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Mental health and isolation – the impact on getting to zero

Chris Williams

Plushealth

www.nhivna.org



MENTAL HEALTH & ISOLATION IMPACT ON GETTING TO ZERO



Chris Williams – Plushealth
The online peer support charity

**MY
DISCLOSURES**

**NOTHING TO
SEE HERE!**

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Introduction & perspective

Thank you to NHIVNA for the invitation to present today

My talk is from the perspective of someone living with HIV and experiences of supporting others either through Plushealth National Online Peer Support Service and the in-clinic peer support service at a multi-clinic HIV service as part of Fast-Track Cities (London) Improvement Collaborative. I'll take you through the following area:

A personal case presentation - mental ill-health & HIV

Social isolation, what the data says and impact on mental ill-health

Challenges posed by mental ill-health & getting to Zero

Meeting these challenges

Final thoughts & questions

A personal case study – mental ill-health & HIV

Mental Health Journey

Mental health crisis 6-months post diagnosis
(12-week counselling intervention)

Referral to local CMHT Recovery Team
Diagnoses - depression, emotionally unstable
personality disorder

Mental health deteriorated 2015

Mood stabilizer added to medication 2016

Discharged to GP for mental health care March 2019

Mental health deteriorated, severe anxiety Oct 2019

Mental health remained stable since Feb 2020

HIV Journey

HIV Diagnosis 2008 – routine regular testing

Started ARV's 2010

Stopped taking ARV's March 2016

2 weeks VL = 140,000, 6 weeks VL = 2,000

Restarted ARV's October 2016

Viral load re-suppressed within 4 weeks

ARV switch Sept 2019 PI > DTG/3TC

Switch back to PI – due to SE's Dec 2019

Switch to NNRTI regimen August 2022

Social isolation – what the data tells us

Met and unmet HIV, health, social and welfare needs of people living with HIV 2017



Note: Non-African black & minority ethnicities 78%

Social isolation – where & why it occurs

HIV can be described as an isolating health condition for many people. Isolation is often driven by perceived or personal experience of stigma, discrimination and fear of persecution. Some examples of where isolation occurs include:

Peer group / community – beliefs about HIV, worries about confidentiality, safety concerns

Family & friends – fear of rejection, being ostracised, bringing shame on family

Relationships – sero-difference, fear of transmission, loss of intimacy / sexual activity

Personal circumstances – immigration, housing, poverty, economic activity

Advanced HIV – complexity of care, experience of illness, loss of control, trauma

Viral suppression – people not on treatment, low level viraemia, viral controllers

HIV Veterans – survivor's guilt, ill-health, emotional trauma, different era in treatment & care

Social isolation – impact on mental health

Reduced levels of self-care & daily structure

Higher risk for the development of depression & general anxiety

Increased risk of suicide planning & ideation

Increased levels of overthinking or catastrophic thinking

Magnifies or exacerbates pre-existing mental health conditions

Increased alcohol and substance use

Development of challenging or antisocial behaviours

Changes in perception of self & others

Challenges posed by mental ill-health & getting to Zero

High incidence of mental ill-health amongst people living with HIV

Positive Voices 2017 indicated 1/3 people living with HIV experienced poor mental health

**Plushealth survey 2022, 90% of the sample reported some form of poor mental health¹
(Caveats – post pandemic, small sample size, people actively seeking support)**

Access to mental health and psychology support not available to all clinics

Fragmented and complex pathway to access appropriate mental health care & treatment

Generic mental health support services (GP, IAPT as examples) not suitable for many people living with HIV

