Health Promotion International, Vol. 29 No. 3
doi:10.1093/heapro/das076
Advance Access published 24 January, 2013

Nature and impact of European anti-stigma depression programmes

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SUMMARY

Stigma associated with depression is a major public health issue in the EU, with over 20 million people experiencing depression and its associated personal distress each year. While most programmes against stigma related to mental health problems are of a general nature, the knowledge about programmes tackling stigma against people with depression is limited. This study therefore aims to assess the nature and impact of depression-specific programmes in EU countries. Using a web-based tool, 26 programmes were identified across the 18 EU countries taking part in the study. Most were universal and targeted the whole population, while many also targeted specific population groups or settings, such as young people or health professionals. The most common programme aim was improving literacy, although reducing stigmatizing attitudes and discriminatory behaviour and promoting help-seeking were also common. Most programmes originated from professional bodies, or as grassroots initiatives from service user groups/NGOs, rather than as part of national and local policy. The approaches used were primarily different forms of education/information, with some, but very limited, use of positive personal contact. Overall, the quality and extent of impact of the programmes was limited, with few leading to peer-reviewed publications. Specific programmes were identified with evidence of positive impact, and we drew on these examples to develop a framework to be used for future programmes against stigma and discrimination associated with depression. These findings are provided in full in the Anti-Stigma Partnership European Network Toolkit available at www.antistigma.eu.

Key words: stigma; European; programmes; depression

INTRODUCTION

Stigma associated with mental health problems is a major public health issue resulting in social isolation (Link *et al.*, 1989), low self-esteem (Wright *et al.*, 2000), limited life chances in areas, such as employment and housing (Rosenfield, 1997), and delayed help-seeking

behaviour (Aromaa *et al.*, 2011). Stigma is a major barrier in preventing those with mental health difficulties from accomplishing their life goals (Corrigan *et al.*, 2002) and one of the main barriers to improving care for those with mental health problems (Zalar *et al.*, 2007). However, there is evidence that different mental health problems attract different patterns of stigma and discrimination with different consequences for those affected (Crisp *et al.*, 2000).

Internationally, a wide range of initiatives have been developed to address mental health stigma and the evidence base for effectiveness is increasing, with three themes of 'education, contact and protest' characterizing successful anti-stigma actions (Corrigan *et al.*, 2007). The potential and effectiveness of educational campaigns in combating and reducing stigma has been documented (Watson *et al.*, 2004; Evans-Lacko *et al.*, 2010). Public education can be effective when messages are carefully targeted to key groups and use social models of mental health (Byrne, 2000; Warner, 2008). Contact has been shown to have the most consistent results in reducing stigma and improving perceptions and recollections about individuals with mental illness (Corrigan *et al.*, 2002). Education and contact together have been shown to lead to reduced stigma (Corrigan *et al.*, 2002). Protesting against stigma can include campaigns and media lobbying, although its effectiveness is difficult to assess and can lead to negative reactions and has been found to have no effect on attitudes (Penn and Corrigan, 2002).

Although the stigma of depression is in some respects less severe than for other mental health problems such as schizophrenia, the high prevalence of depression makes addressing depression stigma an important public health measure. Despite this, there is much less evidence in relation to initiatives specifically designed to tackle stigma associated with depression, including stigma associated with suicide. However, emerging evidence from international studies suggests certain factors can be effective. Parslow and Jorm (Parslow and Jorm, 2002) found contact to be the most effective strategy (of the three main strategies outlined earlier) to tackle stigma against people with depression. This impact is maximized when audience and participants have equal status; when programmes offer 'real-world' rather than contrived interaction opportunities; when contact is sponsored by a well-regarded organization and when the person speaking is seen as typical of a person with depression. This is supported by Scheffer (Scheffer, 2003) who argues that contact with people who fill 'normal' social roles influences attitudes positively. There is also evidence that attitudes towards mental disorders can be improved through educational interventions designed to improve mental health literacy (Thornicroft *et al.*, 2007; Dumesnil and Verger, 2009), and that these can have positive effects on different aspects of stigma, such as the desire for social distance (Jorm and Oh, 2009) and beliefs about dangerousness (Jorm *et al.*, 2012). They may be particularly effective in addressing stigma associated with depression (Silton *et al.*, 2011). Giving consideration to the target audience would seem a key factor when designing depression literacy programmes. In particular, there seems a need for culture-specific educational materials relating to depression, particularly relating to larger minority populations within a country (Knifton *et al.*, 2010). Media and online interventions are offered as two examples of useful methods to increase depression literacy (Finkelstein and Lapshin, 2007). Media interventions can include public service announcements, which have been shown to be a useful means of educating young people about depression (Klimes-Dougan *et al.*, 2009) and the internet can empower those with depression by providing them useful information about their diagnosis about coping with depression in a user-friendly way (Stjernswärd and Ostman, 2006) and can also be useful in providing information about depression because information can be accessed privately and without involving others who may hold stigmatizing attitudes (Berger *et al.*, 2005). As with strategies to influence mental health generally, depression campaigns can benefit from being of a multi-strategy design, such as the European Alliance Against Depression (Hegerl and Wittenburg, 2009). Rix *et al.* (Rix *et al.*, 1999) suggest that a mixed-methods approach using a combination of dissemination routes may be the most effective way to achieve maximum impact. This study therefore aims to develop the knowledge in this area by identifying programmes across 18 major countries and analysing their nature and impact. Promising ingredients for developing depression anti-stigma programmes will be explored. The study was conducted by the Anti Stigma

