Campaigns to reduce mental illness stigma in Europe: a scoping review

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Summary
Background: Evidence has emerged in recent decades about effective and ineffective methods to reduce mental illness related stigma and discrimination. As more European countries start national anti-stigma campaigns, there is potentially more to learn from their experiences, but also a risk that, with such rapid developments, lessons may be missed.

Aim: This scoping review aims to identify and discuss European stigma reduction campaigns conducted to date.

Methods: We searched electronic databases, hand-searched reference lists of identified articles and contacted stigma experts to enquire about ongoing initiatives.

Results: We identified anti-stigma campaigns in 21 European countries and regions. We found considerable variation in their content, delivery formats, duration and target groups.

Conclusions: Although anti-stigma campaigns have been implemented in many European countries, the level of attention paid to sharing lessons learned is variable. It is vital that campaigns are evaluated, to maximise their potential impact both on the target population, and that the findings are disseminated widely to allow international learning.

Zusammenfassung

Ziel: Diese Scoping-Übersicht hat zum Ziel, europäische Antistigmakampagnen zu identifizieren und zu besprechen.

Methoden: Wir haben elektronische Datenbanken, Referenzlisten von identifizierten Artikeln durchsucht und haben uns mit Stigmaexperten in Verbindung gesetzt, um andauernde Initiativen zu erfragen.


Fazit: Obwohl Antistigmakampagnen in vielen europäischen Ländern durchgeführt worden sind, ist das Niveau der Kampagnen variabel. Es ist wichtig, dass Kampagnen bewertet werden, um sowohl ihren potenziellen Einfluss auf die Zielgruppe zu maximieren, als auch die Ergebnisse international zu verbreiten.

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Mental illness and stigma

Stigma refers to problems of knowledge (ignorance or misinformation), attitudes (prejudice), and/or behaviour (discrimination) relating to people with mental illness (1). Stigmatisation of mental illness occurs globally and can contribute to low rates of help-seeking, lack of access to care, under-treatment and social marginalization (2, 3). Stigma has been described as the single most powerful obstacle to successful engagement with mental health care (4) and people with mental illness have stated that the stigma they encounter is often worse than the illness itself (5–7), as it can continue to complicate their lives even as treatment leads to a reduction in symptoms and improved functioning (8). Reducing mental illness stigma should reduce experienced and anticipated stigma as well as the stress it causes the targets of stigma (9), facilitating engagement with mental health services (10) and reducing stress, thus leading to an overall improvement in mental health status.

Effective ingredients in anti-stigma campaigns

In the past two decades evidence has begun to emerge about the effectiveness of interventions to reduce stigma and discrimination (11). A review from the National Institute of Mental Health England (12) identified six core principles of an effective anti-stigma campaign:
1. Service users and carers should be involved throughout the design, delivery monitoring and evaluation of the campaign.
2. Campaigns should be appropriately monitored and evaluated.
3. National campaigns should be supported by local grassroots initiatives (as seen in the Open The Doors programme).
4. Campaigns should address behaviour change with a range of approaches.
5. Clear specific messages should be delivered in targeted ways to identifiable audiences.
6. Long-term planning and funding should be in place to ensure campaign sustainability.

Since this review was published, further evidence has emerged about the most effective modes of campaign delivery as well as the effects of different campaign messages. For example, a recent consensus development study exploring the most effective types of messages to use in population-level campaigns revealed that messages which were recovery-oriented, and those which sought to remove the distance between „us“ and „them“, were recommended most commonly by experts (13). Furthermore, it is known the three strategies most commonly used to address the stigma and discrimination related to mental illness at the individual level are
1) education (the goal of which is to replace preconceived myths and stereotypes about mental illness with facts and accurate conceptions);
2) contact (which challenges public attitudes about mental illness via direct interactions with persons who have such disorders); and
3) protest (the goal of which is to suppress stigmatizing attitudes about mental illness) (14).

A meta-analysis of outcome studies from 2012 revealed that, whilst contact was more effective than education at reducing stigma in adults, the opposite was true for adolescents (15). Additionally, other research has demonstrated that enhancing public understanding of the biological correlates of mental illness does not result in reduced levels of stigma (16).

Recently, numerous initiatives and programmes aiming to reduce mental illness stigma and discrimination have been implemented in many countries (15). Whilst some programmes have targeted specific subgroups of the population, others have been implemented at a population level (or involved a combination). This review focuses on anti-stigma initiatives in European countries. Our aims are to provide a summary of such initiatives and to suggest how this work may be built upon to further reduce mental illness stigma.

