

**Ms Meaghan Kall**  
Public Health England

**Fourth Joint Conference** *of the* **British HIV Association** *with the* **British Association for Sexual Health and HIV**  
Edinburgh International Conference Centre ♦ 17-20 April 2018



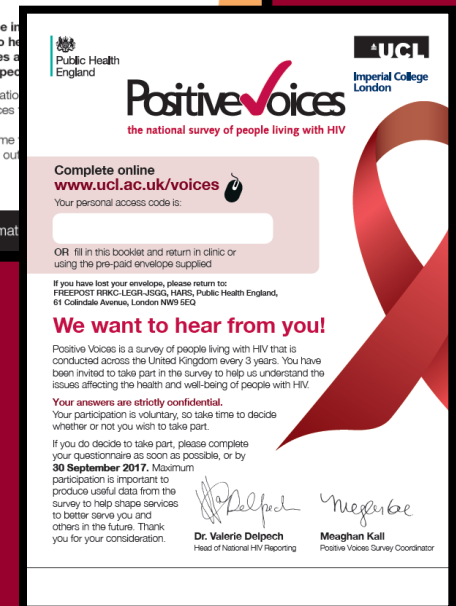
Public Health  
England

**PositiveVoices**  
the national survey of people living with HIV

# Met and unmet health, welfare and social needs of people accessing HIV services

## Findings from Positive Voices survey 2017

Meaghan Kall  
Public Health England  
on behalf of the Positive Voices study group





Public Health  
England

# Disclosures

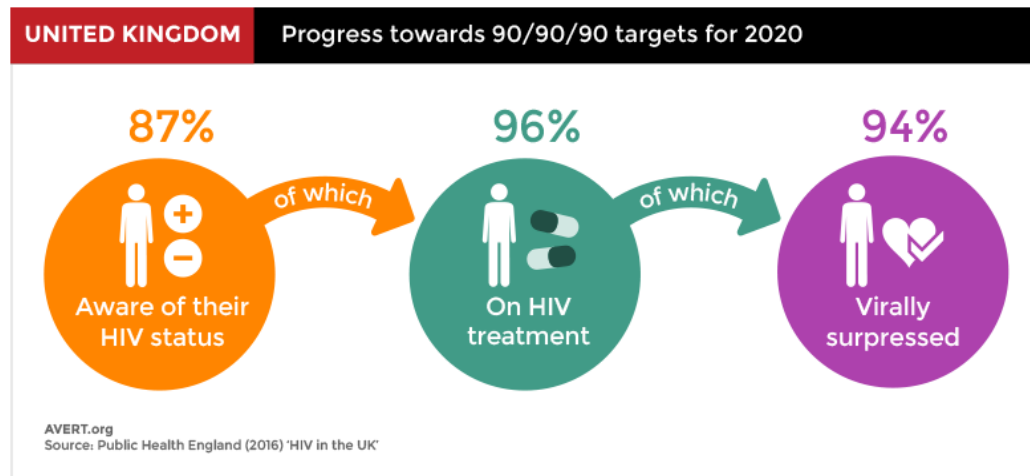
No personal funding disclosures

Positive Voices awarded grants from Gilead and ViiV



# Background

- >90,000 people accessing HIV services in the UK, vast majority on HIV treatment and undetectable
- People with HIV have a wide range of complex health and social care needs, in addition to their HIV
- Their specific needs, and the extent to which these needs are currently being met is unknown





# Presentation objectives

1. Present national estimates of the met and unmet health and social needs of people accessing HIV services in the UK
2. Explore the areas of greatest unmet need and their contributing factors

