity and activism. Social media can be such a powerful tool when used correctly. One attendee of this workshop explained how with HIV you can’t always use your real name due to confidentiality and stigma issues. Does this mean it is less powerful when you don’t use your real name? If this is the case then everything I have to say surely becomes invalid if I am unable to put a real name behind my points?

For the past five years I have become increasingly involved in HIV work, having become a part of the Children HIV Association (CHIVA) youth committee and volunteering at Positively UK. With these roles I have spoken at conferences, presented abstracts and met MPs to see how they can change the way HIV is taught in schools. With anything made public I never use my real name. My definition of public in this sense is any media that could be seen or heard outside the HIV sector. I am still as fearful of stigma and discrimination as I was five years ago. It is mainly the worry of my peers finding out and being met with a bad reaction. No matter how empowered I feel after conferences or meeting with such great people who encourage me to tell my story I still refuse to cross a certain point.

This brings me back to activism, in my opinion a true activist would be able to stand on a pedestal and shout out the issues they want changed. They shouldn’t be hiding behind anything. I want to make a difference in the world mainly due to the fact I can. HIV affects me hugely in my life so it is a way of dealing with my own status; I cannot lie to you and say if HIV didn’t affect me I would be as ignorant as the next person.

If everyone had my status and the supportive role models I have surely they would do the same as me? When I speak at conference or change a disturbing “AIDS” joke into an education and informative opportunity I don’t do it from an activist perspective, instead I do it from mine. I am Mariella – a 19-year-old who would just like the world to be a bit more educated.

That’s why I have decided I am NOT an activist nor do I want to be considered an activist. Perhaps in the future this will change and many people will still consider me one no matter what I say. I don’t feel as yet I have earned the title of activist. In my eyes Jonathan Grimshaw is an activist one I look up to and maybe one day, when I am older, I will aspire to be like. Until I am surer of both the implications and role this will have on me I will stick to being passionate about certain subjects.

For now I leave you with this. I am Mariella, a young girl hoping to change how the world sees me and HIV. One step at a time!

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Interview with Pamela Nash MP and Heather Alcock

Thank you very much for agreeing to do this interview. It would be great if you could introduce yourself for the magazine.

My name’s Pamela Nash (PN). I’m a Member of Parliament, I was elected last year. I’m Member of Parliament for Airdrie and Shotts and I’m Chair of the All Party Parliamentary Group for HIV and AIDS.

HA: My name’s Heather Alcock (HA), I’m the policy adviser for the All Party Parliamentary Group for HIV and AIDS and I work closely with Pamela.

Could you summarise why you are concerned about HIV? PN: My first interest came from international development which is something I’ve been involved in since I was a teenager. When I was elected to Parliament my very close friend David Cairns was Chair of the All Party Committees, if you look at the structures of Parliament are issue-based and attached to Government departments – you might have a Health committee for example – so that interest from the House of Lords where there’s so much experience and expertise in this issue is just fantastic. It is my hope that the coalition Government take the concerns raised by the committee, many of which have been raised today (at the conference), into consideration in the health care reforms.

HA: I hope that the Government will listen. There’s obviously a moral aspect but there’s also a value for money argument, when you talk about the rising costs of HIV treatment: we spend £792 million on HIV treatment and only £3 million on HIV prevention – where we are talking to the Government that doesn’t make sense. We need to do more to raise awareness about HIV, to tackle it and to reduce the rise in prevalence.

Do you think the coalition Government are interested in HIV? PN: It’s fantastic that the House of Lords set up a Select Committee on HIV. Most Select Committees, if you look at the structures, are committee based and attached to a Government department – so you might have a Health committee for example – so that interest from the House of Lords where there’s so much experience and expertise in this issue is just fantastic. It is my hope that the coalition Government take the concerns raised by the committee, many of which have been raised today (at the conference), into consideration in the health care reforms.