Methods

We searched Medline (1948 to November, 2013), Embase (1974 to November, 2013), PsycINFO (1806 to November, 2013), PsycARTICLES (to November, 2013), Global Health (1973 – November, 2013) and Google Scholar (to November, 2013) with variants of the following search terms: “stigma/discrimination/help-seeking/barriers to care” AND “mental illness/psychiatry” AND “programme/initiative/campaign”, combining these with individual searches for the names of 50 European countries and regions. Reference lists of identified articles were hand searched and online searches of anti-stigma alliances – and search engines – were conducted. Finally, leading stigma academics and the Global Alliance Against Stigma were contacted to enquire about new or ongoing anti-stigma initiatives.
Results

We identified evidence of anti-stigma campaigns in 21 European countries and regions (Table 1). We found considerable variation in their content, delivery formats, duration and target groups. Those for which we found evaluation reports are discussed by country below after a discussion of the largest ever global educational anti-stigma campaign; the World Psychiatric Association (WPA)’s ‘Open The Doors’ programme.

‘Open The Doors’

In 1996, the WPA introduced a stigma and discrimination reduction strategy associated with schizophrenia entitled ‘Open The Doors’ (www.openthedoo.com). The campaign has gone on to establish over 200 projects in more than 20 countries (including eight in Europe) (48). Conducting Open The Doors projects involves:
1) Establishing a local action committee;
2) Conducting a survey of local sources of stigma;
3) Selecting target groups for the intervention;
4) Designing locally relevant messages and media;
5) Evaluating the impact of the interventions, whilst continuously refining them.

National experts and non-government organisations are involved from the beginning and all materials are tested on local populations and adapted as necessary to the different settings. Professor Norman Sartorius, founder of Open The Doors, has stated that successful anti-stigma programmes can be launched in any country or region irrespective of its size, economic status or level of development (49).

Austria

‘Open The Doors’

Findings from one Open The Doors programme showed that a combination of education and contact with people with mental illness may improve attitudes towards mental illness (4). Findings from another campaign were less positive; five years after it finished, a general population survey showed that 64.1% agreed with the statement that people with schizophrenia were dangerous; this figure was significantly higher than that reported in a study five years earlier (50). Additionally, only 18.7% of respondents expressed a desire to become better informed about the illness.

Croatia

‘Patient Empowerment Programme’

Results from the ‘Patient Empowerment Programme’ – designed to help 128 people with mental illness develop coping skills to overcome stigma and self-stigma (i.e. when a person with a mental illness believes the negative and inaccurate stereotypes regarding people with mental illness) – showed a significant reduction in both stigma and self-stigma following exposure to the programme (4).

Germany

‘Open The Doors’

Evaluation findings have been mixed (51). On one hand, there was a decrease in negative stereotypes and social distance towards people with schizophrenia over the course of Open The Doors (20). However, although school-children’s stereotypes about people with schizophrenia reduced after the intervention, the positive changes in social distance did not reach statistical significance (52). Worse, evaluation of the film screenings and theatre productions about mental illness revealed that there was an increase in stigmatising beliefs (20).

‘The Nuremberg Alliance Against Depression’

This two-year community-based educational intervention involved three key messages:
1) depression can be treated;
2) depression has many faces; and
3) depression can affect everybody (22–24).

Evaluation findings showed, whilst that there was a significant reduction in some aspects of depression-related stigma at follow-up (22, 24), there was no significant change for statements regarding general attitudes towards depression, beliefs about symptoms or beliefs about side effects of antidepressants. There was a significant reduction in the number of suicidal acts over each of the two years of the campaign when compared to a control-comparison region (23) but no difference was observed in the number of completed suicides between the regions.

Scotland

‘See Me’

‘See Me’ was launched in 2002 (28, 31) and findings have shown that, since that time, there has been a significant
Table 1  Stigma reduction campaigns implemented in Europe. No information was located on campaigns in the following countries and principalities: Albania, Andorra, Armenia, Azerbaijan, Belarus, Bosnia and Herzegovina, Bulgaria, Cyprus, Estonia, Finland, Georgia, Iceland, Kosovo, Latvia, Liechtenstein, Lithuania, Luxembourg, Macedonia, Malta, Moldova, Monaco, Montenegro, Russia, San Marino, Serbia, Switzerland, Ukraine, Vatican City.

