

# How much does mental health discrimination cost: valuing experienced discrimination in relation to healthcare care costs and community participation

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**Aims.** This study builds on existing research on the prevalence and consequences of mental illness discrimination by investigating and quantifying the relationships between experienced discrimination and costs of healthcare and leisure activities/social participation among secondary mental health service users in England.

**Methods.** We use data from the Mental Illness-Related Investigations on Discrimination (MIRIAD) study ( $n = 202$ ) and a subsample of the Viewpoint study ( $n = 190$ ). We examine experiences of discrimination due to mental illness in the domains of personal relationships, community activities, and health care, and how such experienced discrimination relates to patterns of service use and engagement in leisure activities.

**Results.** Our findings show that the cost of health services used for individuals who reported previous experiences of discrimination in a healthcare setting was almost twice as high as for those who did not report any discrimination during the last 12 months (Relative Risk: 1.73; 95% Confidence Interval (CI): 1.39, 2.17) and this was maintained after controlling for symptoms and functioning. Experienced discrimination in healthcare (Relative Risk: 0.83; 95% CI: 0.81, 0.84) or in relationships (Relative Risk: 0.89; 95% CI: 0.87, 0.91), however, was associated with *lower* participation in, and hence lower costs of, leisure activities. Individuals who reported any discrimination in a healthcare setting had, on average, £434 higher costs associated with health service use while reported discrimination in the community was associated with increased leisure costs of £32.

**Conclusions.** These findings make an important initial step towards understanding the magnitude of the costs of mental health-related discrimination.

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**Key words:** Health economics, mental health services, mental illness, stigma.

## Introduction

Research on the prevalence and consequences of discrimination experienced by people with mental illness has been increasing in recent years. Studies include estimating the national and global occurrence of both anticipated and experienced discrimination (Thornicroft *et al.* 2009; Lasalvia *et al.* 2012; Corker *et al.* 2013) and qualitative studies portraying the occurrences of discrimination experienced by people with mental illness (Dinos *et al.* 2004; Rose *et al.* 2011; Jeffery *et al.* 2013). These discrimination experiences can have significant negative consequences for people with mental illness in terms of social exclusion from relationships with friends and family or intimate relationships (Webber *et al.* 2013), barriers to

participation in community activities and social life (Angermeyer *et al.* in press; Lasalvia *et al.* 2012), and also result in treatment avoidance (Clement *et al.* in press). To avoid the consequences of stigma and discrimination, individuals with mental illness may avoid health services and/or treatments in an effort to circumvent the label of mental illness and forego engaging in relationships or social activities as a way to prevent potential stigmatising experiences (Link *et al.* 1997; Schomerus & Angermeyer, 2008; Rusch *et al.* 2011). A recent systematic review highlighted the economic impact of mental health stigma and discrimination (Sharac *et al.* 2010), demonstrating adverse economic consequences in terms of employment and income; however, the review noted a paucity of studies which examined the economic impact of discrimination in relation to health service use and leisure activities/social participation.

This study aims to address this gap in the literature by investigating and quantifying the relationships between experienced discrimination and costs of

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health care and leisure activities/social participation. Specifically, we examine experiences of discrimination due to mental illness in the domains of personal relationships, community activities, and health care, and how such experienced discrimination relates to patterns of service use and engagement in leisure activities.

## Methods

### Data sources

For this study, we combined data from two cross-sectional studies of secondary mental health service users across England: the Mental Illness-Related Investigations on Discrimination (MIRIAD) study ( $n = 202$ ) (Farrelly *et al.* in press) and a subsample of the Viewpoint study ( $n = 190$ ) (Henderson *et al.* 2012; Corker *et al.* 2013). The MIRIAD study received ethical approval by the East of England/Essex 2 Research Ethics Committee (ref. 11/EE/0052). The Viewpoint study received ethical approval from Riverside NHS Ethics Committee (ref. 07/H0706/72).

### MIRIAD data

Participants in the MIRIAD study were recruited from 14 teams, twelve of which were generic and two of which were early intervention community mental health teams. All sites were based in one South London Trust. Data were collected between September 2011 and October 2012. To be eligible to participate in the study, individuals had to be at least 18 years of age and have the following: a clinical diagnosis of either depression, bipolar disorder or a schizophrenia spectrum disorder; self-defined Black, White or Mixed (Black and White) ethnicity; current registration with a community mental health team; sufficient fluency in English to provide informed consent; and to be sufficiently well for participation not to pose a risk to their or others' wellbeing. Individuals of Asian ethnicities were not recruited due to anticipated low prevalence numbers in the target area.

Clinicians were consulted as to whether the service user was sufficiently well to participate, and if so, a letter was posted to the service user inviting them to participate in the study. A total of 4233 service users were screened of whom 1345 (31.7%) were eligible. Of those, 207 provided informed consent (15.4%). Five service users were excluded after interview due to incorrect diagnoses ( $n = 4$ ) or incomplete data ( $n = 1$ ), resulting in a final sample size of 202 participants.

There were no differences between eligible consenting and eligible non-consenting service users in terms of diagnoses, age, gender and ethnicity, suggesting

that the sample was representative in terms of these measured characteristics. Study participants were interviewed face-to-face by a research assistant and clinical data were also extracted from electronic patient records. Interviews were spread over up to four sittings.