HA: I became Chair – the fact that we only spend £3 million on HIV prevention is crazy. I mentioned in my speech earlier (at the conference plenary) that we are starting a campaign on Sex and Relationships education. When I’ve been researching this, each of the four nations of the UK have very different rules and legislation on this issue and the sad fact is there are thousands of children not getting any sex and relationship education at all and this is contributing to not knowing about contraception, not knowing about sexually transmitted diseases and not knowing about HIV and also contributing to the stigma around HIV because they are not learning about it at an age when they should be. We’ve not had any big health campaigns on HIV for 20 or so years and my generation – people in their twenties – don’t know about it. Just asking around my friends they have concerns and look after themselves, they are concerned about sexual health, but HIV is way, way down on their list of priorities – they don’t think it could affect them. So I think the priorities are about educating young people about how to protect themselves from HIV and addressing the stigma. We are not going to get people to get tested and talk about HIV until that stigma is lifted.

And is that why you got tested publicly recently? PN: Yes, definitely. I’m not saying it wasn’t a nerve-wracking experience and it might not have been the most natural experience getting an HIV test with a lighting crew, a camera crew and a microphone, but I’m really glad I did it. It was important for me to show young people, but not just young people – everyone – that an HIV test is nothing to be scared of, it’s a very simply procedure, you’re asked some basic questions about your sexual history – there’s no need to give too much away – and it’s a very simple blood test, a prick test they are not taking away vials of blood and you can learn your results within minutes. So I would encourage everyone to take the plunge.

Have you had a test Heather? HA: I have had one, I had to wait six weeks for the results which was quite nerve-wracking. I think rapid testing is very important. One to the most successful public health interventions we’ve ever had with regards to HIV is the introduction of routine antenatal screening. If you look at the statistics, mother-to-child transmission has almost been eliminated in the UK. That’s a very strong example of where government intervention and testing can have a real impact. Of course women are not just baby-makers, as Silvia (Petretti) pointed out at the UN, women are vulnerable to HIV infection, everyone is vulnerable to and at risk of infection and that comes back to a wider discussion of sexual health and people protecting themselves and people being aware as Pamela has said and general awareness is important.

PN: Actually yes, one of my friends has been tested in the last couple of weeks and I’m working on the rest of them!

Did the fact that you have tests encourage any of your friends to do the same? PN: There are high risk groups but there is no ‘no risk’ group. Everyone has a risk of contracting HIV.

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Why Everyone Doesn't Attend HIV Conferences...

I remember when I attended a conference hosted by UKC, the year was 2004 and it was in Leicester. This was the first conference for HIV positive people and organisations that support people with HIV. There was diversity in the group of people who attended. There were families, children, gay, lesbian, single, married and all races. Organisations brought in representatives to either speak or just attend. It was educational and also lots of fun. I met people that I knew before my diagnosis and I could blend as nobody knew if I was HIV or not or whether I was representing an organisation. I was happy to participate and be me without disclosing my HIV status. As I say HIV does not define who I am, I am an individual holistically containing all the needs and wants of a human being and I deserve to be treated as me. I don’t see myself as a ‘victim’ of HIV but as somebody who unfortunately tripped on a clear pavement.

I attended a few subsequent conferences feeling more confident with who I was and contributing to debates and policies about HIV people who are always stigmatised. Just to be clear, I had never disclosed that I was HIV at work or with my friends. I don’t see why I should, as it does not define who I am or what I do. I have only disclosed to my children who are the epicentre of my heart.

Then for a period of time I endured abusive text messages on my phone about mine and my daughter’s HIV status. Whoever sent me the texts were from my community (as the message was written in my language). They threatened to tell my children, family and friends and, at that point; my children were not aware of mine or their status as they are now. This abuse stripped out the core of my being and I became a paranoid and self-pitying person that I had never been before. I reported the texts to the police but they couldn’t do anything. I got support from HIV organisations, but what else could they do accept to give me emotional support? Every now and again you hear of people who persecute HIV individuals being prosecuted or apprehended. I lived with the fear of my children, friends and family knowing. I lost my fire as a person.

