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Prevalence of HIV in mental health service users: a retrospective cohort study.

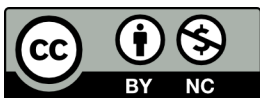
Journal Item

How to cite:

Heslin, Margaret; Jewell, Amelia; Croxford, Sara; Chau, Cuong; Smith, Shubulade; Pittrof, Rudiger; Covshoff, Elana; Sullivan, Ann; Delpuch, Valerie; Brown, Alison; King, Helena; Kakaiya, Mina; Campbell, Lucy; Hughes, Elizabeth and Stewart, Robert (2023). Prevalence of HIV in mental health service users: a retrospective cohort study. *BMJ Open*, 13(4), article no. e067337.

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Version: Version of Record




Link(s) to article on publisher's website:

<http://dx.doi.org/doi:10.1136/bmjopen-2022-067337>

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BMJ Open Prevalence of HIV in mental health service users: a retrospective cohort study

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To cite: Heslin M, Jewell A, Croxford S, *et al.* Prevalence of HIV in mental health service users: a retrospective cohort study. *BMJ Open* 2023;**13**:e067337. doi:10.1136/bmjopen-2022-067337

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2022-067337>).

Received 09 August 2022
Accepted 01 March 2023



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ABSTRACT

Objective To examine the prevalence of HIV in a cohort of people who have used secondary mental health services in the UK.

Design Retrospective cohort study.

Setting Routinely collected clinical data from secondary mental health services in South London, UK available for research through the Clinical Record Interactive Search tool at the National Institute for Health and Care Research Maudsley Biomedical Research Centre were matched with pseudonymised national HIV surveillance data held by the UK Health Security Agency using a deterministic matching algorithm.

Participants All adults aged 16+ who presented for the first time to mental health services in the South London and Maudsley (SLaM) National Health Service Trust between 1 January 2007 and 31 December 2018 were included.

Primary outcome Point prevalence of HIV.

Results There were 181 177 people who had contact with mental health services for the first time between 2007 and 2018 in SLaM. Overall, 2.47% (n=4481) of those had a recorded HIV diagnosis in national HIV surveillance data at any time (before, during or after contact with mental health services), 24.73 people per 1000. HIV point prevalence was highest in people with a diagnosed substance use disorder at 3.77% (n=784). A substantial percentage of the sample did not have a formal mental health diagnosis (27%), but even with those excluded, the point prevalence remained high at 2.31%. Around two-thirds of people had their diagnosis of HIV before contact with mental health services (67%; n=1495).

Conclusions The prevalence of HIV in people who have had contact with mental health services was approximately 2.5 times higher than the general population in the same geographical area. Future work should investigate risk factors and disparities in HIV outcomes between those with and without mental health service contact.

INTRODUCTION

Morbidity is higher in people with mental illnesses compared with the general population.^{1 2} For example, people with depression have a 40% higher risk compared with the general population of developing cardiac disease, hypertension, stroke, diabetes,

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This linkage provides a unique database for examining mental illness and HIV.
- ⇒ A hierarchical matching algorithm was used based on deterministic matching of key fields starting with 'perfect' matches where all fields match and then using 'fuzzy' matching where partial matching is used.
- ⇒ A limitation is that only people who seek HIV testing and mental healthcare will be present in the dataset.
- ⇒ This is the first attempt to link clinical and national data to investigate HIV in secondary mental health service users in the UK.

metabolic syndrome or obesity² and people with severe mental illness (schizophrenia and bipolar disorder) have an increased risk of 1.4–2.0 of all cardiovascular and metabolic diseases.² Despite there being much research on the physical health of people with mental illness in some areas such as cardiovascular diseases, other areas of physical health are relatively unexplored. The Lancet Psychiatry Commission highlighted their finding that infectious diseases such as HIV and hepatitis have been largely ignored in mental health disorders² and Hughes *et al*³ have highlighted that despite sexual health being a major component of physical health, it is often neglected by researchers and policy makers.