### Viewpoint data

In 2011, Viewpoint participants were invited to take part in an additional survey ( $n = 190$ ) on stigma and discrimination to provide additional information on service use and participation in community activities. Participants were from five NHS Mental Health Trusts across England and were recent recipients of specialist mental health care. To be eligible to participate in the Viewpoint survey, individuals had to be aged between 18 and 65, have a psychiatric diagnosis, excluding dementia, and be currently living in the community. As with the MIRIAD study, lists of potential participants were reviewed by clinicians prior to sending out invitations to check eligibility and minimise the risk of causing distress if people were unwell. Due to funding restrictions the sample for the CODA interview was limited to 200 participants. All participants were invited to participate until we reached the desired sample size. Consequently, recruitment was stopped once we received consent forms from 210 individuals. Of those 210, however, only 190 participants were contactable. Consent forms were returned directly to the research team. Data collection was carried out over the telephone by trained and supervised interviewers, the majority of whom had experience of mental illness themselves.

## Measures

### Clinical characteristics

The MIRIAD study extracted data from participants' medical records as to whether they had a Mental Health Act related admission in the previous 5 years. The Viewpoint survey asked participants whether they had ever been treated in the hospital as an involuntary patient. Clinical diagnoses are based on self-report and were categorised in the following groups: schizophrenia spectrum disorders, bipolar disorder, depression and/or anxiety, personality disorder and other disorders. Although the MIRIAD study also collected diagnostic information from clinical records, we use the self-report diagnosis here for comparability with the Viewpoint sample. We compared the clinical record diagnoses with self-reported diagnoses in the MIRIAD study, and agreement was found to be good (Kappa = 0.67). Information on symptoms were collected

via the Brief Psychiatric Rating Scale (BPRS) (Hafkenscheid, 1993) and functioning via the Global Assessment of Functioning (GAF) (Hall, 1995) were collected from MIRIAD participants, but not Viewpoint participants.

### *Discrimination and stigma scale (DISC)*

The DISC is an interviewer-delivered measure of discrimination experiences attributed to the person having a mental health problem. The DISC has a 4-point Likert scale (not at all, a little, moderately, a lot) to ascertain experiences of discrimination across 21 life domains. Psychometric analyses reveal that the DISC has good reliability, validity and acceptability (Brohan *et al.* 2013). Domains of discrimination were conceptually categorised into three areas which were relevant for this study: (1) relationships (comprising discrimination in the following areas: making or keeping friends; dating or intimate relationships; marriage or divorce; family; starting a family or having children; role as a parent to your children; being avoided or shunned); (2) community activities (comprising discrimination in the following areas: social life, religious practices, people in your neighbourhood) and (3) healthcare (comprising discrimination in the following areas: physical health problems, mental health staff). We examined experiences of discrimination over the last 12 months.

### *Cost of discrimination assessment (CODA)*

The CODA aims to collect information to enable the costs of stigma and discrimination to be investigated (Wright *et al.* submitted for publication). It consists of five areas: employment; discrimination in financial institutions or housing; receipt or avoidance of services due to stigma or discrimination; private healthcare purchased because of stigma or discrimination; and participation in, or avoidance of, leisure activities due to stigma or discrimination. It covers a retrospective period of 6 months, with some information also collected for the last 1 month. Service use and leisure and recreational activities are the subject of this paper, and for these the participant is asked how many contacts there have been and whether use has been increased or decreased due to discrimination. We investigated the following types of service use: GP, specialist doctor, dentist, psychiatric nurse, complementary therapist, patient advocate, social worker. For the MIRIAD sample, respondents were also asked about the following: psychiatric hospital or emergency department, care coordinator, counsellor and specialty mental health practitioner. We investigated the following types of leisure and recreational activities: team sports, cinema theatre art galleries/

museums, gym, restaurant, holiday and other. The CODA has been demonstrated to have good test-retest reliability. The cost of each service that was used in the last 6 months was calculated from the recognised national sources for the UK (Curtis, 2011). Exceptions were for dental appointments and contacts with advocates/solicitors (in the absence of other information a nominal cost of £50 per contact was assumed). Reduced help from family members was valued using average wage rates (£12.56 per hour) (Office for National Statistics, 2012) with an assumption, based on previous experience, that a contact with a family member or friend would last two hours. Values were placed on contact/engagement with the following activities based on indicative amounts taken from an internet search: team sports (£4.60 per contact), visits to cinema/theatre (£10.50), visits to art galleries/museums (£5), visits to the gym (£4.60) and visits to pubs/restaurants/cafes (£10.50).

### *Statistical analysis*

Socio-demographic characteristics (gender, age group: 18–35, 35–50 and 51–65, ethnicity: White, Black, Asian, Mixed and Other ethnicity; university education and employment status: employed, in training/education and not employed), clinical characteristics (self-reported psychiatric diagnosis: schizophrenia spectrum disorders, bipolar disorder, depression and/or anxiety, personality disorder and other disorder and receipt of involuntary treatment) and experienced discrimination (in the following domains: healthcare, community and relationships) were described for respondents in the MIRIAD and Viewpoint surveys. As is customary with economic data, a significant proportion of participants had no costs associated with healthcare or foregone leisure activities and thus, the data followed a skewed distribution. Therefore, to optimise the robustness of our estimates, a modified Park test, as proposed by Manning & Mullahy (2001) was used to select the most appropriate distribution, and the parameter estimates suggested that a Gaussian distribution demonstrated the best fit for service costs while a Poisson distribution demonstrated the best fit for leisure costs. Consequently, two generalised linear models were used to examine the univariate and multivariable factors associated with: (i) costs of health service use and (ii) costs associated with use of leisure activities. The risk ratios obtained from the generalised linear models were then combined with mean costs to project the cost differential of service use and foregone leisure activities for those who did compared with those who did not experience discrimination in one of the three domains of interest (i.e., health care, personal relationships, community participation). Costs are only

