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**Analysing trends of psychiatric disorders, treatment and service use across time in adults with borderline intellectual impairment: A cross-sectional study of private households**

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## **Abstract**

While there is evidence that mental health problems are more prevalent in people with borderline intellectual functioning (BIF) compared to the general population, it is not known to what extent this has varied or changed over time and whether there have been changes in access to services. This paper compares the prevalence rates of psychiatric disorders and monitors trends in treatment and services in this population compared to the general population. We conducted secondary analysis on the Adult Psychiatric Morbidity Surveys carried out in England in 2000, 2007 and 2014. The total sample analyzed included 21,796 participants, with 12.8% of individuals identified with BIF ( $n = 2,786$ ). Regression models were used to examine trends in psychiatric disorders, treatment and service use across the three datasets. People with BIF had significantly higher odds of developing mood and anxiety disorders, psychosis, drug dependence and suicidal behaviour than the general population, increasing at each subsequent timepoint. They received significantly more pharmacological treatments than the general population but have had increasingly more access to general practitioners, community care and daycare services over time. This study shows increasing prevalence rates of several mental disorders in people with BIF. Access to day-care, community care and healthcare services has increased over time for this group but not formal psychiatric care. These changes over time underline some of the problems this population faces, emphasizing a need to recognise that this is a population often overlooked in research and clinical practice.

## Introduction

Intellectual disability, otherwise coined as learning disability in the UK, is defined by cognitive (IQ score below 70) and functional impairment, both arising in childhood. People who have an IQ between 70 to 85 have borderline intellectual functioning (BIF; Martínez-Leal et al., 2020). BIF is a descriptive code in *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)* rather than a psychiatric diagnostic criterion and is considered to be a risk factor for increased vulnerability to mental health problems. Population-based cross-sectional studies investigating psychiatric morbidity in the BIF population have established that, compared to the general population, people with BIF are at increased risk of mood disorders (Chen et al., 2006; Dekker & Koot, 2003; Emerson et al., 2010; Hassiotis et al., 2008), phobias (Hassiotis et al., 2008; Gigi et al., 2014), substance misuse (Didden et al., 2009; van Duijvenode et al., 2015), alcohol-related problems (Chen et al., 2006), post-traumatic stress disorder (Wieland et al., 2014), psychosis (Hassiotis et al., 2017), personality disorders (Hassiotis et al., 2008; Wieland et al., 2015), and suicidal behaviour (Hassiotis et al., 2011). Longitudinal studies in Australia (Emerson & Robertson, 2010) and the U.S. (Seltzer et al., 2005) found that young people with BIF had higher odds of developing psychiatric disorders in later life. Emerson, Einfield and Stancliffe (2010) observed higher rates of child psychiatric morbidity in children with BIF. Social disadvantage, such as poverty, has been found to partly explain the association between BIF with neurotic disorders (Hassiotis et al., 2008), drug abuse (Gigi et al., 2014), and suicidal behavior (Hassiotis et al., 2011). McManus and colleagues (2018) reported higher prevalence rates of common mental disorders in women with BIF (31%) than their male counterparts (20%) from the 2014 Adult Psychiatric Morbidity Survey (APMS); however, these differences were not of statistical significance. They did, however, find that women with BIF were three times more likely to meet diagnostic criteria for PTSD and men with BIF were five times more likely to problem gambling than their respective counterparts in the general population.

Treatment and specialised services that accommodate the BIF population vary around the world. The Netherlands is unique in that it offers patients with BIF and comorbid psychiatric disorders specialist psychiatric services in the form of outpatient mental health care centres (Wieland, Haan & Zitman, 2014). The UK provides specialist services for people with intellectual disability; however, these services often impose strict suitability criteria which limits those with BIF from accessing them. Previous research suggests that people with BIF in England are more likely to receive psychotropic medication over psychological therapies compared to the general population (Hassiotis et al., 2008). In most countries, people with BIF are likely to access general mental healthcare services, where mental health workers may not receive special skills training to accommodate the more nuanced needs of this overlooked population (Wieland & Zitman, 2016). Broadly speaking, general mental health services may include contact with general practitioners (GP), psychiatrists, psychologists, and community nurses, and include inpatient and outpatient health care.

Individuals with BIF may have poor adaptive functioning, yet they often have inadequate support to effectively utilise interventions in general mental health services (Peltopuro et al., 2014). This may lead to delays in diagnosis and treatment (Wieland, 2016). They clearly constitute a vulnerable group, yet their needs are overlooked by mainstream services, and access to specialised services is limited (Wieland et al., 2014).

While there is evidence that mental health problems are more prevalent in people with BIF compared to the general population, it is not known to what extent prevalence has varied or changed over time and whether

there have been changes in access to services, particularly psychological treatments. We investigated the trends in psychiatric disorders and the patterns of treatment and service use between 2000 and 2014 using data from the Adult Psychiatric Morbidity Surveys (APMS), by comparing adults with BIF living in private households in the UK and their counterparts in the general population (i.e.: those with an IQ greater than 1 standard deviation below the mean).

The aims of this study were to:

1. Describe and compare the prevalence of common mental health disorders, psychosis, substance misuse and suicidal behaviour in people with BIF and the general population;
2. Describe and compare the prevalence of general psychiatric treatment and service use among adults with BIF and the general population;
3. Describe any changes in the prevalence of psychiatric disorders, treatments and service use between people with BIF and the general population between years 2000 and 2014;

## **Methods**

### **Data source**

We used data from the Adult Psychiatric Morbidity Survey (APMS), a series of surveys carried out in England at four time-points: 1993, 2000, 2007, and 2014. A multi-stage stratified random probability sampling design was employed, where the sampling frame used the Royal Mail's Small User Postcode Address File, defined as delivery points receiving less than 50 pieces of mail each day, to identify private households (McManus et al., 2016). The primary sampling units were individual or groups of postcode sectors, which were stratified before sampling based on a measure of socioeconomic status by region. Addresses were then selected at random, and one individual aged 16 or over per household was selected for interview.

Individuals were invited to take part in phase-1 interviews, where trained interviewers used structured assessments and screening instruments for measuring mental disorders and collected information on service use and socio-demographic factors.

Our study included data from 2000, 2007 and 2014, where a measure of intellectual functioning was available. Participants in 2007 and 2014 included adults aged 16 years and above whereas the 2000 survey only included adults aged 16–74 years. Variables that differ across time-points and our solutions for these differences are further detailed below. The approach has otherwise remained consistent, making the data comparable across survey years.