There is some evidence that people with mental illness are at a higher risk of becoming infected with blood-borne viruses (BBVs) such as HIV and hepatitis C. A systematic review and meta-analysis of BBVs in people with severe mental illness reported that HIV and hepatitis were more prevalent in people with severe mental illness compared with the general population.³ Huang *et al*⁴ reported that depressive disorder increased the risk of subsequent newly diagnosed sexually transmitted infections including HIV infection, syphilis, genital warts, gonorrhoea, chlamydial infection and trichomoniasis. A



systematic review by Fisher *et al*⁵ reported that alcohol drinkers had an increased risk of having HIV compared with non-drinkers (pooled risk estimate of 1.57, 95% CI 1.42 to 1.72) and a further review reported that people with an alcohol disorder had a weighted prevalence of 16.3% for hepatitis C.⁶

However, there is little evidence about the prevalence of BBVs beyond psychosis and alcohol/substance use disorders. Further, much of the research that has been done is based outside the UK. There are numerous reasons why the prevalence of BBVs in people with mental illness could be very different in the UK compared with these other countries such as baseline prevalence of these infections in the general population, differences in healthcare systems, population-level screening approaches and alternative clinical and public health priorities.

We aimed to explore the prevalence of documented HIV infection in people who have had contact with mental health services, by linking electronic data from mental health records and a national HIV and AIDS Reporting System, in a specific geographical area of the UK.

METHODS

Data sources and linkage

This study used a retrospective cohort design based on Electronic Health Records from the South London and Maudsley (SLaM) National Health Service (NHS) Trust electronic Patient Journey System (ePJS). Since 2006, comprehensive health records from over 500 000 patients in the ePJS have been deidentified and made accessible via the Clinical Record Interactive Search tool (CRIS) at the National Institute for Health Research Maudsley Biomedical Research Centre (BRC). CRIS holds all information documented by professionals involved in the provision of specialist mental healthcare for all people in contact with SLaM mental healthcare services.⁷ SLaM provides near-monopoly secondary mental healthcare to the four London boroughs of Lambeth, Southwark, Lewisham and Croydon (approximately 1.3 million residents) as well as some national-level specialist services. Of note, Lambeth and Southwark had the highest HIV prevalence rates in the country at the time of data collation.⁸

Data from CRIS on all adults (aged ≥ 16 years) who had contact with secondary mental health services for the first time between 1 January 2007 and 31 December 2018 (extracted 19 November 2020), were linked with comprehensive national HIV surveillance data held at the UK Health Security Agency (UKHSA), formerly Public Health England. Data on all people diagnosed with HIV in the UK are collected and stored in the HIV and AIDS New Diagnoses Database, with reports submitted by a variety of clinical and community settings (eg, GUM clinics, general practice, accident and emergency, etc) and the HIV and AIDS Reporting System (HARS) which collects data on all consultations and is reported by all HIV clinics. The HIV diagnosis could have occurred at any time (before, during or after contact with mental health services) up to

the point of the data linkage date (1 March 2021). The starting point for the cohort of 2007 was chosen as this was the point at which full coverage of mental healthcare data was available for the geographic catchment area. The end date of the end of 2018 was chosen as this was the last complete year at the point at which permission was sought for all necessary approvals allowing data linkage.