**Table 1.** Characteristics of study participants by survey

Participant characteristic	Viewpoint participants <i>n</i> = 190 <i>n</i> (%)	MIRIAD participants <i>n</i> = 202 <i>n</i> (%)
Sociodemographic characteristics		
Gender		
Male	73 (38.4)	92 (45.5)
Female	116 (61.1)	110 (54.5)
Transgender	1 (0.5)	0 (0)
Age		
18–35	43 (22.9)	60 (29.7)
36–50	78 (41.5)	92 (45.5)
51–65	67 (35.6)	50 (24.8)
Ethnicity		
White	172 (90.5)	108 (53.5)
Black	4 (2.1)	77 (38.1)
Asian	9 (4.7)	0 (0)
Mixed	2 (1.1)	17 (8.4)
Other	3 (1.6)	0 (0)
University education		
Yes	61 (32.1)	60 (29.7)
No	129 (67.9)	142 (70.3)
Employment status		
Employed	51 (26.8)	47 (22.8)
Training/education	8 (4.2)	25 (12.4)
Not employed	135 (71.1)	126 (62.3)
Missing	0 (0)	4 (2.5)
Clinical characteristics		
Clinical diagnosis		
Schizophrenia/schizoaffective disorder	31 (16.3)	77 (38.1)
Bipolar disorder	37 (19.7)	48 (23.8)
Depression and/or anxiety	75 (39.5)	41 (20.3)
Personality disorder	15 (7.9)	3 (1.5)
Other disorder	32 (16.8)	33 (16.3)
Received involuntary treatment <sup>a</sup>		
Yes	66 (34.7)	37 (18.8)
No	122 (64.9)	160 (81.2)
Experienced discrimination		
Experienced discrimination in healthcare		
Yes	99 (52.1)	127 (62.9)
No	87 (45.8)	75 (37.1)
N/A	4 (2.1)	0 (0)
Experienced discrimination in community		
Yes	88 (46.3)	94 (46.5)
No	90 (47.4)	107 (53.2)
N/A	12 (6.3)	1 (0.5)
Experienced discrimination in relationships		
Yes	149 (77.4)	167 (82.7)
No	41 (22.6)	35 (17.3)
N/A	0 (0)	0 (0)

<sup>a</sup>For the MIRIAD survey, the question refers to receiving involuntary treatment in the last 5 years, while the Viewpoint survey refers to lifetime service use.

presented for those variables which are significant in the multivariable models. We also looked at the cost differential by type of service use i.e., psychiatric

inpatient service, emergency service and/or Emergency Department, specialty mental health service (psychiatric nurse, care coordinator, psychiatrist,

psychologist, counsellor and specialist mental health services) and primary care and/or physical health care (dentist, specialty doctor, GP) to better understand how the magnitude of the difference varied by type of service. All costs reflect a period of 6 months as assessed by the CODA. All analyses were adjusted for dataset (MIRIAD *v.* Viewpoint). Additional sensitivity analysis investigated costs associated with individuals who ever reported experiencing 'a lot' of discrimination in any of the domains of interest. All analyses were carried out using SAS version 9.3 and Stata version 11.

## Results

### Participant characteristics

Table 1 describes participant characteristics by data source (i.e., MIRIAD study and Viewpoint study). Overall, participants had a mean age of 43 years. The majority of participants were female (58%) and were not employed (67%). Seventy-one per cent of the sample reported White ethnicity and 21% reported Black ethnicity, with the remaining participants reporting Asian, mixed or other ethnicity. Almost one-third of the sample had a university degree. In terms of clinical characteristics, the most prevalent diagnoses reported by participants were depression and/or anxiety (30%), schizophrenia spectrum (28%), bipolar disorder

(22%) and personality disorder (5%). About one-third of the Viewpoint sample (35%) had ever had involuntary treatment and one-fifth of the MIRIAD sample had experienced involuntary treatment in the last 5 years. Experienced discrimination was common; about half of participants reported experiencing discrimination in healthcare settings or in community activities, and more than three-quarters reported experiences of discrimination in relationships.