I am a passionate activist and I still attend conferences on humanitarian issues and what constitutes humanity but from then on I no longer attend any HIV conferences or seminars.

I am comfortable with myself with the HIV, but it’s not embossed in my forehead and I do not see it as anybody else’s business except my children and my partner. My children and my partner now know of my status and this has not changed their love towards me which makes me thrive. Just like people who have other long term illnesses rarely do they go around saying, “Hello, I am so and so, I am diabetic, I have MS, I have motor-neurone disease, I have cancer, I am bi-polar.” All these life-long conditions are managed by medication and can be life-threatening. Unless I am in a position where the illness is affects my daily living, let it be my business who should know.

I have written more than five different articles in this magazine all from the comfort of my sofa and use a nom-de-plume. I have written several articles in other magazines and newspapers with my real name. These articles get the “all clear” as they do not contain issues around HIV. I am contributing to improving services, policies and banishing the stigma, but this I do “behind the scenes”. Why? Because, if I am honest, I worry I might be persecuted for just being me. My children are not comfortable with it being made everybody’s business because of the stigma it carries; they want to live a fulfilling life. My teenage daughter, who is living with HIV, does not want it to be anybody’s business but our families’ and the medical professionals. There is an epidemic of disconnection: people living with HIV are already ostracised and yet they continue to ostracise their peers instead of being supportive. Chief Seattle said that all things are connected like the blood that unites people, like the web of life, whatever we do to the web, we do to ourselves.

I am not anti those who are open with their HIV status. It works for some people, but it does not work for me and probably others. I am still on the journey of sanctifying myself and one day I believe that I will be there, openly HIV positive, when I feel comfortable. For now I choose to live, I do not breathe just to exist but have peace in myself through God’s blessing. HIV does not make people dangerous to know, but the danger is what people do with information that they have when somebody is HIV positive.

Mercy
How has HIV Treatment has Changed over the Years

Tristan J Barber, Research Physician, St Stephen’s AIDS Trust/Chelsea and Westminster Hospital

Back in 1996 I was working as a secretary in my summer holidays from medical school. I was lucky enough to spend six weeks in a large London HIV centre, which gave me a huge insight into the history of HIV therapeutics up to that date, and prepared the ground for my postgraduate training in the specialty. 1996 was a turning point in terms of anti-retroviral therapy (ART). Data had been presented at the International AIDS Conference in Vancouver that year showing that combination ART could reduce HIV replication below the level of detection – and this was, sadly, not sustained.

These days, it goes, without saying, tough. In the absence of specific HIV therapy in the early years, treatment was targeted at opportunistic infections and relief of disease associated symptoms. As for infants, this was a period of learning, and falling over a lot on the way.

The first drug to be used was zidovudine (AZT). This is a nucleoside reverse transcriptase inhibitor (NRTI or “nuke”) that had been sitting on the shelves of a drug company as a potential anti cancer drug. There was a lot of controversy about its use and many people experienced toxicity at the doses used. It wasn’t possible to monitor viral loads then, but patients taking AZT got a small benefit in terms of their CD4 count that was, sadly, not sustained.

Other drugs from the NRTI class came along and were used in combination with AZT. These included ddI, ddC, 3TC and d4T. Even in 1996 there was a legacy of people who were treated with dual NRTI therapy, with slightly longer CD4 benefit, but, ultimately, treatment failure, development of toxicity and, as we now know, the development of resistance.

Anemia was a big problem with AZT, and the other drugs included many of the so-called “d” drugs, which are now not commonly used in clinical practice in the UK. They caused a whole heap of problems, affecting people’s perception of therapy even up to the current day, causing nausea, neuropathies, body fat changes, lactic acidosis and pancreatitis.