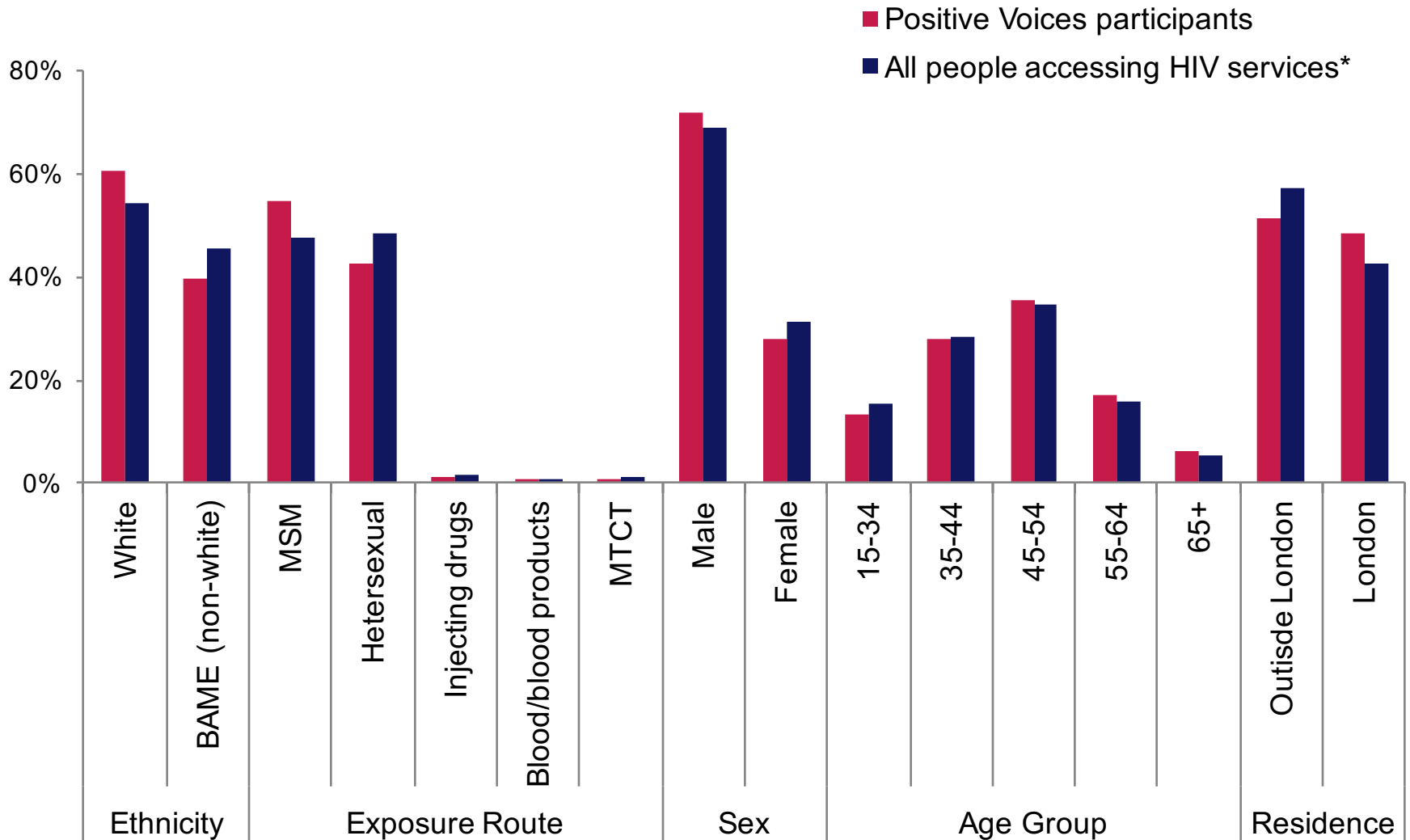


- ◆ February – September 2017
- ◆ Nationally representative
  - Random sample from HARS
  - ~20% patients/clinic
- ◆ Clinic-based recruitment
  - Face to face, post or email
- ◆ Self-completion
  - Paper (87%) or online (13%)
- ◆ Incentive
  - £5 high street voucher
- ◆ Results:
  - 73 clinics**
  - 4,418 responses**
  - 51% response rate**





# Participant characteristics



\* 2016 HIV clinic attendees, aged ≥18 resident England and Wales



# Met and unmet needs

## Three sections

HIV-related services (6)

Health-related services (11)

Social & Welfare services (12)

**SECTION E:**

**E2 HEALTH 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.

**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 **Population** that is closest to your experience.

# 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 checked="" 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:

Empty text box for providing reasons for not receiving help.



## E1 HIV RELATED SERVICES

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

Population

# Defining “Unmet need”:

those who received this help in the past year, of those who needed it

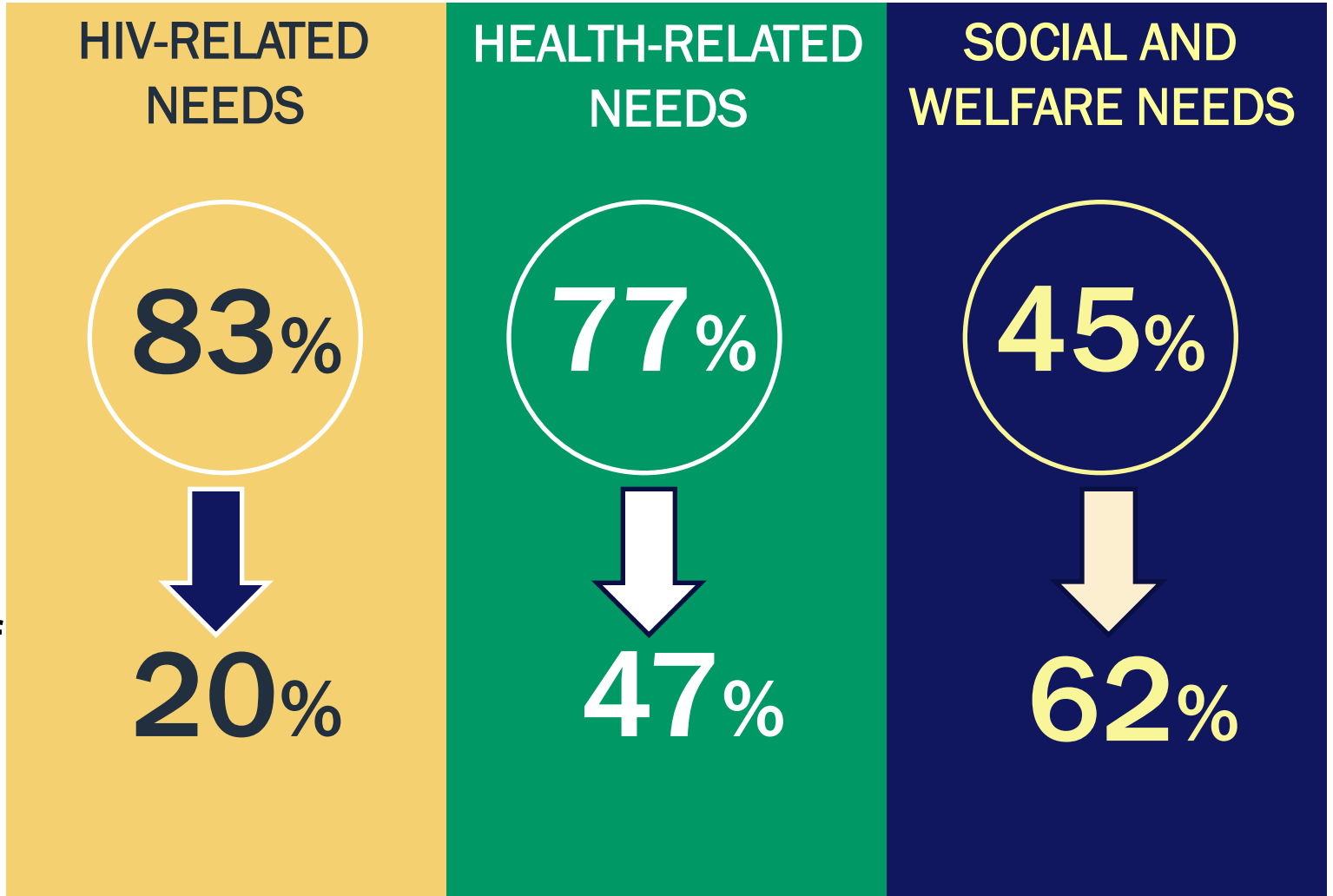
In the last YEAR...	I have received this help.	I needed this help, but could not get it.	I needed this help, but did not ask or look for it.	I did not need this help.	
Information about living with HIV (including websites)	<input type="checkbox"/>	<b>UNMET NEED</b>		<input type="checkbox"/>	
HIV treatment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

Empty text box for providing reasons for unmet need.