Programme European Network (ASPEN), which aims to reduce stigma and discrimination of people with depression in the EU member states. ASPEN is a consortium of 20 EU partner sites in 18 European countries and a multitude of stakeholders from across Europe including universities, governmental agencies, public health bodies, human rights groups, NGOs, charities and mental health service user groups. The project ran over 3 years (2009–11) and received funding from the European Commission. The findings of this project as a whole are reported in the ASPEN Toolkit which is available at www.antistigma.eu.

METHOD

An online survey tool for completion by ASPEN researchers in each country was designed in consultation with the ASPEN lead partners. Initial categories were identified based upon a limited number of known anti-stigma initiatives by a multidisciplinary expert reference group from a range of countries, academic backgrounds and disciplines. Multiple choice questions were used to make the data manageable and provide prompts. Open questions were also used, where it was not possible to anticipate expected responses. The questionnaire allowed researchers to attach or provide links to evaluation documents. The tool was piloted amongst the ASPEN lead partners, who identified 10 initiatives, which were analysed thematically to identify the major constructs and themes. A significant issue that emerged at this point was that many of the initiatives sometimes had a broader focus than either stigma or depression. The tool was distributed to ASPEN researchers in each of the 18 ASPEN countries due to issues of language and knowledge of national and local context. The researchers were provided with instructions on how to collect information from a range of key informants in organizations such as relevant government departments NGOs, academic and research institutions, service users and civil society organizations. Researchers were requested to search a range of sources, including the web, relevant databases, gray literature or publications on anti-stigma programmes on depression. The researchers were given search terms so that we could be confident that a comprehensive search could be undertaken in each country and ensure the study would contain a balanced range of programmes from across the EU. For depression, the following terms were included: Depress* or Dysthymi* or 'Adjustment Disorder*' or 'Mood Disorder*' or 'Affective Disorder' or 'Affective Symptoms'. For stigma: Stigma, attitudes, Prejudice, Stereotype*, Discrimina*. For locating anti-interventions: intervention, 'health education', 'mass media', communication*, 'multimedia', multimedia*, 'mass communication', 'audiovisual equipment', 'patient information', 'visual information', radio, 'television', leaflet*, posters*, pamphlet*, 'print media', 'printed media', skit*, 'folk media', broadcast*, film*, telecommunication*. Researchers were asked to collect information on all major anti-stigma programmes addressing stigma associated with depression in their country at national and regional levels.

The survey responses were analysed in relation to the broad categories identified before the survey was undertaken. Information supplied for each category within each project was analysed to identify emerging themes in all categories which were not multiple choice. Descriptors were developed for each of the themes and the frequency of each of the themes was counted. A further analysis was undertaken with evaluations associated with the intervention.

RESULTS

Across the 18 countries, 26 depression-specific programmes were identified in all. Most programmes (58%) were generic, targeting the whole population. However, in addition, many also targeted specific groups, the most common being: health professionals (39%); young people (39%) and service users (35%). Details of all the programmes are represented in Table 1.

Some programmes also target specific population subgroups, for example the 'Campaign for the prevention of female depression' in Italy, or the 'Frozen Hearth' project in Slovenia, focusing on the needs of women with post-partum anxiety and depression.

