

# Positive Voices: Experiences & Unmet Needs of people with HIV in England & Wales

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# LONDON

## FAST-TRACK CITIES 2019

SEPTEMBER 8-11, 2019 | BARBICAN CENTRE

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# Positive<sup>✓</sup>voices Methods

the national survey of people living with HIV



- February – September 2017
- Nationally representative
  - Random sample from national surveillance dataset
  - ~1 in 5 patients/clinic
- Clinic-based recruitment
  - Face to face, post or email
- Self-completion
  - Paper (87%) or Online (13%)
- Incentive £5 shop voucher



**73 clinics**

**51% response rate**

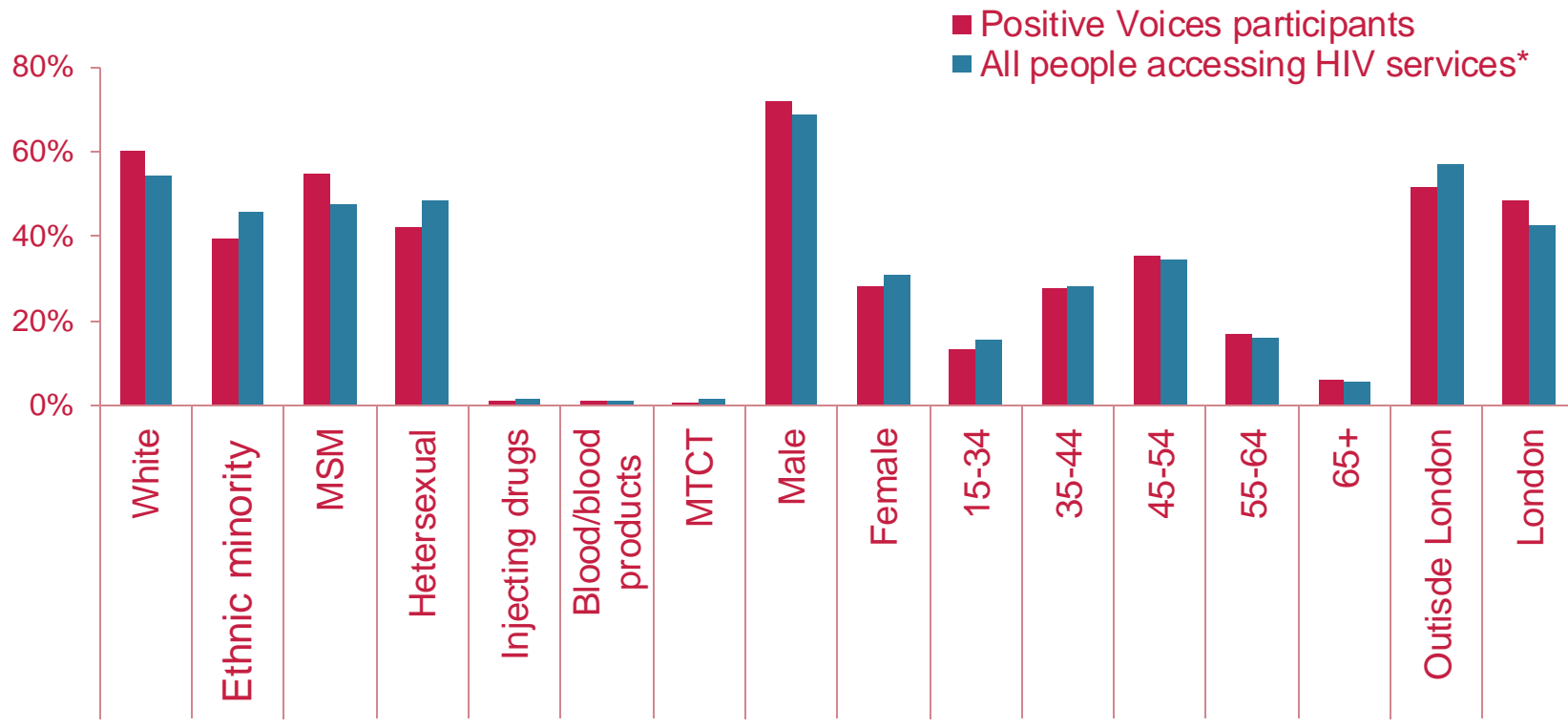
**4,422 responses**

**1 in 20 people with HIV**

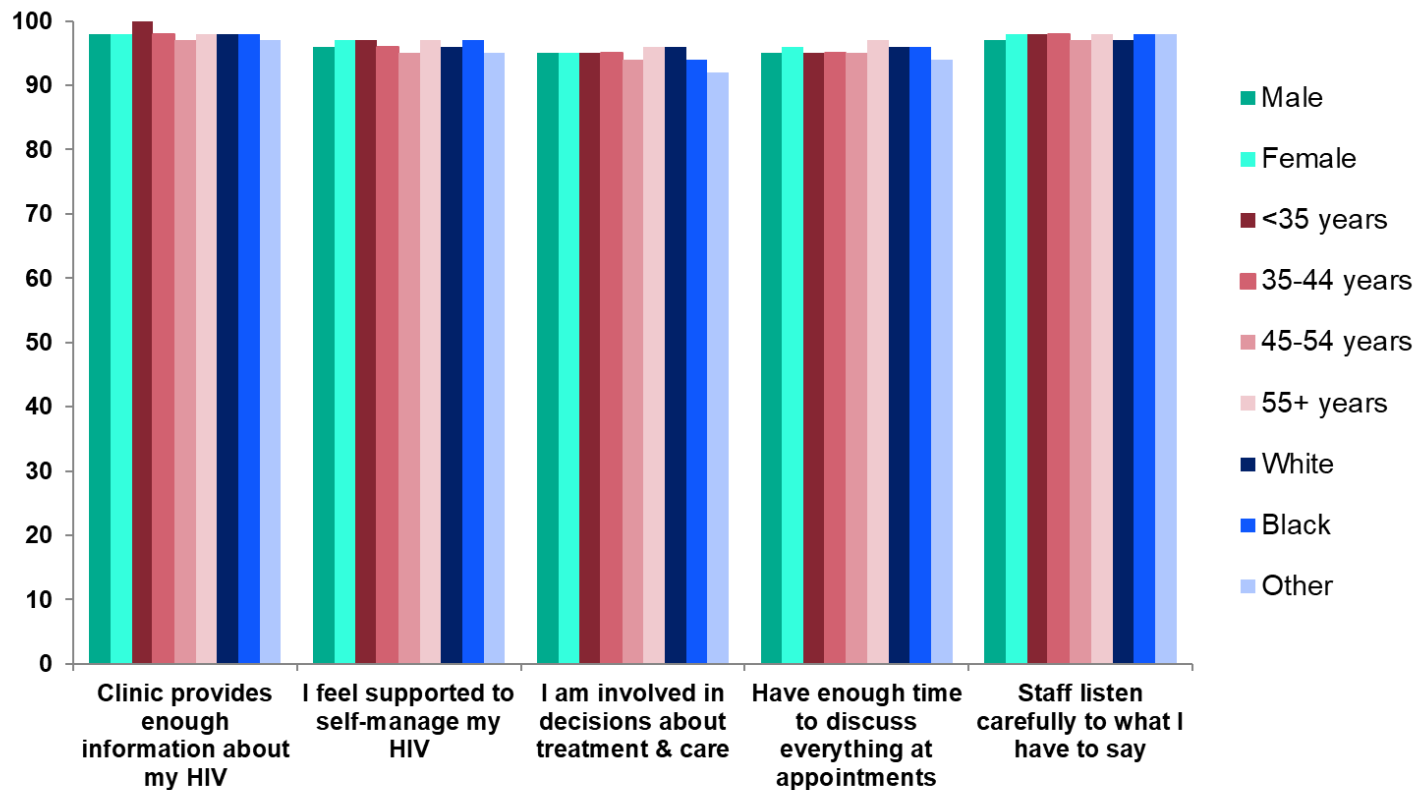