# Results: What help do you need?



Percentage of patients with a need

Percentage of needs that were unmet



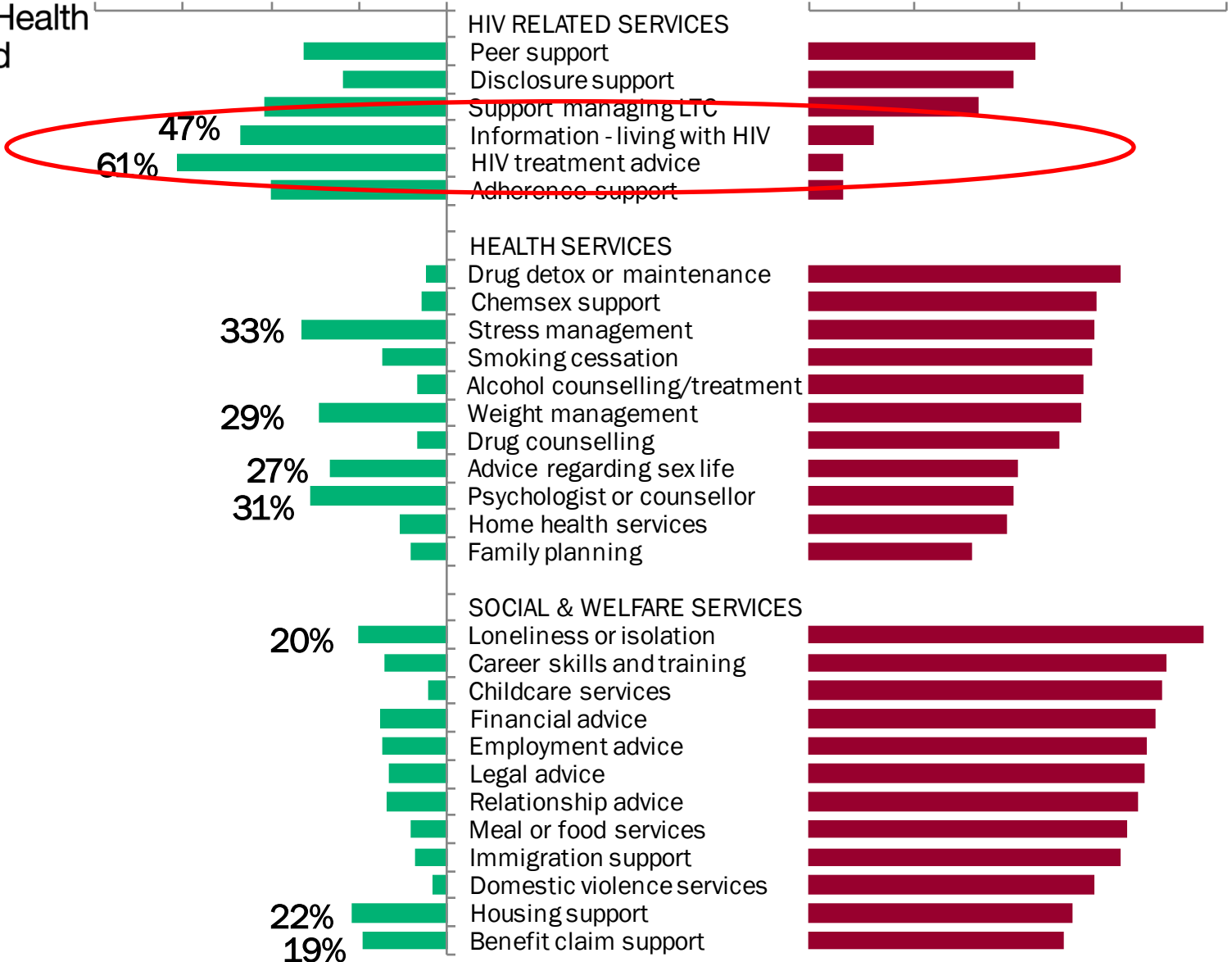
# Public Health England

## % NEED

80% 60% 40% 20% 0%

## % UNMET NEED

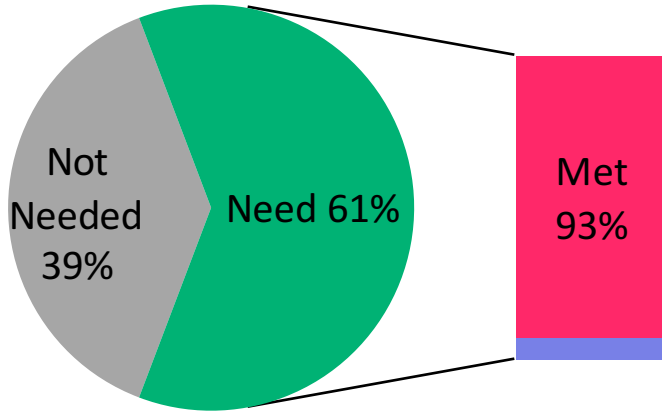
0% 20% 40% 60% 80%



