International Journal of Population Data Science

Journal Website: www.ijpds.org

Cohort profile: working age adults accessing secondary mental health services in South London (UK) and benefits – a data linkage of electronic mental health records and benefits data

Ava Phillips[1,*], Ray Leal[1,2], Amelia Jewell[3], Ira Madan[4,5], Johnny Downs[1,3], Matthew Broadbent[3], Matthew Hotopf[1,3], Sarah Dorrington[1,3], Nicola T. Fear[1,2,6,†], and Sharon A.M. Stevelink[1,2,†]

Submission History

Submitted:	18/12/2023
Accepted:	25/03/2024
Published:	23/05/2024

[1]Department of Psychological Medicine, Institute of Psychiatry, Psychology and Neuroscience, King's College London, London, UK
[2]King's Centre for Military Health Research, Department of Psychological Medicine, Institute of Psychiatry, Psychology and Neuroscience, King's College London, London, UK
[3]NIHR Maudsley Biomedical Research Centre, South London and Maudsley Mental Health NHS Trust, London, UK
[4]Department of Occupational Health, Guy's and St Thomas' Hospitals NHS Trust, London, UK
[5]King's College London, London, UK
[6]Academic Department of Military Mental Health, Department of Psychological Medicine, Institute of Psychiatry, Psychology and Neuroscience, King's College London, London, UK

Abstract

Introduction
In the UK, mental disorders are one of the most common reasons for claiming a benefit relating to unemployment, income, sickness and disability. Limited information exists regarding the demographic characteristics and psychiatric profiles of working age individuals claiming benefits in London. Until recently, detailed data on both mental disorders and benefit receipt were unavailable.

Objectives
To establish and describe a cohort of working age adults accessing secondary mental health services and benefits related to unemployment, income, sickness, and disability.

Methods
Using a novel data linkage containing electronic secondary mental health records from the South London and Maudsley (SLaM) NHS Foundation Trust and benefits data from the Department for Work and Pensions (DWP), we present descriptive statistics on sociodemographics, psychiatric diagnoses, and benefits received among a cohort of working age adults. The DWP benefits data window covers the period January 2007-June 2020, the SLaM data window covers the period January 2007-June 2019.

Results
We identified n = 150,348 patients (18-65 years), who had attended SLaM secondary mental health services, 78.3% of which had received a benefit relating to unemployment, income, sickness and disability. Of this group, 68% had a recorded primary psychiatric diagnosis. We found that a much higher percentage of those with a primary psychiatric diagnosis received more than one benefit (69.4%) compared to those who had not received a primary psychiatric diagnosis (30.6%). Almost 70% of claimants who obtained more than one benefit were identified as living within the two quintiles representing the highest levels of deprivation in the South-east London boroughs served by SLaM.

Conclusions
We showed types of benefits received among working age adults accessing secondary mental health services. This cohort will be further examined to explore trajectories of mental health care and benefit receipt and provide evidence that will help to inform both DWP policies and mental health care delivery.

Keywords
linked data; benefits; administrative data; mental health records; secondary care; UK

*Corresponding Author:
Email Address: ava.1.phillips@kcl.ac.uk (Ava Phillips)
†Joint last authors

https://doi.org/10.23889/ijpds.v9i1.2377

Introduction

Mental disorders are one of the most frequently reported working age disabilities and/or health conditions and reasons for claiming government unemployment, income, sickness, and disability related benefits in the UK [1]. It was reported by the Department for Work and Pensions (DWP) that spending on benefits for people with disabilities and people with long-term health conditions is at its highest, with over £30 billion being spent in 2019/20 on working age health and disability benefits [2]. This is predicted to increase to £31–40 billion by 2025/26 [2].

In the UK, the DWP provides social security for those in need, known as "benefits". Different types of benefits are provided depending on people's needs and circumstances e.g., unemployment benefits for people who are out of work, benefits for those on a low income, or sickness and disability benefits for people with a disability, long-term illness, or mental disorder [3]. The standard entitlement amounts for each benefit differ and are also dependent on people's circumstances such as their income, whom they live with, if they are married and how many children they have [4]. There have been substantial changes to the UK benefits system in the past two decades, specifically the introduction of "Universal Credit" (UC) which is a benefit provided for people who are out of work as well as for those who are in work but on a low income and require extra support. It replaced 6 other benefits (Housing Benefit, Income Support, income-based Jobseeker's Allowance, income-related Employment and Support Allowance, Child Tax Credit and Working Tax Credit). Although these are being phased out, some people still receive these benefits, known as "legacy benefits", as they have not yet been transferred onto UC. UC was introduced as part of the *Welfare Reform Act 2012*, in order to reduce the complexity of claiming various different benefits [5]. Another key reform is the change over from Disability Living Allowance (DLA), a benefit for people who need support with mobility or care costs, to Personal Independence Payment (PIP). PIP is a non-means tested benefit, meaning a person's income is not considered in the entitlement of receiving this benefit, and is similarly provided to help with extra costs due to having ill health or a disability, whether the claimant is in or out of work. Individuals are required to undergo a points-based assessment to determine how their condition impacts their functional ability [6].

Despite the notion that these reforms support the government's drive to help people feel motivated to obtain and remain in employment [5], research indicates evidence of concern for those with mental disorders in particular as a result of these changes. Research has shown that people experience further distress and, therefore, a reduced likelihood of employment [6, 7]. It has also been shown consistently across UK studies and other high-income countries that policies aimed at enhancing social security benefits are linked to improved mental health outcomes and reduced inequalities, whilst policies that decrease or restrict benefits are linked to negative mental health outcomes [8].

No UK-wide dataset currently provides combined individual level, routinely collected mental health record data and benefits data. It is vital that research into the provision and ongoing needs of people with a disability, long-term illness or mental disorder is carried out to inform policy on how best to support some of the most vulnerable members of society. This paper aimed to establish and describe a working age cohort within a novel record-level linkage which provides an opportunity to better understand benefit receipt among those with mental disorders, the patterns of engagement with both National Health Service (NHS) secondary mental health services and the benefits system, and the impact of changes to the benefits system over the past two decades. We present sociodemographic characteristics and data on psychiatric diagnosis and benefit receipt among working age adults accessing secondary mental health services and benefits in South-east London.

