

# Supported self-management in action: the value of HIV Support Services

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# HIV support services: State of the nation

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# What are HIV support services?



- ▶ Any service provided to meet HIV-relevant needs of people living with HIV, other than those provided by clinical treatment and care.
  - ▶ Address psychological and emotional needs, condition self-management, sex and relationships & social need.
  - ▶ Provide information (advice, advocacy, referral) and support change.
  - ▶ From professionals or peers.

# Context



- ▶ Legacy of ASG (AIDS Support Grant) ending
- ▶ Impact of Health and Social Care Act

# NAT's support services project



- ▶ What HIV support services must be available for people living with HIV to maintain their health and wellbeing
- ▶ How services should be provided
- ▶ Evidence that services are effective and necessary
- ▶ 'State of the nation' data to show trends in HIV support service provision across all 4 nations of the UK

# The value of HIV support services



- “It saved my life, I attempted suicide twice... if it wasn't for [THT newly diagnosed group] I might not be here today” (focus group participant)
- 100% of HIV clinicians surveyed refer their patients to, or advise them to use HIV support services
- Over 1/3 of people living with HIV use HIV support services in any one year (Public Health England)

# Trends in service provision



- ▶ 23% of LAs didn't provide services in 2015/16
- ▶ By 2016/17 a further 28% had either decommissioned services entirely or reduced commissioning expenditure

# Trends in service provision



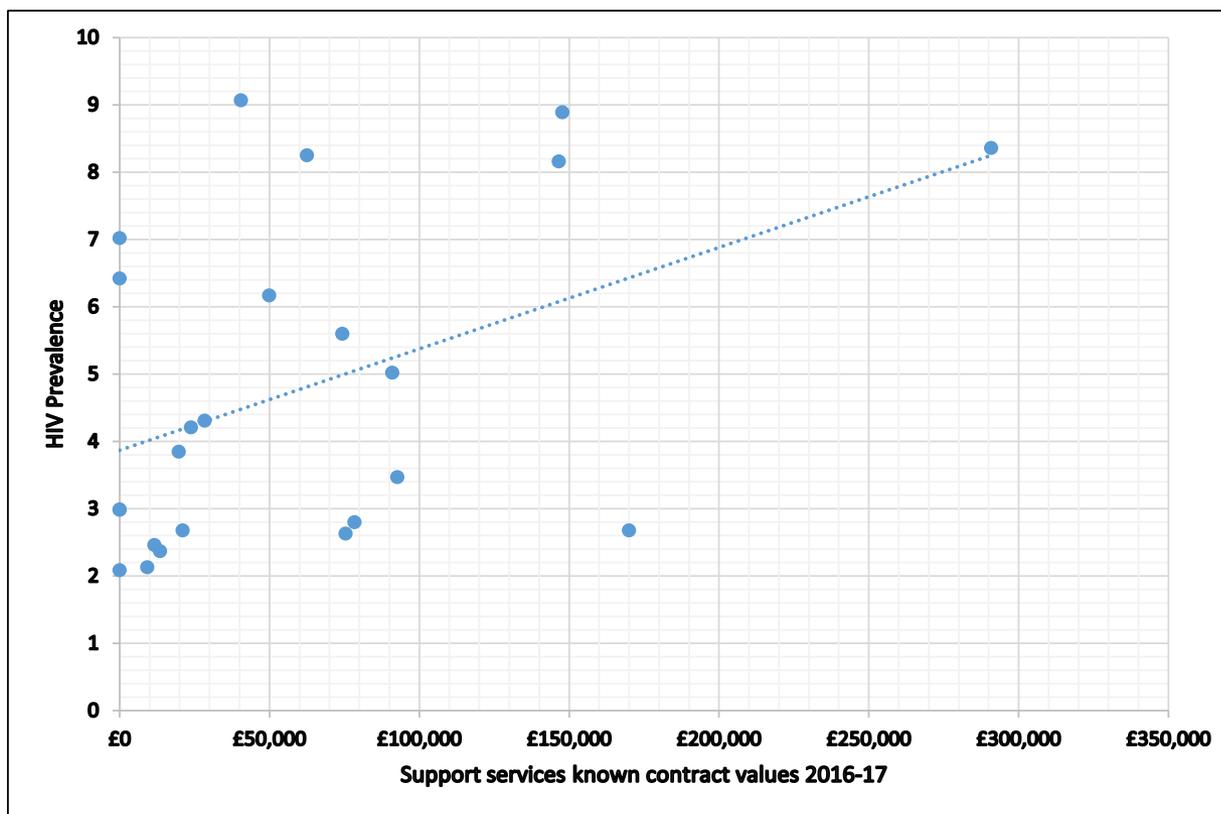
- ▶ The average change in expenditure 2015/16 → 2016/17 was a 17.3% decrease
  - ▶ In London, the average decrease was 23.1%
  - ▶ 5 of the 19 London boroughs with good data reported a decrease in contract value of > 50%