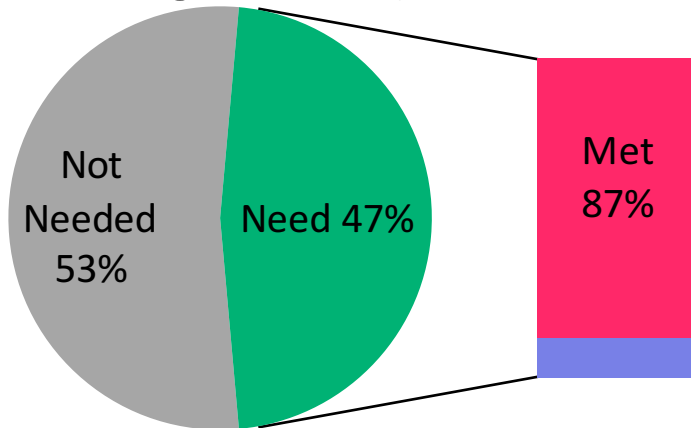


# HIV treatment advice and information

## 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



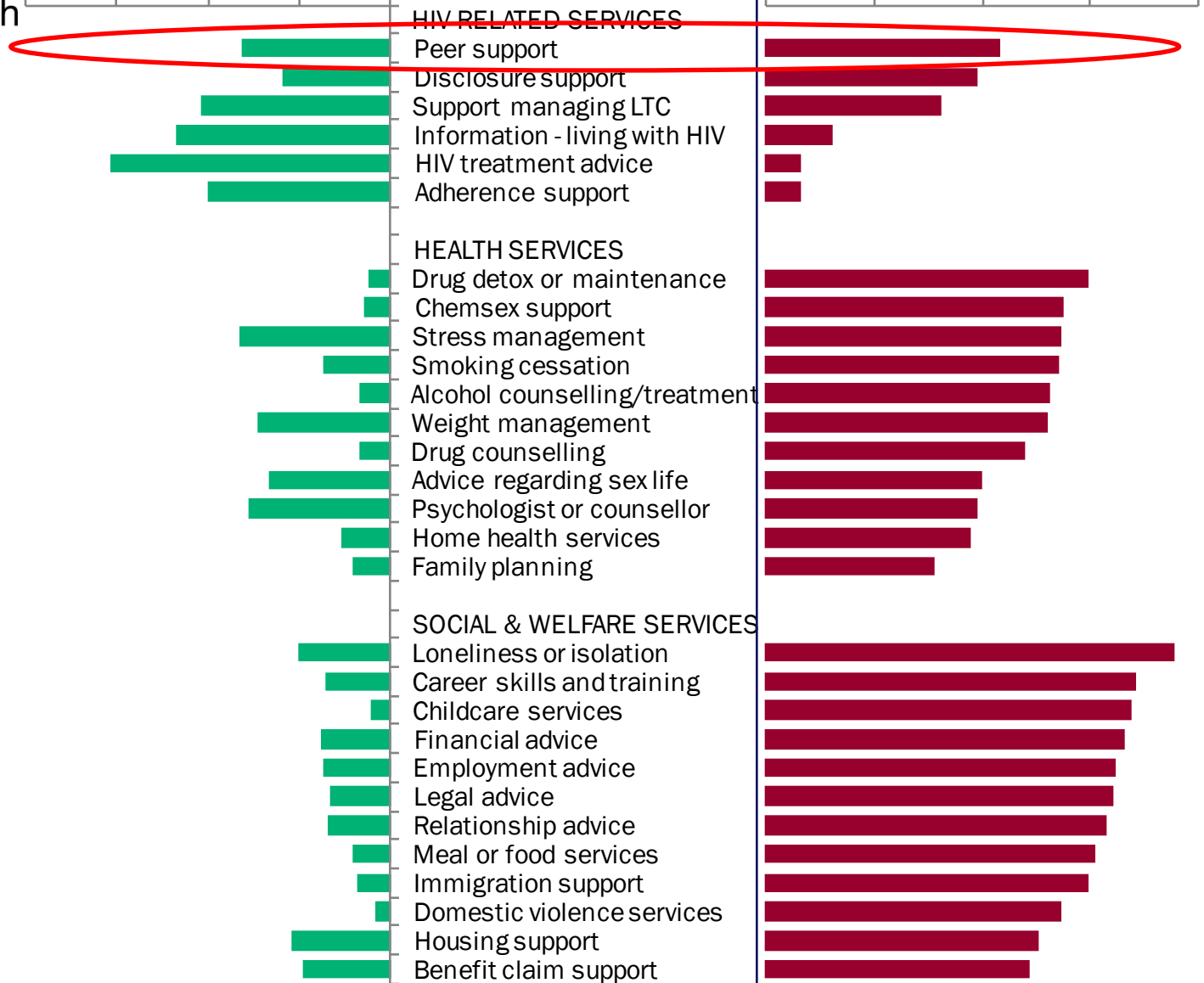
Public Health  
England

### % NEED

80% 60% 40% 20% 0%