Ethics approval

The South London and Maudsley (SLaM) NHS Foundation Trust and DWP data linkage resulted in a linked data set of longitudinal data from SLaM electronic mental health records and DWP benefits data. All data used is de-identified. The use of SLaM mental health records data for research purposes received full ethical approval from the NHS Research Ethics Committee (Oxford South Central ref 18/SC/0372). Ethical approval for the data linkage was granted from the Oxford South Central REC (Ref: 22/SC/0400), and the data linkage was legally permitted by the Health Research Authority Confidentiality Group (CAG) under Section 251 of the NHS Act 2006 (ref 17/CAG/0055).

The NIHR Maudsley Biomedical Research Centre (BRC) Data Linkage Service User and Carer Advisory Group is a Patient and Public Involvement and Engagement (PPIE) group containing members with lived experience of mental disorders or caring for someone with a mental disorder who has accessed mental health services. Members were involved in early discussions around the data linkage and were supportive of the linkage. In addition, two PPI members have joined our research team and are regularly involved in discussions regarding projects using the linked data. Consultation and discussion with all PPI members will continue as work progresses [9].

Methods

Cohort description

Mental health data was extracted from the electronic health care records of the SLaM NHS Foundation Trust; one of Europe's largest providers of secondary mental health services, providing services to the South London boroughs of Lambeth, Lewisham, Southwark, and Croydon, covering a catchment area of over 1.3 million residents [10]. SLaM provides specialist secondary mental health services for a number of disorders, including eating disorders and psychosis related disorders, as well as outpatient services for low level common mental disorders (for example, the NHS Talking Therapies for Anxiety and Depression (TTad) programme; formerly known as Improving Access to Psychological Therapies (IAPT)). Patients who accessed SLaM services vary in their level and method of contact with services, for example patients may a have one-off presentation or referral from a general

practitioner (GP), or ongoing hospitalisations and treatment. Patients included in the current cohort are those who had accessed SLaM secondary mental health services (some of whom will have also accessed the TTad programme). Those who only accessed the TTad programme were excluded from this cohort (n = 208,689), as the focus was on patients who were likely to meet clinical thresholds for a mental disorder. The BRC Clinical Records Interactive Search (CRIS) system was established to provide a service-user led governance framework, that could safely and securely de-identify clinical data from SLaM's electronic health records for research purposes [11].

Benefits data come from the DWP. DWP are responsible for policy implementation relating to most benefits in the UK. The linkage of these two datasets took place in 2020 using an ad hoc deterministic approach, achieving a linkage rate of 92.3%. This approach attempts to match combinations of personal identifiers (name, dob, sex and postcode history) between different datasets. A paper detailing the ad hoc deterministic linkage process has been published [see Reference 12 for full details].

This profile paper reports on a cohort of patients of working age who accessed SLaM services between 1st January 2007 and 30th June 2019. We defined working age as those between the ages of 18-65 years, including those aged 18 years and above at SLaM window start date (January 2007) and those aged 65 years and below at SLaM window end date (June 2019) (Figure 1). This is because people in the UK turning age 66 years were eligible for State Pension and this was generally considered as the standard retirement age [13]. We describe the working age patients who had accessed SLaM (n = 150,348) and any benefits received relating specifically to unemployment or income, sickness or disability, or Housing Benefit, which are referred to as benefits of interest.

Cohort timeline

The linkage provides data covering a 15-year window, with benefits data starting from 1st January 2005 until 30th June 2020, and data from SLaM covering the period 1st January 2007 until 30th June 2019. Due to the longitudinal and administrative nature of the linkage, data can exist for people, in relation to both mental health data and benefits data at multiple timepoints. For some, data on mental health and benefits exist together throughout the period under study. For others, there may be only one instance for both mental health and benefits data. It should be noted that the CRIS data is 'live', so for each new project specific data extraction using the linked data, details can vary as the SLaM patient journey is ongoingly edited by health professionals.

Cohort measures

Mental health electronic record data: All patient level information within the CRIS system was pseudonymised, including structured fields and unstructured text from clinical notes. Data included individual level socio-demographic characteristics (e.g., sex, month and year of birth, date of death, ethnicity, marital status, neighbourhood deprivation) and time variant clinical data such as psychiatric diagnosis, assessments, mental health treatment (medication and therapies), and engagement with SLaM services including admissions, recorded attendance, and adherence to treatments. Note that it is possible patients received different psychiatric diagnoses over time; the psychiatric diagnosis reported in the tables refers to the first instance of a psychiatric diagnosis a patient received within the SLaM data window (January 2007–June 2019).