### **Ethics and Access to Data**

Ethical approval for APMS in 2000, 2007 and 2014 were obtained from appropriate ethical bodies as detailed in each respective APMS report (Singleton et al., 2001; McManus et al., 2009; McManus et al., 2016). Ethical clearance for 2007 and 2014 were obtained from the Royal Free Hospital and Medical School Research Ethics Committee (Reference number: 06/Q0501/71), and the West London National Research Ethics Committee (Reference number: 14/LO/0411) respectively. All data collected by the APMS surveys are now held by NatCen Social Research and NHS Digital. Access to all APMS datasets for the conduct of additional research and re-analysis is reviewed and subject to approval by NHS Digital. The authors received approval to access anonymized data files from NHS Digital to carry out this research on 26/05/21.

Informed consent for further use and secondary analysis of the APMS data was obtained by the researchers who carried out each survey. Participants were provided with written information detailing permitted reuse of anonymized datasets and asked for informed verbal consent for re-analysis of data. Approval has therefore been obtained by the appropriate bodies and the research has been performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki.

## **Sample**

Our study included all respondents of the APMS in 2000, 2007 and 2014. A total of 12,792; 13,171 and 13,313 adults were contacted for years 2000, 2007, and 2014 respectively, of which 8,886; 7,461, and 7,546 responded (response rates: 69%, 57%, and 57%). Out of these samples, 1,733 (7.4%) participants who did not complete the intellectual functioning assessment were excluded. The final sample consisted of 21,796 participants, of which 2,786 (12.8%) were identified as having BIF. Sociodemographic characteristics of the sample groups are summarised by survey year in Supplementary Table. The rate of people BIF remained consistent across all survey years, with 12.6% ( $n=1012$ ), 13.2% ( $n=909$ ) and 12.6% ( $n=865$ ) in years 2000, 2007, and 2014 respectively. Mean age is similar in both population groups each survey year. There was no significant difference in distribution of gender in the BIF population (Females with BIF by survey year - 2000: 55.6%,  $n=563$ ; 2007: 52.1%;  $n=474$ ; 2014: 54.3%,  $n=470$ ; Males with BIF by survey year: 2000: 44.4%,  $n=449$ ; 2007: 47.9%,  $n=435$ ; 2014: 45.7%;  $n=395$ ).

## **Measures**

### **Intellectual functioning**

Intellectual functioning was assessed using the National Adult Reading Test (NART) (Nelson, 1982), which measures the level of premorbid intelligence in adults. It consists of 50 words that are presented in ascending order of difficulty. A verbal IQ score is estimated by computing the total number of reading errors made. Participants who obtained a score of 70–85 and have no to low educational qualifications were identified as having BIF. Those with scores of 85 or lower but have obtained higher academic qualifications (A-Levels or higher) and those with normal intellectual functioning (verbal IQ score of 86 or more) were classified as the general population. This follows the methodology of a previous study using the APMS to study this population (Hassiotis et al., 2017).

### **Socio-demographic variables**

Standardized questions about age, sex, ethnicity, marital status, and occupation were asked. We re-categorized marital status into relationship status: single, in a relationship (includes married, cohabiting, or same-sex couple), and other (includes divorced, separated or widowed). To account for socioeconomic status, we classified participants into social class based on occupation and employment status.

### **Common mental disorders**

The surveys used the revised Clinical Interview Schedule (CIS-R) (Lewis et al., 1992) to assess any neurotic symptoms presenting in the 7 days preceding the phase-1 interview. This was administered by trained non-clinical interviewers. Diagnoses of specific neurotic disorders were classified according to the answers to each section of the CIS-R using algorithms based on the ICD-10 diagnostic criteria (World Health Organization, 1992). Six categories of common mental disorders were created: mixed anxiety and

depressive disorder (MADD), generalized anxiety disorder (GAD), depressive episodes, phobias, obsessive compulsive disorder (OCD) and panic disorder. We also included a variable for any neurotic disorder. MADD was not available in the 2004 survey.

### **Psychosis**

At phase-1 interviews, participants were screened for probable psychotic disorders using the following criteria: self-report symptoms suggestive of psychosis; taking anti-psychotic medication; history of admission to a mental hospital or ward; and a positive response to a question about auditory hallucinations from the Psychosis Screening Questionnaire (Bebbington & Nayani, 1995). Individuals who gave a positive response on any one of these criteria were asked to participate in a phase-2 interview using the Schedule for Clinical Assessment in Neuropsychiatry (SCAN) (World Health Organization, 1999) for a definitive diagnosis of psychosis. Our analyses are based on a composite measure of 'probable psychosis' comprising of those who met diagnosis using SCAN and those from phase-1 who meet at least two of the screening criteria.

### **Substance misuse**

Participants were assessed for alcohol dependence using the Alcohol Use Disorders Identification Test (AUDIT) (Babor et al., 1992) and the Severity of Alcohol Dependence Questionnaire (SAD-Q) (Stockwell et al., 1983). A combined score from both questionnaires of 8 or more indicated hazardous alcohol use and classed as a drinking problem.

Drug dependence was assessed through five questions taken from the U.S. ECA study (Regier et al., 1990). A positive response to any of the questions indicated drug dependence. Participants were asked about dependence on eight types of drugs (cannabis, amphetamines, cocaine, crack, opiates, ecstasy, tranquillizers and solvents).

### **Suicidal behavior**

Participants were asked to self-report on suicidal thoughts and behaviors. We assessed suicidal behavior from responses to the following questions during phase-1 interviews:

- Have you ever deliberately harmed yourself in any way but not with the intention of killing yourself?
- Have you ever made an attempt to take your life, by taking an overdose of tablets or in some other way?

Two variables were created to assess suicidal behavior – self-harm and history of suicide attempt. Responses were dichotomized into positive and negative responses.

### **Services and treatments**

Participants were asked about contact with mental health services in the year preceding the interview. These included:

- Contact with general practitioners (GP) for mental health care;
- Community care services ranging from contact with a psychiatrist, psychologist, community psychiatric nurse, community learning difficulty nurse, other nursing services, social worker, self-help/support group, home help/homecare worker or outreach worker;

- Daycare services, including use of community mental health centres, day activity centres, sheltered workshops and other nursing services;
- Types of medication prescribed;
- Other types of interventions they had access to, including counselling and therapy.

Participants were also asked about in-patient hospital admissions and out-patient hospital treatments 3 months prior to the interview.