**2,451 – London    56 – Liverpool**

**150 – Manchester    218 – Brighton**

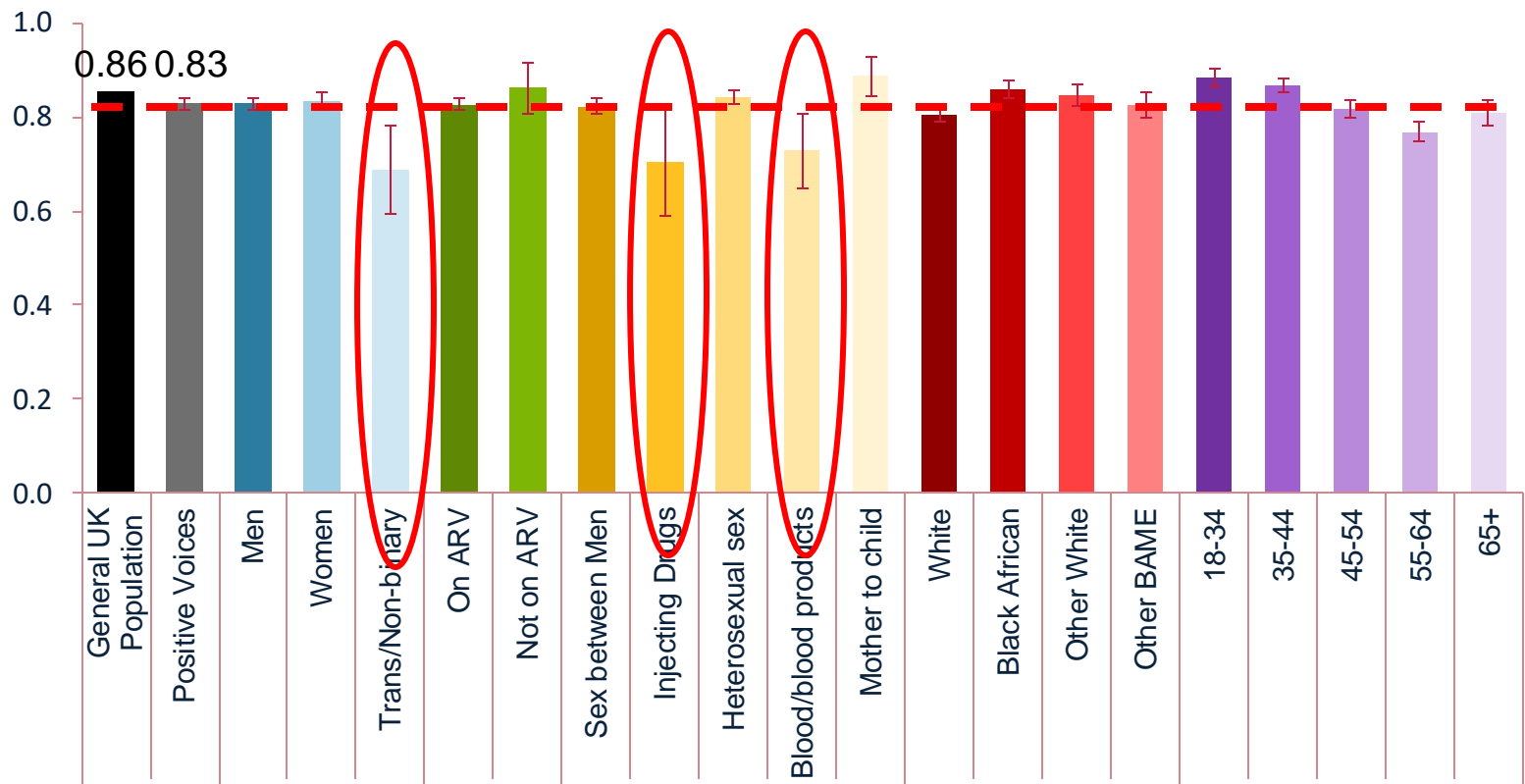




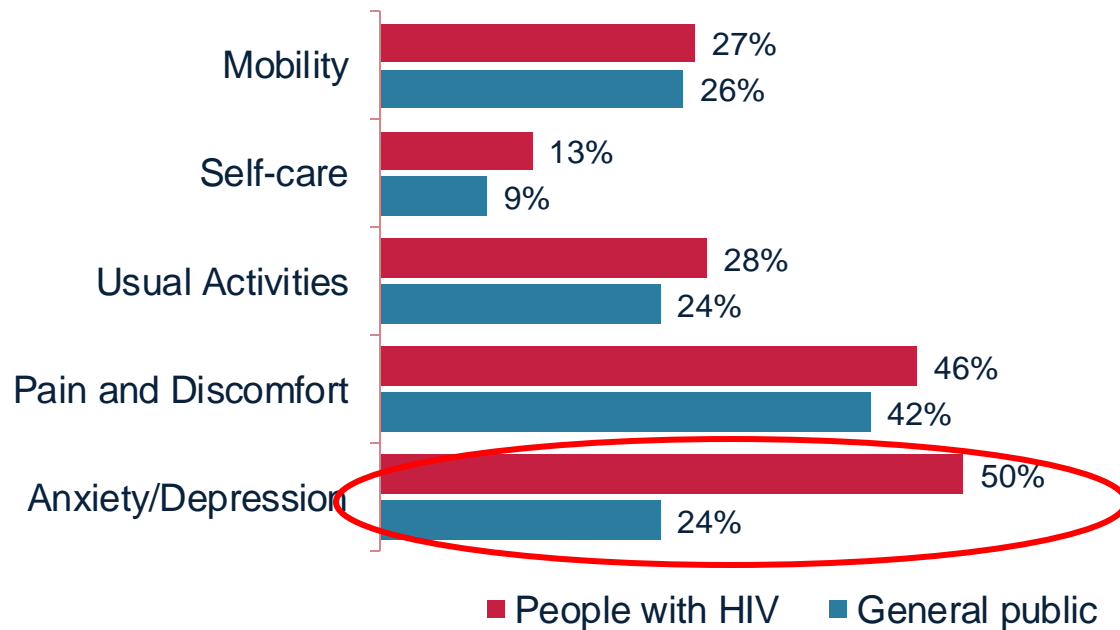
# Satisfaction with HIV clinic: 2017



# Quality of life: utility score (EuroQol)



# EuroQol % reporting problems: people with HIV vs gen pop



# Met and unmet needs

## Three sections

- HIV-related services (6)
- Health-related services (11)
- Social & Welfare services (12)