### Use and cost of services and leisure activities

The vast majority of participants had GP contacts during the last 6 months and the numbers were similar in each group (Table 2). More Viewpoint participants had contacts with other types of services (excluding those which were not recorded for this group). The most common activities undertaken were visits to pubs and restaurants, followed by visits to the cinema/theatre and galleries/museums. For the MIRIAD sample the services contributing most to total service costs were psychiatric inpatient care and GP contacts. For the Viewpoint sample the main contributors were contacts with other doctors and psychiatric nurses. The mean total cost of services that were measured for both samples was £607 for MIRIAD participants and £992 for Viewpoint participants. For both samples visits to pubs/restaurants were the largest contributor to

Table 2. Use and costs of services and leisure activities

Service/activity	MIRIAD ( <i>n</i> = 202)			Viewpoint ( <i>n</i> = 190)		
	<i>n</i> (%) users	Mean (s.d.) contacts	Mean (s.d.) cost (£s)	<i>n</i> (%) users	Mean (s.d.) contacts	Mean (s.d.) cost (£s)
GP	183 (91)	5.7 (6.0)	211 (239)	171 (90)	5.2 (5.1)	189 (204)
Other doctor	68 (34)	3.7 (7.5)	177 (658)	108 (57)	3.0 (4.3)	243 (503)
Dentist	106 (52)	1.8 (1.3)	48 (66)	129 (68)	1.5 (1.0)	50 (52)
Care coordinator	109 (54)	7.0 (6.0)	166 (222)	–	–	–
Psychiatric nurse	35 (17)	7.7 (12.0)	52 (221)	106 (56)	11.1 (13.1)	237 (428)
Counsellor	33 (16)	12.8 (18.1)	127 (517)	–	–	–
Complementary healthcare	17 (8)	5.8 (9.7)	25 (161)	34 (18)	11.1 (30.7)	99 (678)
Social worker	16 (8)	10.1 (18.1)	88 (613)	41 (22)	6.6 (6.5)	154 (436)
Psychiatric inpatient	19 (9)	19.1 (15.4)	611 (2426)	–	–	–
Emergency department	53 (26)	1.9 (1.4)	66 (141)	–	–	–
Specialist mental health worker	34 (17)	9.4 (14.9)	62 (270)	–	–	–
Advocate	25 (12)	2.6 (2.3)	8 (30)	19 (10)	3.4 (5.8)	8 (52)
Sports	25 (12)	23.8 (39.5)	14 (74)	21 (11)	16.6 (18.7)	9 (37)
Cinema/theatre	92 (46)	4.5 (6.5)	22 (52)	88 (46)	4.6 (5.4)	23 (46)
Art galleries, museums	67 (33)	5.4 (8.6)	9 (28)	66 (35)	3.3 (3.1)	6 (12)
Gym	34 (17)	32.9 (48.6)	26 (108)	39 (21)	30.2 (29.0)	29 (82)
Pub/restaurant	140 (69)	18.9 (28.9)	142 (271)	143 (75)	16.9 (34.7)	134 (325)

leisure costs. The leisure costs amounted to £213 for MIRIAD and £196 for Viewpoint.

#### *Relationship between costs of health service use and experiences of stigma and discrimination*

The first two columns of [Table 3](#) describe the relationship between cost of health services used and sociodemographic characteristics, clinical characteristics and experience of discrimination. The most influential factor on cost of health service use was experience of discrimination in a healthcare setting during the last 12 months. The cost of health services used for individuals who reported previous experiences of discrimination in a healthcare setting was almost twice as high as for those who did not report any discrimination during the last 12 months (Relative Risk: 1.73; 95% Confidence Interval (CI): 1.39, 2.17). Interestingly, although cost of service use was higher for individuals who reported discrimination in healthcare settings, individuals who reported discrimination in a healthcare setting were also more likely to report avoiding or being unwilling to visit their GP because of stigma and discrimination ( $\chi^2=27.5$ ,  $p<0.0001$ ). In the multivariate model, but not the univariate model, receipt of involuntary treatment was related to higher costs of health service use (Relative Risk: 1.35; 95% CI: 1.03, 1.76). We tested the interaction between involuntary treatment and reported discrimination in a healthcare setting and the interaction was significant ( $p<0.0001$ ). In terms of sociodemographic characteristics, our findings suggest that individuals of white ethnicity had lower costs associated with health service use compared with individuals of non-White ethnicity. We also collected information on symptoms and functioning from MIRIAD participants and were thus able to perform sensitivity analysis to investigate whether the relationship between cost of health services used and experiences of discrimination in a healthcare setting was maintained among MIRIAD participants when controlling for symptoms (as measured by BPRS total score) and functioning (as measured by GAF total disability score) in the multivariable model. Experience of discrimination in a healthcare setting during the last 12 months was still associated with greater health service costs when controlling for functioning (Relative Risk = 1.71,  $p=0.002$ ) and marginally associated with higher costs when controlling for symptoms (Relative Risk = 1.30,  $p=0.07$ ).

#### *Relationship between costs associated with use of leisure activities and experiences of stigma and discrimination*

The last two columns of [Table 3](#) describe the relationship between costs associated with participation in

leisure activities and sociodemographic characteristics, clinical characteristics and experience of discrimination. In terms of experienced discrimination, individuals who reported experiencing discrimination in the community in the last 12 months had higher costs associated with participation in leisure activities, whereas individuals who reported experiencing discrimination in personal relationships or in a healthcare setting had lower costs associated with participation in leisure activities. Sociodemographic characteristics associated with higher costs of participation in leisure activities include: male gender, younger age, being of non-White ethnicity and being employed. In terms of clinical and diagnostic characteristics, individuals who reported a diagnosis of bipolar disorder, depression and/or anxiety, or individuals categorised as having an 'other' diagnosis (relative to schizophrenia spectrum diagnosis) had higher costs, while individuals who reported a diagnosis of personality disorder had significantly lower costs compared with individuals reporting a diagnosis of a schizophrenia spectrum disorder. Individuals who had received involuntary treatment had significantly higher costs associated with leisure activities compared with those who had not received involuntary treatment.

