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NATIONAL HIV NURSES ASSOCIATION

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21st Annual Conference *of the* National HIV Nurses Association (NHIVNA)

27–28 June 2019 · Manchester Conference Centre

21st

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Challenges of getting people on treatment

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Declaration of interests relating to this presentation

- None

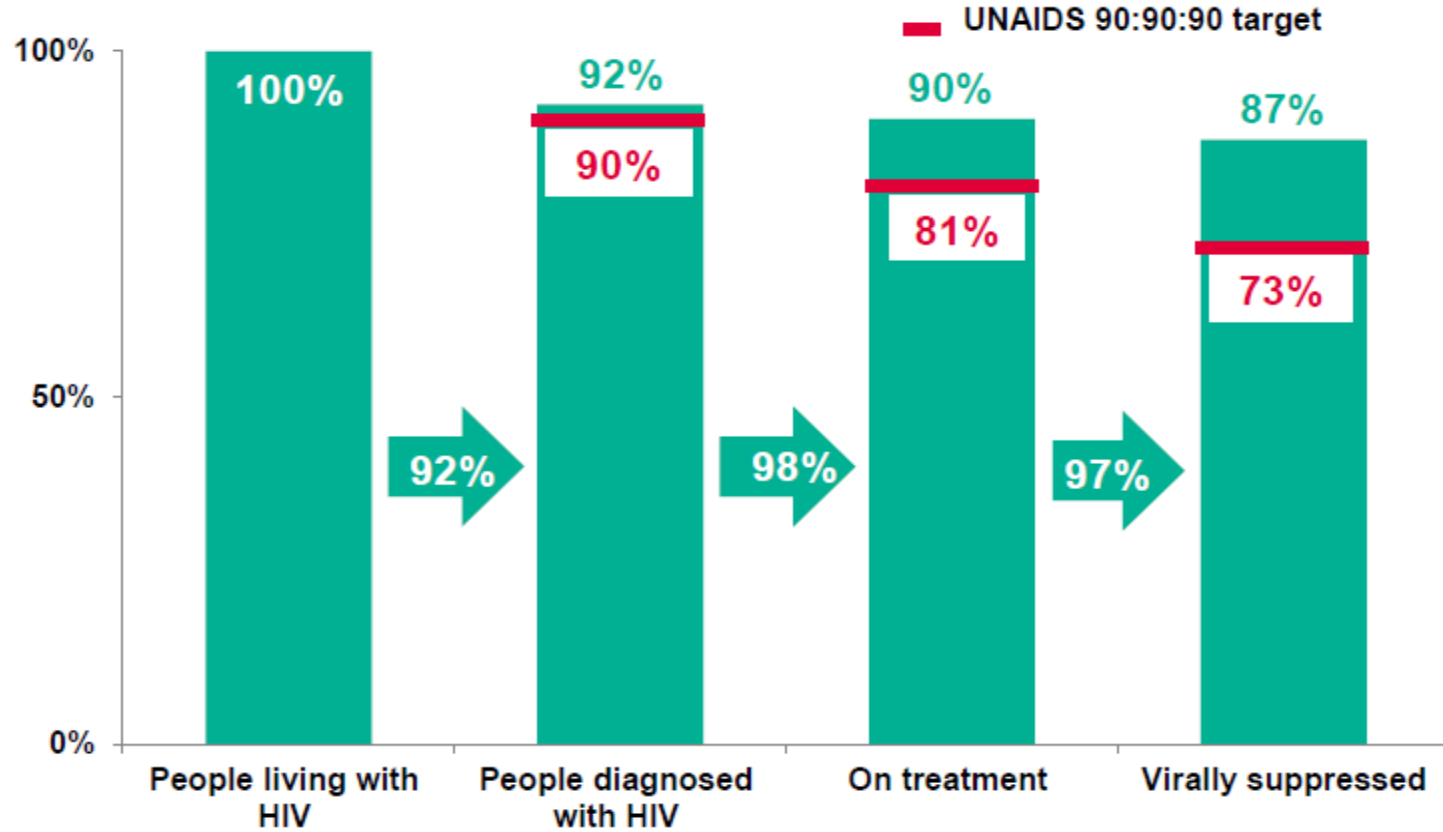




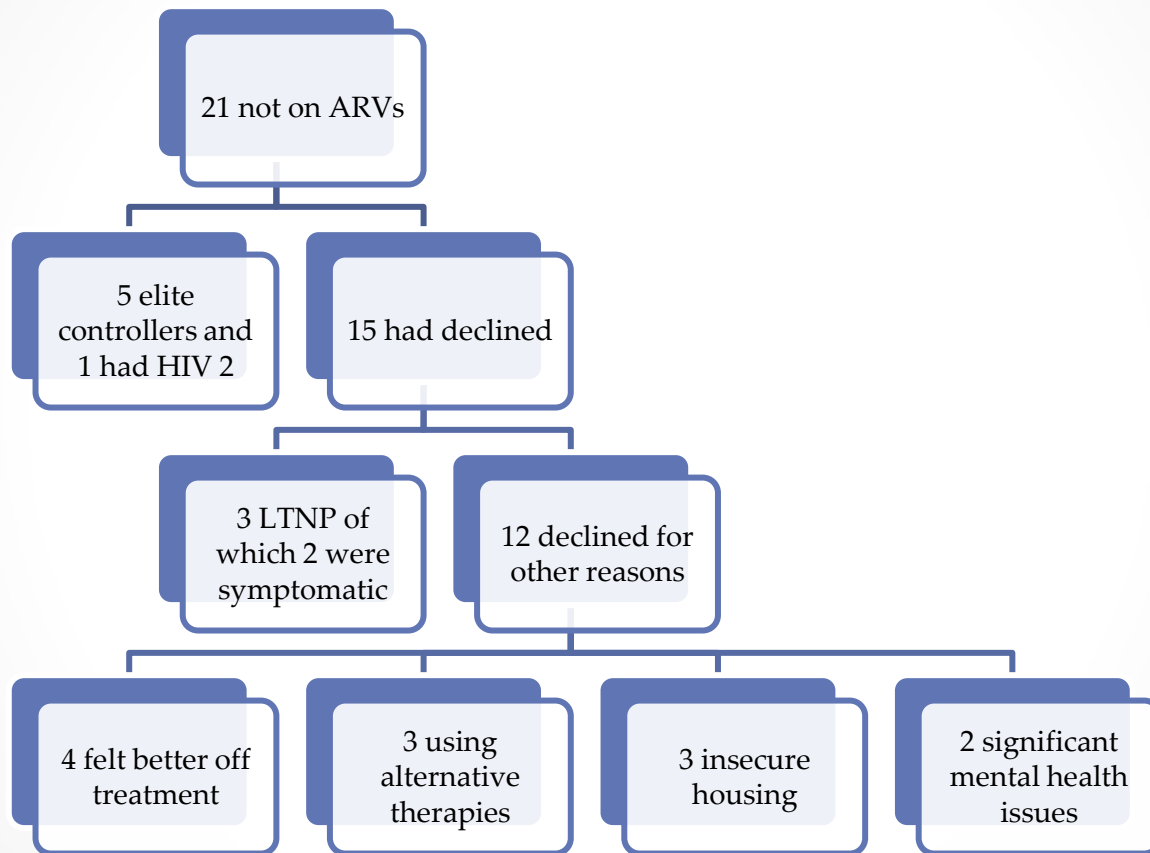
Plan for session

- Explore reasons why people are not on ARVs
- Look at some strategies to support people to start or re-start ARVs
- Outline our role as nurses in addressing the complexities of getting people on ARVs

