

HIV in the future NHS



Redesigning the NHS:

Report of focus groups of people living with HIV in England for the HIV in the Future NHS Conference.

January 2016



Despite the often abstract or technical nature of policy and commissioning conversations, NHS reform is ultimately about how people will experience services in future. For this reason, NAT believed it was essential that we sought direct input from a range of people living with HIV.

We therefore held three focus groups, too findings of which informed the agenda planning for the HIV in the Future NHS conference.

The focus groups addressed four main themes:

Whether long-term condition management' is a helpful or accurate reflection of life with HIV.

What support people need from NHS services to live well with HIV.

New Models of Care set in the Five Year Forward View.

What people living with HIV believe 'patient-centred care' looks like.

About the focus groups

Three 90 minute focus groups were held, in the following locations:

- Mixed-age focus group (Manchester, hosted by George House Trust)
- Young people's focus group (London, hosted by Gilead Young Advocates Advisory Board)
- Mixed-age focus group (London, hosted by Positive East)

The partner organisations ensured that a diverse range of participants were recruited, including appropriate representation of the two populations most-affected by HIV in the UK (men who have sex with men and African-born women and men). There was a range of ages and time since diagnosis.

There was no requirement for participants to be accessing particular services, as long as they were living with diagnosed HIV. However, all recruited were attending an HIV clinic on a regular basis (i.e. in line with appointments set by clinic) and all were registered with a GP.

Participants were thanked for their time with a £20 voucher.

1. Is 'long-term condition management' a helpful or accurate reflection of life with HIV?

Participants were familiar with the idea that HIV is best considered a 'long term' (some said 'chronic') condition, but not all agreed that 'long-term condition management' (hereafter LTC management) was a helpful or accurate reflection of life with HIV.

As observed by one participant, views on whether HIV is a LTC may differ depending on when someone was diagnosed with HIV, how much HIV-related illness they had experienced and what treatments were available to them at the point of diagnosis. For example, there was universal acceptance of the term in the young advocate focus group. Conversely, in another focus group where most people had been diagnosed at least 10 years ago, LTC management was not generally considered a helpful or accurate way to talk about life with HIV.

Those who used or supported the use of the LTC approach

Reasons for using or supporting the use of LTC management in relation to life with HIV were:

- LTC terminology normalises HIV and helps challenge stigma.
- Saying you are living with a LTC is an alternative to naming HIV, in situations where you want to maintain confidentiality/privacy.
- LTC management is a helpful concept for talking to (especially non-specialist) services about treatment, care and support needs.
- The terminology reflects the reality that managing HIV isn't only about the clinical aspects, but also about managing how other people respond to your diagnosis.

There was also significant support for the idea of 'self-management', which was mentioned without prompting by participants in all focus groups. Self-management implied greater personal autonomy but also responsibility (whether wanted or not) in managing one's health. Some seemed empowered by self-management, but others accepted it as necessity more than choice.

Why some believe that it is unhelpful to frame HIV as a 'long-term condition'

The reasons for not finding LTC management a useful term included:

- HIV is a unique, complex and stigmatised condition, so should not be put in the same category as diabetes or cancer.
- The communicable (participant used the term "contagious") nature of HIV means it is still fundamentally an infectious disease – and there is stigma attached to this.
- Thinking of HIV as a 'terminal condition', because if they don't take meds, they may become ill and die.
- HIV is simply a virus, which may be associated with various other conditions such as depression, neuropathy etc – but not a LTC in itself.

2. What support people need from NHS services to live well with HIV

Perhaps not surprisingly, when asked about the support received for managing HIV, participants focussed on the role of the HIV clinic and specialist clinicians. When asked where there were gaps in the support received, participants tended to focus on problems they had experienced in non-specialised and in particular primary care settings. Participants also mentioned concerns about reduced frequency of HIV clinic appointments.

Where support is meeting the need

There was a high degree of satisfaction with the support provided by HIV clinics. There was frequent mention of the value of accessing treatment and care in a setting where HIV was understood and HIV stigma was not tolerated. Participants who had a long-standing clinical relationship with a particular consultant found this valuable.

Peer navigators in clinic were highlighted as an important source of support. More than one participant said it would be good to have equivalent support from people living with HIV in non-HIV specialised services, someone to help "smooth the path" for you.

Those who were accessing non-clinical support services in the community (such as those provided by the partner organisations) indicated that these were extremely valuable to their wellbeing. However, as one participant said, even the best support service cannot resolve clinical issues, if the NHS is not meeting the need.

We are champions of self-management.

I say long-term condition instead of HIV if I think people will freak out.

HIV is a painful disease.

'Long term condition management' is a meaningless phrase. What is the point of the phrase? It is just re-categorising HIV.

Gaps in current support

Participants were more expansive in describing what they experience as gaps in their current healthcare services, compared to the discussion on what was positive about their care.

In contrast to the satisfaction described above with services provided in the HIV clinic were concerns about reduced frequency of appointments (two per year, in some cases only one of which is with a consultant). When probed about why they were concerned, participants indicated that they were not confident that there was a sufficient safety net of clinical expertise and access to appropriate services and medication, if they experienced serious health problems between appointments. More than one participant shared an experience of struggling to gain access to ART in an emergency; this was an issue which made participants feel particularly vulnerable. Others mentioned building up a small dossier of questions for their consultant between appointments, meaning they may need to wait weeks or months to address what is for them a pressing concern.

Don't get me wrong, one pill a day is great, better than mixing up paste and everything I had to do back in 1996.

It is really 6 months of self-management with 10 minute appointments in-between.

You can't treat someone like a car and just give them an MOT once a year. Because with a car at least you can see if something has gone wrong in the meantime. You can't see HIV and the impact it is having inside the body - this causes me worry.