The big decision for patients and clinicians was balancing the risk of waiting to start therapy, with the risk of starting and developing side effects. Patients were seeing friends being well, not only from AIDS but also from medications. It was a big step to start therapy, and many patients still feel that they survived because they delayed treatment until triple therapy was available, whilst others feel that despite having some resistance to drugs, and some long standing toxicities, had they not started therapy back in those early days they wouldn’t have made it thought to 2011.

Two things changed in the years before Vancouver. Firstly, it became possible to quantify the amount of virus in blood due to the availability of a technique known as the polymerase chain reaction (PCR). Secondly, there was excitement about the development of new drugs from a new class – nevirapine and efavirenz – the non nucleoside reverse transcriptase inhibitors (NNRTIs).

Growing up? “The Young Adult Years” (1997-2007)

Combination triple therapy really started to take off after 1996. The following 10 years allowed us to:

- Monitor viral loads
- Learn how to successful combine anti-retroviral agents for successful long term outcomes
- Begin to reduce side effects
- Test people for resistance and learn how to interpret the results
- Allow women to give birth to uninfected babies
- Save lives

These years didn’t start easily. Firstly this was because new drugs had new toxicities and drugs were often given at doses that were too high. We didn’t know how to “boost” protease inhibitors (PIs) with low dose ritonavir, and efavirenz and nevirapine both showed toxicities in some that were difficult to manage or, more rarely, fatal. The numbers of pills remained high.

Despite this, this period really represented a time of growth, maturity, and new found confidence in using ART and tools (such as viral load monitoring and PCR) that enabled us to tailor therapy to the needs of an individual patient.

An important development in this period was the development of fixed dose combination tablets, allowing patients to take fewer tablets. The first of these were Combivir (combining AZT and 3TC) and Kaletra (combining lopinavir and ritonavir). Subsequent developments resulted in the now commonly used Kivexa (abacavir/3TC) and Truvada (tenofovir/FTC), as well as the first 1 pill once a day treatment for HIV – Atripla. There are many more fixed dose combinations and single tablet regimens being developed, offering welcome convenience.

Perhaps less convenient, in this period we also used an injectable agent (T20/enfuvirtide) which was a good anti-retroviral, but often poorly tolerated by patients due to the need to inject twice a day and subsequent injection site reactions. This therapy fell out of favour with the development of newer oral agents that could be used instead.

“Approaching Thirty” (2008 to now)

After the successes of the previous decade – reduction in pill burden, minimizing toxicity and achieving long term viral suppression, we still had a small cohort of patients who were stuck on “salvage” regimens. Studies existed to look at ways of using old drugs to try and help these people, such as giving four or more drugs together (which was not shown to be beneficial). Many of these people had detectable viral loads in their blood but were being “held” on failing regimens (often including boosted PIs) whilst waiting for new drugs to be developed. Fortunately for most, this is exactly what happened. In the later part of this decade and up to the current day, there really has been a revolution in HIV therapy. There were new drugs in existing classes, developed for salvage use but many of which have subsequently been shown to be as good (or better) than comparator drugs for first line therapy. These drugs included darunavir and etravirine. New classes of drug also became available for the first time, including a co-receptor antagonist (marinavir) and an integrase inhibitor (raltegravir).

We’ve also been able to better tailor therapy. For instance, we can test for viral tropism, to see whether someone would benefit from a CCR5 inhibitor, and we can use genetic testing (HLAB5701) to predict whether or not someone might develop a severe allergic reaction to abacavir.

The Future

The future certainly seems bright with regard to treating HIV. New drugs in existing and novel classes mean we can confidently minimise side effects in both the short and long term whilst enjoying the benefits of viral suppression and immune restoration. As drugs become safer so we are also seeing the benefits of earlier anti-retroviral therapy, with international guidelines moving to a CD4 treatment cut off of 350 and ongoing research looking at the benefits of treating even earlier. We can prevent AIDS with early testing and early therapy, whilst yet more ongoing research looks at reducing the non-AIDS conditions which those living with HIV are still prone to, such as bone disease, kidney disease, neurocognitive impairment, cardiovascular disease and cancer.