SECTION E:


E2 HEALTH SERVICES

E3 SOCIAL AND WELFARE SERVICES

Below a list of services or help that you may have needed and/or received, **in the last YEAR**. For each of these, please tick the box that is closest to your experience.

In the last YEAR...	I have received this.	I needed this, but <b>could not</b> get it.	I needed this, but did not try to get it.	I did not need this.
Housing support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Meal or food services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Childcare services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Relationship advice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help dealing with loneliness or isolation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Employment advice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Career skills and training	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help claiming benefits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Financial advice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Legal advice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Immigration support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Domestic violence services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you were not able to get the help you needed, please tell us the reason(s) why:





## E1 HIV RELATED SERVICES

Below a list of services that you may have needed and/or received in the **past YEAR**. For each of these services, please tick the box that is closest to your experience.

Population

# Defining “Need”:

those who needed this  
help in the past year

In the last YEAR...	I have received this help.	I needed this help, but could not get it.	I needed this help, but did not ask or look for it.	I did not need this help.
Information about living with HIV (including websites)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HIV treatment advice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Professional help to take your HIV tablets on time or correctly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Peer support/social contact with other people with HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help disclosing your HIV status	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Long term condition management support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you were not able to get the help you needed, please tell us the reason(s) why:

NEED

## E1 HIV RELATED SERVICES

Below a list of services that you may have  
**YEAR**. For each of these services, please  
closest to your experience.

Population

in the **past**  
ment that is

# Defining

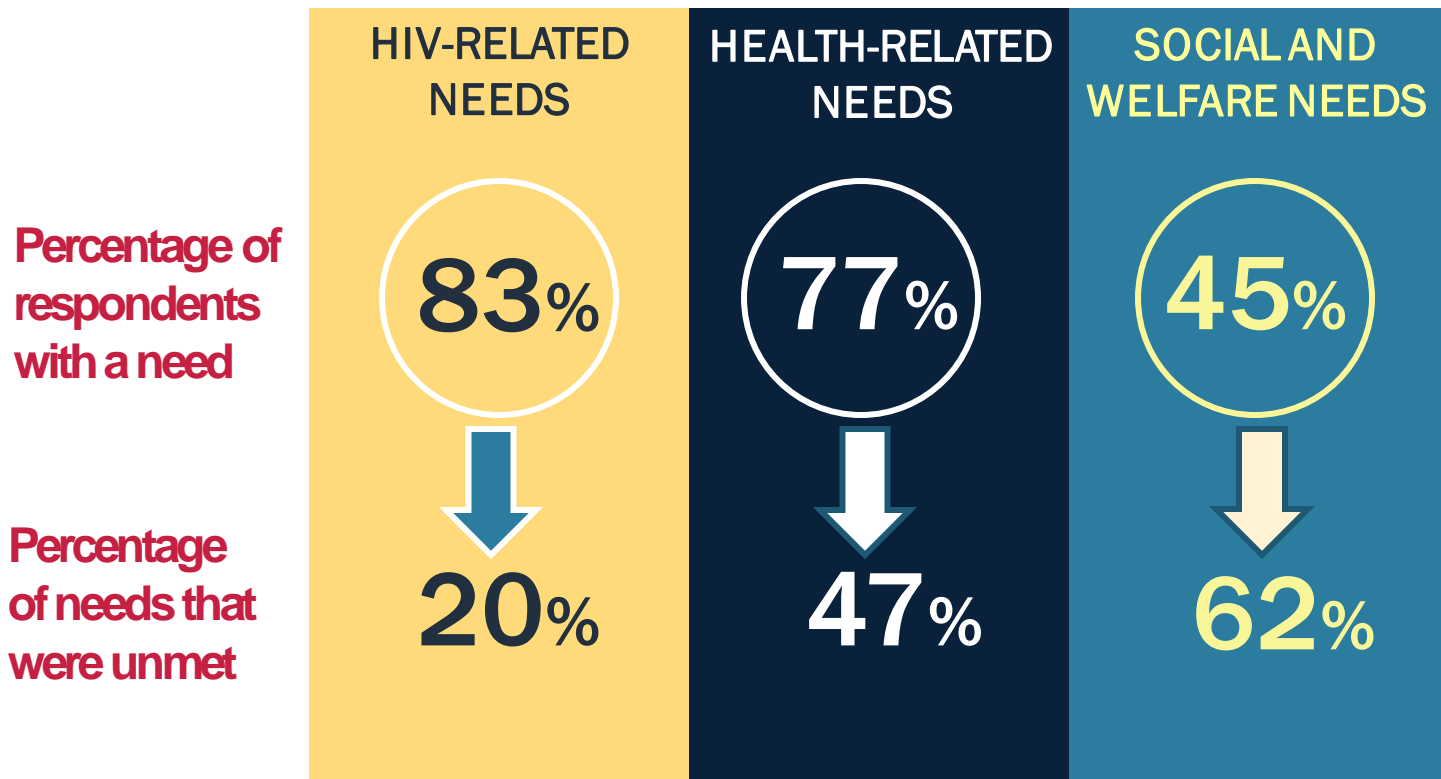
“Unmet need”:

those who did not receive this  
help in the past year, of those  
who needed it

In the last YEAR...	I have received this help.	I needed this help, but could not get it.	I needed this help, but did not ask or look for it.	I did not need this help.
Information about living with HIV (including websites)	<input type="checkbox"/>	<b>UNMET NEED</b>		<input type="checkbox"/>
HIV treatment advice	<input type="checkbox"/>			<input type="checkbox"/>
Professional help to take your HIV tablets on time or correctly	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Peer support/social contact with other people with HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help disclosing your HIV status	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Long term condition management support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

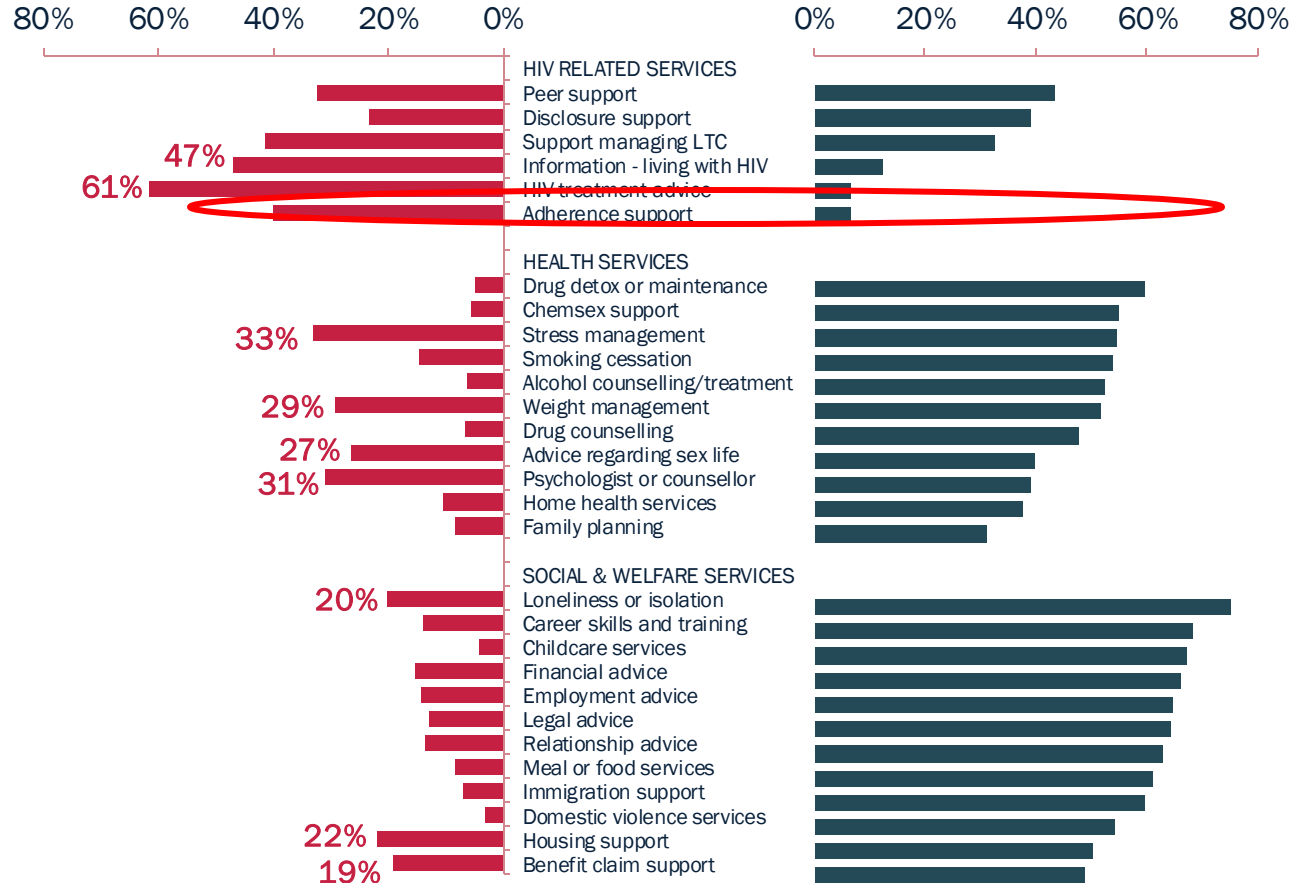
If you were not able to get the help you needed, please tell us the reason(s) why:

# What help do you need?



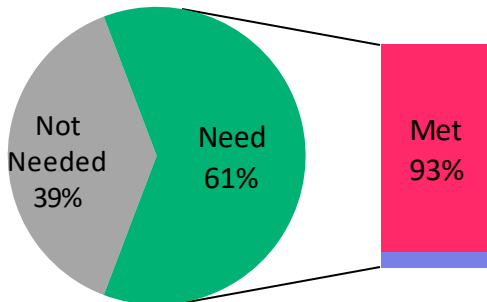
## % NEED

## % UNMET NEED

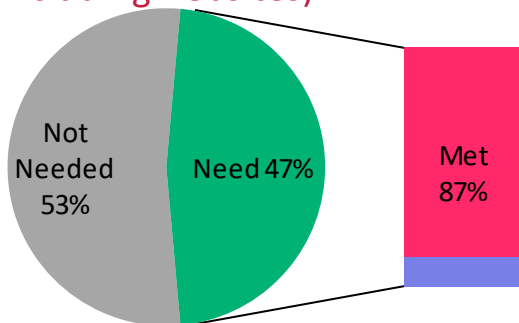


# Met and Unmet Needs: HIV treatment advice and information

## HIV treatment advice



## Information about living with HIV (including websites)



**98%**

Enough information



**94%**

Involved in decisions



**95%**

Supported to self-manage



**96%**

Enough time at appts

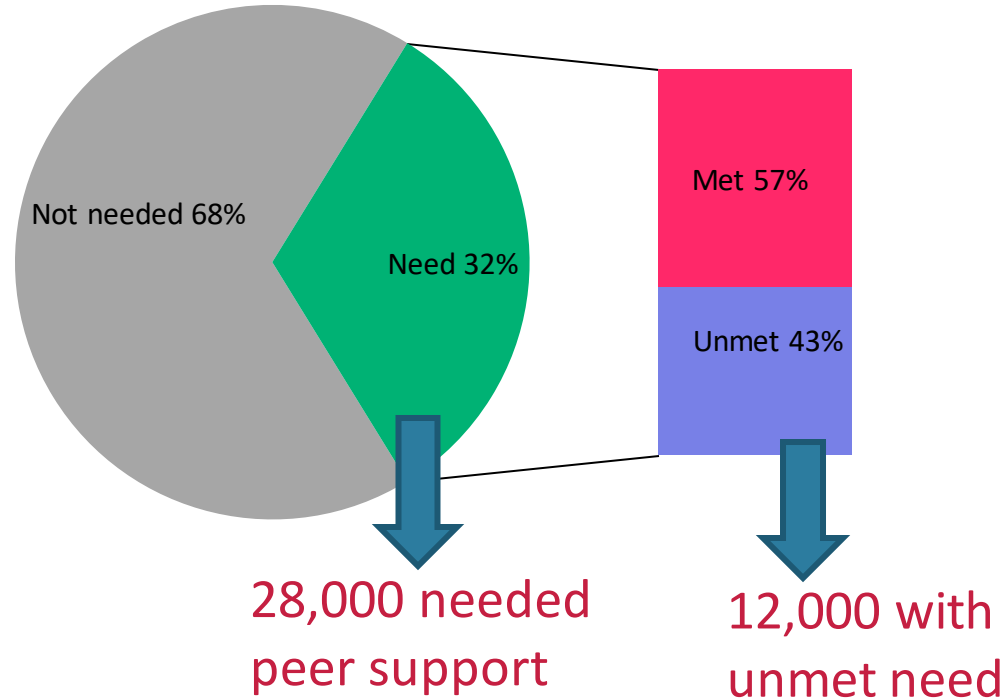


**97%**

Staff listen

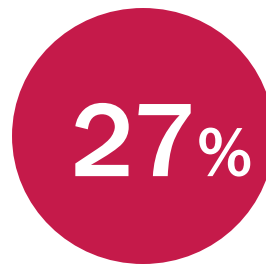
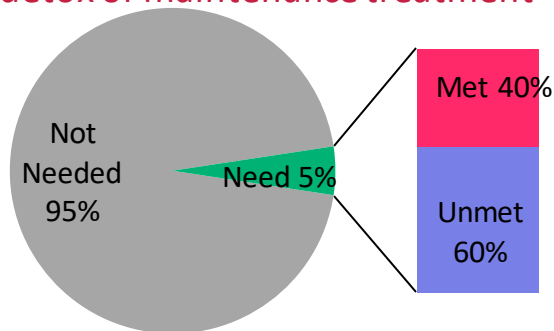
# Met and Unmet Needs: Peer support

Peer support/social contact with other people living with HIV

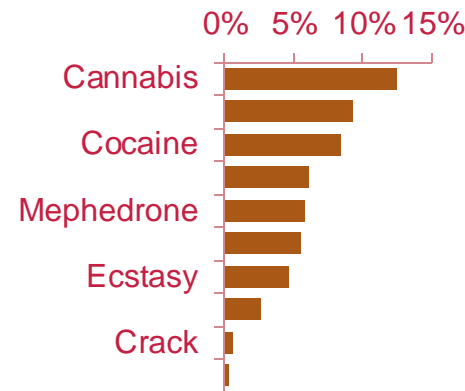


# Met and Unmet Needs: Drug treatment and Chemsex Support

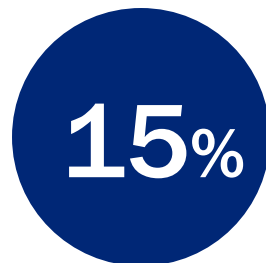
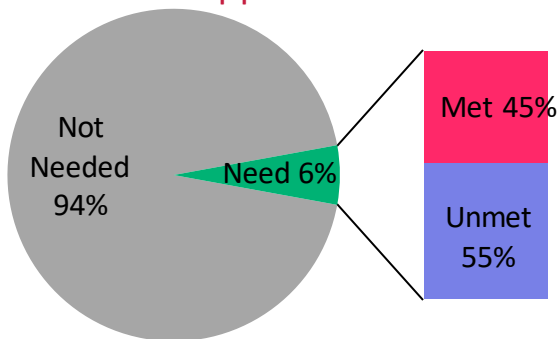
## Drug detox or maintenance treatment