The most common aim was improving literacy (92%), followed by reducing stigmatizing attitudes and discriminatory behaviour (62%), promoting help-seeking (58%), empowerment of people with mental health problems (23%) and suicide prevention (16%). For example the 'Adult depression: to know more about it to recover' programme in France aimed to improve

Table 1: Depression specific anti-stigma programmes

Title of programme	Country	Time frame	Aims	Target groups	Methods
Being mentally fit, feeling well; 10 steps for positive mental health	Belgium	2006	Improving literacy and information giving; promoting help seeking	General population; young people	Written materials; media information; web information; web testimonies
Youth: mentally healthy? Information day youth, depression and suicide	Belgium	19 January 2006	Reducing stigma; improving literacy and information giving; suicide prevention	Young people	Direct workshops; training
Training 'Employment of people with psychiatric disorders: Challenges and Opportunities'	Bulgaria	May to July 2007	Improving literacy and information giving	Workplace managers	Written materials; workshops and guidance for professionals
Training 'Emotional and mental problems in the common medicine-practical skills'	Bulgaria	March to April 2006	Improving literacy and information giving; improving services	GPs	Written materials; workshops and guidance for professionals
Defeat Depression	England	1992–97	Reducing stigma; improving literacy and information giving; promoting help seeking	General population; health professionals; GPs; people with depression	Written materials; workshops and guidance for health professionals
The Masto project	Finland	2008–11	Improving literacy and information giving; promoting help seeking	Workplace managers; occupational health and safety staff	Workshops and guidance for professionals; written information; media information; web information
Adult depression: to know more about it to recover	France	2007 to present	Improving literacy and information giving; promoting help seeking	General population	Written information; advertising; web information
We open the dialogue for depression	Greece	2008–12	Reducing stigma; improving literacy and information giving; promoting help seeking; empowerment of people with mental health problems; promoting human rights	General population; young people; health professionals; mental health professionals; journalists; people who are vulnerable to depression (e.g. people who display disorders with high comorbidity with depression, older people, people from lower educational and socio-cultural background)	Written materials; advertising; telephone information and support; workshops and guidance for professionals; workshops for public; workshop for schools; workshop for universities; arts events
Hungarian Alliance Against Depression (Hungarian part of the European Alliance Against Depression programme)	Hungary	2004–08	Promoting help seeking	General population; young people; health professionals; teachers	Written information; DVD; workshops and guidance for professionals

Opened Doors	Hungary	2006 to present	Reducing stigma; improving literacy and information giving	General population; young people; medical students; service users; family carers	Written materials; advertising; media information; workshops for young people; workshops for universities; workshops for public; arts events; direct workshops and training
Anti-stigma programme of Foundation for Balance	Hungary	2006 to present	Reducing stigma; improving literacy and information giving; improving services	Health professionals; GPs; midwives; social workers; police; NGO volunteers	Written information; media information; workshops and guidance for professionals
An idea for the school	Italy	School year 2007	Improving literacy and information giving; promoting help seeking	Teachers; young people	Workshops and guidance for professionals; workshops for young people
Development of an intervention to promote mental health in schools, with particular attention to primary prevention of depression	Italy	2006	Improving literacy and information giving; promoting help seeking	Young people	Workshops and guidance for professionals; workshops for young people
The ship against depression	Italy	23 July 2008 and 23 September 2008	Reducing stigma; empowerment of people with mental health problems	Service users	Capacity building
EAAD (European Alliance Against Depression) Prevention Project Trentino Alto Adige region	Italy	2004–08	Reducing stigma; improving literacy and information giving; empowerment of people with mental health problems; suicide prevention	General population; health professionals; community facilitators; service users	Written information; media information; web information; telephone information and support; workshops and guidance for professionals; workshops with public; arts events
Fourth European Day on Depression	Italy	19 October 2009	Reducing stigma; improving literacy and information giving	General population	Written information; media information; workshops for the public
Campaign for the prevention of female depression	Italy	March to October 2008	Reducing stigma; improving literacy and information giving	Young people	Written materials; arts events
Association for the research on Depression	Italy	1996 to date	Reducing stigma; improving literacy and information giving; promoting help seeking	General population; family carers	Written materials; media information; web information; workshops for the public
Let's not call it the obscure disease anymore	Italy	2006	Reducing stigma; improving literacy and information giving; promoting help seeking	Inequality groups: women	Written materials; workshops for the public
Informative Campaign 2005 about depression	Italy	2005	Reducing stigma; improving literacy and information giving; suicide prevention	General Population; young people; health professionals; service users	Survey; written materials; media information; web information; workshops and guidance for health professionals