All variables were cross-checked across survey years – where there were differences in categorizing medication and therapy subtypes (2000), derived variables were created to be comparable to data available in the 2007 and 2014 surveys. These include binary variables on use of any antipsychotics (including depot injections), any antidepressants, any psychotropic drugs and any therapy (including counselling, psychotherapy, behavioral or cognitive therapy, art therapy, social skills training, family therapy, and sex therapy). A binary variable dichotomizing whether a person received any treatment (medication and/or therapy) or not was created.

### **Statistical Analyses**

Statistical program STATA version 15 was used to carry out data analyses. The survey data were weighted to correct for the clustered sampling design, using probability weights to account for non-responses and the different probabilities of selecting respondents in different-sized households, ensuring that our sample population reflected the total population. All results reported are based on probability weights. Prevalence rates of each category of psychiatric outcomes, services accessed, and treatments received were calculated for those with BIF and those without.

Our analytical strategy included logistic regression analyses of psychiatric disorders associated with borderline intellectual functioning status, analysed separately by survey year and all years combined. The same strategy was applied to treatments and service use. We then ran multivariable logistic regressions with intellectual functioning and survey year as interaction terms and obtained global p-values for differences across the three time-points. Separate logistic regression analyses were subsequently fitted for each survey year to obtain individual odds ratios to compare across the three years. All analyses were adjusted for potential confounders by including sociodemographic factors as covariates (these included age, sex, ethnicity, employment status and social class)

## **Results**

### **Comparing prevalence rates of psychiatric disorders by survey year**

The differences in the prevalence of psychiatric disorders between people with BIF and the general population are presented in Table 1.

We found strong evidence that people with BIF were more likely to meet diagnostic criteria for phobias, agoraphobia, depressive episodes, and any neurotic disorder across all three survey years.

GAD, psychosis, OCD, and drug dependence were also more likely to occur in people with BIF, although evidence was initially weak in 2000. The odds of these disorders were significantly higher in 2007 and 2014 compared to the general population. Although people with borderline intelligence appeared to be significantly more likely to meet criteria for psychosis in 2007 (OR: 3.00, 95% CI: 1.39 - 6.49,  $p= 0.005$ ) and 2014 (OR: 3.67, 95% CI: 2.13 - 6.31,  $p< 0.001$ ), the range of the 95% confidence intervals was wide, which is likely due to the small numbers of people with psychosis in both groups. There was no evidence of a difference between the two populations in the likelihood of drinking problems.

There were higher prevalence rates of self-harm in people with BIF (2000: 3.7%, 2007: 4.8%, 2014: 9.2%) compared to the general population (2000: 2.1%, 2007: 2.9%, 2014: 5.1%). The same observation was made for reported suicide attempt, with a higher proportion of people with BIF reported having previously attempted suicide (2000: 7.4%, 2007: 7.3%, 2014: 10.8) than the general population (2000: 4.6%, 2007: 5.1%, 2014: 5.4%). The odds of people with BIF reporting self-harming behavior and previous suicide attempt were higher than the general population.



**Table 1** Prevalence rates and unadjusted odds ratios (OR) for psychiatric disorders comparing people with BIF and general population by survey year

Variable	Borderline intellectual functioning (BIF) N (%) <sup>a</sup>	General population N (%) <sup>a</sup>	OR (95% CI)	p-value
<b>Year 2000</b>	N= 1012	N= 7035		
Common mental disorders				
Panic disorder	11 (1.09)	52 (0.74)	1.40 (0.67 – 2.94)	0.366
GAD	63 (6.23)	327 (4.65)	1.36 (1.00 – 1.85)	0.049
MADD	105 (10.38)	610 (8.67)	1.13 (0.89 – 1.44)	0.321
OCD	17(1.68)	84 (1.19)	1.36 (0.75 – 2.47)	0.316
Phobia	31 (3.06)	133 (11.89)	<b>1.80 (1.15 – 2.81)</b>	<b>0.009</b>
Agoraphobia	21 (2.08)	69 (0.98)	<b>2.23 (1.29 – 3.87)</b>	<b>0.004</b>
Depressive episode	11 (1.09)	52 (0.74)	<b>1.98 (1.37 – 2.85)</b>	<b>&lt; 0.001</b>
Any neurotic disorder	217 (21.44)	1169 (16.62)	<b>1.32 (1.10 – 1.58)</b>	<b>0.002</b>
Probable psychosis	12 (1.19)	39 (0.55)	1.97 (0.99 – 3.94)	0.054
Substance misuse				
Drinking problem <sup>b</sup>	238 (23.68)	1742 (24.81)	0.94 (0.81 – 1.10)	0.437
Any drug dependence <sup>b</sup>	47 (4.67)	204 (2.90)	1.36 (0.95 – 1.96)	0.092
Suicidal behaviour				
Self-harm <sup>b</sup>	37 (3.66)	150 (2.13)	<b>1.67 (1.11 – 2.52)</b>	<b>0.014</b>
Suicide attempt <sup>b</sup>	75 (7.41)	322 (4.58)	<b>1.54 (1.15 – 2.06)</b>	<b>0.004</b>
<b>Year 2007</b>	N= 909	N=5963		
Common mental disorders				
Panic disorder	13 (1.43)	60 (1.01)	1.89 (0.97 – 3.66)	0.060
GAD	58 (6.38)	268 (4.49)	<b>1.44 (1.03 – 2.02)</b>	<b>0.034</b>
MADD	85 (9.35)	504 (8.45)	1.23 (0.93 – 1.61)	0.143
OCD	19 (2.09)	55 (0.92)	<b>2.78 (1.45 – 5.31)</b>	<b>0.002</b>
Phobia	32 (3.52)	112 (1.88)	<b>2.30 (1.46 – 3.61)</b>	<b>&lt; 0.001</b>
Agoraphobia	20 (2.20)	65 (1.09)	<b>2.31 (1.32 – 4.04)</b>	<b>0.003</b>
Depressive episode	48 (5.28)	189 (3.17)	<b>1.84 (1.26 – 2.69)</b>	<b>0.002</b>
Any neurotic disorder	189 (20.79)	978 (16.40)	<b>1.44 (1.18 – 1.76)</b>	<b>&lt; 0.001</b>
Probable psychosis	11 (1.21)	26 (0.44)	<b>3.00 (1.39 – 6.49)</b>	<b>0.005</b>
Substance misuse				
Drinking problem <sup>b</sup>	194 (21.37)	1178 (19.76)	1.10 (0.91 – 1.34)	0.301
Any drug dependence <sup>b</sup>	46 (5.09)	146 (2.46)	<b>2.26 (1.55 – 3.30)</b>	<b>&lt; 0.001</b>
Suicidal behaviour				
Self-harm <sup>b</sup>	43 (4.75)	172 (2.89)	<b>1.87 (1.27 – 2.76)</b>	<b>0.002</b>
Suicide attempt <sup>b</sup>	66 (7.28)	303 (5.09)	<b>1.61 (1.17 – 2.21)</b>	<b>0.003</b>
<b>Year 2014</b>	N=865	N=6012		
Common mental disorders				
Panic disorder	4 (0.46)	32 (0.53)	0.60 (0.20 – 1.79)	0.358
GAD	84 (9.71)	350 (5.82)	<b>1.55 (1.15 – 2.08)</b>	<b>0.004</b>
MADD	-	-	-	-
OCD	24 (2.77)	68 (1.13)	<b>2.43 (1.36 – 4.36)</b>	<b>0.003</b>
Phobia	51 (5.90)	132 (2.20)	<b>2.97 (2.00 – 4.42)</b>	<b>&lt; 0.001</b>
Agoraphobia	34 (3.93)	97 (1.61)	<b>2.32 (1.48 – 3.64)</b>	<b>&lt; 0.001</b>
Depressive episode	63 (7.28)	192 (3.19)	<b>2.33 (1.64 – 3.31)</b>	<b>&lt; 0.001</b>
Any neurotic disorder	225 (26.01)	987 (16.42)	<b>1.78 (1.47 – 2.16)</b>	<b>&lt; 0.001</b>
Probable psychosis	29 (3.35)	54 (0.90)	<b>3.67 (2.13 – 6.31)</b>	<b>&lt; 0.001</b>
Substance misuse				
Drinking problem <sup>b</sup>	132 (15.56)	1078 (18.61)	0.80 (0.63 – 1.00)	0.051
Any drug dependence <sup>b</sup>	32 (4.43)	117 (2.08)	<b>2.53 (1.58 – 4.04)</b>	<b>&lt; 0.001</b>
Suicidal behaviour				
Self-harm <sup>b</sup>	79 (9.15)	308 (5.13)	<b>1.92 (1.41 – 2.61)</b>	<b>&lt; 0.001</b>
Suicide attempt <sup>b</sup>	93 (10.78)	324 (5.40)	<b>1.95 (1.46 – 2.60)</b>	<b>&lt; 0.001</b>