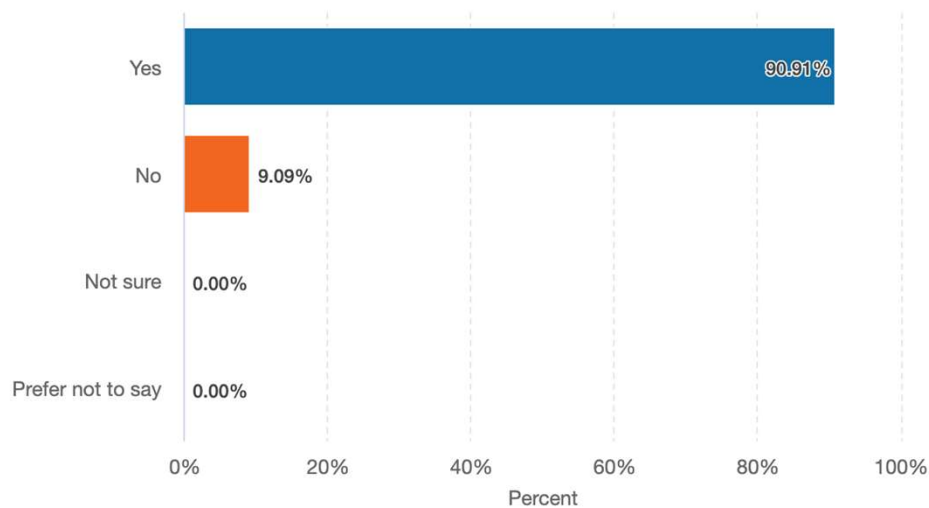
No significant or ringfenced funding for HIV specific mental health support

¹Source: Understanding mental health & HIV survey June 2022

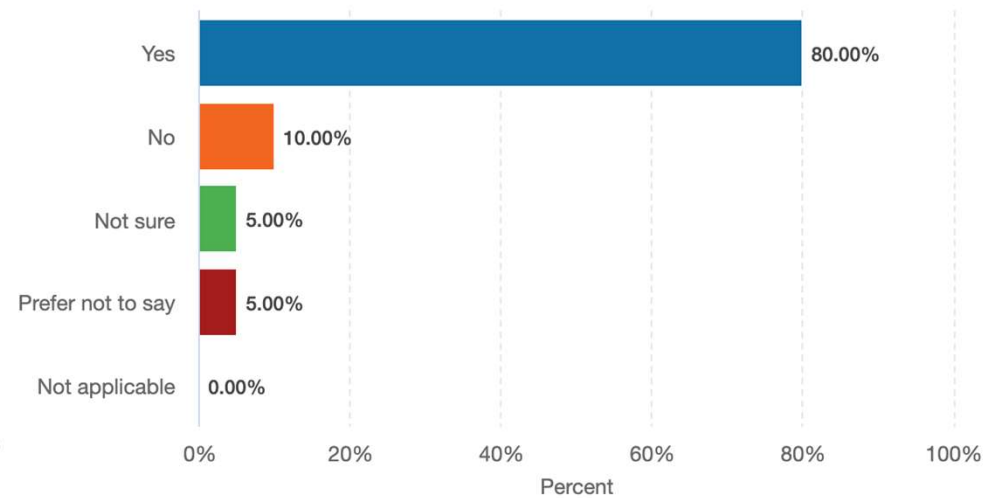
Mental ill-health – what the data tells us

Source: Understanding mental health & HIV survey June 2022

Do you currently (or in the past) experienced mental health difficulties?

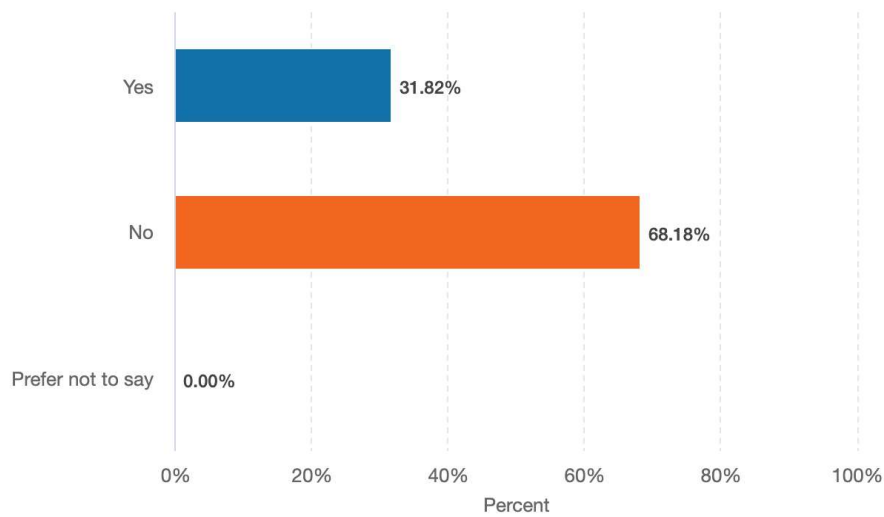


Have you been diagnosed with a long-term mental health condition?(such as depression, anxiety, personality disorder, bipolar disorder, psychosis, schizophrenia, other not listed)