Figure 1: Continuum of HIV care, UK: 2017



Audit of those not on ARVs in Brighton, June 2019



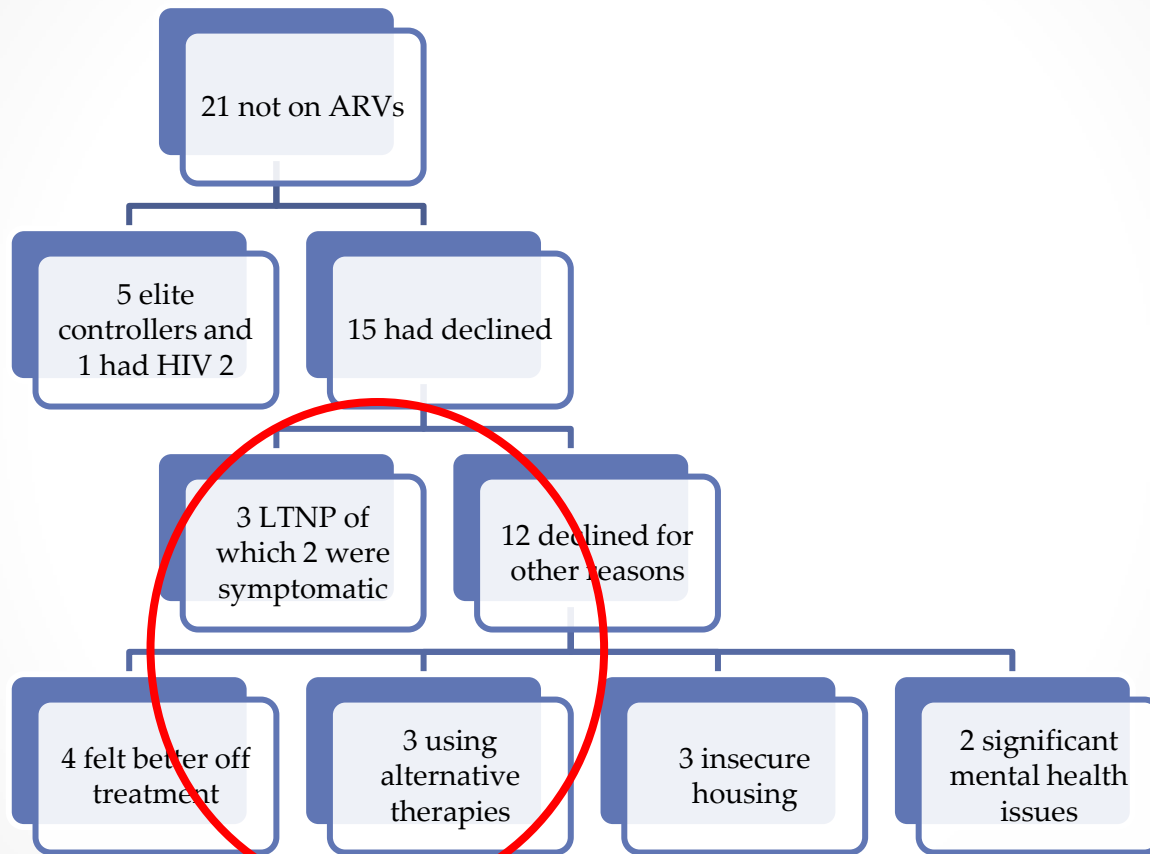
Overall 7/15 expressed concerns about side effects

Key messages for patients

[illegible]

- Many side effects are short term and most can be managed
- Modern ARVs have a better side effect profile
- We have a lot of ARVs to choose from
- Long term side effects are less common and are monitored for
- Direct to online patient resources such as aidsmap, i-base and myHIV
- Involve Peer Mentors where available

Audit of those not on ARVs in Brighton, June 2019



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Common-sense origins of HAART Necessity and Concerns

NECESSITY

Doubts about personal need for HAART associated with:

- Perceiving oneself to be in relatively good physical health ($r = -0.24, p < 0.005$)
- Higher CD4 count ($r = -0.18, p < 0.03$)
- Longer time since HIV diagnosis ($r = -0.32, p < 0.001$)
- Scepticism about efficacy of HAART ($r = 0.58, p < 0.001$)
- Negative attitudes towards medicines in general

(General harm ($r = -0.26, p < 0.005$), general overuse ($r = -0.30, p < 0.001$))

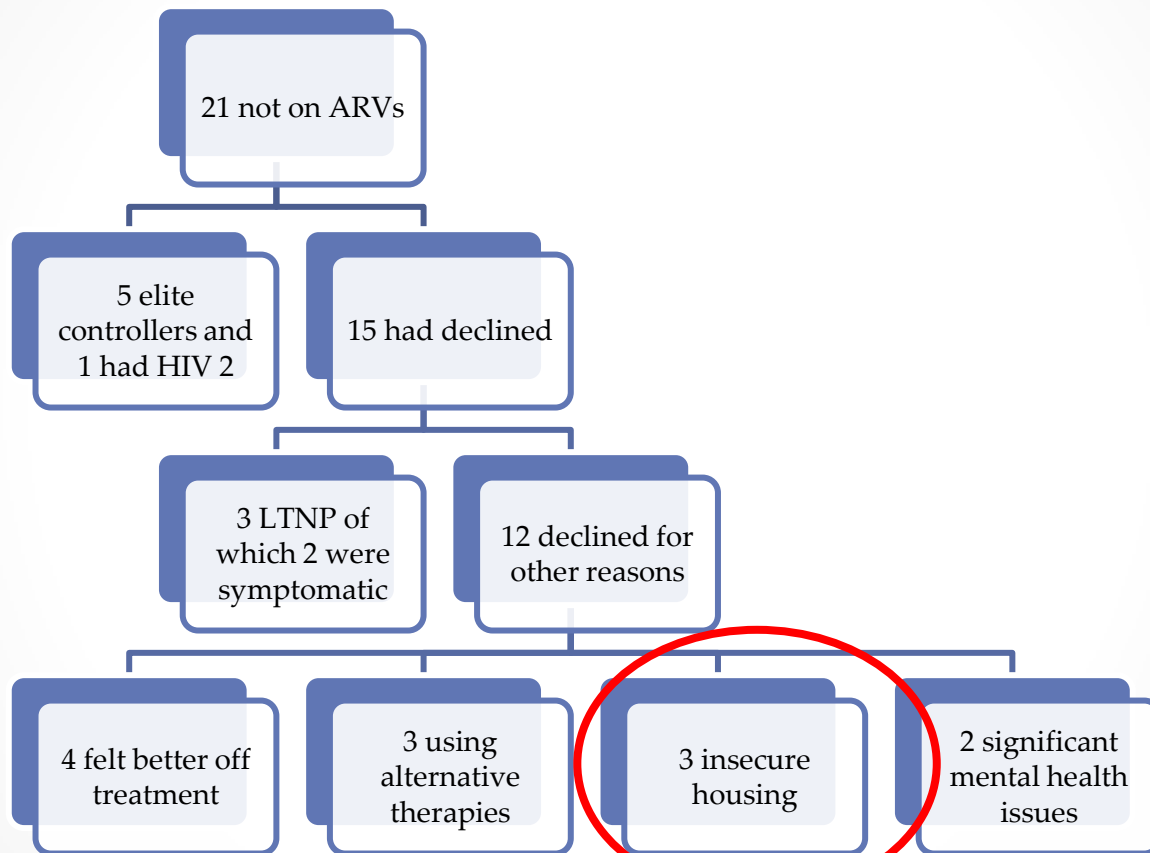
CONCERNS

HAART-Concerns associated with:

- Perceived sensitivity to adverse effects from medicines ($r = 0.38, p < 0.001$)
- Perception that medicines in general are harmful ($r = 0.42, p < 0.001$) and over-prescribed ($r = 0.28, p < 0.001$)
- Depression (HADS) ($r = 0.46, p < 0.001$)
- Anxiety (HADS) ($r = 0.47, p < 0.001$)

NOT associated with depression, anxiety, VL or disease classification (asymptomatic/symptomatic/AIDS)

Audit of those not on ARVs in Brighton, June 2019



Overall 7/15 expressed concerns about side effects

Insecure housing



- ARVs not a priority
- Often nowhere to store tablets
- Food restrictions can be a limiting factor
- Financially insecure
- Drug and alcohol issues can co-exist

Case Management

- Keeping individuals engaged in HIV care
- Individualised care plans working with their priorities

Assessing need/priorities

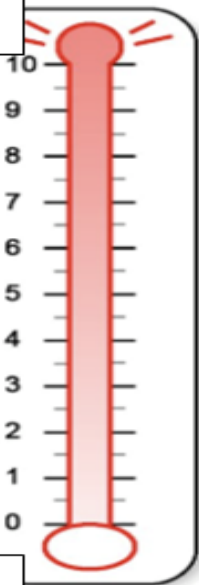
HOSPITAL NO:

NAME:

DOB:

We would like to know about your worries and concerns today. Please circle a number on the thermometer below and tick any boxes that are relevant to you.

10 Many Worries



0 No Worries

PRACTICAL PROBLEMS

- ☐ Housing
- ☐ Financial
- ☐ Benefits
- ☐ Immigration
- ☐ Employment
- ☐ Childcare
- ☐ Transport

SOCIAL PROBLEMS

- ☐ Relationships (family, friends, partner)
- ☐ Difficulty telling others about your diagnosis

MEDICATION PROBLEMS

- ☐ Side effects of medication
- ☐ Difficulty remembering medication

PSYCHOLOGICAL PROBLEMS

- ☐ Loneliness or isolation
- ☐ Depressions or sadness
- ☐ Worries about the future
- ☐ Difficulty accepting your diagnosis
- ☐ Concerns about stigma/confidentiality