**Note:** All analyses used probability weights. <sup>a</sup> Reported number and percentage of people who meet diagnostic criteria of psychiatric outcome.

<sup>b</sup> Adjusted for missing data.

## Comparison of differences between both populations across three time-points

### Psychiatric disorders

We found significant differences in the interaction between intellectual functioning and survey year and the odds of having a diagnosis of mental disorder across survey years, where the prevalence and odds of people with BIF meeting diagnostic criteria for GAD, OCD, phobias, agoraphobia, depressive episodes, any neurotic disorders, psychosis, and drug dependence, increased at subsequent 7-year intervals (Table 2). The prevalence and odds of people reporting self-harming and suicide attempts also increased by survey year. For panic disorder, the apparent increase in 2007 and sudden drop in 2014 could be explained by low cases of panic disorder in both the general population [2000: n= 52 (0.74%), 2007: n=60 (1.01%), 2014: n=32 (0.53%)] and BIF group [2000: n= 11 (1.09%), 2007: n=13 (1.43%), 2014: n=4, (0.46%)]. There is no evidence of a difference in drinking problems between people with BIF and the general population, although it appears those with BIF were less likely to develop drinking problems than the general population.

We illustrate the changes in clinical outcomes across the three 7-year intervals in Figure 1. The data within each box represents the absolute percentage difference in prevalence estimates between people with BIF meeting diagnostic criteria for a disorder and people in the general population meeting criteria for the same disorder. Positive values indicate that more of the BIF group suffered from a condition than the rate observed in the general population, with values being represented by darker colours as the difference *increases* from equilibrium (being represented by a zero value). A darker colour would represent a more severe difference between the two populations. Negative values indicate that the general populations diagnostic rate of a condition was higher than the rate observed from the BIF group, where values are represented by lighter colour as the magnitude *decreases* from equilibrium.

Figure 1 shows notable increase in the prevalence of self-harming, psychosis, agoraphobia, depressive episodes, GAD, any neurotic disorders, and any phobias. More people with BIF were assessed positive for drug dependence, with an increase from 2000 to 2007 but a small decrease in 2014. The prevalence rate of MADD in BIF decreases from 2000 to 2007. There is no apparent difference between the BIF group and the general population for panic disorder. More people with BIF report previous suicide attempts compared to the general population, with little difference between years 2000 and 2007, increasing sharply in 2014.

**Table 2** Comparison of differences in psychiatric disorders between people with borderline intellectual functioning and the general population across 3 survey years (after including interaction by survey year)