Continued

Table 1: *Continued*

Title of programme	Country	Time frame	Aims	Target groups	Methods
European Alliance Against Depression (EAAD)	Austria, Belgium, Estonia, Finland, France, Germany, Hungary, Iceland, Ireland, Italy, Luxembourg, The Netherlands, Portugal, Slovenia, Spain UK	2004–08	Reducing stigma; improving literacy and information giving	General population; young people; health professionals; GPs; priests; counsellors; police; high-risk groups and self-help	Written information; media information; advertising; web information; workshops and guidance for professionals; workshops for public
Look OK . . . Feel Crap?	Scotland	2007 to present	Improving literacy and information giving; promoting help seeking; empowerment of people with mental health problems	Vulnerable groups, i.e. students, young men, minority groups such as lesbian, gay, bisexual and transgender people, people with disabilities	Written materials; advertising; web information; web testimonies; individual support
Breathing Space	Scotland	2002 to present	Reducing stigma; improving literacy and information giving; promoting help seeking	General population; targeted are those at risk of death by suicide, i.e. men aged between 16 and 40 years old.	Written materials; advertising; web information; telephone support; workshops with the public; research
Frozen hearth	Slovenia	2008–09	Improving literacy and information giving; promoting Help Seeking	General population; health professionals; women; family members	Written materials; workshop and guidance for professionals
De-stigmatizing Depression and Anxiety disorders and raising public awareness on mental illness.	Slovenia	2004	Reducing stigma; improving literacy and information giving; promoting help seeking; empowerment of people with mental health problems	General population	Written materials; web information; workshops for public; capacity building; individual support
Strengthening mental health and mitigating the problem of suicide in the Celje region	Slovenia	2000 ongoing	Reducing stigma; improving literacy and information giving; promoting help seeking; empowerment of people with mental health problems; suicide prevention; improving services	General population; health professionals; teachers; social workers; journalist; NGOs; workplace managers; people with depression	Written materials; advertising; workshops and guidance for professionals; workshops for public; individual support

literacy through distributing information material on depression and the use of advertising on TV, internet and radio. 'The Breathing Space' programme in Scotland aimed to reduce stigma indirectly through promoting help-seeking by the use of a free, confidential and anonymous phone line and web-based service.

In terms of the origins of the programmes, many stem from professional bodies (46%) or as part of national and local policy (38%), with 19% starting as grassroots initiatives from service user groups/NGOs (19%).

Education/information approaches were the most common form of tackling stigma associated with depression, particularly written/DVD materials, followed by the delivery of workshops, media and web information. A few used positive personal contact and user empowerment through, for example, directly delivered workshops and online testimony, but this was rare.

Service user involvement was found in 46% of programmes, in the planning, delivery or evaluation phases. For example, in the 'Youth: mentally healthy? Information day youth, depression and suicide' programme in Belgium, this took the form of service user testimonies. Involvement also took the form of building capacity through developing online forums, live networks and training to empower individuals and groups, for example in the 'Strengthening mental health and mitigating the problem of suicide' programme in Slovenia, which involves the use of self-help groups and e-counselling.

Overall, the quality and extent of evidence underpinning the anti-stigma programmes was limited; 46% of programmes had no type of evaluation, 46% had report-level evaluations, and only two of the programmes had peer review evaluations. The results of the peer-reviewed evaluations are shown in Table 2.

DISCUSSION

Our findings contrast with non-EU countries, in particular the USA and Australia, where there is much more evidence on programmes to tackle stigma against people with depression, often within the context of depression literacy campaigns (Dumesnil and Verger, 2009). This difference may well be due to the low visibility of depression stigma in policy terms in many EU countries compared with countries such as the USA, where there are many anti-stigma depression programmes, possibly also due to availability of funding from pharmaceutical companies. We also found depression-specific programmes were focused on improving mental health literacy and individual help-seeking, which may be because of the growing interest in mental health literacy-based work within the literature in relation to depression (Goldney and Fisher, 2008) and its success at targeting different aspects of stigma such as the desire for social distance (Jorm and Oh, 2009). This suggests a need for a rigorous evaluation of how literacy interventions can reduce different forms of stigmatizing beliefs (Jorm *et al.*, 2012).