SPIRITUAL/RELIGIOUS ISSUES

- ☐ Questioning beliefs and values
- ☐ Conflicts between faith and HIV

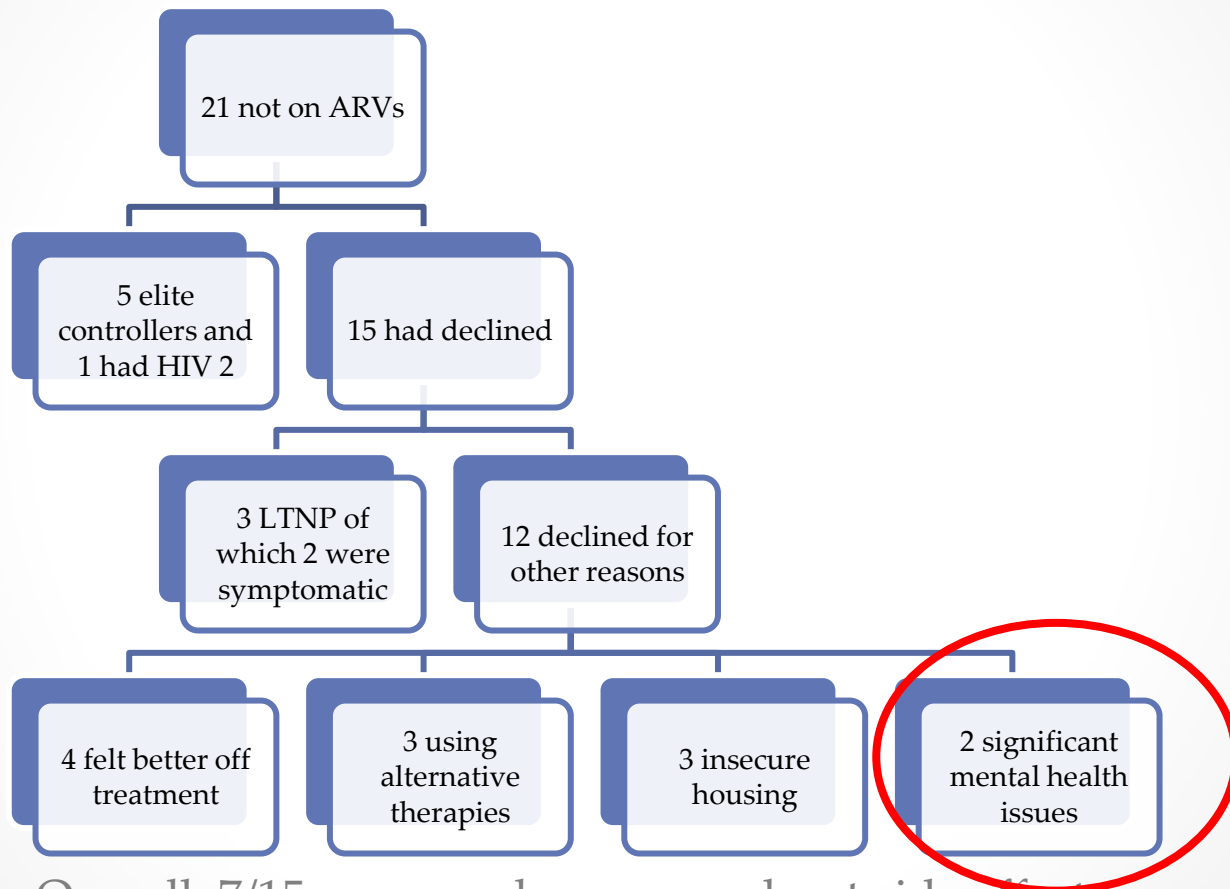
OTHER

☐

Case Management

- Keeping individuals engaged in HIV care
- Individualised care plans working with their priorities
- Build relationships with housing and outreach services
- Focus on getting people off the streets where possible
- Flexible approach to follow-up and ARV supplies