A hierarchical matching algorithm was devised to match the datasets (online supplemental appendix 1). This was based on deterministic matching and included the following fields: date of birth, scrambled surname (Soundex code⁹), first initial, alternative scrambled surname (available in a small number of cases where a patient was reported with more than one surname in UKHSA data), alternative first initial (available where a patient was reported with more than one first name in UKHSA data), gender, ethnicity and country of birth. Records, where all these fields (including at least one of the surnames or first names in UKHSA data) were the same in both datasets, were considered 'perfect' matches and assigned first. The algorithm then gradually relaxed the matching criteria. 'Fuzzy' matching was used with relaxation on date of birth (two components had to match, eg, month and year of birth), gender (in case missing or trans) and first two characters of Soundex (to account for slightly different spelling). All 'fuzzy' matches were manually reviewed independently by a UKHSA scientist and rejected matches were removed. If a record matched on more than one match criterion, it was assigned to the first match criteria as this was strongest in the hierarchy. Any identifiable information was stripped post-matching so that it would not be possible for either organisation to create a flag for severe mental illness or HIV status. The full CRIS-HARS linkage process is reported in online supplemental appendix 1.

Sample

People matched during the linkage process were those who have had contact with secondary mental health services for the first time between 2007 and 2018 and had an HIV diagnosis recorded in the UK Health Security Agency's HIV and AIDS New Diagnoses Database. No formal mental health diagnosis was necessary for inclusion.

Measurements

Mental health diagnosis was taken from mental health records and defined as the most recent primary mental health diagnosis from structured data. Diagnoses were categorised into the ICD-10 mental and behavioural disorder categories¹⁰ plus a category for no formal mental health diagnosis. People were categorised as having a recorded diagnosis of HIV or not, based on whether they were matched to the HIV dataset.

Analysis

We present data on the number of people who have had contact with mental health services in the defined

period and their diagnosis, and the number of those with recorded HIV. Additionally, we calculate the point prevalence of HIV in each group and overall. Point prevalence is calculated as although we collate the cohort over time, we include any HIV diagnosis recorded within the dataset at the point of the data linkage. As HIV is treatable but not curable, the diagnosis is still valid at the data linkage point. Sample characteristics (age, gender, ethnicity) are described using numbers, percentages and mean, SD as appropriate.

Date of HIV diagnosis and the date of first contact with secondary mental health services were used to determine whether HIV diagnosis or contact with mental health services occurred first. Due to the way the cohort was created, that is, selecting all cases with a first contact with mental health services between 2007 and 2018, and then selecting those with an HIV diagnosis, including all cases would artificially increase the number of people who received their HIV diagnosis before their mental health contact. Therefore, for the examination of whether HIV diagnosis or first contact with secondary mental health services came first, we included only those people who had been given a diagnosis of HIV during the cohort collation period (2007–2018).

Patient and public involvement

The research idea was presented to the Maudsley BRC Service User Advisory Group and BRC's Young Person's Mental Health Advisory Group and was amended following consultation. Service users were directly

involved in interpretation of results and drafting of the manuscript.

RESULTS

Prevalence of HIV in people who have had contact with mental health services

A total of 181177 people who had first contact with secondary mental health services between 1 January 2007 and 31 December 2018 were identified and their details were sent to the UKHSA for matching. Of these, 4481 people were identified as having been diagnosed with HIV in the UK at any time (before, during or after contact with mental health services). Ninety-nine per cent (n=4456) were 'perfect' matches and 1% (n=25) were matched using fuzzy identifiers.

Details on the number of people identified for the cohort and their diagnoses, as well as the number of people identified with HIV and prevalence for each diagnostic group are presented in [table 1](#). Although all people in the cohort had contact with secondary mental health services, 27% of people identified with HIV (n=1188) had no formal mental health diagnosis. The largest mental health diagnostic group was substance disorders with 18% (n=784) of the sample, followed by mood disorders (15%, n=683), neurotic and stress-related disorders (13%, n=585) and people with unspecified mental health diagnoses (12%, n=516). The point prevalence of diagnosed HIV in people who had contact with mental health services was 2.47%, 24.73 people per 1000. This

Table 1 Numbers and percentage of people in contact with mental health services, those with HIV, plus point prevalence of HIV