Combination therapies mean that more people can enjoy convenient therapy in the form of single tablet regimens. Of course the ultimate goal is HIV eradication or cure. It remains to be seen if this is achievable, but approaches in using therapeutic vaccines, immune based therapies and anti-retroviral drugs (existing and new) remain hot areas of HIV research.

In thirty years we’ve come from the reporting of a new disease to being able to control HIV in plasma, prevent deaths and prevent AIDS related illness. We are now in a position to look forward to the future, a possible cure, and ensuring access to simple and safe treatment or everyone globally. I am sure, and hope, looking back on the past, that the next thirty years will bring even more incredible innovations in HIV care and treatment.
No Decision About Me, Without Me

The venue was the Congress Centre, Great Russell Street just a few minutes walk from Tottenham Court Road, it was an early start for a Saturday morning, but I was quite excited and full of anticipation as I made my way to the Congress Centre Building, eager to take part in the workshops which I had selected before-hand and looking forward to meeting friends I hadn’t seen in ages. I felt the warmest of welcomes as I met colleagues from Positively UK. The welcome pack included a copy of the HIV Treatment Bulletin, an overview of the HIV networks involved in the conference, and the findings from the Terrence Higgins Trust national survey of people over 50 living with HIV amongst others, all cutting edge and fresh off the press information to peruse at home later.

The foyer was lined with long tables on either side, each draped in white table cloths, on the tables to the left were our refreshments manned by a very attentive waiting staff and on the tables on the right were leaflets and pamphlets advertising a wealth of information and services for the HIV community manned by members of the different organisations. The atmosphere was buzzing. I was soon catching up with old friends and making new ones as I met people hailing from all across the UK including Scotland, Manchester and Wolverhampton.

Elisabeth Crafer, then Director of Positively UK, gave us all a warm welcome and reminded the now brimming Congress Hall of the reason of the conference and the partnerships that made the conference a reality. Elisabeth also introduced us to speakers who included Pamela Nash MP (Labour) and Chair of the All Party Parliamentary Group on HIV and AIDS, Jonathan Grinshaw activist, Mariella Volunteer/Activist and Neil Beasley Trustee of the THF, all of whom received rapturous applause from the audience after their speeches which were all uplifting and energising, making each and every one feel that we were ready to make a difference in the HIV field.

My first workshop was HIV Journey: Adulthood to Old Age chaired by Garry Brough and Professor Jane Anderson. The workshop discussed the age related health issues affecting the HIV community following on the findings of the Terrence Higgins Trust national survey of people over 50 living with HIV – based on the 2010 statistics, approximately 14,266 people in the UK living with HIV are over 50 – and the issues that it brought up. This was a lively session which saw several hands raised to ask questions which were all duly answered.

The next workshop I attended was on Treatments and Technology chaired by Simon Collins who discussed the developments surrounding available treatment choices and the benefits of changing treatment and implications to the individual regime. Similarly there were a lot of questions and answers particularly relating to the London Commissioning model on health care costs. As we broke off for lunch I wished the session would have gone on for much longer as I found it very engaging and educational on a personal level.

Lunch was also an opportunity to visit the community stands as well as to check-in with the doctor in the house for advice. During this time I collected some i-Base information booklets and signed myself up for Life Coaching with Living Well. My next workshop Positive Prevention chaired by Silvia Petretti from Positively UK and Lynda Shentall from George House Trust. The workshop reviewed the definition of positive prevention, the existing means of intervention and the gold standards of prevention for people living with HIV. Towards the end we were placed in sub-groups to discuss the different needs of the different communities in tailoring positive prevention strategies and then reported these back to the other groups.

The closing plenary as also held in the Congress Hall where Elisabeth Crafer wrapped the day up and invited some results from the rapporteuring for each workshop so I was able to gain some insight into the workshops I didn’t have the opportunity to attend. The closing plenary was swiftly followed by a drinks reception in the foyer area. The day had ended and it was an opportunity for all to share ideas, network, and share ideas on moving forward.