Psychiatric disorder	BIF	General Population	Univariate Analysis <sup>a</sup>		Global p-value	Separate analysis for each survey year OR (95% CI), p-value			
	N (%)	N (%)	OR (95% CI)	p-value		2000 (N= 8,047)	2007 (N= 6,872)	2014 (N=6,877)	
Common mental disorders	Panic disorder	28 (1.01)	144 (0.76)	1.40 (0.88 – 2.24)	0.157	0.012	1.40 (0.67 – 2.93), 0.367	1.82 (0.94 – 3.53), 0.076	0.60 (0.20 – 1.80), 0.364
	GAD	205 (7.36)	945 (4.97)	1.42 (1.17 – 1.71)	< 0.001	< 0.001	1.36 (1.00 – 1.85), 0.049	1.42 (1.01 – 1.99), 0.042	1.5 (1.15 – 2.07), 0.004
	MADD <sup>b</sup>	190 (9.89)	1,114 (8.57)	1.16 (0.96 – 1.39)	0.124	0.280	1.13 (0.89 – 1.44), 0.322	1.23 (0.93- 1.61), 0.146	-
	OCD	60 (2.15)	207 (1.09)	1.90 (1.33 – 2.72)	< 0.001	0.0006	1.36 (0.75 – 2.47), 0.316	2.81 (1.47 – 5.39), 0.002	2.43 (1.36 – 4.36), 0.003
	Phobia	114 (4.09)	377 (1.98)	2.22 (1.71 – 2.87)	< 0.001	< 0.001	1.80 (1.16 – 2.81), 0.009	2.30 (1.47 – 3.62), < 0.001	3.00 (2.00 – 4.47), < 0.001
	Agoraphobia	75 (2.69)	231 (1.22)	2.26 (1.65 – 3.11)	< 0.001	< 0.001	2.23 (1.29 – 3.88), 0.004	2.29 (1.31 – 4.00), 0.004	2.33 (1.49 – 3.66), < 0.001
	Depressive episode	158 (5.67)	557 (2.93)	2.03 (1.63 – 2.52)	< 0.001	< 0.001	1.98 (1.37 – 2.85), < 0.001	1.84 (1.26 – 2.69), 0.002	2.32 (1.63 – 3.20), < 0.001
	Any neurotic disorder	631 (22.65)	3,134 (16.49)	1.45 (1.29 – 1.62)	< 0.001	< 0.001	1.32 (1.10 – 1.58), 0.002	1.43 (1.17 – 1.75), < 0.001	1.77 (1.46 – 2.15), < 0.001
Psychosis	52 (1.87)	119 (0.63)	2.72 (1.86 – 3.97)	< 0.001	< 0.001	1.97 (0.99 – 3.94), 0.054	2.89 (1.35 – 6.22), 0.007	3.73 (2.17 – 6.43), < 0.001	
Substance misuse	Drinking problem <sup>c</sup>	564 (20.81)	3,998 (21.30)	0.94 (0.84 – 1.05)	0.287	< 0.001	0.92 (0.78 – 1.09), 0.354	1.10 (0.90 – 1.33), 0.342	0.79 (0.63 – 0.99), 0.050
	Drug dependence <sup>d</sup>	125 (4.75)	467 (2.51)	1.79 (1.42 – 2.26)	< 0.001	< 0.001	1.36 (0.95 – 1.96), 0.092	2.26 (1.54 – 3.30), < 0.001	2.57 (1.60 – 4.12), < 0.001
Suicidal behaviour	Self-harm <sup>e</sup>	159 (5.72)	630 (3.32)	1.80 (1.46 – 2.22)	< 0.001	< 0.001	1.67 (1.11 – 2.52), 0.014	1.87 (1.27 – 2.76), 0.002	1.93 (1.42 – 2.63), < 0.001
	Suicide attempt <sup>f</sup>	234 (8.42)	949 (5.00)	1.66 (1.39 – 1.98)	< 0.001	< 0.001	1.54 (1.15 – 2.06), 0.004	1.60 (1.17 – 2.21), 0.004	1.95 (1.46 – 2.60), < 0.001

Note: All analysis used probability weights.

Results reported relative to the general population

<sup>b</sup> Includes data from only 2000 and 2007 (Total N= 14,919; 2000 & 2007 N remain the same)

<sup>c</sup> Total N= 21,476; 2000 N= 8,026; 2007 N=6,860; 2014 N= 6,590.

<sup>d</sup> Total N= 21,226; 2000 N= 8,034; 2007 N=6,849; 2014 N= 6,343.

<sup>e</sup> Total N= 21,777; 2000 N= 8,044; 2007 N=6,861; 2014 N= 6,872.

<sup>f</sup> Total N= 21,772; 2000 N=8,040; 2007 N= 6,865; 2014 N= 6,867.

## **Treatments and service use**

Compared to the general population, adults with BIF were more likely to receive antipsychotics, antidepressants, any psychotropic medication, and any type of treatment. When analysed separately by survey year, people with BIF were significantly more likely to receive antipsychotic medication compared to the general population, and increasingly so at each subsequent 7-year interval (see Table 3). Use of (any) antidepressants, psychotropic medication, or any type of treatment did not differ in 2000 and 2007, but in 2014 people with BIF had 1.47 (95% CI: 1.17 – 1.83,  $p=0.001$ ), 1.58 (95% CI: 1.28 – 1.9,  $p<0.001$ ), and 1.56 (95% CI: 1.28 – 1.90,  $p<0.001$ ) higher odds of receiving antidepressants, psychotropic medication and any type of treatment respectively compared to the general population. There was no evidence that people with BIF received less counselling or psychological interventions in 2000 and 2007. However, in 2014, people with BIF had 1.54 higher odds of receiving therapy (95% CI: 1.03 – 2.30,  $p=0.034$ ) than the general population.

Service use was significantly different between the two populations. Those with BIF received more daycare and community services in the year preceding interview. They also visited their GPs for mental complaints in the past year more than the general population. People with BIF had 3.31 higher odds of admissions to psychiatric wards than the general population (95% CI: 1.16 – 9.46,  $p=0.025$ ), but confidence interval range was large. There was no evidence that the groups differed in out-patient hospital care or contact with a psychiatrist or psychologist. People with BIF had two times more contact with community psychiatric nurses and community learning disability nurses (95% CI: 1.35 – 2.96,  $p=0.001$ ). Individuals with BIF were 1.38 times more likely to access any healthcare services compared to the general population (95% C: 1.21 – 1.56,  $p<0.001$ ).

There was moderate evidence for an interaction between intellectual functioning and survey year and use of services, apart from in-patient hospital admissions, out-patient hospital treatment and contact with psychiatrists, which did not significantly differ over the years (see Table 3). People with BIF received increasingly more community care and daycare services. They received more healthcare services and visits to their GP for mental complaints.

**Table 3** Comparison of differences in treatments and services use between people with borderline intellectual functioning and the general population across 3 survey years (after including interaction by survey year)