Most recent diagnosis from mental health records	People with contact with mental health services n (%)	People with contact with mental health services and diagnosed with HIV n (%)	Point prevalence of HIV (%)	Diagnosed prevalence rate of HIV per 1000
F0: organic disorders	22 340 (12%)	270 (6%)	1.21%	12.09
F1: substance disorders	20 780 (11%)	784 (18%)	3.77%	37.73
F2: schizophrenia and related	8562 (5%)	174 (4%)	2.03%	20.32
F3: mood disorders	24 141 (13%)	683 (15%)	2.83%	28.29
F4: neurotic, stress-related and somatoform disorders	21 362 (12%)	585 (13%)	2.74%	27.39
F5: behavioural syndromes associated with physiological disturbances and physical factors	6355 (4%)	103 (2%)	1.62%	16.21
F6: disorders of adult personality and behaviour	4034 (2%)	101 (2%)	2.50%	25.04
F7: intellectual disability	1196 (1%)	15 (<1%)	1.25%	12.54
F8: disorders of psychological development	2056 (1%)	11 (<1%)	0.54%	5.35
F9: behavioural and emotional disorders with onset usually occurring in childhood and adolescence	4937 (3%)	51 (1%)	1.03%	10.33
F99: unspecified	27 062 (15%)	516 (12%)	1.91%	19.07
No mental health diagnosis	38 352 (22%)	1188 (27%)	3.10%	30.98
Total	181 177 (100%)	4481 (100%)	2.47%	24.73

**Table 2** Demographic information

	People with contact with mental health services who had an HIV diagnosis
Demographics	
Age in years at HIV diagnosis, mean (SD), n=4468	34 (10)
Gender, % (n), 4473	
Female	25% (1104)
Male	75% (3368)
Ethnic group, % (n)	
White British	34% (1509)
White Irish	2% (93)
White other	11% (472)
Mixed race	2% (81)
Asian	3% (129)
Black Caribbean	3% (146)
Black African	13% (594)
Black other	6% (276)
Other	8% (344)
Unknown	19% (837)

ranged from 0.54% for people with a diagnosis of disorders of psychological development to 3.77% for people with a substance use disorder. If we exclude people whose

most recently recorded primary diagnosis was not a mental health diagnosis, the prevalence rate was 2.31% (3293/142825), 23.06 per 1000.

Demographic information for people who have had contact with mental health services and had an HIV diagnosis is presented in [table 2](#). The mean age of the sample was 34 years (SD 10). Seventy-five per cent (n=3368) of the sample were men and 25% (n=1104) were women. Thirty-four per cent of the sample (n=1509) was white British, 13% (n=594) black African and 11% (472) white other. Nineteen per cent of the sample (n=837) had no ethnicity recorded.

Timing of HIV diagnosis and contact with mental health services

As described in the methods, to examine the timing of the HIV diagnosis, only those who had a first contact with mental health services and who had their HIV diagnosis in the same time period were included (n=2239). Of these, 33% (n=744) had contact with mental health services before their HIV diagnosis, while 67% (n=1495) had the diagnosis of HIV before contact with mental health services. This is presented by diagnostic group in [table 3](#).

DISCUSSION

Principal findings

Overall, 2.47% of people who have had contact with mental health services had a recorded diagnosis of HIV. This equates to a diagnosed HIV rate of 24.7 people per 1000 people. For some diagnostic groups this was

Table 3 Data on chronology of mental health contact and HIV diagnosis

Most recent diagnosis from mental health records	People with mental health service contact before HIV diagnosis % (n)	People diagnosed with HIV before contact with mental health services % (n)
F0: organic disorders	21% (23)	79% (87)
F1: substance disorders	39% (176)	61% (272)
F2: schizophrenia and related	38% (36)	63% (60)
F3: mood disorders	36% (117)	64% (209)
F4: neurotic, stress-related and somatoform disorders	24% (66)	76% (207)
F5: behavioural syndromes associated with physiological disturbances and physical factors	41% (21)	59% (30)
F6: disorders of adult personality and behaviour	38% (21)	63% (35)
F7: intellectual disability	67% (2)	33% (1)
F8: disorders of psychological development	50% (3)	50% (3)
F9: behavioural and emotional disorders with onset usually occurring in childhood and adolescence	43% (15)	57% (20)
F99: unspecified	37% (99)	63% (171)
No mental health diagnosis	29% (165)	71% (400)
Total	33% (744)	67% (1495)