Audit of those not on ARVs in Brighton, June 2019

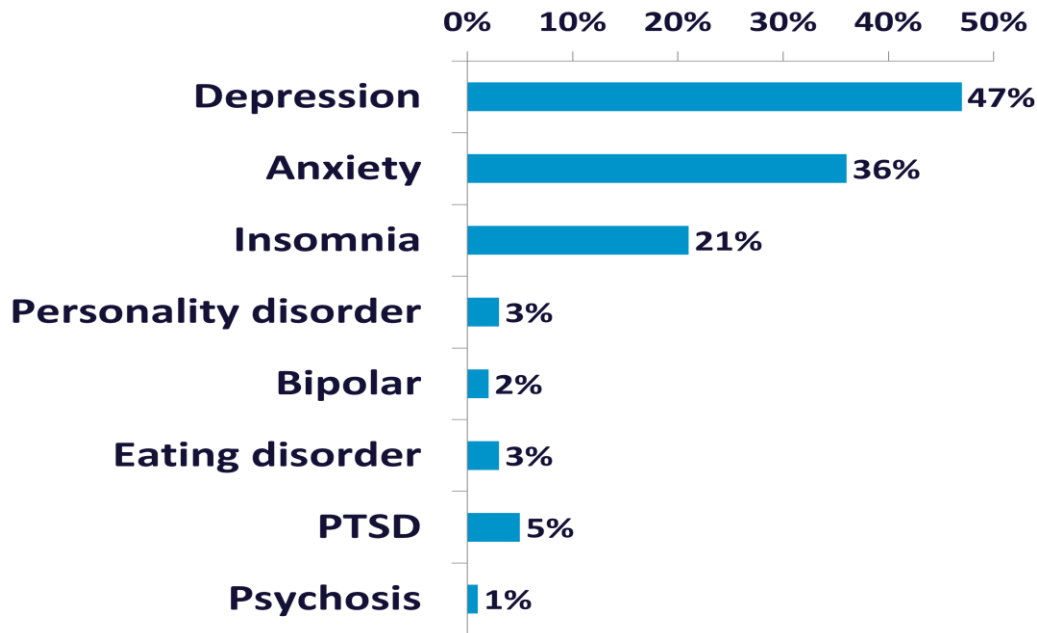


Overall 7/15 expressed concerns about side effects



Public Health
England

Prevalence of Mental Health Conditions Royal Sussex County Hospital



Depression

33% of PLHIV nationally

19% in the general population

Anxiety

25% of PLHIV nationally

15% in the general population

Sleep Disorder

15% in PLHIV nationally

Integrated care

- Work in partnership with mental health services
- Professionals Meetings / Case Conferences
- Identify the patient's priorities

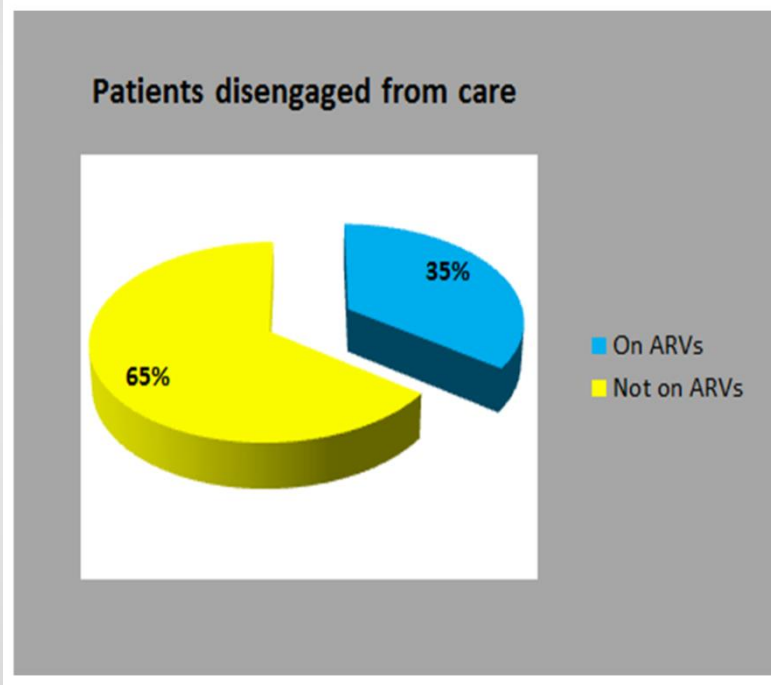
Screen all patients using PHQ4. If PHQ 4 score is > 4 do both a GAD7 and PHQ 9

GAD-7 score	Anxiety Severity	Proposed Treatment Actions	Depression Severity	PHQ-9 score
0 - 4	Mild	None	None/ Minimal	0 - 4
5 - 9	Moderate	Watchful waiting; repeat GAD-7 and PHQ 9	Mild	5 - 9
10 - 14	Moderately severe	<p>1. Onward referral for further evaluation and assessment to GP OR</p> <p>2. Self referral to health and well-being service https://www.brightonandhove wellbeing.org/</p> <p>AND relevant referral for practical support such as THT, Housing, Peer Support, Mind out, Headspace, LGBT helpline AND consider referral to HIV Community Specialist team for support or mental health input.</p> <p>www.nhs.uk/oneyou for generic stress, anxiety, sleep</p> <p>Online apps: https://www.mindcharity.co.uk/advice-information/how-to-look-after-your-mental-health/apps-for-wellbeing-and-mental-health/</p> <p>Also see mental resource sheet in Lawson nurses file.</p>	Moderate	10 - 14
15 - 21	Severe	<p>Active treatment psychotherapy and/or pharmacotherapy by GP.....OR</p> <p>If HIV related refer to SPNT.HIVMHREF@nhs.net and encrypt or password protect the letter</p> <p><i>What is HIV related?</i></p> <p><i>When HIV is the cause of the anxiety / depression or the anxiety/depression is likely to compromise stable HIV infection.</i></p>	Moderately severe or Severe	<p>15 - 19</p> <p>20 - 27</p>