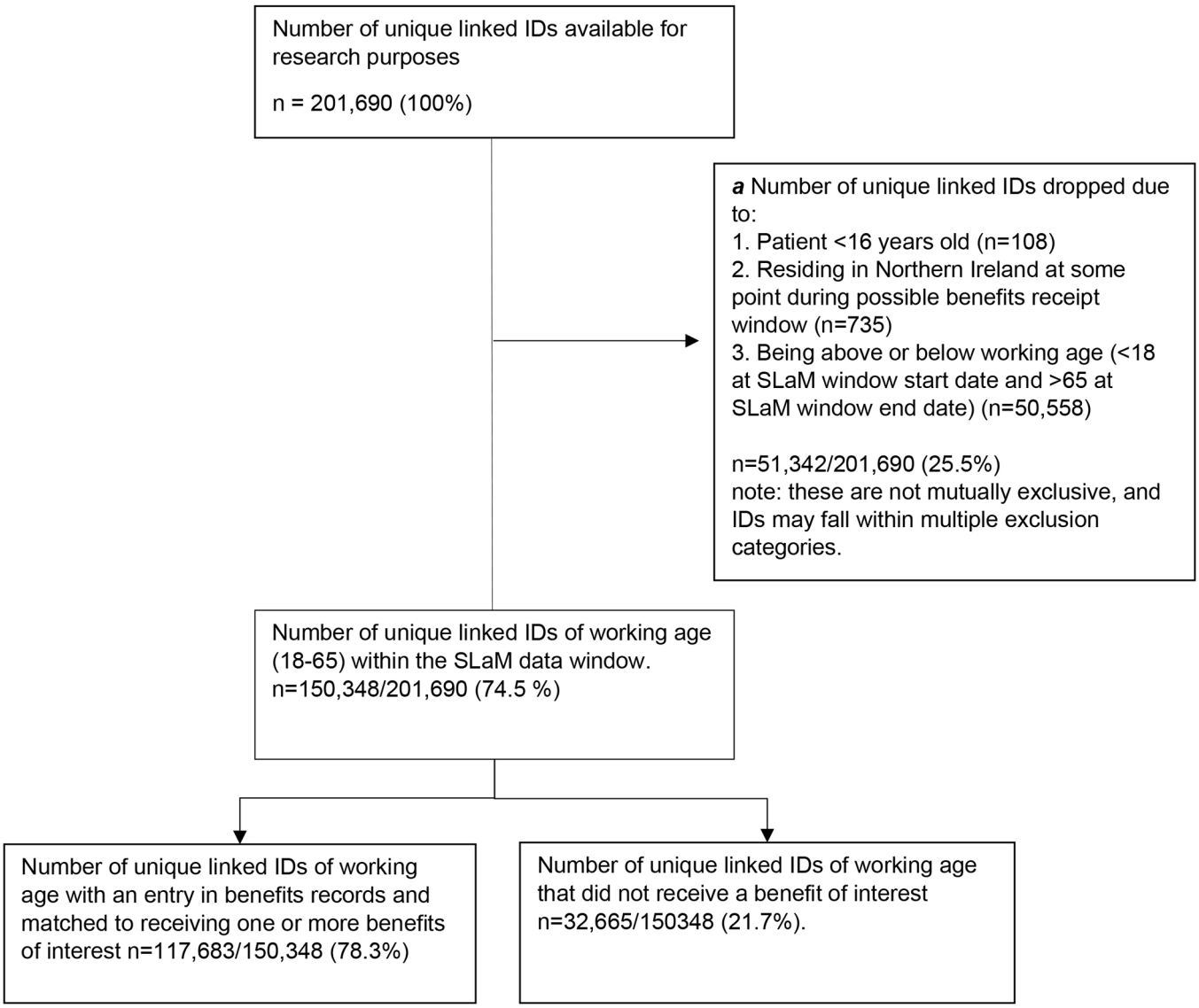
Benefits data: Socio-demographic data included sex, date of death and truncated postcode. Time variant data included dates of benefit receipt. The benefits data were derived from various benefits sources, for example, the "National Benefits Database" (NBD) contains certain benefit types, many of which were legacy benefits, whilst the newer benefits, UC, and "Personal Independence Payment" (PIP) were extracted from separate administrative data sources, all of which are held by the DWP. There were also separate benefit "flags" for Pension Credit and Housing Benefit (HB) within the NBD database. NBD benefits include Incapacity Benefit (IB), Carer's Allowance, Income Support (IS), Jobseeker's Allowance (JSA), Attendance Allowance, Retirement/State Pension, DLA, Severe Disablement Benefit (SDA), Widow's Benefit, Passported Incapacity Benefit, Bereavement Benefit and Employment and Support Allowance (ESA). Data contained benefit spell dates and payment entitlements. A benefit spell indicated a period of time a person was receiving a benefit without a break. There was also information on work-related interventions provided by DWP, as well as work capability assessments (WCAs), which are used to determine someone's capacity for work and entitlement to ESA. The WCA was introduced as part of a wider benefit reform in 2008 [14].

For the purpose of this paper, we only examined benefits relating to unemployment or income, sickness or disability, or HB, all of which may be relevant for working age adults who have accessed secondary care services for their mental health. These benefits of interest include UC, PIP, HB, IB, IS, JSA, DLA, SDA, and ESA. Although not an unemployment, income, sickness or disability related benefit, HB was included in the benefits of interest, as this is a key benefit that is only received alongside another benefit and is crucial in providing a fuller picture of someone's benefits situation.

Table 1. presents key variables. This is not an exhaustive list of every specific benefit related variable in the benefits data, or all clinical variables held within the CRIS data.

This data linkage enables us to look at the on and off flows of benefit receipt and mental health service utilisation among all patients. We can determine how long people are receiving a benefit(s) for, entitlement amounts, as well assessment dates and outcomes. Data on interventions from DWP provide information on a variety of different intervention types that have been offered to patients, including but not limited to "Skills for Work", "Job Search Support Centre" and "Job Club", as well as the start and end dates of when these opportunities have been provided and the "end reason" such as "Found Work". These interventions aim to support people in developing skills that help them get work, such as CV writing and preparing for interviews.

Figure 1: Overview of unique IDs in the data linkage used for this cohort study



Note: [a]We excluded those aged under 16 as ethical approvals only applied for aged 16 and above. We also excluded those with a Northern Ireland postcode as ethical approvals only applied to England and Wales. Note these categories are not mutually exclusive, patients may have been excluded on the basis of one, two or all three of the exclusion criteria listed.
The DWP data spans across the following window: 1st January 2005 until 30th June 2020. The SLaM data spans across the following window: 1st January 2007 until 30th June 2019.

Results

We have previously reported initial findings on the linkage process between SLaM and DWP records and described the linkage process and sensitivity analysis exploring factors associated with linkage success between SLaM patients and their DWP records. [10]. Of the characteristics studied, female sex, ethnic minority status, being aged between 21-60 years relative to other ages below or above, and not having a recorded primary psychiatric diagnosis were associated with non-successful linkage [12].

For the current paper, we explored the socio-demographic and clinical characteristics of working age adults who were either receiving or not receiving benefits of interest, and present descriptive statistics. Of the 150,348 working age adults who were successfully linked, 78.3% received a benefit of interest (n = 117,683). Of this group, 68.0% had a recorded primary psychiatric diagnosis.

Of those who either did not receive a benefit at all or received a benefit that was not of interest (e.g., State Pension) (n = 32,665), 58.1% had a recorded primary psychiatric diagnosis (Table 2).

It should be noted that the group of patients who were of working age but did not receive a benefit of interest (n = 32,665) included: those who had engaged with DWP as evidenced by an entry in benefits records but did not receive any benefits (n = 273), those who had no entry in benefit records (n = 31,538), and those who engaged with DWP and received benefits that were not of interest (e.g. State Pension) (n = 854). We have included the breakdown of the demographics of these patients in a supplementary table (see Appendices: Supplementary Table 1).