I found the conference very empowering, motivational and inspirational, like a Bunsen burner under a chemical solution I felt it was "enabling" in making all its attendants aware of their power to make a change in the HIV field and on HIV policy. I thought, “I can make a difference in the HIV field!” It was an infectious feeling because at once my thoughts went to my many positive friends who would have been similarly enthused by the kind of day I’d had, had they attended. So I hope for another “No Decision About Me, Without Me” conference in the near future: a meeting of minds and a sharing of ideas, maybe this time over two days to enable more detailed discussions and allow more time for questions.

Lungile

What’s Next?

So we’ve held a conference, we’ve done lots of talking and networking, but what next? The aim of the conference was to identify actions for change; here’s some suggestions:

Join an HIV Network

There are a number of HIV networks available:

CHIVA
The Children’s HIV Association has areas for parents exploring issues such as talking to your child; a secure website made for and by HIV positive young people; a resource library; medical guidelines and identifies family health services across the UK and Ireland. Visit www.chiva.org.uk

Ffena
The network, co-ordinated by AHPN, enables African people living with and affected by HIV in the UK to share their experiences and make their voices heard. Ffena informs and invigorates the African Health Policy Network’s work in policy, research and practice. Visit www.ahpn.org/ffena

Forum Link
Aims to provide a coordinated “voice for HIV patient groups across the UK”, and beyond. While retaining a strong HIV positive person-centred ethos, it focuses on strengthening HIV patient group representation in service delivery and development locally, regionally and nationally. Visit www.forum-link.org

HIV Activists Network
NAT regularly identifies issues that people living with HIV have told us are important, and HIV activists can choose which one(s) they get involved with. Current topics include changes to HIV prescribing in London, benefit cuts and social care. Email HIVactivist@nat.org.uk

My HIV

The site, run by THF, offers a range free online services, tools and community spaces tailored to your personal needs. It provides information and support services, personal experiences of living with HIV via videos, stories and diaries and the opportunity to link into national and local peer support via Community Forums message boards. Visit www.myhiv.org.uk

PoizFem-UK

The national network of women living with HIV who have a desire to be advocates for the rights of women living with HIV in the UK. Co-ordinated by Positively UK network members hold meetings and training sessions developing skills and confidence to influence decisions. For more information contact Silvia Petretti on spetretti@positivelyuk.org

UK Community Advisory Board (UK-CAB)

For HIV treatment advocates across the UK, it aims to develop and strengthen the network of treatment advocates, provide expert training on current treatment issues and opportunities to meet with doctors, researchers and pharmaceutical companies. To join go to www.ukcab.net/join

Join an Activists’ Network

38 Degrees
Named, as 38 Degrees is the angle at which an avalanche happens. An online forum open to anyone, it canvasses members’ opinions as to policy areas it should prioritise. One campaign is focused on stopping NHS changes. It then tackles this through online petitions, contacting MPs, and gathering members locally. Visit www.38degrees.co.uk

UK Uncut

Opposing government cuts to public services with a focus on activism through demonstrations and occupying buildings such as banks and shops. Visit www.ukuncut.org.uk

Join a Local Forum

NHS LINks

Activism takes many forms and you may decide to influence NHS decision on the inside. Local Involvement Networks, aim to develop relationships between the public and health and social care providers, and hold services to account. Find your local LINks at www.nhslinks.org.uk
So, here is autumn, with all the glorious colours of turning leaves and harvest. It is traditionally a time of gathering in, thanks giving and, if it’s been a good year, abundance. When I was a child, I loved harvest festival more than Christmas. I grew up in a village in Wales where the community was largely centered on either church or chapel and the local pub! It was a farming community and their ancestors had been tilling the soil there, way back into ancient and pagan times – no surprise then that the festivals in the church calendar still contained a rich weave of pagan ritual, which were perhaps most obvious at weddings and in the harvest festival.