Healthcare	BIF N (%)	General Population N (%)	Univariate Analysis <sup>c</sup>		Global p-value	Separate analysis for each survey year OR (95% CI), p-value			
			OR (95% CI)	p-value		2000	2007	2014	
<b>Treatment</b>	Antipsychotics N= 21,7771	56 (2.02)	135 (0.71)	2.75 (1.90 – 3.96)	< 0.001	< 0.001	2.36 (1.17 – 4.73), 0.016	2.91 (1.46 – 5.80), 0.002	3.18 (1.90 – 5.32), < 0.001
	Antidepressants N= 21, 782	258 (9.28)	1396 (7.35)	1.19 (1.01 – 1.40)	0.037	< 0.001	1.07 (0.79 – 1.44), 0.658	1.05 (0.74 – 1.49), 0.781	1.47 (1.17 – 1.83), 0.001
	Any psychotropic N= 21, 774	346 (12.46)	1725 (9.08)	1.30 (1.13 – 1.51)	< 0.001	< 0.001	1.14 (0.88 – 1.49), 0.302	1.29 (0.96 – 1.71), 0.086	1.58 (1.28 – 1.95), < 0.001
	Any therapy N=21, 795	101 (3.63)	534 (2.81)	1.17 (0.90 – 1.52)	0.233	0.023	0.88 (0.54 – 1.42), 0.592	1.45 (0.94 – 2.22), 0.093	1.54 (1.03 – 2.30), 0.034
	Any treatment N= 21, 774	390 (14.04)	1997 (10.51)	1.26 (1.10 – 1.45)	0.001	< 0.001	1.09 (0.85 – 1.39), 0.504	1.29 (0.99 – 1.68), 0.060	1.56 (1.28 – 1.90), < 0.001
<b>Services</b>	Day-care services N= 21,793	142 (5.10)	644 (3.39)	1.41 (1.13 – 1.76)	0.002	< 0.001	1.68 (0.94 – 3.00), 0.08	1.28 (0.92 – 1.78), 0.149	1.41 (1.03 – 1.93), 0.033
	Community care N= 21, 793	290 (10.41)	1446 (7.61)	1.26 (1.07 – 1.48)	0.005	0.0001	1.09 (0.83 – 1.45), 0.524	1.28 (0.99 – 1.66), 0.064	1.60 (1.24 – 2.07), < 0.001
	GP N= 21, 790	473 (16.98)	2434 (12.81)	1.36 (1.20 – 1.55)	< 0.001	< 0.001	1.37 (1.12 – 1.67), 0.002	1.15 (0.92 – 1.44), 0.222	1.57 (1.27 – 1.94), < 0.001
	In-patient hospital admissions <sup>a</sup> N= 21,789	9 (0.32)	22 (0.12)	3.31 (1.16 – 9.46)	0.025	0.092	3.41 (0.58 – 20.19), 0.176	2.36 (0.52 – 10.68), 0.264	3.75 (0.78 – 18.12), 0.100
	Out-patient hospital care <sup>b</sup> N= 21, 786	28 (1.01)	144 (0.76)	1.29 (0.81 – 2.06)	0.291	0.105	0.91 (0.43 – 1.93), 0.800	2.69 (1.29 – 5.60), 0.008	0.71 (0.30 – 1.67), 0.428
	Psychiatrist N= 21,793	36 (1.29)	189 (0.99)	1.23 (0.81 – 1.87)	0.342	0.067	1.18 (0.59 – 2.37), 0.632	1.12 (0.49 – 2.56), 0.787	1.38 (0.72 – 2.65), 0.328
	Psychologist N= 21,793	20 (0.72)	119 (0.63)	1.03 (0.60 – 1.76)	0.928	0.006	1.00 (0.37 – 2.67), 0.995	1.84 (0.83 – 4.06), 0.133	0.59 (0.19 – 1.91), 0.360
	Community nurse (psychiatric or learning disabilities) N= 21,793	51 (1.83)	177 (0.93)	2.00 (1.35 – 2.96)	0.001	0.0006	1.59 (0.77 – 3.29), 0.211	2.76 (1.56 – 4.89), < 0.001	2.00 (1.04 – 3.85), 0.038
	Any healthcare services N= 21,793	<b>479 (17.21)</b>	<b>2474 (13.02)</b>	<b>1.38 (1.21 – 1.56)</b>	<b>&lt; 0.001</b>	<b>&lt; 0.001</b>	1.38 (1.13 – 1.68), 0.002	1.17 (0.94 – 1.47), 0.168	1.60 (1.29 – 1.98), < 0.001

Note: All analysis used probability weights

<sup>a</sup> In past year (12 months) as time of assessment unless otherwise stated.

<sup>b</sup> In last 3 months at time of assessment.

<sup>c</sup> Results reported relative to the general population

## **Discussion**

### **Summary of findings**

This study is the first to compare psychiatric disorders, treatment and service use in individuals with BIF across time, using standardized clinical assessments in a nationally representative sample. Our results suggest that the BIF population were significantly more likely to have a diagnosis of GAD, phobias, psychosis, depressive episodes, any neurotic disorders, self-harm and suicide attempts in 2014 from previous survey years. The odds of meeting criteria for agoraphobia or depressive episodes were approximately two times greater in people with BIF than in the general population across all three survey years. Rates of agoraphobia and OCD in people with BIF also increased between years 2000 and 2014. There were no significant differences between the two populations in meeting diagnostic threshold for panic disorder, MADD, or drinking problems. Drinking problems generally appear to be more prevalent in the general population. A higher percentage of the BIF population were assessed positive for drug dependence compared to the general population, with an increase from 2000 to 2007 and a small decrease in 2014. The prevalence rate of people with BIF and MADD decreased from 2000 to 2007. People from the BIF group were increasingly more likely to self-report previous suicide attempts, with little difference between years 2000 and 2007 and a sharp increase in 2014. The trend showing increases in prevalence of psychiatric disorders highlight the growing psychiatric morbidity in this population.

Although people with BIF have been receiving increasingly more therapy and any type of treatment at later time-points, they also appear to have received substantially more psychotropic medications such as antidepressants, antipsychotics and any psychotropic medication in 2014 compared to previous years. Overall, people with BIF appear to have accessed more community care, daycare services and contacted GPs about mental complaints over time, with significant increases between years 2007 and 2014. These changes may reflect the increase in prevalence of psychiatric disorders over time. There is no obvious change in in-patient admissions, out-patient hospital treatments and access to psychologists and psychiatrists for both groups over time.

### **Integration of findings with existing literature**

Our results are consistent with previous studies that show higher prevalence rates for mood and anxiety disorders, drug dependence, psychosis, and suicide-related behaviour. The trend towards an increasing prevalence of common psychiatric disorders in people with BIF may explain why more people from this population reported receiving any type of treatment and healthcare services at each subsequent time-point, reaching an all-time high in 2014. It is interesting to note that the prescribing patterns of psychotropic medications were higher in this group in 2000 and 2007, but not for psychological interventions, suggesting possible overuse of psychotropic medications and poorer access to psychological interventions. This finding is consistent with studies of people with intellectual disability that have demonstrated excessive use of psychotropic medications, particularly in individuals without mental illness (Sheehan et al., 2015). However, a more positive finding was that access to psychological treatments appeared to improve in 2014, suggesting that psychological services were likely better at making reasonable adjustments to enhance access to psychological therapy for this vulnerable group.

## **Strengths and limitations**

This study is the first study to map changes in the prevalence of psychiatric disorders and service use in people with borderline intellectual functioning across time, in relation to the general population, using a population-based, representative sample.