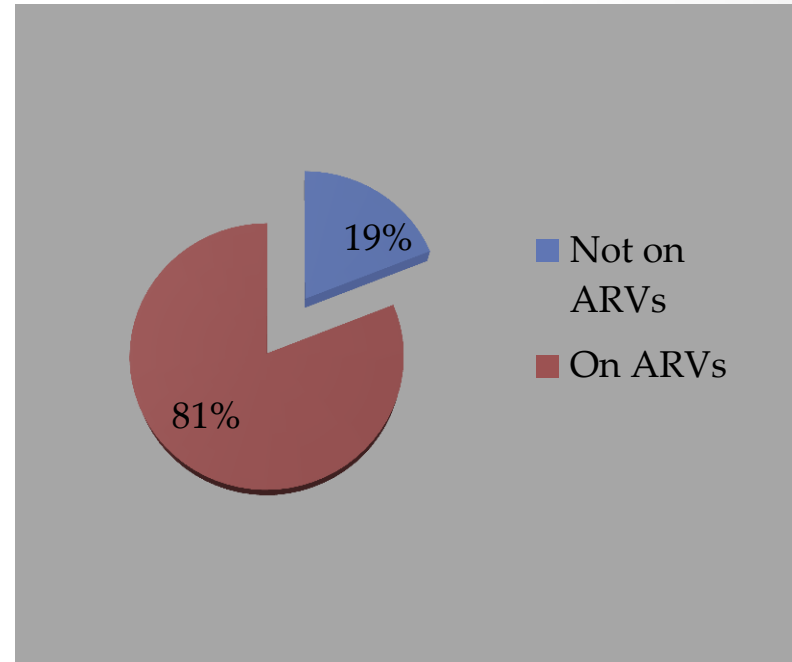
Keeping people engaged with
treatment and care

ARV use in people not engaged with care

Lost to follow-up data 2014-2016, Brighton



PHE National data 2017



Risk Factors for poor attendance

- General Risk factors
 - Younger age
 - Diagnosed with HIV for longer
 - Having children
 - Female
 - Telling family about HIV status
 - Not getting help when sick in bed
 - Not having money for basic needs
 - Drug/alcohol dependency

- Missed 1 or more appt /year
 - Poorer recent health
 - Symptoms of neurocognitive impairment,
 - Depression
 - Having complex needs (HARS 3)
 - HIV-related hospitalisation
 - Uncertainty about being in charge of life
- Absence of 1 year or more
 - Not being registered with a GP
 - Not being a homeowner
 - Not feeling listened to by the nurse
 - Less educated
 - Recreational drug use

Principles for sustaining retention in care

1. Proactive DNA management approach
2. Identify who is at risk of disengaging
 - Review frequency of appointments
 - Individualised care planning
 - Community bloods / yearly attendance
 - Incentives for reduced attendance
 - Consider alternative venues to see patients
 - ?Engaged with any healthcare
3. Consider our responses when people return to care
4. Keep the door open for people to return

The forgotten few: the challenge of opting out of ART

Liverpool HIV community nursing
June 2018

Pauline Jelliman, 20th Annual Conference of NHIVNA, Brighton 2018

Patient right to refuse treatment



- Quality statement 7: Supporting patient choice
- “Patients are made aware that they have the right to choose, accept or decline treatment and these decisions are respected and supported”



Conclusion

- We need to balance respect for people's decisions to refuse treatment with tackling any barriers that may help them to start or restart
- But, we also need to remember that for some people not taking ARVs is *their* quality of life