Table 1: Key variables from SLaM mental health electronic record data and benefits data from DWP

Summary of key variables			
Mental health electronic record data		**Benefits data**	
Socio-demographic data	***Mental health data***	***Socio-demographic data***	***Benefits data***
Month and year of birth	[a]Psychiatric diagnosis based on ICD-10 codes	Sex	[c]National Benefits Database
Sex	Dates of first and last contact with SLaM	Date of death	Universal Credit
Ethnicity	Medication – prescription, type, dosage)	Postcode truncated to district level	Personal Independence Payment
Date of death	[b]Interventions (therapies – type and whether or not received)		Benefit spells start and end date
Deprivation (Indices of Multiple Deprivation quintile)	Inpatient admissions		[d]Work Capability Assessment date and outcome
			Weekly monetary entitlement at start and end of benefit
			Date of payment
			Work programme interventions

Note: [a]Psychiatric diagnosis is based on the International Classification of Disease (ICD) version 10.
[b]Interventions include various therapy types offered. Dates are attached to these, alongside if a patient did not attend and how many sessions were completed.
[c]National Benefits Database includes information on the following benefits: Incapacity Benefit, Carer's Allowance, Income Support, Jobseeker's Allowance, Attendance Allowance, Retirement/State Pension, Disability Living Allowance, Severe Disablement Benefit, Widow's Benefit, Pension Credit, Passported Incapacity Benefit, Bereavement Benefit, Employment and Support Allowance.
[d]Benefit spell start, and end dates indicate a period of time a person was receiving a benefit without a break, not necessarily the date they first claimed a benefit.

Table 3 shows that a much higher percentage of patients aged over 24 received more than one benefit compared to those between 18-24 years. This result is likely a consequence of patients in older age brackets having a higher propensity to seek housing benefits compared to young people who may be living with family. Moreover, belonging to an older age group may suggest an extended duration of benefit receipt, indicating a potential combination of receiving legacy and newer benefits, alongside an elevated need that contributes to a higher frequency of benefit claims.

A higher percentage of those within categories "White British" and "White Other" received more than one benefit (53.6%), relative to other ethnic groups. The distribution of ethnic groups corresponds to the demographic distribution in the relevant boroughs.

People identified as living within the two quintiles representing the highest deprivation levels in South-east London boroughs served by SLaM made up nearly 70% of claimants that had received more than one benefit. This indicates patients residing in more disadvantaged areas need additional support, highlighting the importance of further investigation into this particular group.

A much higher percentage of those with a primary psychiatric diagnosis received more than one benefit (69.4%) compared to those who had not received a primary psychiatric diagnosis (30.6%). This finding aligns with earlier reports [1], indicating that a prevalent working-age disability and common reason for claiming unemployment and sickness-related benefits is a mental disorder. Consequently, individuals with a formal psychiatric diagnosis within this group may be more likely to need and receive increased benefits.

Of patients receiving a benefit of interest with a recorded primary psychiatric diagnosis, the most common diagnoses were alcohol related disorders (F10) and substance related disorders (F11–F19) (17.1%), followed by mood (affective) disorders (F30–F39) (16.5%), in particular a single episode of major depressive disorder (F32), and those with anxiety, dissociative, stress-related, somatoform and other nonpsychotic mental disorders (F40–F48) (12.6%) (Table 4).

Discussion

For the first time, we provide a comprehensive sociodemographic and diagnostic profile of working age adults accessing secondary mental health services in South-east London and receipt of their benefits. We showed that a significant majority, 78.3%, received a benefit of interest, with 68.0% of this group having a recorded primary psychiatric diagnosis. Age-related patterns indicate a higher prevalence of multiple benefits among older individuals, potentially linked to housing needs and prolonged benefit receipt. Almost 70% of claimants who

Table 2: Socio-demographic characteristics of working age patients who have received or not received a benefit related to unemployment, sickness, disability, housing, or income support

	Working age patients N=150,348 (100.0%) n (%)	[a]Received benefits of interest n = 117,683 (78.3%) n (%)	Did not receive benefits of interest n = 32,665 (21.7%) n (%)
Sex			
Female	72,074 (48.0)	54,116 (46.0)	17,958 (55.0)
Male	78,171 (52.0)	63,490 (54.0)	14,681 (45.0)
[b] **Age (years)**			
18–24 years	12,443 (8.3)	8,491 (7.2)	3,952 (12.1)
25–34 years	36,735 (24.3)	28,556 (24.3)	8,179 (25.0)
35–44 years	37,480 (24.9)	28,202 (24.0)	9,278 (28.4)
45–54 years	35,432 (23.6)	28,701 (24.4)	6,731 (20.6)
55–65 years	28,258 (18.8)	23,733 (20.1)	4,525 (13.9)
Ethnicity			
White British / White Other	79,052 (52.6)	62,535 (53.1)	16,517 (50.6)
Black/African/Caribbean/Black British	21,022 (14.0)	18,614 (15.8)	2,408 (7.4)
Asian/Asian British	7,465 (5.0)	5,279 (4.5)	2,186 (6.7)
Mixed/Multiple racial and ethnic groups	3,347 (2.2)	2,844 (2.4)	503 (1.5)
Other racial and ethnic minority groups	9,539 (6.3)	6,934 (5.9)	2,605 (7.9)
Not stated	29,923 (19.9)	21,477 (18.3)	8,446 (25.9)
Recorded death between 2005–2020			
No	138,835 (92.3)	107,126 (91.0)	31,709 (97.1)
Yes	11,513 (7.7)	10,557 (9.0)	956 (2.9)
[c]**Deprivation (IMD quintile)**			
First (most deprived)	32,266 (22.6)	27,760 (25.0)	4,506 (14.4)
Second	55,016 (38.6)	43,985 (39.5)	11,031 (35.2)
Third	31,419 (22.1)	23,362 (21.0)	8,057 (25.7)
Fourth	14,988 (10.5)	10,284 (9.2)	4,704 (15.1)
Fifth (least deprived)	8,860 (6.2)	5,859 (5.3)	3,001 (9.6)
[d] **Resident within SLaM local catchment area**			
No	48,538 (34.0)	38,104 (34.2)	10,434 (33.3)
Yes	94,243 (66.0)	73,352 (65.8)	20,891 (66.7)
Age (years) at first presentation to SLaM			
<18 years	10,040 (6.9)	8,035 (7.0)	2,005 (6.3)
18–24 years	28,797 (19.6)	22,257 (19.4)	6,540 (20.6)
25–34 years	42,856 (29.2)	32,544 (28.3)	10,312 (32.5)
35–44 years	36,338 (24.8)	28,896 (25.2)	7,442 (23.5)
45–54 years	22,762 (15.5)	18,542 (16.1)	4,220 (13.3)
55–65 years	5,841 (4.0)	4,632 (4.0)	1,209 (3.8)
[d]**Psychiatric diagnosis received**			
Received primary psychiatric diagnosis	98,974 (65.8)	79,981 (68.0)	18,993 (58.1)
Did not receive primary psychiatric diagnosis	51,374 (34.2)	37,702 (32.0)	13,672 (41.9)

Note: [a]Benefits received: these include having received one or more of the following at any point in the DWP data window (January 2005–June 2020): Universal Credit, Personal Independence Payment, Housing Benefit, Incapacity Benefit, Income Support, Jobseeker's Allowance, Disability Living Allowance, Severe Disablement Benefit, Employment and Support Allowance. Those in the 'did not receive benefits' column will not have any instances of receiving the relevant benefits listed, but may have received other benefits (e.g., State Pension) or no benefits at all.