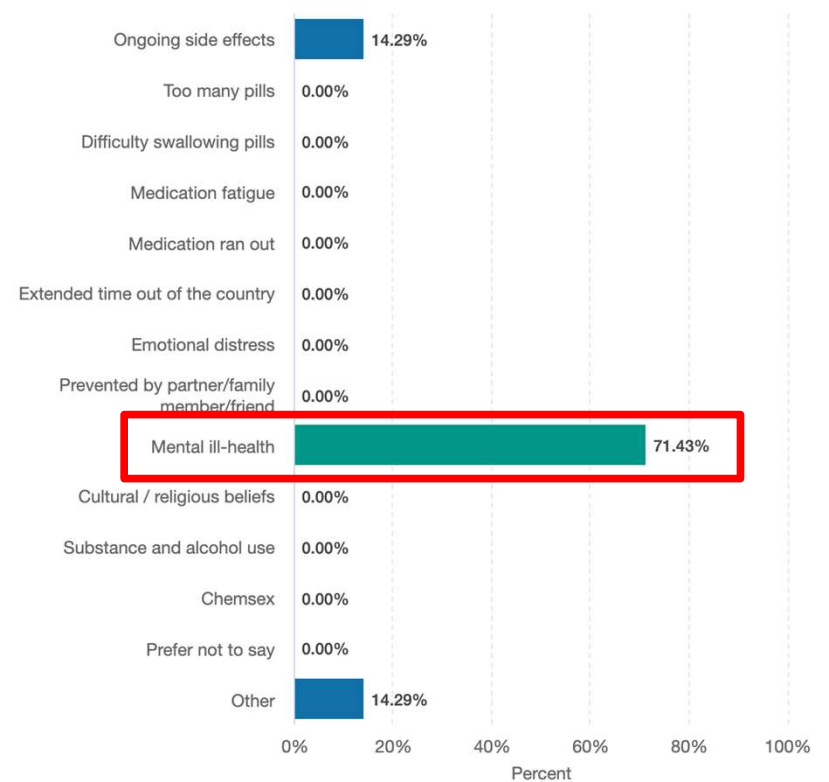


Over 70% of those who stopped treatment did so due to mental ill-health

Have you ever stopped taking your HIV medication?



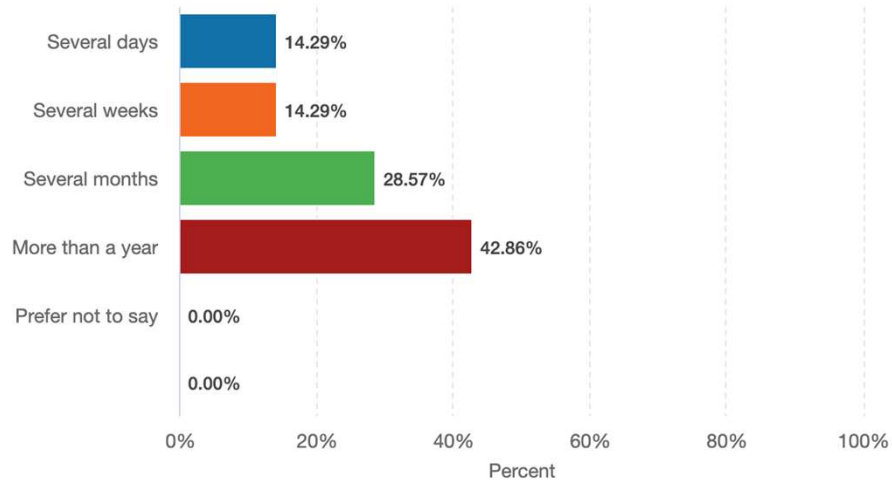
What was the MAIN reason you stopped taking your medication?(you may only select one option, but can add more information in the comment box)