However, the study is limited by its cross-sectional design, restricting inferences of causality. Our study simply describes the prevalence of psychiatric disorders, treatments, and service use at three separate time-points, it does not directly reveal underlying changes that have occurred. We note that there are fluctuations in prevalence rates of psychiatric disorders across the survey years in both the BIF group and the general population. While we are unable to draw any conclusive explanations as to why this is, we can consider possible reasons for this: this may reflect a general trend in the prevalence rates of psychiatric morbidity across time due to increased awareness and acceptance of mental illness in society or changes in diagnostic criteria and improved assessment of specific psychiatric conditions. There may be socio-economic and political factors over time (e.g. austerity measures in the UK) that have led to an increase in the vulnerability of people with BIF to mental illness such as changes to social security and benefits, and reduced access to employment opportunities and adequate housing. Alternatively, there is a probability of chance that some of the significant results out of our 27 outcome measures may be due to chance, resulting in possible Type-1 errors.

Participants were drawn from private households, and as such exclude people living in residential care, hospital in-patient services, prisoners and the homeless. People with BIF and people with mental ill health tend to be overrepresented in these settings, which may introduce sampling bias to our results. Our results are only generalizable to the community population, but we argue that the best sampling frame to assess people with BIF who do not access statutory services is in community samples. Intelligence cut-offs were determined using the NART, which may have underestimated the true proportion of BIF within the population. Although the NART correlates well with more comprehensive neurocognitive tests, it is limited to native English speakers, and therefore individuals whose first language was not English were excluded. However, this was a nationally representative sample with large sample sizes to reduce sampling errors, which closely reflect the estimated 13.6% prevalence rate of the population having IQ scores between 70 and 85.

## **Implications for research and policy**

The lack of recognition of BIF as a separate diagnostic entity in current classification systems has hindered research and has created challenges in implementing policy changes that could benefit this group (Salcador-Carulla et al., 2013). However, our study provides further evidence of the importance of ensuring that the psychiatric needs of this group are addressed. BIF is a complex health meta-condition (Martínez-Leal et al., 2020; Contena & Taddei, 2017) and our findings highlight that the mental health needs in this group increased over time. The key question for practitioners and policy makers is how to ensure that these needs are met within service structures that do not recognize borderline intellectual functioning as a separate diagnostic entity. Our findings demonstrated some improvements in interventions and service access in 2014 but it is unclear whether improvements are due to overall improvement in frontline mental healthcare provision in England over the years or came as a response to the increasing mental ill-health problems of presenting patients including those with BIF. It should be noted that improvements in services and

treatments in 2014 was not uniform; there was substantial variation in treatment and service access in the 2014 data – with improvements in accessing treatments and primary/community care but no changes in specialist services (psychiatry, psychology, hospital care). It is noteworthy that services and treatments accessed by people with BIF in the present study would have been made available to them in the absence of knowledge that BIF is present, because services in the UK do not routinely measure IQ and BIF is not a formal diagnostic code entitled to specialist support in the UK. Nevertheless, our findings suggest that inequalities in service access are present. An important step for future research will be to investigate the differential pathways of help-seeking and service provision in this population.



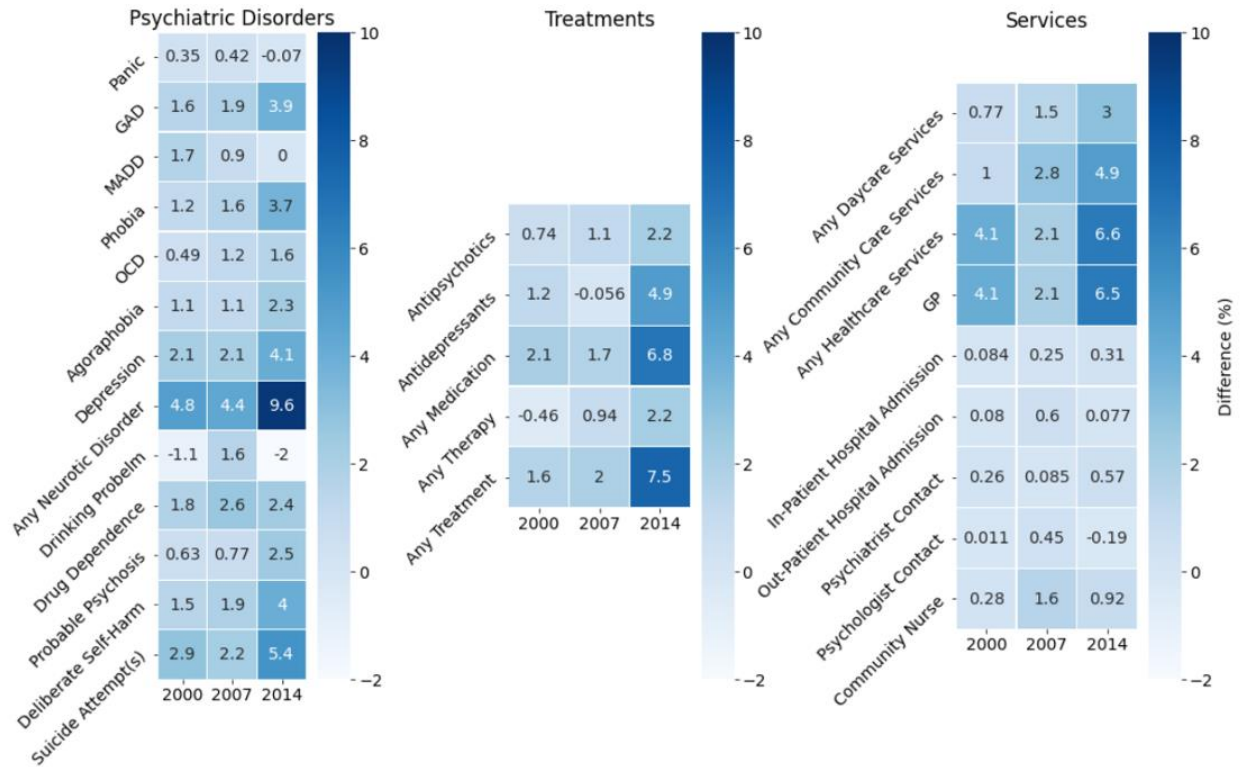
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**Figure 1** Heat map illustrating the absolute percentage difference in prevalence estimates between the two groups in relation to psychiatric disorders, treatments and services across three 7-year intervals



**Supplementary Table** Distribution of socio-demographic variables among adults with BIF and the general population, by survey year