# Trends in service provision



- ▶ 13% of LAs didn't know either whether they were going to re-commission services, or what the value of the contracts would be
  - ▶ This figure rises to 25% in London Boroughs
- ▶ 17% of LAs couldn't distinguish the support services element of joint contracts

# Trends in service provision



# Next steps



- Policy recommendations
- 'State of the nation' launch
- Stop HIV Cuts campaign

# (NAT) National AIDS Trust

SHAPING ATTITUDES



CHALLENGING INJUSTICE



CHANGING LIVES



# The benefits and challenges of providing online self-management tools and support

## National Voices Annual Conference 2017

Alex Sparrowhawk  
**Membership & Involvement Officer**  
Terrence Higgins Trust

myHIV

# myHIV – Terrence Higgins Trust's online support service



- Terrence Higgins Trust implemented myHIV, an online service for people living with HIV approximately six years ago
- To date myHIV has over 11,660 clients and more than 3,880 of these are also registered on our online community forums
- I joined myHIV in 2011, later volunteering for the service before successfully applying for my current role at Terrence Higgins Trust 18 months ago

# New clients in 2016

## Sign-ups

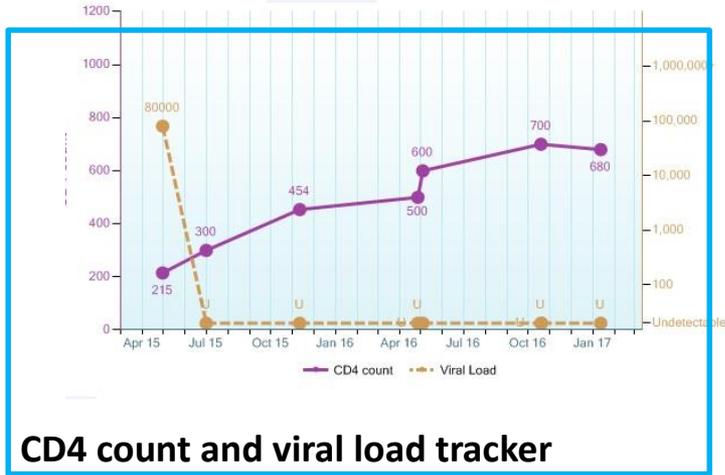
Diagnosed prior to 2016	Diagnosed in 2016
480	648



## Referrals

Terrence Higgins Trust	Online and social media	Other external referrals
From our staff by telephone or online (75)	From an advert or link on the internet (118)	From a healthcare professional, e.g. doctor or nurse (440)
I'm already in touch with THT and a staff member registered me (40)	Social media (31)	From the press (37)
I'm new to Terrence Higgins trust and a staff member registered me (30)	Google or other search engine (281)	I heard about the site at an event (21)

# Self-management tools and information



CD4 count and viral load tracker

Medication reminder

Online reminders  
to me  
Yesterday [View details](#)

Remember to take your medication at 7.00 PM

[To unsubscribe from this reminder, click here](#)

Privileged/Confidential Information may be contained in this message. If you are not the intended recipient of this email (or responsible for delivery of the message to such

**Medication and appointment email alerts**

Notes

- [www.tht.org.uk/myhiv](http://www.tht.org.uk/myhiv)  
04/05/16
- I need a letter for my medical...  
04/05/16
- This is an example note: Why n...  
14/11/14

bad PDF

Add a note

Category\*

Note\*

Save

Personal notes

Terrence HIGGINS TRUST

Our charity Get involved Sexual health Living With HIV

Get help now Donate

You are here: Living With HIV > Staying healthy

Online services Staying healthy

Online tools

HIV and you

Telling people you're HIV positive

Staying healthy

Mental health

Healthy eating

Alcohol and drugs

Exercise

Sex

Confection

Parenthood

Living with HIV long term

Flu vaccine

50 plus and living with HIV?