#### *Difference in costs associated with health service use and participation in leisure activities among individuals with and without experience of discrimination*

[Table 4](#) presents the cost differential for use of health services and participation in leisure activities between those who did *v.* did not experience discrimination in the last 12 months based on the areas of discrimination which were statistically significant in the multivariate generalised linear model presented in [Table 3](#). Reported discrimination in a healthcare setting was associated with the greatest economic impact: individuals who reported any discrimination had, on average, £434 higher costs associated with health service use. When focusing specifically on individuals who reported a higher degree of discrimination in healthcare settings (endorsing the response 'a lot') these individuals had even greater service use costs (£576).

To better understand which type of service use was contributing most to greater healthcare costs, we also looked at differences by type of service used. Inpatient service use and emergency department use were collected from MIRIAD participants only and so among MIRIAD respondents, reported discrimination in a healthcare setting was associated with higher costs in psychiatric inpatient settings (£2009), emergency department settings (£65) and general primary

**Table 3.** Factors associated with higher costs of health service use and use of leisure activities/social participation due to stigma and discrimination generalised linear model<sup>a</sup>

Variable	Cost of health service use (unadjusted) GLM estimates	Cost of health service use (adjusted) GLM estimates	Cost of leisure activities/ social participation (unadjusted) GLM estimates	Cost of foregone leisure activities/social participation (adjusted) GLM estimates
Gender				
Female	1.08 (0.88, 1.83)	1.12 (0.90, 1.39)	***0.82 (0.81, 0.83)	***0.76 (0.75, 0.77)
Male	Ref.	Ref.	Ref.	Ref.
Age				
18–35	0.95 (0.73, 1.23)	1.05 (0.80, 1.38)	***1.65 (1.62, 1.68)	**1.90 (1.86, 1.93)
36–50	0.79 (0.63, 1.00)	0.83 (0.64, 1.05)	*0.97 (0.95, 0.98)	1.19 (1.16, 1.21)
51–65	Ref.	Ref.	Ref.	Ref.
Ethnicity				
White	0.83 (0.65, 1.07)	*0.77 (0.59, 0.99)	***0.50 (0.49, 0.51)	***0.51 (0.50, 0.52)
non-White	Ref.	Ref.	Ref.	Ref.
University education				
Yes	1.17 (0.94, 1.45)	1.03 (0.82, 1.29)	**1.11 (1.09, 1.13)	0.99 (0.97, 1.01)
No	Ref.	Ref.	Ref.	Ref.
Employment				
Employed	0.86 (0.67, 1.09)	0.81 (0.62, 1.04)	***2.02 (1.99, 2.5)	**1.83 (1.80, 1.86)
Not employed	Ref.	Ref.	Ref.	Ref.
Primary diagnosis				
Other disorder	*1.39 (1.01, 1.89)	1.31 (0.92, 1.86)	***1.39 (1.35, 1.43)	***1.38 (1.34, 1.42)
Bipolar disorder	1.16 (0.86, 1.55)	1.21 (0.87, 1.67)	***2.12 (2.08, 2.16)	***1.70 (1.65, 1.73)
Depression and/or anxiety	1.30 (0.99, 1.72)	1.34 (0.99, 1.82)	***1.63 (1.58, 1.67)	***1.48 (1.45, 1.52)
Personality disorder	1.40 (0.85, 2.32)	1.23 (0.73, 2.10)	1.03 (0.99, 1.07)	***0.71 (0.68, 0.74)
Schizophrenia/ schizoaffective disorder	Ref.	Ref.	Ref.	Ref.
Received involuntary treatment				
Yes	*0.74 (0.58, 0.93)	*1.35 (1.03, 1.76)	**1.07 (1.05, 1.09)	***1.33 (1.30, 1.35)
No	Ref.	Ref.	Ref.	Ref.
Experienced discrimination in healthcare				
Yes	***1.69 (1.38, 2.07)	***1.73 (1.39, 2.17)	***0.90 (0.89, 0.91)	***0.83 (0.81, 0.84)
No	Ref.	Ref.	Ref.	Ref.
Experienced discrimination in community				
Yes	*1.27 (1.03, 1.56)	1.16 (0.91, 1.48)	**0.94 (0.93, 0.96)	***1.15 (1.13, 1.17)
No	Ref.	Ref.	Ref.	Ref.
Experienced discrimination in relationships				
Yes	1.09 (0.84, 1.41)	0.80 (0.60, 1.08)	**0.97 (0.95, 0.99)	***0.89 (0.87, 0.91)
No	Ref.	Ref.	Ref.	Ref.

\* $p < 0.05$ , \*\* $p < 0.01$ , \*\*\* $p < 0.001$ .<sup>a</sup>The model also controlled for dataset (i.e., MIRIAD *v.* Viewpoint).