[b]Age (years) represents the age at SLaM window end date (30th June 2019). All patients in this cohort are of working age between the SLaM window start and end date (1st January 2007–30th June 2019) (18-65 years). The total N may differ between variables due to missing data.

[c]Indices of Multiple Deprivation (IMD) is a summary measure of relative deprivation for fixed areas of the UK, informed by seven domains (income, employment, education, crime, housing, health, and living environment), scores are grouped into quintiles based on relative disadvantage. This was informed by 2019 data, using individual level postcodes (closest to first ever psychiatric diagnosis date, and if no diagnosis, closest to first SLaM contact date). [d]These measures are taken from the time point that is closest to the SLaM window start date (January 2007).

Table 3: Socio-demographics of working age patients receiving benefits related to unemployment, sickness, disability, housing or income support

Sociodemographics \ Type ofbenefit	Universal Credit (UC) n(%)	Jobseeker's Allowance (JSA) n(%)	Employment and Support Allowance (ESA) n(%)	Incapacity Benefit (IB) n(%)	Severe Disablement Allowance (SDA) n(%)	Personal Independence Payment (PIP) n(%)	Disability Living (DLA) n(%)	Income Support (IS) n(%)	Housing benefit (HB) n(%)	Received more than one benefit of interest n(%)
Sex										
Female	22,293 (53.8)	27,007 (41.5)	31,105 (43.3)	15,486 (39.8)	1,138 (44.2)	19,221 (47.6)	16,795 (43.4)	27,003 (54.2)	34,897 (46.4)	44,949 (45.2)
Male	19,168 (46.2)	38,036 (58.5)	40,737 (56.7)	23,461 (60.2)	1,435 (55.8)	21,126 (52.4)	21,888 (56.6)	22,815 (45.8)	40,292 (53.6)	54,383 (54.8)
[a]Age (years)										
18–24 years	5,265 (12.7)	2,188 (3.4)	2,832 (3.9)	<10 (<0.1)	<10 (<0.1)	3,461 (8.6)	3,163 (8.2)	971 (1.0)	1,992 (2.7)	5,775 (5.8)
25–34 years	12,99 (31.3)	20,553 (31.6)	14,789 (20.6)	3,146 (8.1)	<10 (<0.1)	7,724 (19.1)	7,056 (18.2)	8,571 (17.1)	15,547 (20.7)	22,900 (23.0)
35–44 years	10,324 (24.9)	17,960 (27.6)	16,644 (23.2)	9,186 (23.6)	458 (17.)	8,414 (20.8)	7,142 (18.5)	12,631 (25.4)	19,597 (26.0)	23,884 (24.0)
45–54 years	8,261 (19.9)	14,691 (22.6)	19,974 (27.8)	13,529 (34.7)	963 (37.4)	10,706 (26.5)	10,359 (26.8)	15,174 (30.5)	21,275 (28.3)	25,575 (25.7)
55–65 years	4,656 (11.2)	9,696 (14.9)	17,642 (24.5)	13,087 (33.6)	1,153 (44.8)	10,064 (24.9)	10,979 (28.4)	12,482 (25.1)	16,815 (22.3)	21,258 (21.4)
Ethnicity										
White British/ White Other	19,935 (48.0)	33,992 (52.2)	40,422 (56.2)	23,396 (60.2)	1,479 (57.5)	21,769 (53.9)	21,717 (56.1)	27,261 (54.7)	39,953 (53.1)	53,227 (53.6)
Black/African/Caribbean/ Black British	7,296 (17.6)	10,294 (15.8)	11,963 (16.6)	6,572 (16.9)	567 (22.0)	6,782 (16.8)	6,723 (17.4)	9,508 (19.1)	13,961 (18.6)	16,807 (16.9)
Asian/Asian British	1,926 (4.6)	2,682 (4.1)	3,040 (4.2)	1,577 (4.1)	116 (4.5)	1,746 (4.3)	1,702 (4.4)	2,011 (4.1)	3,059 (4.1)	4,253 (4.3)
Mixed/Multiple racial and ethnic groups	1,218 (2.9)	1,638 (2.5)	1,748 (2.4)	859 (2.2)	64 (2.5)	1,024 (2.5)	933 (2.4)	1,338 (2.7)	1,903 (2.5)	2,473 (2.5)
Other racial and ethnic minority groups	2,628 (6.3)	4,117 (6.3)	3,918 (5.5)	1,752 (4.5)	49 (1.9)	2,145 (5.3)	1,636 (4.2)	2,587 (5.2)	4,516 (6.0)	5,680 (5.7)
Not stated	8,499 (20.5)	12,365 (19.0)	10,790 (15.0)	4,794 (12.3)	299 (11.6)	6,903 (17.1)	5,988 (15.5)	7,124 (14.3)	11,834 (15.7)	16,952 (17.1)
Recorded death between 2005–2020										
No	40,365 (97.3)	60,925 (93.6)	64,638 (89.9)	32,823 (84.3)	2,065 (80.2)	37,047 (91.8)	33,294 (86.0)	43,795 (87.9)	67,512 (89.7)	89,711 (90.3)
Yes	1,137 (2.7)	4,163 (6.4)	7,243 (10.1)	6,127 (15.7)	509 (19.8)	3,322 (8.2)	5,405 (14.0)	6,034 (12.1)	7,714 (10.3)	9,681 (9.7)
Deprivation (IMD quintile)										
First (most deprived)	10,381 (26.6)	15,205 (24.9)	17,901 (26.5)	9,939 (27.3)	566 (23.2)	10,105 (26.5)	9,843 (26.7)	13,552 (28.9)	19,512 (27.7)	24,590 (26.3)
Second	15,775 (40.5)	24,775 (40.5)	27,002 (40.0)	15,083 (41.5)	979 (40.1)	14,848 (38.9)	14,238 (38.7)	19,767 (42.1)	29,790 (42.2)	37,764 (40.3)
Third	7,940 (20.4)	12,849 (21.0)	13,693 (20.3)	7,249 (19.9)	575 (23.5)	7,775 (20.4)	7,358 (20.0)	9,135 (19.5)	13,945 (19.8)	19,115 (20.4)
Fourth	3,266 (8.3)	5,418 (8.9)	5,741 (8.5)	2,694 (7.4)	221 (9.0)	3,434 (9.0)	3,356 (9.1)	3,113 (6.6)	4,966 (7.0)	7,907 (8.4)
Fifth (least deprived)	1,634 (4.2)	2,862 (4.7)	3,168 (4.7)	1,393 (3.8)	103 (4.0)	1,994 (5.2)	2,026 (5.5)	1,408 (3.0)	2,320 (3.3)	4,306 (4.6)