### % UNMET NEED

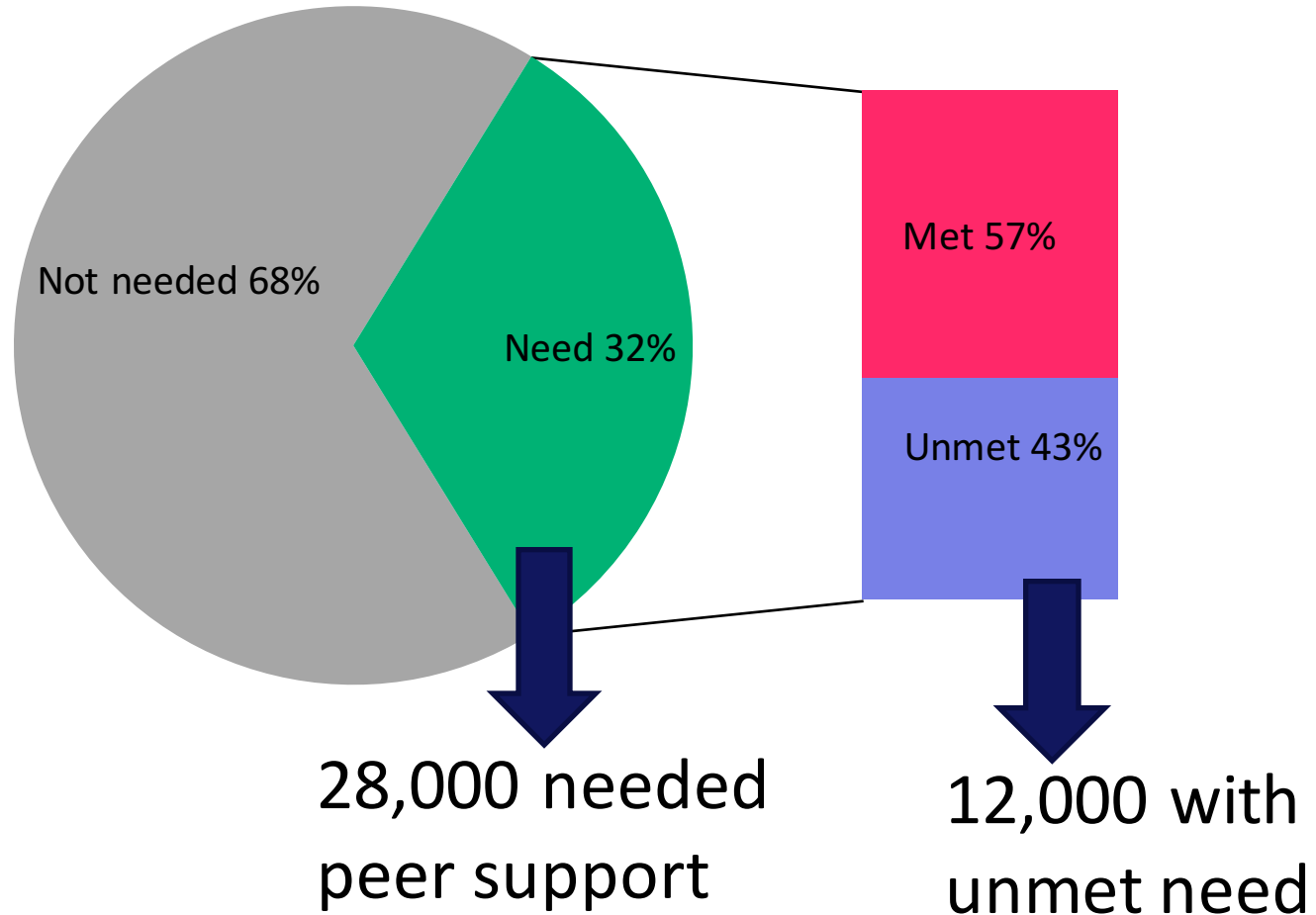
0% 20% 40% 60% 80%





# Peer support

Peer support/social contact with other people living with HIV





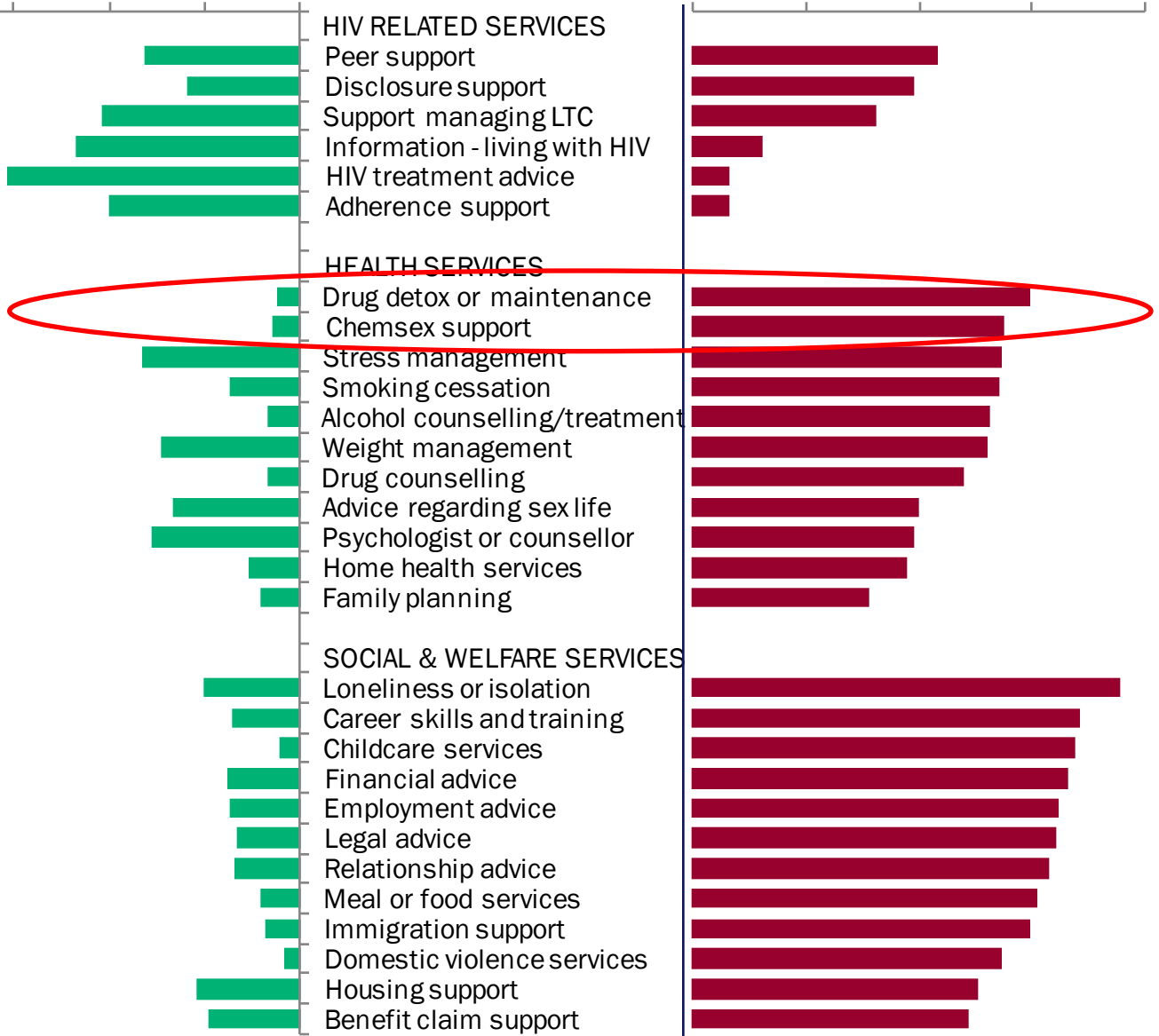
Public Health  
England

**% NEED**

80% 60% 40% 20% 0%

**% UNMET NEED**

0% 20% 40% 60% 80%