We found that there is a range of stakeholders in anti-stigma work and that programmes driven by the enthusiasm of professionals can sit alongside programmes initiated by local and national policy, especially clustered in the few more active countries where there is a stronger policy commitment to tackling stigma. Where there is a policy gap, then professional groups have emerged to fill this void. However, there were relatively few programmes initiated by grassroots groups, possibly due to lack of an identifiable service user movement for people with depression or the impact of depression on individuals' energy and hope for change.

The study found that the majority of programmes are universal and target the whole population. There are strong arguments for universal programmes as they can reach relatively large populations and informal opinion leaders. However, in focusing on the population as a whole they may not affect social inequality (Wilkinson, 2005).

There is also emerging evidence that targeted interventions may be effective (Byrne, 2001), for example in schools or in the workplace (Pinfold *et al.*, 2003; Little *et al.*, 2011). A particular advantage of this approach is that targeted messages can be linked with anti-discrimination activity, for example, recruitment policy within workplaces. Yet they have not often been specifically targeted at vulnerable groups, excluded on the basis of inequalities such as poverty, gender and ethnicity.

The wide range of approaches and methods used suggests the lack of a coherent model for depression-focused anti-stigma work, including the lack of direct evidence on culturally specific concepts of depression.

We have found that few projects formally evaluate their impact, which may be due to a

Table 2: Summary of impact of programmes

Name of programme	Key outcomes/impact	Sources
Defeat Depression	• Reduction in stigma • More positive attitudes to depression • Increase in media coverage • Increase in celebrities willing to acknowledge their own depression • 60% of GPs knowing about key materials • Highlighted positive news about depression in the media	Paykel *et al.* (1998) Rix *et al.* (1999) White (1998)
European Alliance Against Depression (Hungary)	• In the Szolnok region, suicide decreased significantly during the project period	Purebl *et al.* (2008)
European Alliance Against Depression (Italy)	• Deeper knowledge of depression and better treatment for it in the Alto Adige population compared with other areas • In South Tyrol (Alto Adige) region, the suicide rate had a significant decrease in the suicide rate among men between 2001–03 and 2005–07 following the EAAD project • More positive public attitudes towards depression and its treatment	Giupponi *et al.* (2008)
European Alliance Against Depression (EAAD)	• In a pilot of EAAD in Nuremberg, suicidal acts decreased by 20% in Nuremberg where the campaign was located, whereas no decrease was detected in the control town Wurzburg • In a further series of population, surveys conducted in Nuremberg and Wurzburg in the years negative attitudes towards depression decreased in Nuremberg in the subgroup of people being aware of the campaign but not in the control town Wurzburg	Scheerder *et al.* (2011) Hegerl and Wittenburg (2009)

lack of resources, being more action-oriented and less interested in evaluation, or that the activity is seen as too small-scale for sound evaluation. It may also be because stigma-related outcomes are seen to be complex and the problems of measuring (changes in) stigma, but also because some interest groups, for example the profession of psychiatry, have not seen anti-stigma work as a core element of their role in most European countries. The evidence that we have reviewed suggests that multi-level campaigns, such as 'Defeat Depression' or the EAAD, do show evidence of modest impact in the short to medium term. Particularly promising avenues from non-EU settings include the use of the arts for interventions and online approaches, for example, to promote depression-related literacy (Finkelstein and Lapshin, 2007).

There is a clear disconnection between the major public impact of depression and the lack of evidence on the impact of depression stigma or the relative absence of public programmes to reduce depression-related stigma. The ASPEN Toolkit is therefore timely to inform EU member states about the very latest evidence of effective interventions. Without a strong body of evidence on depression-specific programmes, we need to refer to the wider evidence base on programmes intended to reduce stigma across the whole field of mental illness (Byrne, 2001; Pinfold *et al.*, 2005; Thornicroft *et al.*, 2007). Notably, the key active ingredient most often identified is direct social contact with people with mental health problems, (Parslow and Jorm, 2002), yet such contact is not at present a cardinal feature of most depression programmes. Educational interventions, by contrast are more common, while protest-based interventions (where the evidence of effectiveness is weakest) are very rare for these programmes. Social contact has mostly been achieved in interventions where service users act directly as teachers or educators to target groups. Yet this was not a common feature across the projects identified, possibly due to the symptoms experienced by people with depression, and it may be that adopting a human rights perspective, emphasizing equity, is an approach that will foster this form of participation more

strongly in the future. There are a number of limitations of this study: the sample size in most countries was modest; the data quality of the returns was variable; cultural variations and language translations needed to carefully address key terms, including 'depression' or 'intervention'; and some sites may have taken the survey as an opportunity to uncritically showcase their own projects. At the same time, this is the largest-ever EU survey conducted of anti-stigma depression programmes, it included most (18) EU countries, and we were able to go back to respondents to validate their data. We deliberately adopted a multi-stakeholder approach, and data were reported in a way designed to have a direct and positive impact on national mental health policy.