as high as 37.7 per 1000. It is important to consider that three out of four of the included boroughs were in the top 10 boroughs for HIV prevalence in London in 2019 (just after the end of the study period). The prevalence for these four boroughs combined in 2019 was approximately 10 per 1000.⁸ Therefore, the prevalence of HIV in people who have had contact with mental health services was approximately two and a half times higher than the general population in the same geographical area of London.

Some people in the sample did not have a formal recorded mental health diagnosis. Reasons for this include: (1) diagnosis takes time—it may be too early in the illness for a formal diagnosis to be made and recorded; (2) people may have been referred to MH services and assessed, and therefore be in the mental health notes system, but not have had a diagnosable mental illness and not taken on by services. Even if we exclude people who did not have a recorded mental health diagnosis, the prevalence of HIV was still 2.31% which equates to 23.1 per 1000—still 2.3 times higher than the general population in the same geographical area of London.

The relationship between HIV and mental illness is a complex one. The increased prevalence of HIV among people in contact with mental health services could be a real increase resulting from people with mental health needs being more at risk of acquiring HIV,^{11 12} or from people with HIV being more likely to develop a mental illness.¹³ However, there is the possibility that people with mental illness are more likely to be tested for, and identified as having HIV, compared with the general population due to being in contact with mental health services. Although this seems unlikely as other studies have found that mental health and drug-related hospital admissions were common among people living with undiagnosed HIV.¹⁴ Further, there are environmental factors, for example, social inequalities,^{15 16} which are associated with both increased risk of HIV and increased risk of mental illness that means it is likely the two disorders will co-occur together. The real picture is likely to be a combination of all these things. The relationship between HIV and mental illness is also challenging to pick apart due to the lag between initial illness and diagnosis in both HIV and mental illness. The National Aids Trust¹⁷ reported that in 2019, 42% of people diagnosed with HIV had been living with HIV for around 3–5 years before diagnosis. Duration of untreated illness in mental illness is variable between diagnoses but has been reported as a mean of 19 weeks in common mental disorders (74 weeks SD),¹⁸ and 58 weeks in severe mental illness (148 weeks SD).¹⁹

The lag between initial illness and diagnosis of mental illness and HIV is also an important consideration in the interpretation of the finding that 67% of people diagnosed with HIV and in contact with mental health services were diagnosed with HIV prior to attending mental health services meaning the findings should be interpreted with caution.

Future work should include examination of individual and area level risk factors for HIV in people in contact with mental health services, and parity of HIV care between people with and without mental illness. Further, from this data, it is also not possible to know if the NHS mental health services were aware of the HIV status of the person, or whether this comorbidity was factored into their care plans. Given that there has been a lack of attention paid to physical illness in general, and sexual health specifically, it is important to investigate whether there is awareness of HIV status and any coordinated or integrated care between HIV and mental health services.

Data quality and completeness

Data from mental health records are provided by an NHS trust which provides near-monopoly mental healthcare to the four London boroughs of Lambeth, Southwark, Lewisham and Croydon (approximately 1.3 million residents) as well as some national-level specialist services. However, data are only complete from 2007, meaning that some people could have had contact with services prior to this which was not recorded. National HIV surveillance systems held by the UKHSA capture data on all people ever diagnosed with HIV and/or treated for HIV in the UK.