**Table 4.** Difference in expenditure over the last 6 months for those who did v. did not experience discrimination during the last 12 months (standard error in parentheses)

	Discrimination experienced in Healthcare		Discrimination experienced in Community		Discrimination experienced in Relationships	
	Any discrimination v. no discrimination	Moderate/a lot of discrimination v. no discrimination	Any discrimination v. no discrimination	Moderate/a lot of discrimination v. no discrimination	Any discrimination v. no discrimination	Moderate/a lot of discrimination v. no discrimination
Cost associated with health service use	£434 (44.3)	£576 (58.51)	Not significant	Not significant	Not significant	Not significant
Cost associated with psychiatric inpatient service use <sup>a</sup>	£2009 (376.76)	Not significant	Not significant	Not significant	Not significant	Not significant
Cost associated with emergency service use <sup>a</sup>	£65 (8.98)	Not significant	Not significant	Not significant	Not significant	Not significant
Specialty mental health care	Not significant	Not significant	Not significant	Not significant	Not significant	Not significant
Primary health care	308	Not significant	Not significant	Not significant	Not significant	Not significant
Cost associated with participation in leisure activities	-£37 (4.78)	-£39 (5.06)	£32 (3.65)	Not significant	-£23 (3.92)	-£17 (1.95)

<sup>a</sup>Estimates of expenditure for costs associated with emergency service use and psychiatric inpatient service use were based on MIRIAD participants only as these data were not available for Viewpoint participants. All other estimates include both samples of participants and service use variables which were collected from both groups of respondents.



care settings (£308). There were no significant differences for specialty mental health care use.

In terms of costs associated with participation in leisure activities, any reported discrimination in the community in the last 12 months was associated with increased leisure costs of £32. Reported discrimination in a healthcare setting or in relationships was, however, associated with lower leisure costs. Any reported discrimination in a healthcare setting was associated with reduced costs of £37 almost the same as those who reported a higher degree of discrimination ('a lot') (reduced costs of £39). In terms of relationships, individuals who reported discrimination in relationships had on average £23 less in leisure costs compared with those who reported no discrimination, while those who reported a higher degree ('a lot') of discrimination in relationships had on average £17 less in leisure costs compared with those who reported no discrimination.

## Discussion

Previous research has demonstrated the common occurrence of stigma and discrimination experienced by people with mental health problems (Thorncroft *et al.* 2009; Lasalvia *et al.* 2012; Corker *et al.* 2013); however, there is little research on the potential economic impact of stigma and discrimination. This study estimates the costs associated with health service use and participation in leisure activities and investigates how potential factors such as experience of discrimination are associated with costs.

Our findings suggest that experiences of stigma and discrimination in a health care setting are associated with more costly health service use, after controlling for severity of symptoms and functioning in addition to sociodemographic characteristics. Experiences of discrimination in healthcare or in relationships however, were associated with lower participation in, and hence lower costs of, leisure activities. Importantly, this study looks at actual use which allows us to estimate and attach a value to the experience of discrimination rather than simply asking individuals to characterise the impact of discrimination subjectively.

Two recent reviews have highlighted stigma as an important factor which may impede help-seeking and lead to avoidance of health services (Schomerus & Angermeyer, 2008; Clement *et al.* 2014). Public stigma and social rejection of people with mental illness, more generally have been shown to be a significant factor related to willingness to seek help and/or treatment from a healthcare professional (Corrigan, 2004; Mojtabai, 2010; Evans-Lacko *et al.* 2012). Our study also suggests that experienced stigma might

have a substantial financial impact in terms of use of healthcare resources, especially in terms of increased emergency services, psychiatric inpatient services and primary healthcare services. Some research has postulated pathways upon which stigma may lead to healthcare avoidance and subsequently, more costly service use. For example, one study found that among people with serious and chronic mental illness, higher self-stigma was associated with a lower likelihood of help-seeking and that this may have been an important factor which contributed to higher levels of subsequent hospitalisations (Rusch *et al.* 2009). Similarly a study of people living with chronic illnesses used path analysis to show that previous experiences of stigma from healthcare workers was associated with greater anticipated stigma from healthcare workers and that this led to less use of health services and a lower quality of life (Earnshaw & Quinn, 2012). Other research has demonstrated that even among individuals with serious mental illness, timely and appropriate use of health services can be important for averting costly inpatient service use or emergency care (Logan *et al.* 2008; Evans-Lacko *et al.* 2010). It may be that improving the experience and engagement with outpatient services could be important for avoiding acute episodes of illness which warrant inpatient or emergency service use. We also showed that individuals of non-White ethnicity had higher costs of health service use. Other research has emphasised the complex relationship which exists between race, health and discrimination (Clark *et al.* 1999) and more specifically, how this may lead to greater barriers to mental health care by ethnic minorities (Gary, 2005).

In terms of leisure activities, it is interesting that experienced discrimination in a healthcare setting or in personal relationships was associated with lower costs (and participation) in leisure activities; however, experience of discrimination in the community was associated with higher costs. This suggests that there seems to be some specificity in terms of the domain in which discrimination was experienced and that experiences of discrimination in the wider community do not necessarily impact avoidance of engaging in leisure activities. Moreover, in addition to the specificity of the relationship, it is possible that higher costs associated with participation in activities for those who experienced discrimination in the community may be related to higher exposure and greater engagement in social activities. Similar research which used the Viewpoint data to examine the relationship between experienced discrimination and social capital found that although experienced discrimination from friends and close family members was associated with lower social capital, the relationship did not hold for wider family or people in the community

(Webber *et al.* 2013). Notably, the specificity of domains was also present in terms of health service use, as experienced discrimination in a healthcare setting was related to higher costs; but, discrimination in personal relationships or in the community did not demonstrate a significant association with health service use.