The church dated back to Norman times and was stone built with deep window sills and heavy oak doors. On the Saturday before harvest festival these window sills would be stacked with fruit, nuts and vegetables; pickles and jams that had been made from the produce of the congregations’ gardens and allotments or gathered in from the hedgerows and wild places. Not a shop bought tin or packet in sight! Flowers and herbs were arranged in vases and pots and a huge hand tied bundle of wheat was put beneath the pulpit, with a sack of stone milled flour and freshly baked bread.

The doors of the church would be locked until the Sunday night, when we processed by candle light from the lichgate to the church door, singing as we went. When the vicar opened the door, the smell that flooded out was intoxicating – earthy aromas of the soil everything had grown in, mingled with the scent of ripe fruit, flowers and herbs. When the service ended, the whole congregation processed to the village hall for a pie and pea supper and to entertain each other with well-practiced turns. The highlight of the evening was when Tubby Watkins sang ‘If I were a Rich Man’ before we all went home to our beds!

Next week I’ll be going to my grand-daughters school harvest festival – I expect it will be a very different experience but no less poignant for all that it signifies. She is part of my abundant life harvest. She signifies a time I never expected to see when I was first diagnosed with HIV.

So right now I’m giving thanks for all the amazing and unexpected things that gather to form the blessings of my life. And yes, I give thanks for my daily bread but more than that I give thanks for the years of my life that have allowed me to experience the growing up of my children with all its joys and challenges, the advent of grandchildren, the forth coming marriage of my eldest son and all the loves and losses that have lined my path as it wended its way through stony ground and smooth.

And here’s something I never thought I’d hear myself say; I give thanks for the medication too – next year’s harvest depends upon it!
### What's Happening Around the UK?

#### BIRMINGHAM
Universal Women’s Group and is on the last Friday of every month. Contact Alex on 021 622 6471 or email alexbergman@abplus.org.uk

Terrence Higgins Trust Birmingham provides support or advocacy services for women living with HIV. Contact Michaela on 0121 694 6440

#### BRIGHTON
Body Positive Dorset
Women’s support group on the first Tuesday of the month. Contact 01202 297386

#### BOURNEMOUTH
Body Positive Dorset
Women’s support group on the first Tuesday of the month. Contact 01202 297386

#### BURLINGTON
The Sussex Beacon run a Women’s Group and provide one-to-one support in Brighton. The group is run once a month from 10:30am – 3:30pm. Contact Paula Evenden on 01273 645096 or e-mail paula.evenden@sussexbeacon.org.uk

#### BRISTOL
Terrence Higgins Trust multicultural women’s group. Monthly on Saturdays. Contact Bonnie on 0117 955 1000 Saturdays 11-30am-4pm

#### CARDIFF
Terrence Higgins Trust: African women last Thursday of every month 1-4pm, women and carers group – 2nd Monday 11am-1pm, parents group. Contact on 02920 666 465

#### CORNWALL
Kernow Positive Support (KPS) runs a monthly women’s support group, dates and times now vary. Contact on 01872 262221

#### DERBYSHIRE
Derbyshire Positive Support runs a women’s group on the first Wednesday of the month. Contact 01332 204 020

#### DERBYSHIRE
Positive run support services for all women living with HIV in Derbyshire and their families. Contact Michaela on 01246 559 431 or email michaela.swallow@nhs.net

#### EAST ANGLIA
PLP – Support group for HIV positive women. Contact 01502 537 985 or email info@plea.org.uk

Women Living Positively runs a monthly support group for infected and affected women. Contact Joe on 01473 692 616 for more details

#### EAST SUSSEX
Women’s groups meet monthly, in Hastings on the first Monday and Eastbourne on the third Thursday of the month. Contact 01323 649 927

#### EDINBURGH
ISIS – a group for women living with or affected by HIV, continues to meet every Tuesday from 1-3.30pm at Waverley Care, 1 Mansfield Place, Edinburgh EH3 6NB