Strengths and limitations

The use of routinely collected data is both a strength and a limitation of this project. Examining the prevalence of HIV in people with contact with mental health services using routine data linkage is dependent on people presenting at mental health services and HIV testing services. It is possible that people with mental illness are less likely to present to services for HIV testing. However, it is estimated that only 6% of people living with HIV in the UK are undiagnosed^{20 21}; although it is possible that people with mental illness could be over-represented in this group.

There are a number of alternative ways in which diagnosis could have been defined. As mental health diagnosis changes over time,²² we wished to use the most available time for diagnosis to stabilise and hence the most recent primary mental health diagnosis from structured data was used. This means that people could have had multiple different diagnoses but only been categorised as having the last diagnosis. Future work should explore the data for previously recorded mental health diagnoses, look at patterns of diagnosis, and comorbidity.

Despite the limitations, using a linkage of routinely collected data provides a fast, less costly and ethically viable research option compared with conducting a prevalence study of HIV in people in contact with mental health services. Additionally, both mental illness and HIV are potentially stigmatising areas of health which are likely to influence participation in any primary data collection research. The use of routinely collected data improves representativeness of the sample by reducing bias due to sampling selection and bias due to missing



data. Additionally, as the HIV data are national, if a person receives an HIV diagnosis or treatment elsewhere in the UK, this would still be captured.

Conclusion

Significantly higher rates of HIV diagnoses were found among people who have had contact with mental health services compared with the general population in the same geographical area. This is likely to be an underestimate of the prevalence as it only includes those who have been tested. This study supports calls to extend HIV testing to non-specialist services²³ but also highlights the importance of signposting and/or supporting the sexual health needs of people in contact with mental health services more broadly, including sexual health testing, treatment and prevention.

Acknowledgements This paper represents independent research funded by the National Institute for Health and Care Research (NIHR) Biomedical Research Centre at South London and Maudsley NHS Foundation Trust in partnership with King's College London. The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care. We acknowledge and are very grateful for the support of the Maudsley Biomedical Research Centre's Young Person's Mental Health Advisory Group, and the Maudsley Biomedical Research Centre's Service User Advisory Group.

Contributors MH and CC completed the analyses. MH wrote the draft of the paper. MH, AJ, SC, CC, SS, RP, EC, AS, VD, AB, HPK, MK, LC, LH and RS made substantial contributions to the conception, design and interpretation of the work, critically input and approved the final version of the paper, and agree to be accountable for all aspects of the work. MH is guarantor for this work, accepts full responsibility for the finished work and/or the conduct of the study, had access to the data, and controlled the decision to publish.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors. RS is part-funded by: i) the National Institute for Health Research (NIHR) Biomedical Research Centre at the South London and Maudsley NHS Foundation Trust and King's College London; ii) the National Institute for Health Research (NIHR) Applied Research Collaboration South London (NIHR ARC South London) at King's College Hospital NHS Foundation Trust; iii) the DATAMIND HDR UK Mental Health Data Hub (MRC grant MR/W014386).

Competing interests MH and EH report funding by NIHR. No other authors reported competing interests.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Ethics approval Ethical approval was also granted by the South Central - Oxford C Research Ethics Committee (REC reference: 18/SC/0372). Section 251 of the NHS Act 2006 by the Health Research Authority (HRA) Confidentiality Advisory Group (CAG) (CAG reference: 19/CAG/0127) was granted. Any SLaM patient that registered a local or national opt-out were excluded.

Provenance and peer review Not commissioned; externally peer-reviewed.

Data availability statement Data may be obtained from a third party and are not publicly available. Data are owned by a third party, the Biomedical Research Centre at South London and Maudsley NHS Foundation Trust, which provides access to anonymised data derived from SLaM electronic medical records. These data can only be accessed by permitted individuals within a secure firewall (i.e. the data cannot be sent elsewhere), in the same manner as the authors. For more information please contact: cris.administrator@slam.nhs.uk. HIV data are available from: <https://www.gov.uk/government/publications/odr-data-request-form>.

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