Any drugs in past 3 months

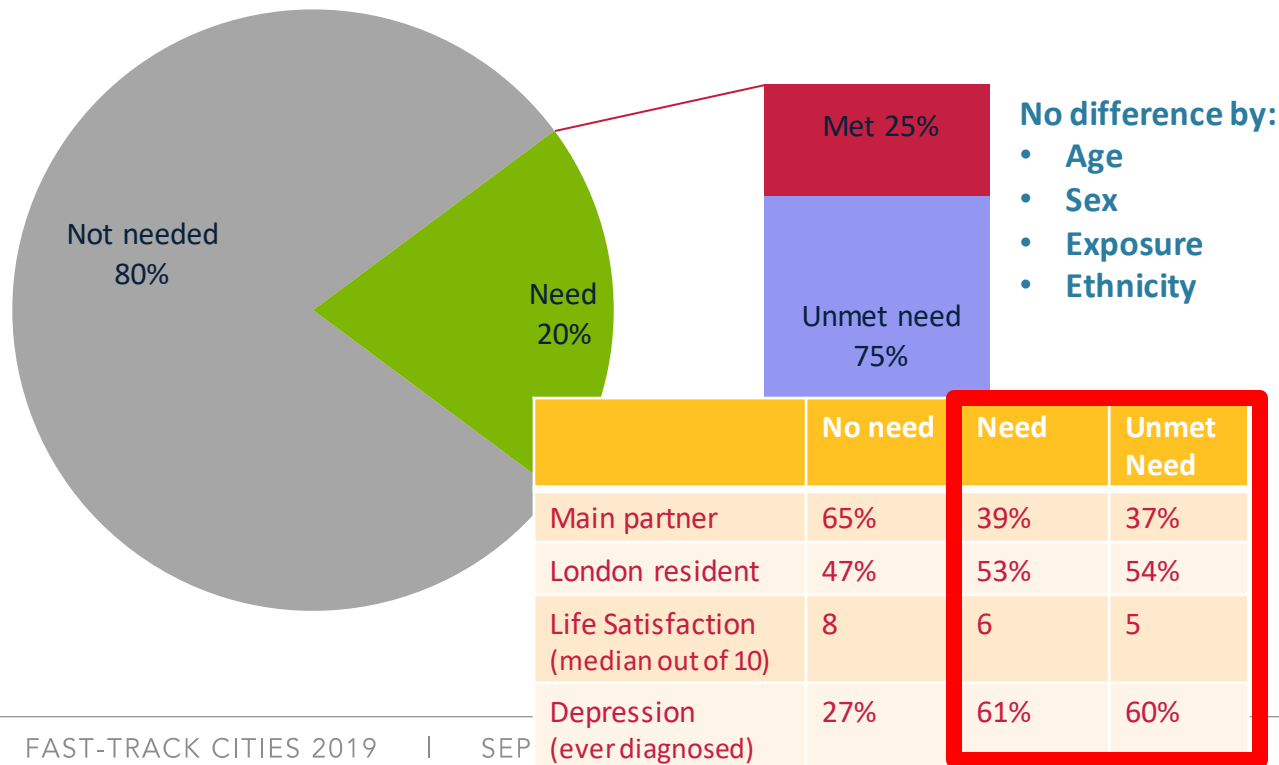


## Chemsex support

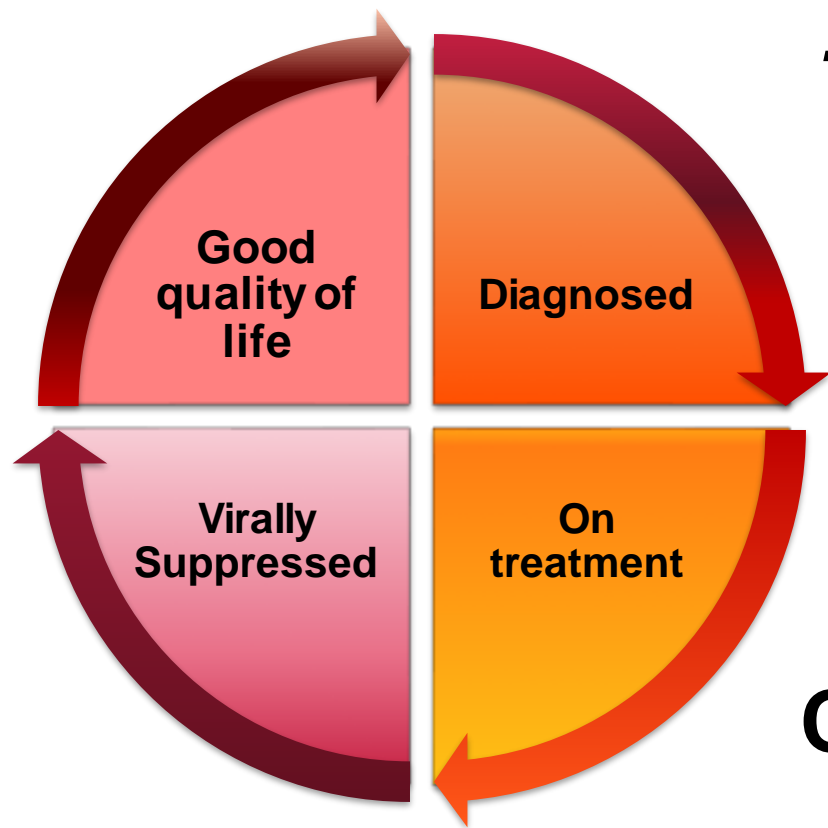


Gay and bisexual men reported chemsex in past 3 months

# Met and Unmet Needs: Help dealing with loneliness & isolation







## ***The 4<sup>th</sup> 90***

People with HIV deserve a good quality of life at all stages of life

## **Challenges ahead...**

# Good HIV care and support DOES make a difference ...

“Once you are diagnosed with HIV your self esteem goes down, your activities decline and I feel that you really need psychological, social and spiritual support for your well being.”

“Having the HIV nurse has made a massive increase to my overall emotional and physical well-being.”

“The HIV clinic is very important to manage and provide vital information to patients. This increases their confidence and quality of life.”





# How do health systems ensure good quality of life for people with HIV?



- Integrated, patient-centred approach to long-term HIV care
  - **Prevention** of other poor health conditions
  - Diagnosis and treatment of other **long term conditions**
  - **Personalised care** plan
  - Integrate **mental health** services
  - Focus on **sexual and reproductive** health
  - **Involvement** of people with HIV in their care
- Combat stigma and discrimination
- Scale up involvement of HIV community

# EuroQol % reporting problems: people with HIV vs gen pop



How can cities align efforts  
to achieve a good  
standard of care for all  
people with HIV?



Department  
for Work &  
Pensions



England