### **Strengths and limitations**

This study addresses a gap in the literature in terms of developing our understanding of and methods of evaluating the economic impact of stigma and discrimination, especially in terms of health service use and foregone leisure activities and attaching a cost and/or value to the consequences of stigma and discrimination. We have analysed a dataset which includes information on a range of experiences and associated impacts of stigma and discrimination from a large group of secondary mental health service users. The relatively low response rate and number of Asian respondents, however, limits the generalisability of our findings. Although we had information about diagnosis and involuntary treatment, we did not have detailed information on illness severity which could be important for both service use and experience of discrimination. Both the MIRIAD and Viewpoint studies recruited individuals who were currently registered with a secondary mental health service contact and thus, we were not able to investigate identified relationships among service users who were not registered with a service. Finally, these data were cross-sectional, so it was not possible to examine the pathway or mechanism by which e.g., health service avoidance or foregone leisure activities represent a direct consequence of experienced discrimination. Additionally, it is possible that individuals who experience inpatient service use have greater exposure to discrimination. The findings from this study make a step towards understanding the magnitude of the costs of mental health related discrimination, specifically in relation to health service use and avoidance and participation in leisure activities. The study highlights the significant costs, especially in relation to health service use associated with experienced discrimination in health care settings and the impact of discrimination on foregone leisure activities and social participation. Importantly, interventions exist which are effective for reducing stigma among healthcare staff (Clement *et al.* 2012; Friedrich *et al.* 2013) and at the community level (Corrigan *et al.* 2012). Little data, however, is available on the economic impact of interventions to reduce stigma and discrimination (McCrone *et al.* 2010; Evans-Lacko *et al.* 2013), the economic consequences of doing nothing and the structural factors which impede the delivery and development of health systems and structures which are associated with stigma and

discrimination (Hatzenbuehler *et al.* 2013). Longitudinal studies are needed for examining pathways and mechanisms in the relationship between discrimination and costs in this important research field.

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### **Conflict of interest**

The authors declare that they have no conflict of interest. The funders did not contribute to the study design, data collection, data analysis, data interpretation or writing of the report. The views expressed in this publication are those of the authors and not necessarily those of the NHS, the National Institute for Health Research or the UK Government Department of Health.

### **Ethical standard**

The authors assert that all procedures contributing to this work comply with the ethical standards of

the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008.

## References

- Angermeyer MC, Matschinger H, Schomerus G. Attitudes of the German public to restrictions on persons with mental illness in 1993 and 2011. *Epidemiology and Psychiatric Sciences*. First published online: 4 April 2014, doi:10.1017/S2045796014000183
- Brohan E, Clement S, Rose D, Sartorius N, Slade M, Thornicroft G (2013). Development and psychometric evaluation of the Discrimination and Stigma Scale (DISC). *Psychiatry Research* 208, 33–40.
- Clark R, Anderson NB, Clark VR, Williams DR (1999). Racism as a stressor for African Americans. A biopsychosocial model. *American Psychologist* 54, 805–816.
- Clement S, van Nieuwenhuizen A, Kassam A, Flach C, Lazarus A, de Castro M, McCrone P, Norman I, Thornicroft G (2012). Filmed v. live social contact interventions to reduce stigma: randomised controlled trial. *British Journal of Psychiatry* 201, 57–64.
- Clement S, Schauman O, Graham T, Maggioni F, Evans-Lacko S, Bezborodovs N, Morgan C, Rusch N, Brown JS, Thornicroft G. What is the impact of mental health-related stigma on help-seeking? A systematic review of quantitative and qualitative studies. *Psychological Medicine*. First published online: 26 February 2014, doi: 10.1017/S0033291714000129.
- Corker E, Hamilton S, Henderson C, Weeks C, Pinfold V, Rose D, Williams P, Flach C, Gill V, Lewis-Holmes E, Thornicroft G (2013). Experiences of discrimination among people using mental health services in England 2008–2011. *British Journal of Psychiatry* 55, s58–s63.
- Corrigan P (2004). How stigma interferes with mental health care. *American Psychologist* 59, 614–625.
- Corrigan PW, Morris SB, Michaels PJ, Rafacz JD, Rusch N (2012). Challenging the public stigma of mental illness: a meta-analysis of outcome studies. *Psychiatric Services* 63, 963–973.
- Curtis L (2011). *Unit Costs of Health and Social Care*. Personal Social Services Research Unit, University of Kent: Canterbury.
- Dinos S, Stevens S, Serfaty M, Weich S, King M (2004). Stigma: the feelings and experiences of 46 people with mental illness. Qualitative study. *British Journal Psychiatry* 184, 176–181.
- Earnshaw VA, Quinn DM (2012). The impact of stigma in healthcare on people living with chronic illnesses. *Journal of Health Psychology* 17, 157–168.
- Evans-Lacko SE, Spencer CS, Logan JE, Riley AW (2010). Patterns and predictors of restrictive health care service use by youths with bipolar disorder. *Administration and Policy in Mental Health and Mental Health Services Research* 37, 379–387.
- Evans-Lacko S, Brohan E, Mojtabai R, Thornicroft G (2012). Association between public views of mental illness and self-stigma among individuals with mental illness in 14 European countries. *Psychological Medicine* 42, 1741–1752.
- Evans-Lacko S, Henderson C, Thornicroft G, McCrone P (2013). Economic evaluation of the anti-stigma social marketing campaign in England 2009–2011. *British Journal of Psychiatry* 55, s95–101.
- Farrelly S, Clement S, Gabbidon J, Jeffery D, Dockery L, Lassman F, Brohan E, Henderson C, Williams P, Howard LM, Thornicroft G (in press). Anticipated and experienced discrimination amongst people with schizophrenia, bipolar disorder and major depressive disorder: a cross-sectional study. *BMC Psychiatry*.
- Friedrich B, Evans-Lacko S, London J, Rhydderch D, Henderson C, Thornicroft G (2013). Anti-stigma training for medical students: the Education Not Discrimination project. *British Journal of Psychiatry* 55, s89–s94.
- Gary FA (2005). Stigma: barrier to mental health care among ethnic minorities. *Issues in Mental Health Nursing* 26, 979–999.
- Hafkenscheid A (1993). Reliability of a standardized and expanded Brief Psychiatric Rating Scale: a replication study. *Acta Psychiatrica Scandinavica* 88, 305–310.
- Hall RC (1995). Global assessment of functioning. A modified scale. *Psychosomatics* 36, 267–275.
- Hatzenbuehler ML, Phelan JC, Link BG (2013). Stigma as a fundamental cause of population health inequalities. *American Journal of Public Health* 103, 813–821.
- Henderson C, Corker E, Lewis-Holmes E, Hamilton S, Flach C, Rose D, Williams P, Pinfold V, Thornicroft G (2012). England's time to change antistigma campaign: one-year outcomes of service user-rated experiences of discrimination. *Psychiatric Services* 63, 451–457.
- Jeffery D, Clement S, Corker E, Howard LM, Murray J, Thornicroft G (2013). Discrimination in relation to parenthood reported by community psychiatric service users in the UK: a framework analysis. *BMC Psychiatry* 13, 120.
- Lasalvia A, Zoppei S, Van Bortel T, Bonetto C, Cristofalo D, Wahlbeck K, Bacle SV, van Audenhove C, van Weeghel J, Reneses B, Germanavicius A, Economou M, Lanfredi M, Ando S, Sartorius N, Lopez-Ibor JJ, Thornicroft G (2012). Global pattern of experienced and anticipated discrimination reported by people with major depressive disorder: a cross-sectional survey. *Lancet* 381, 55–62.
- Link BG, Struening EL, Rahav M, Phelan JC, Nuttbrock L (1997). On stigma and its consequences: evidence from a longitudinal study of men with dual diagnoses of mental illness and substance abuse. *Journal of Health and Social Behavior* 38, 177–190.
- Logan JE, Riley AW, Barker LE (2008). Parental mental and pain-related health and pediatric ambulatory care sensitive emergency department visits and hospitalizations. *Health Services Research* 43, 656–674.
- Manning WG, Mullahy J (2001). Estimating log models: to transform or not to transform? *Journal of Health Economics* 20, 461–494.
- McCrone P, Knapp M, Henri M, McDaid D (2010). The economic impact of initiatives to reduce stigma:

- demonstration of a modelling approach. *Epidemiology and Psychiatric Sciences* **19**, 131–139.
- Mojtabai R** (2010). Mental illness stigma and willingness to seek mental health care in the European Union. *Social Psychiatry and Psychiatric Epidemiology* **45**, 705–712.
- Office for National Statistics** (2012). *Annual Survey of Hours and Earnings*.
- Rose D, Willis R, Brohan E, Sartorius N, Villares C, Wahlbeck K, Thornicroft G** (2011). Reported stigma and discrimination by people with a diagnosis of schizophrenia. *Epidemiology and Psychiatric Sciences* **20**, 193–204.
- Rusch N, Corrigan PW, Wassel A, Michaels P, Larson JE, Olschewski M, Wilkniss S, Batia K** (2009). Self-stigma, group identification, perceived legitimacy of discrimination and mental health service use. *British Journal of Psychiatry* **195**, 551–552.
- Rusch N, Evans-Lacko S, Clement S, Thornicroft G** (2011). Stigma, discrimination, social exclusion, and mental health. In *Routledge Handbook in Global Public Health* (ed. R. Parker and M. Sommer), pp. 394–401. Routledge: New York.
- Schomerus G, Angermeyer MC** (2008). Stigma and its impact on help-seeking for mental disorders: what do we know? *Epidemiology and Psychiatric Sciences* **17**, 31–37.
- Sharac J, McCrone P, Clement S, Thornicroft G** (2010). The economic impact of mental health stigma and discrimination: a systematic review. *Epidemiology and Psychiatric Sciences* **19**, 223–232.
- Thornicroft G, Brohan E, Rose D, Sartorius N, Leese M** (2009). Global pattern of experienced and anticipated discrimination against people with schizophrenia: a cross-sectional survey. *Lancet* **373**, 408–415.
- Webber M, Corker E, Hamilton S, Weeks C, Pinfold V, Rose D, Thornicroft G, Henderson C** (2013). Discrimination against people with severe mental illness and their access to social capital: findings from the Viewpoint survey. *Epidemiology and Psychiatric Sciences* **23**, 155–165.
- Wright S, Henderson C, Thornicroft G, Sharac J, McCrone P** (submitted for publication). Measuring the economic costs of discrimination experienced by people with mental health problems: Development of the Costs of Discrimination Assessment (CODA).