Continued

Table 3: Continued

Sociodemographics \ Type ofbenefit	Universal Credit (UC) n(%)	Jobseeker's Allowance (JSA) n(%)	Employment and Support Allowance (ESA) n(%)	Incapacity Benefit (IB) n(%)	Severe Disablement Allowance (SDA) n(%)	Personal Independence Payment (PIP) n(%)	Disability Living (DLA) n(%)	Income Support (IS) n(%)	Housing benefit (HB) n(%)	Received more than one benefit of interest n(%)
[b]Resident within local catchment area										
No	11,687 (29.9)	19,939 (32.6)	24,608 (36.4)	12,062 (33.1)	692 (28.1)	15,059 (39.3)	15,013 (40.6)	14,082 (29.9)	22,041 (31.2)	31,936 (34.0)
Yes	27,350 (70.1)	41,247 (67.4)	43,049 (63.6)	24,394 (66.9)	1,767 (71.9)	23,211 (60.7)	21,929 (59.4)	32,975 (70.1)	48,588 (68.8)	61,936 (66.0)
Age (years) at first presentation to SLaM										
<18 years	4,101 (10.1)	3,337 (5.3)	3,670 (5.2)	387 (1.0)	13 (0.5)	3,104 (7.9)	3,526 (9.3)	1,951 (4.0)	3,196 (4.3)	6,380 (6.6)
18–24 years	9,994 (24.7)	13,349 (21.0)	11,699 (16.6)	3,943 (10.3)	101 (4.1)	6,816 (17.3)	7,001 (18.5)	7,575 (15.5)	11,725 (16.0)	17,788 (18.3)
25–34 years	12,144 (30.0)	20,913 (32.9)	18,839 (26.8)	10,213 (26.8)	657 (26.4)	9,548 (24.2)	8,660 (22.9)	13,898 (28.5)	21,679 (29.5)	27,208 (28.0)
35–44 years	8,555 (21.1)	14,918 (23.5)	19,458 (27.7)	13,117 (34.4)	988 (39.6)	10,127 (25.6)	10,037 (26.6)	14,770 (30.1)	21,068 (28.6)	25,447 (26.2)
45–54 years	4,548 (11.2)	8,937 (14.1)	13,305 (18.9)	8,601 (22.6)	602 (24.2)	7,581 (19.2)	6,993 (18.5)	8,795 (18.1)	12,949 (17.6)	16,335 (16.8)
55–65 years	1,153 (2.9)	2,162 (3.4)	3,348 (4.8)	1,861 (4.9)	132 (5.3)	2,300 (5.8)	1,538 (4.1)	1,744 (3.6)	2,913 (4.0)	3,932 (4.1)
B Primary psychiatric diagnosis										
Received primary psychiatric diagnosis	27,314 (65.8)	42,680 (65.6)	52,201 (72.6)	28,975 (74.4)	2,046 (79.5)	29,615 (73.4)	28,465 (73.6)	35,822 (71.9)	52,648 (70.0)	68,989 (69.4)
Did not receive primary psychiatric diagnosis	14,188 (34.2)	22,408 (34.4)	19,680 (27.4)	9,975 (25.6)	528 (20.5)	10,754 (26.6)	10,234 (26.4)	14,007 (28.1)	22,57 (30.0)	30,403 (30.6)

Note: [a]Age years represents the age at SLaM window end date (30th June 2019). All patients in this cohort are of working age between the SLaM window start and end date (18–65 years). The total N may differ between variables due to missing data.

[b]These measures are taken from the time point that is closest to the SLaM window start date (January 2007).

[c]Indices of Multiple Deprivation (IMD) is a summary measure of relative deprivation for fixed areas of the UK, informed by seven domains (income, employment, education, crime, housing, health, and living environment), scores are grouped into quintiles based on relative disadvantage. This was informed by 2019 data, using individual level postcodes (closest to first ever psychiatric diagnosis date, and if no diagnosis, closest to first SLaM contact date). Cell sizes of less than <10 are shown as <10 (<0.1%).

Table 4: Diagnostic categories of working age patients who have received or not received a benefit related to unemployment, sickness, disability, housing, or income support