Your stories

Related content

Various people talk about their experiences of living with HIV.

More for me

- HIV and you
- Telling people you're HIV positive
- Staying healthy
- Your rights

My health status

'The forums are a life line to me, they make a huge difference to my life'

Information about living with HIV

# Online Advice, Counselling and Peer Support

## Online Advice

- Ongoing advice sessions delivered via Skype, email and WhatsApp
- Ad-hoc queries received via email and WhatsApp, phone support also provided
- Between April and December 2016 our online accredited adviser delivered 574 hours of support and had 303 interventions

## Online Counselling

- Sessions delivered via Skype
- Between April and December 2016 our online counsellor delivered 354 hours of support and had 102 interventions

## Online Peer Support

- Currently facilitated by a team of 10 online peer support volunteers all living with HIV located across the UK
- Volunteers are scheduled to spend 1-2 hours each week delivering a peer support session, speaking to clients in a group chat area or via one-to-one private messaging
- Between April and December 2016 volunteers delivered 477.5 hours of support and had 657 interventions

# Top five intervention activity types (Apr-Dec 2016)

## Online Advice

- Benefits: Welfare advice (216)
- Charity Application: Hardship Fund (100)
- Benefits: ESA – review/appeal (56)
- Benefits: PIP – New claim/other (35)
- Work: Employment work issues (31)

## Online Counselling

- Emotional: Depression (116)
- Emotional: Living with HIV (105)
- Emotional: Anxiety (56)
- Emotional: Relationships (25)
- Wellbeing: Disclosure of status (18)

## Online Peer Support

- Wellbeing: Living with HIV (223)
- Information: Recently diagnosed (166)
- Information: Treatment basic info (121)
- Emotional: Emotional support (64)
- Navigation: Accessing services (18)

# Benefits

- Clients have access to private, confidential and accessible tools and support wherever they live in the UK from the comfort of their own home.
- Support available at times convenient to clients:
  - Access to the information, tools and community forums 24/7.
  - Users have an equal opportunity to book Online Advice and Counselling services, no waiting lists as with many face-to-face services.
  - Online Peer Support available six nights a week during the evenings
  - Clients can self-refer to support services (59% of Online Advice and Counselling interventions were self-referred Apr-Dec 2016), virtually all Online Peer Support interventions are self-referred.
- Clients can choose to access services ad-hoc i.e. ‘drop-in’ peer support, email one-off questions to advocacy staff or book a series of appointments as required, with guidance from staff.
- Clients are able to ‘supplement’ the support they may already receive from face-to-face HIV support services.

# Current challenges

- Technology has moved at a considerable pace over the past six years, there are financial and logistical challenges to ensure services work via all digital devices and to create mobile-optimised content.
- Furthermore, today people live ‘online’ and via their digital devices – clients compare and have higher expectations e.g. comparing online services with big digital players (Amazon, Apple, Google, Facebook).
- Practical challenges of online communication if not using a webcam facility.
- Social and cultural challenges to provide a service that meets the needs of all communities affected by HIV.

# Future challenges

- Face-to-face HIV support services across the UK are being cut. This will continue over the next few years as ring-fencing of health budgets is removed. We anticipate an increase in numbers and vulnerability of clients, and the possibility that their needs could differ from a current 'average user'.
- Clients are living longer and into old age, 34% of people accessing HIV care in 2015 were 50 or older. A substantial number of this group are attempting to self-manage their HIV as well as other conditions.
- Terrence Higgins Trust is currently looking at the redevelopment of its website and the future of its digital services, including myHIV. Ensuring that people with HIV continue to have access to a universal service – building upon successes of myHIV and THT Direct – our HIV and sexual health helpline service.