The ASPEN Toolkit, which is also informed by a structured literature review available at www.antistigma.eu, therefore constitutes a comprehensive, broad-based and policy and practice relevant synthesis of promising practice for effective interventions to reduce stigma related to depression. This points to the value of multilevel campaigns, including interventions that promote direct social contact, and to clearly determining the target audience(s). The findings from this ASPEN project therefore can make an important contribution to the future development of anti-stigma work across the EU.

FUNDING

Funding was provided by the European Commission, Directorate General for Health and Consumers, Public Health Executive Agency.

ACKNOWLEDGEMENTS

*The ASPEN Project Group
Staff at ASPEN Project Co-ordinating Centres: Graham Thornicroft, Tine Van Bortel, Elaine Brohan (King's College London, Institute of Psychiatry, London, England); Kristian Wahlbeck, Esa Aromaa, Fredrica Nyqvist, Carolina Herberts (National Institute for Health and Welfare/THL, Helsinki, Finland); Oliver Lewis, Jasna Russo, Dorottya Karsay, Rea Maglajlic (Mental Disability Advocacy Centre, Budapest, Hungary); Antonio Lasalvia, Silvia Zoppei, Doriana Cristofalo, Chiara Bonetto (Department of Public Health and Community Medicine, Section of Psychiatry and Clinical Psychology, University of Verona, Italy); Isabella Goldie, Lee Knifton, Neil Quinn (Mental Health Foundation, Glasgow, Scotland). Staff at ASPEN Project Partner Centres: Chantal Van Audenhove, Gert Scheerder, Else Tambuyzer (Katholieke Universiteit Leuven (KU Leuven), Belgium; Valentina Hristakeva, Dimitar Germanov (Global Initiative on Psychiatry Sofia (GIP-Sofia), Bulgaria); Jean Luc Roelandt, Simon Vasseur Bacle, Nicolas Daumerie, Aude Caria (Etablissement Public Santé Mentale Lille-Métropole (EPSM/C.C.OMS), France); Harald Zaske, Wolfgang Gaebel (Heinrich-Heine-Universitat Dusseldorf, Rheinische Kliniken Dusseldorf (RKD), Germany); Marina Economou, Eleni Louki, Lily Peppou, Klio Geroulanou (University Mental Health Institute (UMHRI (EPIPSI), Greece); Judit Harangozo, Julia Sebes, Gabor Csukly (Awakenings Foundation (AWF), Hungary); Giuseppe Rossi, Mariangela Lanfredi, Laura Pedrini (Provincia Lombardo Veneta Ordine Ospedaliero di San Giovanni di Dio – Fatebenefratelli, Brescia, Italy); Arunas Germanavicius, Natalja Markovskaja, Vytis Valantinas (Vilnius University (VU), Lithuania); Jaap van Weeghel, Jenny Boumans, Eleonoor Willemsen, Annette Plooy (Kenniscentrum Phrenos, Netherlands); Teresa Duarte, Fatima Jorge Monteiro (Associação para o Estudo e Integração Psicossocial (AEIPS), Portugal); Radu Teodorescu, Iuliana Radu, Elena Pana (Asociatia din Romania de Psihiatrie Comunitara (A.R.P.C.), Romania); Janka Hurova, Dita Leczova (Association for Mental Health INTEGRA, o. z. (Integra o.z.), Slovakia); Vesna Svab, Nina Konecnik (University Psychiatric Hospital (PKL), Slovenia); Blanca Reneses, Juan J. Lopez-Ibor, Nerea Palomares, Camila Bayon (Instituto de Psiquiatria at the Hospital Universitario San Carlos, Spain); Alp Ucok, Gulsah Karaday (Foundation of Psychiatry Clinic of Medical Faculty of Istanbul (PAP), Turkey).

Graham Thornicroft is funded in relation to a National Institute for Health Research (NIHR) Applied Programme grant awarded to the South London and Maudsley NHS Foundation Trust, and in relation to the NIHR Specialist Mental Health Biomedical Research Centre at the Institute of Psychiatry, King's College London and the South London and Maudsley NHS Foundation Trust.

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