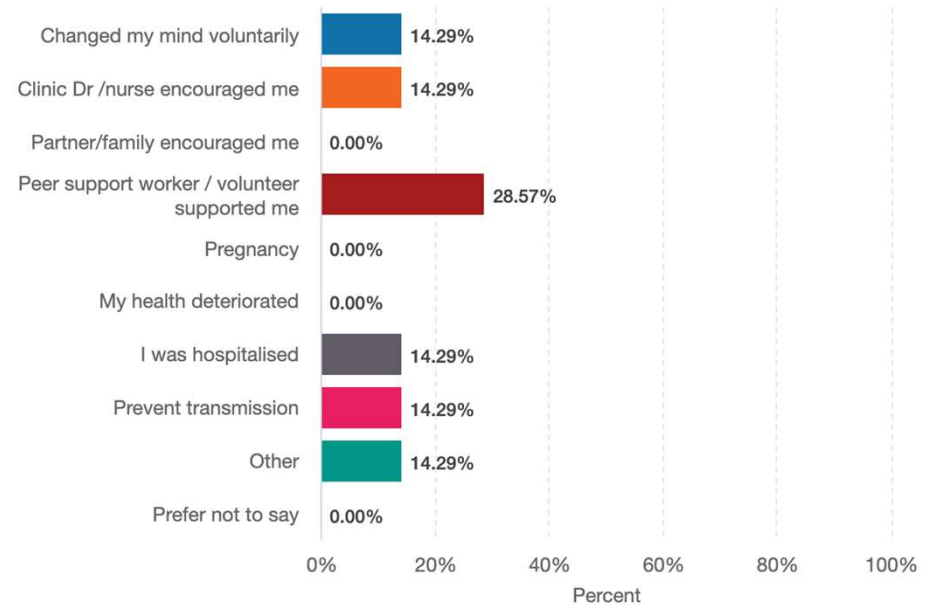
Source: Understanding mental health & HIV survey June 2022

Nearly 43% of those who interrupted treatment did so for more than a year

How long did you stop taking your HIV medication for?(please do not include the occasional missed dose)



What was the MAIN reason you to re-started taking your medication?(you may only select one option, but can add more information in the comment box)



¹Source: Understanding mental health & HIV survey June 2022

Some examples of mental health conditions associated with treatment interruption - peer support practice

Depression – poor motivation, treatment fatigue, little interest in self or life, lack of daily structure

General anxiety – actual or perceived stigma, catastrophic thinking

Health anxiety – actual or perceived side effects of treatment

Post traumatic stress disorder – immune reconstitution inflammatory syndrome

Emotionally unstable personality disorder – impulsive actions, intense switch in emotions, risk taking behaviour, feelings of abandonment

Schizophrenia – delusional thinking about HIV, hallucinations about treatment (hearing, smell, taste, visual)

Meeting the challenges posed by mental ill-health and getting to zero

Peer led interventions

Embed peer support from day of diagnosis

Peer led adherence / ARV switch support

Peer navigation for mental health support

Mental health training for peer mentors

Clinic Reviews

Mental health review at each clinic visit

Stepped care approach towards mental ill-health

Assess risk of poor treatment adherence & disengagement from care

Where consented, work with GP's & community mental health teams

MDT approach to mental health & social support

Clinic MDT

Regional networks / virtual MDT

Include peer support team as part of MDT

Invite the patient for their input where possible

Treatment considerations

Include the person living with HIV in all treatment & care decisions

Try to get it right first time – final choice of regimen rests with patient

Consider pre-existing mental health conditions when selecting regimen

Treatment simplification where possible

Adherence support clinics

Mental health & isolation – impact on getting to zero

My final thoughts

Theory:

Where people living with HIV experience isolation & mental ill-health challenges and are unable to consistently achieve undetectable viral load there is a possible risk of onward transmission, thereby impacting on getting to zero.

Real-life (peer) perspective:

Isolation and mental ill-health often have a significant negative impact on sustaining or forming new intimate and sexual relationships. Depression & anxiety often result in loss of confidence, self-worth, reduced libido & sexual activity.

Those who exhibit chaotic or challenging behaviours often able to sustain good enough levels of treatment adherence to remain undetectable

Paucity of evidence - more research required to identify the impact on getting to zero

The bigger challenge is to ensure people living with HIV who experience isolation and mental ill-health remain well and experience a good quality of life (#Fourth90)

Questions?



Chris.williams@plushealth.org.uk