Benefit receipt		
Recorded first primary psychiatric diagnoses (ICD-10 codes and description)	**Received benefits of interest n = 117,683 n (%)**	**Did not receive benefits of interest n = 32,665 n (%)**
Schizophrenia, schizotypal, delusional disorders, and other non-mood psychotic disorders (F20–F29)		
	Total n = 10,586/117,683 (9%)	*Total n = 1,043/32,665 (3.2%)*
Schizophrenia (F20)	5,752 (54.3)	306 (29.3)
All other psychosis (e.g., unspecified nonorganic psychosis) (F21–F29)	4,834 (45.7)	737 (70.7)
Mood (affective) disorders (F30–F39)		
	Total n = 19,401/117,683 (16.5%)	*Total n = 5775/32,665 (17.7%)*
Major depressive disorder, single episode (F32)	12,058 (62.2)	3,610 (62.5)
All other mood affective disorders including bipolar (F30, F31, F33, F34, F38, F39)	7,343 (37.8)	2,165 (37.5)
Anxiety, dissociative, stress-related, somatoform and other nonpsychotic mental disorders (F40–F48)		
	Total n = 14,838/117,683 (12.6%)	*Total n = 5118/32,665 (15.7%)*
Reaction to severe stress, and adjustment disorders (F43)	6,110 (41.2)	1,673 (32.7)
Phobic anxiety disorders (F40), obsessive compulsive disorders (F42), dissociative and conversion disorders (F44), somatoform disorders (F45), Other non-psychotic mental disorders (F48)	4,808 (32.4)	1,833 (35.8)
Other anxiety disorders (F41) (e.g., panic disorders, generalised anxiety disorders, mixed anxiety, and depressive disorders)	3,920 (26.4)	1,612 (31.5)
Mental and behavioural disorders due to psychoactive substance use (F10–F19)		
	Total n = 20,095 /117,683 (17.1%)	*Total n = 2931/32,665 (9%)*
Alcohol related disorders (F10)	8,991 (44.4)	1,627 (55.5)
Substance related disorders (F11–F19)	11,104 (55.6)	1,304 (44.5)
Behavioural syndromes associated with physiological disturbances and physical factors F50–F59		
	Total n = 2,482 /117,683 (2.1%)	*Total n = 1911/32,665 (5.9%)*
Eating disorders (F50) and all other behavioural syndromes (F51, F53, F54, F55, F59)	2,482 (100.0)	1,911 (100.0)
Disorders of adult personality and behaviour (F60–F63)		
	Total n = 2,856 /117,683 (2.4%)	*Total n = 411/32,665 (1.3%)*
Personality disorders and adult behavioural disorders (F60–F63)	2,856 (100.0)	411(100.0)
Other disorders – intellectual disabilities (F70–F79), pervasive and specific developmental disorders (F80–F89), and behavioural and emotional disorders with onset usually occurring in childhood and adolescence (F90–F98)		
	Total n = 9723/117,683 (8.3%)	*Total n = 1804/32,665 (5.5%)*
Intellectual disabilities (F70–F79)	1,851 (19.0)	35 (1.9)
Autism and Asperger's related development disorders (F84)	2,385 (24.5)	272 (15.0)
ADHD related disorders (F90)	4,089 (42.1)	1,204 (66.7)
Other disorders (F80, F81, F83, F88, F89, F91, F92, F93, F94, F95, F98)	1,398 (14.4)	293 (16.2)
No recorded primary psychiatric diagnosis	*Total n = 37,702/117,683 (32.0%)*	*Total n = 13,672 /32,665 (41.9)*
	37,702 (100.0)	13,672 (100.0)

Note: Benefits of interest include having received one or more of the following at any point in the DWP data window (January 2005–June 2020): Universal Credit, Personal Independence Payment, Housing Benefit, Incapacity Benefit, Income Support, Jobseeker's Allowance, Disability Living Allowance, Severe Disablement Benefit, Employment and Support Allowance. All patients in this cohort are of working age between the SLaM window start and end date (18–65 years). The following diagnostic categories were excluded as they were not of interest for the purpose of this study and/or had very small numbers: F01 to F09: Mental disorders due to known physiological conditions, F52 Sexual dysfunction not due to a substance or known physiological condition, F64 Gender identity disorders, F65 Paraphilias, F66 Other sexual disorders, F68 Other disorders of adult personality and behaviour, F69 Unspecified disorder of adult personality and behaviour. If a patient received a first psychiatric diagnosis of FXX or F99, the next F* code diagnosis they received closest to window start date of the SLaM data window is considered their first psychiatric diagnosis.

obtained more than one benefit were identified as living within the two quintiles representing the highest levels of deprivation in the South-east London boroughs served by SLaM. Our findings are in line with previous reports that show that a large proportion of people claiming benefits also report symptoms of mental disorders, and that this continues to rise [1, 15, 16].

Strengths and limitations

This data linkage is the first of its kind to link electronic mental health records with benefits data in the UK, providing in depth data spanning a 15-year window and opportunity to explore the complex longitudinal relationships between benefit receipt among a substantial number of adults accessing secondary mental health across areas of South-east London. The mental health data provides rich clinical information on psychiatric diagnoses, illness severity, assessment, history of appointments and treatments and interventions received. Benefits data provides substantial detail such as type, level, dates of and entitlement amounts of benefits received, WCAs and work-related interventions offered.

Previous research reporting on mental health and benefit receipt has been limited in detail, as well as the methods used. The Adult Psychiatric Morbidity Survey (APMS) (2014) [17] reported that mental disorders are more common among those who were unemployed and receiving an out of work benefit, namely ESA, due to poor health and disability. The current data linkage presents extensive data recorded by health service professionals, as opposed to self-report, and provides more detailed benefits related information. Unlike cross-sectional studies, such as the APMS [17] the longitudinal nature of the linkage presents an opportunity to understand ongoing changes and potential challenges in the provision of mental health services and benefits, as well as capture individuals using mental health services more sporadically.

Although we reported a high linkage rate (92.3%), we previously described a linkage bias showing certain characteristics such as age, gender, and ethnicity were associated with an increased risk of not being successfully linked [12]. A further source of bias relating to linkage error is false links, which can be challenging to identify [18]. To mitigate this, dates pertaining to variables are cross-checked during the data cleaning and coding phases of all data analyses. This protocol ensures that chronological inconsistencies, such as the date of death preceding other relevant events, are identified and removed where necessary.

Another limitation is that our sample only contains patients who have been referred to SLaM, meaning we cannot compare our findings to a population with mental disorders who have not accessed secondary mental health services. Further, we do not hold reliable data across the cohort specifically indicating whether a patient is currently in or out of work, though there are indicators among those receiving UC as to whether someone is currently in, out of, or looking for work.

Conclusion

We have identified the sociodemographic and diagnostic characteristics of a working age population accessing secondary mental health services in South-east London and their receipt of benefits. This data linkage provides a unique opportunity to advance our understanding of the complex relationships between benefit receipt and mental health among this group, as well as deliver evidence to support and answer areas of research interest stated by the DWP relating to health and disability and welfare provision [2, 19], and around mental health service provision.

Future research using the linked data will explore both the level of interaction with secondary mental health services and the duration of benefits received over time across different groups (e.g., across diagnostic groups and by socio-demographic factors), as well as assessing temporality between receiving a mental health diagnosis or accessing secondary mental health services and receiving a benefit. The data linkage also presents opportunities to look at the impact of the benefit reforms on mental health outcomes (e.g., mental health severity and diagnosis over time). Insights gained from this research can have a meaningful impact on shaping policies that directly address the intricate interplay between the benefit system and mental health, enabling improved support and well-being for the working age population.

Data access

The linked data is not freely available due to ethical and legal restrictions that exist for the current data linkage to ensure the privacy of patients. The team welcomes research enquiries for project proposals and collaboration. Those who are interested should contact the study lead, Dr Sharon Stevelink (Sharon.stevelink@kcl.ac.uk) who will advise on the practicality, processes and required permissions for using the data linkage.