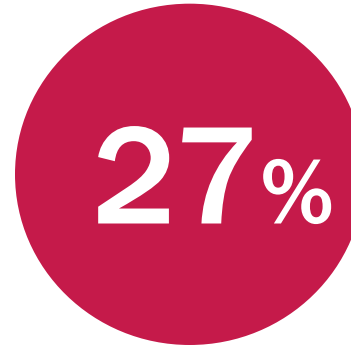
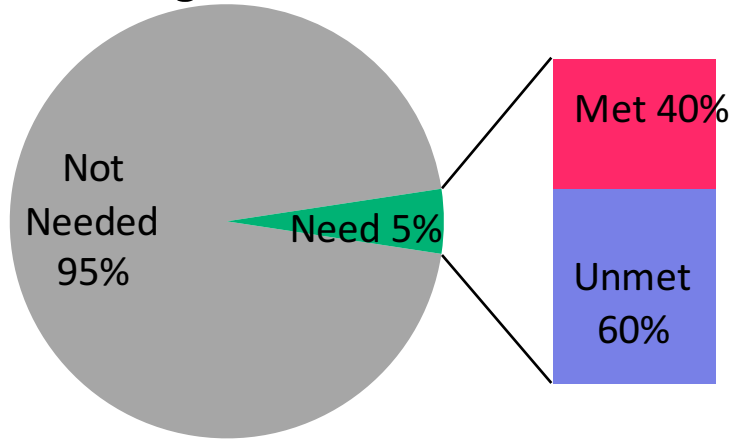




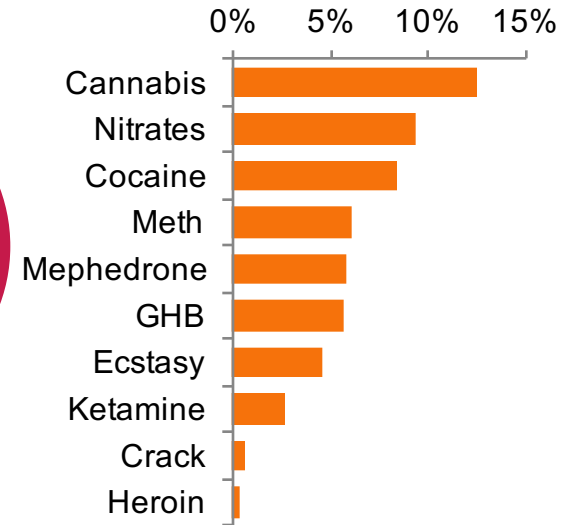


# Drug treatment and Chemsex

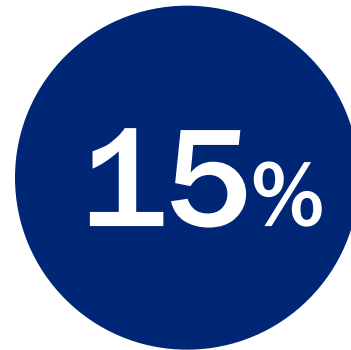
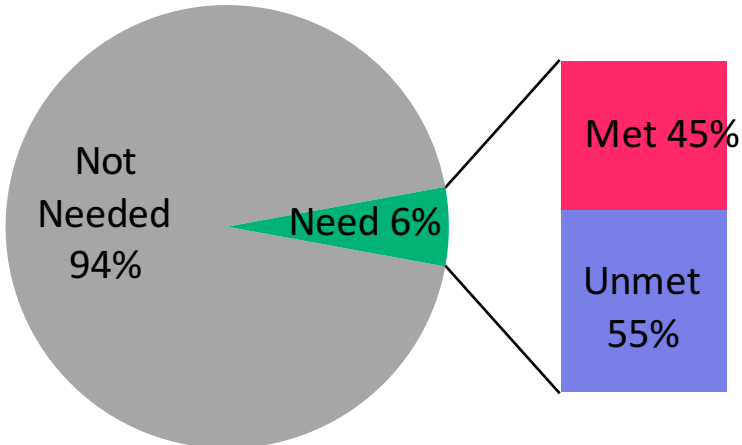
## Drug detox or maintenance treatment