Contact Maro on 0131 558 1425 or email fhaith'http://waverley-care.org

Waverley Care – Offers a number of services providing practical and emotional support to people living with HIV in Scotland and to their partners and families. Contact 031 661 0982 or visit www.waverleycare.org

Positive Help – Practical support for people affected by HIV and AIDS. Contact on 031 558 1122

#### LIVERPOOL
Sahe House hosts a monthly mentor-led women’s support group. Contact Serena on 0151 237 3989 or email info@sahe.uk.com

#### LONDON
LUTON/ BEDFORDSHIRE
Bi-positive HIV-positive women’s support group. Wednesdays 4-6pm. Food and refreshments available. Visit www.lbppositive.com

Psychological Support now available at CAFPH. Contact on 0203 622 7001 or email info@cafph.org

#### MANCHESTER
George House Trust HIV positive women’s support group and African Service: Alternate Tuesdays. Contact Lynda on 0161 274 4499

Body Positive North West women’s support group. Weekly, Friday mornings. Contact 0161 882 2202

Body Positive North West runs an African Women’s group on Thursday afternoons. Contact 020 862 2200

#### HAMPSHIRE
Monthly Support group for women infected or affected by HIV/AIDS. Contact 01252 345 019 or email info@positivaction.org.uk

HERTFORDSHIRE
Herts Aid hosts a HIV positive women’s support lunch monthly – the 3rd Tuesday of each month from 1pm-3pm. Contact 01902 484786

The Crescent run two support groups for specifically for women: a ladies lunch which takes place every other month and a mother’s support group known as the Fountain Group in Watford, which takes place every month. Contact 01727 842 532 or visit www.thecrescent.org.uk

#### NEWCASTLE
Sahir House holds a monthly support group. Wednesdays 4-6pm. Food and refreshments available. Call 020 7713 0444 for details or e-mail losman@positivelyuk.org

#### SOUTHAMPTON
Positive Action runs a monthly support group for women affected by HIV. Contact 023 802 5511 or email info@positivaction.org.uk

#### SURREY
Monthly Support group for women. Contact 01932 354 019 or email info@positivaction.org.uk

#### SWANSEA
AIDS Trust Cymru runs a women’s support group on the last Wednesday of the month. Contact 01792 461 848.

#### WEST SUSSEX
HIV Peer and Advocacy Service (SHPPASS) offers: A confidential monthly support group for Women Living with HIV. Contact 01582 76 063 or email info@cafph.org

#### WOLVERHAMPTON
Terrence Higgins Trust – Support for African women who’ve been diagnosed HIV positive, monthly on Thursday afternoon. Contact Jane on 01902 711 818

**Support Groups:**

**Positively UK – Islington**
Monthly support groups:
- HIV positive women’s group every first Thursday of the month, 4-8pm
- Lesbian, bi-sexual and transgender positive women’s group every second Thursday of the month, 5-8pm
- African Group every third Thursday of the month, 12-3pm (men welcome)
- Str8 Talk – Heterosexual group for HIV positive women. Every third Thursday, 5-8pm

**Cara – Ladbroke Grove**
Weekly groups for HIV positive women. Every Thursday 11am-3pm
Contact 020 7243 6147 for details

**Lighthouse – Ladbroke Grove**
Str8 Talk – Heterosexual group for HIV positive people. Every first Wednesday, 6-9pm
Call 020 7713 0444 for details

**Monks Park – Brent**
Mixed peer group for HIV positive people. Every last Thursday of the month 11am-3.30pm
Call 020 7713 0444 for details

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### What’s Happening Around the UK?

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The copy deadline for the next issue is 15 February 2011.
YOU WANT TO KEEP QUIET ABOUT YOUR HIV

LET’S TALK

BODY CHANGES

Talk to your doctor if you are concerned about how HIV and HIV-related therapy may affect your physical and mental well-being.

The person depicted in this advert is a model.