Author contributions

AP, SAMS and NTF conceptualised the design of this cohort profile study. MH, JD, NTF, SD and SAMS were part of initial discussions, the various processes and then finalization of the data linkage itself. MB, RL and AJ took lead in data curation. AP led on project administration and analysis, wrote initial draft of the paper including all sections and revised the paper. SAMS, NTF, MH and SD provided supervision and supported on drafts of the paper. RL provided data cleaning and statistical support. AP and SAMS acquired funding for the study with support from NTF and MH. All authors commented on final draft of the paper. NTF and SAMS are joint last authors.

Conflict of interest

MH is principal investigator of the RADAR-CNS consortium, a public private pre-competitive consortium on mobile health, and as such received research funding to his university from five pharmaceutical companies (Janssen, UCB, MSD, Lundbeck and Biogen).

Patient and public involvement statement

This project was informed by discussions with the NIHR Maudsley BRC Data Linkage Service User and Carer Advisory Group.

Ethical approval

We submitted the proposed linkage to the South Central—Oxford C Research Ethics Committee for ethical approval. A favourable opinion was received in 2017 (ref 17/SC/0581). We also successfully applied in 2017 for Section 251 approval under the NHS Health Research Authority Confidential Advisory Group (ref 17CAG0055). We believed that it was not practical or appropriate for the proposed linkage to be successfully achieved through a consent-based methodology. Once ethical approvals were in place, we developed a data sharing agreement. This agreement outlines the data sharing agreements between SLaM and the Department for Work and Pensions in relation to the data linkage. The agreement sets out lawful basis of the data linkage as well as the principles and procedures for data sharing and the use of the linked data.

Patient consent for publication

Not applicable.

Acknowledgements

We would like to thank Megan Pritchard at the National Institute for Health and Care Research (NIHR) Maudsley Biomedical Research Centre (BRC) for their support with this study. We would also like to thank the members of the NIHR Maudsley BRC Data Linkage Service User and Carer Advisory Group for their input. We are very grateful to the DWP/Department of Health and Social Care joint Work and Health Directorate staff, who supported us in creating this linked dataset and for all the advice provided.

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Appendix

Supplementary Table 1: Socio-demographic characteristics of working age patients who have not received a benefit related to unemployment, sickness, disability, housing, or income support

Did that not receive benefits of interest n = 32,665			
	Patients that engaged with DWP as evidenced by an entry in benefits records but did not receive any benefits (n = 273) n (%)	**Patients that engaged with DWP and received benefits that were not of interest (e.g. State Pension) (n = 854) n (%)**	**Patients that had no entry in benefit records (n = 31,538) n (%)**
Sex			
Female	160 (58.6)	610 (71.4)	17,188 (54.5)
Male	113 (41.4)	244 (28.6)	14,324 (45.5)
[b]Age (years)			
18–24 years	19 (7.0)	27 (3.2)	3,906 (12.4)
25–34 years	79 (28.9)	82 (9.6)	8,018 (25.4)
35–44 years	88 (32.2)	164 (19.2)	9,026 (28.6)
45–54 years	57 (20.9)	205 (24.0)	6,469 (20.5)
55–65 years	30 (11.0)	376 (44.0)	4,119 (13.1)
Ethnicity			
White British/White Other	126 (46.2)	458 (53.6)	15,933 (50.5)
Black/African/Caribbean/Black British	28 (10.3)	54 (6.3)	2326 (7.4)
Asian/Asian British	23 (8.4)	55 (6.4)	2,108 (6.6)
Mixed/Multiple racial and ethnic groups	<10 (<0.1)	<10 (<0.1)	489 (1.6)
Other racial and ethnic minority groups	17 (6.2)	60 (7.0)	2528 (8.0)
Not stated	73 (26.7)	219 (25.6)	8154 (25.9)
Recorded death between 2005–2020			
No	266 (97.4)	823 (96.4)	30,620 (97.1)
Yes	<10 (<0.1)	31 (3.6)	918 (2.9)
[c]Deprivation (IMD quintile)			
First (most deprived)	49 (18.6)	133 (16.0)	4,324 (14.3)
Second	95 (36.3)	275 (33.1)	10,661 (35.3)
Third	59 (22.5)	206 (24.7)	7,792 (25.8)
Fourth	35 (13.4)	126 (15.1)	4,543 (15.0)
Fifth (least deprived)	24 (9.2)	92 (11.1)	2885 (9.6)
[d]Resident within SLaM local catchment area			
No	108 (41.2)	308 (37.0)	10,018 (33.1)
Yes	154 (58.8)	525 (63.0)	20,212 (66.9)
Age (years) at first presentation to SLaM			
<18 years	<10 (<0.1)	17 (2.0)	1,981 (6.5)
18–24 years	59 (22.2)	77 (9.2)	6,404 (20.9)
25–34 years	99 (37.2)	147 (17.6)	10,066 (32.9)
35–44 years	53 (19.9)	198 (23.8)	7,191 (23.5)
45–54 years	41 (15.4)	240 (28.7)	3,939 (12.9)
55–65 years	<10 (<0.1)	156 (18.7)	1,046 (3.3)
[d]Psychiatric diagnosis received			
Received primary psychiatric diagnosis	160 (58.6)	491 (57.5)	18,342 (58.2)
Did not receive primary psychiatric diagnosis	113 (41.4)	363 (42.5)	13,196 (41.8)

Note: [a]Benefits received: these include having received one or more of the following at any point in the DWP data window (January 2005–June 2020): Universal Credit, Personal Independence Payment, Housing Benefit, Incapacity Benefit, Income Support, Jobseeker's Allowance, Disability Living Allowance, Severe Disablement Benefit, Employment and Support Allowance. Those in the 'did not receive benefits' column will not have any instances of receiving the relevant benefits listed, but may have received other benefits (e.g., State Pension) or no benefits at all.

[b]Age (years) represents the age at SLaM window end date (30th June 2019). All patients in this cohort are of working age between the SLaM window start and end date (1st January 2007–30th June 2019) (18–65 years). The total N may differ between variables due to missing data.

[c]Indices of Multiple Deprivation (IMD) is a summary measure of relative deprivation for fixed areas of the UK, informed by seven domains (income, employment, education, crime, housing, health, and living environment), scores are grouped into quintiles based on relative disadvantage. This was informed by 2019 data, using individual level postcodes (closest to first ever psychiatric diagnosis date, and if no diagnosis, closest to first SLaM contact date).

[d]These measures are taken from the time point that is closest to the SLaM window start date (January 2007). Cell sizes of less than <10 are shown as <10 (<0.1%).