Investment in HIV clinic services is diminishing all the time. It feels like a form of judgement and blame.

I've tried calling the clinic between appointments but they are so busy and they'll say they can get back to me in 24-48 hours

Primary care issues

Specific complaints about HIV clinic services aside, the desire for more access to HIV specialised services emerged chiefly from dissatisfaction with those aspects of the HIV care pathway which are the responsibility of primary care – including areas which HIV clinics may have previously been able to address directly.

Recurring issues raised were:

- Difficulty getting a GP appointment in a timely way.
- Lack of HIV knowledge among GPs and non-specialists.
- Narrowly averted drug-drug interactions.
- Experiences of HIV-stigma and discrimination in non-specialist services.
- Poor communication between GP and HIV clinic – more than one participant talked about having to carry their own notes and letters and to insist that the GP read what their HIV consultant had written.
- GPs believing that the HIV clinic provides a more holistic service than it does – and referring patients back to the clinic for this reason.

- GPs providing a less holistic service than they used to e.g. no longer notifying people living with HIV about the flu jab.
- Ping pong between the HIV clinic and the GP – made worse if the next HIV clinic appointment is not scheduled for several months.
- Being sent around different services (and geographical locations) in order to access a specific test or appointment.
- Confidentiality concerns around reception staff.

My GP asked how I got HIV. So I stood up and walked out.

I think what we are all saying is we are not very confident in non-specialist health services and their HIV knowledge.

How participants would redesign services

When asked how service could be improved, participants favoured any new model of care which would reduce the amount of running around between services which they currently experience.

Possibilities included:

- Specialists, GPs, pathology etc. all in the one building.
- Better communication between the various care professionals.
- GPs and other non-specialises with a good HIV knowledge.

Active support between HIV clinic appointments was considered important, even if this was just a quick contact (text or phone call) to see how you were managing - without the patient having to ask.

There was lots of support for a holistic HIV service/multi-clinic in a specialist clinic setting, however participants acknowledged that this was unlikely to be possible outside of London and other major centres.

It's taken me a long time to stop being nervous in existing NHS services... any changes should be introduced slowly.

If they want us to keep using the services they have to make it accessible... or people will drop out of care.

3. New Models of Care

Participants were introduced to the New Models of Care outlined in the Five Year Forward View. Visual aids representing different types of care (e.g. HIV treatment, maternity care) and sites of care (e.g. GP surgery, hospital) were used to describe the New Models.

Participants in all focus groups were circumspect in their comments on all of the New Models of Care – the strongest support expressed was that proposals to integrate care were ‘good in theory’. There was a high degree of awareness about the financial constraints facing the NHS and participants thought it would be difficult for services to be improved as long as this was the case.

Multispecialty Community Providers (MSCPs)

Pros: Participants were interested in the possibility of being able to access certain specialties (including possibly HIV treatment and care) in a primary or community care setting. Several participants said they would like to be able to access their routine blood tests in a community-based clinic. There was particular support for anything which improved access to psychological support. It was also agreed that it would be positive if MSCPs led to improved communication and greater knowledge transfer from specialists to GPs.

Cons: It was not clear to participants why MSCPs would be better for patients than attending services in traditional acute settings. Given the significant problems most participants had experienced in primary care settings, there were concerns about increasing the responsibility which GP practices had in the delivery of more specialist services.

Primary and Acute Care Systems (PACS)

Pros: The chief potential benefit of PACS, a more integrated experience of care, was supported by participants who had experienced ping-pong between specialists and GPs. Single care organisations which offered one-stop-shop services were also of interest, although this is not necessarily how PACs will be experienced. Some participants also thought a single set of care records with a single organisation would make their experience of care more streamlined and safe.

Cons: There were concerns about confidentiality of a single organisation with a single care record. Also, as one participant put it, if you found you were on a patient list for a PACs with ‘rubbish’ secondary care services, you wouldn’t have any choice to move your care elsewhere.

Others options, including digital/remote technology.

Participants were then asked if any other new model of care could improve the experience of NHS services.

This was an area of discussion of particular interest to the group of Young Advocates, who made the following suggestions:

- Using remote and digital platforms for sexual health (e.g. ordering tests) and psychological support (e.g. CBT).
- Phone call or skype consultations with HIV clinics.
- Booking appointments digitally.
- Community settings for counselling and peer support.
- Psychological support and sexual health testing provided in community settings.
- Psychological support in HIV clinics, especially around the time of diagnosis when people may want support more urgently than they can get it from mainstream community services.

In other groups, there was some experience of booking appointments on line but also comments that people wouldn’t want to do this by choice. Others talked about security concerns with any online systems.

4. What people living with HIV believe 'patient-centred care' looks like.

All participants were asked the question, What does the term 'patient centred' care mean to you?

All answers provided are quoted below:

"All about me."

"Listen to the patient."

"Whole-person, and everything is considered in your care."

"Involvement. I get the final say."

"Holistic, well-being, rounded."

"I am an equal partner in the decision-making process. Information is shared to allow me to make my care decisions."

"It is a long-term programme of care."

"A service that fits for me, not making me fit the service."

"Patient involvement in all care."

"Service provider listens to patients."

"Communication is very good."

"The care I've had for 12 years – I'm 100% satisfied with my GP and HIV clinic and wouldn't want it to change. I went in as palliative care, and now I'm 72."

"Financial investment – the bottom line."

"Patient empowerment."

"Patient involvement in policy making."

"I'm the one who has to deal with the consequences so I'd rather be in charge. This is not for everyone, but we should have the option to self-manage – you're the one who is there all the time."

"Being allowed to manage yourself."

"Centred around the patient."

"It makes it easier for the doctor as well to learn what you want and need and how to help."

"Control of my own data."

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