Any drugs in past 3 months



## Chemsex support



MSM reported chemsex in past 3 months



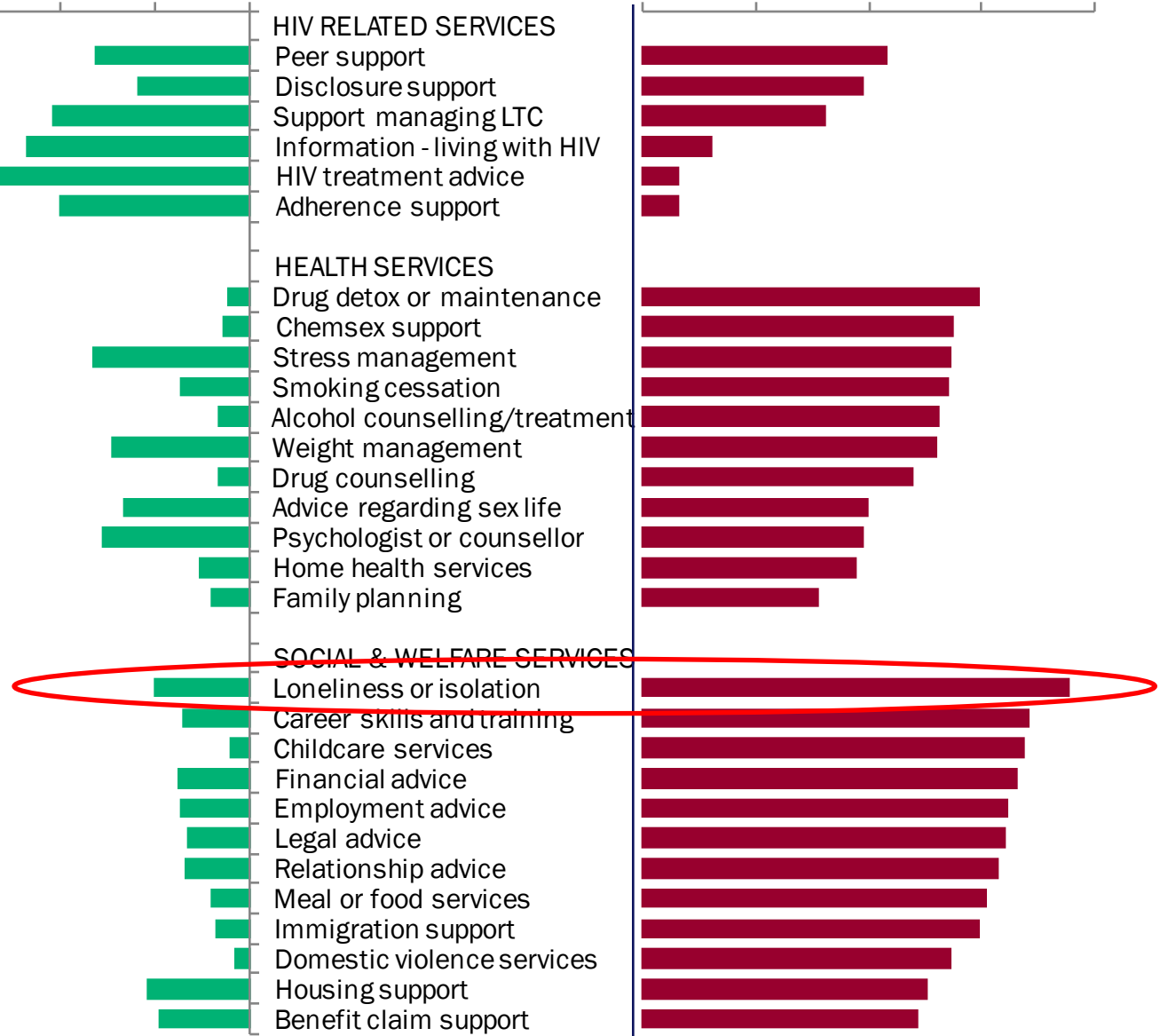
Public Health  
England

### % NEED

80% 60% 40% 20% 0%

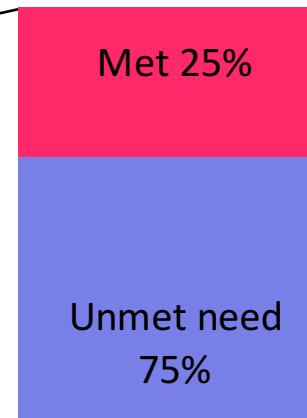
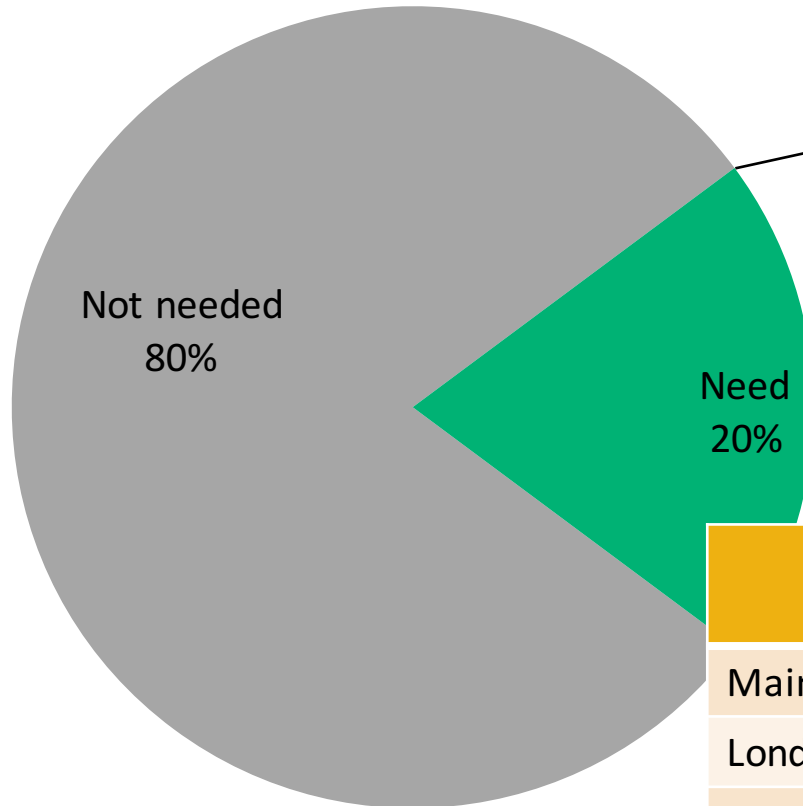
### % UNMET NEED

0% 20% 40% 60% 80%





# Help dealing with loneliness and isolation



**No difference by:**

- Age
- Sex
- Exposure
- Ethnicity

	No need	Need	Unmet Need
Main partner	65%	39%	37%
London resident	47%	53%	54%
Life Satisfaction (median out of 10)	8	6	5
Depression (ever diagnosed)	27%	61%	60%