		Borderline Intellectual Functioning	General Population	Unadjusted Comparison
Year 2000	n=8047 ( 12.6% BIF) <sup>a</sup>	N (%)	N (%)	
<b>Age</b> (20-year bands)	<b>Mean (S.D.)</b>	43.45 (17.57)	45.76 (15.29)	t = 4.39 , p< 0.001
	16 - 34	382 (37.7)	1928 (27.4)	χ <sup>2</sup> = 61.98, p< 0.001
	35 - 54	300 (29.6)	2883 (41.0)	
	55 - 74	330 (32.6)	2224 (31.6)	
	75+	-	-	
<b>Sex</b>	Male	449 (44.4)	3140 (44.6)	χ <sup>2</sup> = 0.03, p=0.873
	Female	563 (55.6)	3895 (55.4)	
<b>Ethnicity</b>	White	964 (95.3)	6777 (96.3)	χ <sup>2</sup> = 12.39, p= 0.015
	Asian	9 (0.9)	60 (0.9)	
	Black	29 (2.9)	104 (1.5)	
	Other/Mixed	10 (1.0)	82 (1.2)	
	<i>Missing</i>	-	12 (0.2)	
<b>Relationship Status</b>	Single	333 (32.9)	1804 (25.6)	χ <sup>2</sup> =31.62, p< 0.001
	In a relationship <sup>a</sup>	440 (43.5)	3673 (52.2)	
	Divorced/Separated/ Widowed	239 (23.6)	1558 (22.1)	
<b>Employment Status</b>	In Employment	514 (50.8)	4519 (64.2)	χ <sup>2</sup> = 74.61, p 0.001
	Unemployed	49 (4.8)	187 (2.7)	
	Economically Inactive	449 (44.4)	2320 (33.0)	
	<i>Missing</i>	-	9 (0.1)	
<b>Social Class</b>	Professional	2 (0.2)	397 (5.6)	χ <sup>2</sup> = 689.83, p< 0.001
	Managerial	71 (7.0)	2266 (32.2)	
	Skilled, non-manual	153 (15.1)	1805 (25.7)	
	Skilled, manual	286 (28.2)	1117 (15.9)	
	Semi-skilled	297 (29.4)	976 (13.8)	
	Unskilled	141 (13.9)	305 (4.3)	
	Armed forces	2 (0.2)	11 (0.2)	
<i>Missing</i>	60 (5.9)	158 (2.3)		
Year 2007	n=6872 (13.2% BIF) <sup>a</sup>	N (%)	N (%)	
<b>Age</b> (20-year bands)	<b>Mean (S.D.)</b>	50.70 (21.04)	51.72 (18.10)	t= 1.55, p=0.12
	16 - 34	248 (27.3)	1174 (19.7)	χ <sup>2</sup> = 44.56, p< 0.001
	35 - 54	241 (26.5)	2104 (35.3)	
	55 - 74	280 (30.8)	1925 (32.3)	
	75+	140 (15.4)	760 (12.7)	
<b>Sex</b>	Male	435 (47.9)	2514 (42.2)	χ <sup>2</sup> = 10.44, p= 0.001
	Female	474 (52.1)	3449 (57.8)	
<b>Ethnicity</b>	White	838 (92.2)	5738 (96.2)	χ <sup>2</sup> = 53.33, p< 0.001
	Asian	9 (1.0)	58 (1.0)	
	Black	45 (5.0)	89 (1.5)	
	Other/Mixed	15 (1.7)	69 (1.2)	
	<i>Missing</i>	2 (0.2)	9 (0.1)	
<b>Relationship status</b>	Single	248 (27.3)	1054 (17.7)	χ <sup>2</sup> = 77.53, p< 0.001
	In a relationship <sup>a</sup>	10.2 (43.1)	3452 (57.9)	
	Divorced/Separated/ Widowed	269 (29.6)	1457 (24.4)	
<b>Employment Status</b>	In Employment	349 (38.4)	3376 (56.6)	χ <sup>2</sup> = 112.33, p< 0.001
	Unemployed	36 (4.0)	108 (1.8)	
	Economically Inactive	524 (57.6)	2479 (41.6)	
<b>Social Class</b>	Professional	4 (0.5)	314 (5.4)	χ <sup>2</sup> = 598.80, p< 0.001

	Managerial	97 (12.0)	2072 (35.9)	
	Skilled, non-manual	126 (15.5)	1428 (24.7)	
	Skilled, manual	234 (28.9)	931 (16.1)	
	Semi-skilled	235 (29.0)	808 (14.0)	
	Unskilled	114 (14.1)	209 (3.6)	
	Armed forces	1 (0.1)	14 (0.2)	
	<i>Missing</i>	98 (10.8)	177 (3.1)	
<b>Year 2014</b>	<b>n=6877 (12.6% BIF) <sup>a</sup></b>	<b>N (%)</b>	<b>N (%)</b>	
<b>Age</b>	<b>Mean (S.D.)</b>	53.95 (20.65)	53.15 (18.43)	t= -1.18, p= 0.240
(20-year bands)	16 - 34	199 (23.0)	1156 (19.2)	
	35 - 54	232 (26.8)	1964 (32.7)	
	55 - 74	265 (30.6)	2040 (33.9)	$\chi^2= 30.69, p < 0.001$
	75+	169 (19.5)	852 (14.2)	
<b>Sex</b>	Male	395 (45.7)	2419 (40.2)	
	Female	470 (54.3)	3593 (59.8)	$\chi^2= 9.22, p= 0.002$
<b>Ethnicity</b>	White	797 (92.1)	5701 (94.8)	
	Asian	22 (2.5)	118 (2.0)	
	Black	30 (3.5)	109 (1.8)	
	Other	11 (1.3)	78 (1.3)	$\chi^2= 34.71, p < 0.001$
	<i>Missing</i>	6 (0.1)	5 (0.6)	
<b>Relationship status</b>	Single	231 (26.7)	1197 (19.9)	
	In a relationship <sup>a</sup>	358 (41.4)	3375 (56.1)	$\chi^2= 66.30, p < 0.001$
	Divorced/Separated/ Widowed	276 (31.9)	1440 (24.0)	
<b>Employment Status</b>	In Employment	289 (33.4)	3329 (55.4)	
	Unemployed	44 (5.1)	140 (2.3)	$\chi^2= 153.20, p < 0.001$
	Economically Inactive	532 (61.5)	2543 (42.3)	
<b>Social Class</b>	Professional	6 (0.8)	371 (6.4)	
	Managerial	99 (12.8)	2203 (38.1)	
	Skilled, non-manual	116 (14.9)	1300 (22.5)	
	Skilled, manual	199 (25.6)	728 (12.6)	
	Semi-skilled	237 (30.5)	954 (16.5)	$\chi^2= 602.39, p < 0.001$
	Unskilled	119 (15.3)	200 (3.5)	
	Armed forces	-	12 (0.2)	
	<i>Missing</i>	-	14 (0.2)	

Notes: <sup>a</sup>Total number of sample population and percentage of people with BIF in corresponding survey year.