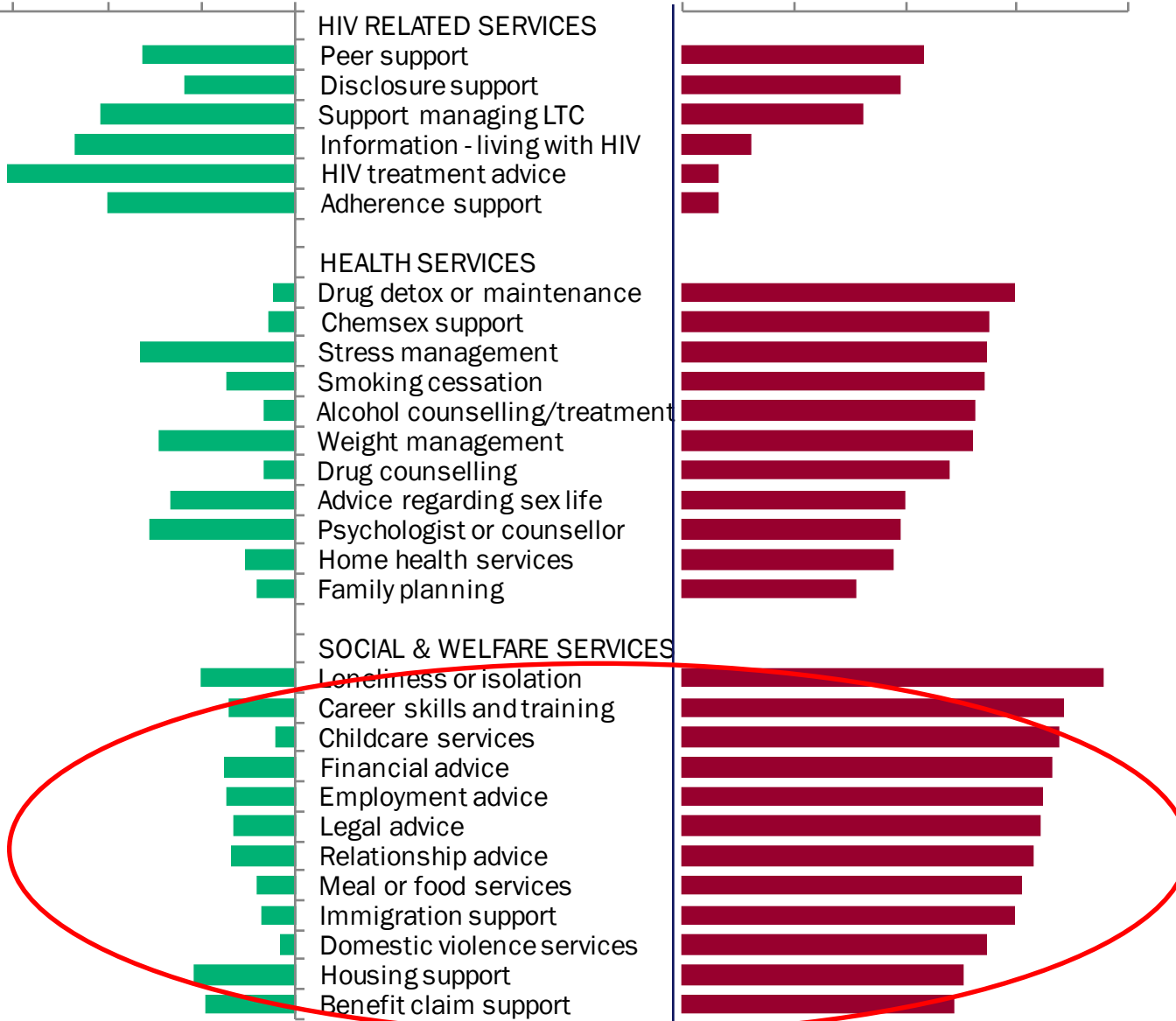
# Public Health England

## % NEED

80% 60% 40% 20% 0%

## % UNMET NEED

0% 20% 40% 60% 80%





# Positive Voices 2017 outputs

## SPRING 2018

Presentations at  
BHIVA 2018 & AIDS 2018



## SUMMER 2018

Clinic-level reports  
Local meeting  
presentations



## AUTUMN 2018

Full national report

Community-led report with  
Positively UK and National  
AIDS Trust



## NOW UNTIL ...

Scientific manuscripts  
Research collaborations  
Bespoke reports and outputs  
for stakeholders





# Limitations

- Non-response bias
- Self-reporting does not always reflect actual need
- No specific detail on where, when, how services were accessed
- Limited data on why services were not accessed



# Conclusions

- Provision of HIV-related services for those who need them is very good
- There are major gaps in the provision of social and welfare services, as well as certain health-related services
- This comprehensive needs assessment provides important data for local commissioners, health service providers and support organisations to identify gaps in service provision and inform the development of service specifications
- Further breakdowns (e.g. by risk-group, lifestyle risk behaviours, geography) are needed to inform advocacy and tailor local response



to all Positive Voices survey participants  
&  
staff at 73 recruiting HIV clinics

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**Positive Voices Study Group**

Dr Richard Gilson (UCL), Dr Anthony Nardone (PHE), Dr Maryam Shahmanesh (UCL), Prof Helen Ward (Imperial College) Prof Graham Hart (UCL), Prof Jane Anderson (PHE), Yusef Azad (NAT), Prof Jonathan Elford (City University), Dr Ann Sullivan (C&W), Dr Cath Mercer (UCL), Dr Alan McOwan (C&W), Jess Peck (NHS England), Prof Jackie Cassell (Brighton and Sussex Medical School), Julie Musonda (UK-CAB), Jane Bruton (NHIVNA), Meaghan Kall (PHE), Dr Valerie Delpech (PHE)