<table>
<thead>
<tr>
<th>Country/ Region</th>
<th>Campaign</th>
<th>Time period</th>
<th>Website</th>
<th>Formal evaluation completed?</th>
<th>English language evaluation completed?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Austria</td>
<td>‘Open The Doors’</td>
<td>1998 – present</td>
<td><a href="http://www.openthedooors.com/greek/01_05_01.html">www.openthedooors.com/greek/01_05_01.html</a></td>
<td>Yes: (17, 18)</td>
<td>No</td>
</tr>
<tr>
<td>2 Croatia</td>
<td>‘Patient Empowerment Programme’</td>
<td>1998 – present</td>
<td></td>
<td>Yes: see (4)</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>‘The program of diminishing stigma and discrimination of mental patients’</td>
<td>2002 – 2008</td>
<td></td>
<td>Yes: (19)</td>
<td>No</td>
</tr>
<tr>
<td>3 Czech Republic</td>
<td>‘Open The Doors’</td>
<td>2004 – present</td>
<td><a href="http://www.stopstigma.cz">www.stopstigma.cz</a></td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>4 Denmark</td>
<td>‘En Af Os’ (One Of Us)</td>
<td>2011 – present</td>
<td><a href="http://www.en-af-os.dk">www.en-af-os.dk</a></td>
<td>In progress</td>
<td>Planned</td>
</tr>
<tr>
<td>5 Germany</td>
<td>‘Open The Doors’</td>
<td>1999 – present</td>
<td><a href="http://www.openthedooors.com/greek/01_05_05.html">www.openthedooors.com/greek/01_05_05.html</a></td>
<td>Yes: (20)</td>
<td>Yes: (20, 21)</td>
</tr>
<tr>
<td></td>
<td>‘Nuremberg Alliance Against Depression’</td>
<td>2001 – 2003</td>
<td></td>
<td>Yes: (22–24)</td>
<td>Yes: (22–24)</td>
</tr>
<tr>
<td></td>
<td>‘National Program for the Destigmatization of Mental Illness’</td>
<td>2004 – present</td>
<td></td>
<td>Yes: (25)</td>
<td>No</td>
</tr>
<tr>
<td>6 Greece</td>
<td>‘Open The Doors’</td>
<td>1999 – present</td>
<td><a href="http://www.openthedooors.com/greek/01_05_06.html">www.openthedooors.com/greek/01_05_06.html</a></td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>‘ASPEN project’</td>
<td>2009 – present</td>
<td><a href="http://www.antistigma.eu/taxonomy/term/132">www.antistigma.eu/taxonomy/term/132</a></td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>8 Ireland</td>
<td>‘See Change’</td>
<td>2010 – present</td>
<td><a href="http://www.seechange.ie">www.seechange.ie</a></td>
<td>Yes: (26)</td>
<td>Yes: (26)</td>
</tr>
<tr>
<td>9 Italy</td>
<td>‘Open The Doors’</td>
<td>1999 – present</td>
<td><a href="http://www.openthedooors.com/greek/01_05_08.html">www.openthedooors.com/greek/01_05_08.html</a></td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>10 The Netherlands</td>
<td>‘Samen Sterk Tegen Stigma’ (‘Together Strong Against Stigma’)</td>
<td>2013 – present</td>
<td><a href="http://www.samensterktegenstigma.nl">www.samensterktegenstigma.nl</a></td>
<td>Planned</td>
<td>No</td>
</tr>
<tr>
<td>11 Norway</td>
<td>‘Et Apent Sinn’ (‘An Open Mind’)</td>
<td>2007 – 2008</td>
<td></td>
<td>Yes: see (4)</td>
<td>No</td>
</tr>
<tr>
<td>12 Poland</td>
<td>‘Open The Doors’</td>
<td>2000 – present</td>
<td><a href="http://www.openthedooors.com">www.openthedooors.com</a></td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>13 Portugal</td>
<td>‘Stand Up Against Stigma and Discrimination Toward Mental Disorders’</td>
<td>2007 – 2016</td>
<td><a href="http://www.upafazadiferenca.encontrarse.pt">www.upafazadiferenca.encontrarse.pt</a></td>
<td>Yes: (4)</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td><a href="http://www.porto.ucp.pt/fep/abrivespasaudamental">www.porto.ucp.pt/fep/abrivespasaudamental</a></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14 Romania</td>
<td>‘Open The Doors’</td>
<td>2000 – present</td>
<td><a href="http://www.openthedooors.com/english/01_05_16.htm">www.openthedooors.com/english/01_05_16.htm</a></td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>‘Trust My Mind! STOP The Prejudices Against Mental Illness’</td>
<td>2007 – 2008</td>
<td></td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>‘Schizophrenia Should Not Be A Reason For Discrimination’</td>
<td>2008 (Jan-Apr)</td>
<td></td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>
reduction (30% vs. 19%) in the proportion of respondents who agreed that people with mental illness are often dangerous and a significant increase in willingness to interact with someone who had a mental illness (53). The proportion of people with a mental illness who reported experiencing discrimination also dropped significantly between 2002 and 2008 (27).

United Kingdom

‘Defeat Depression’

The ‘Defeat Depression’ campaign was launched in 1991 (54, 55) and its evaluation showed a significant improvement regarding public attitudes towards depression (37). Attitudes were found to be mostly favourable, except towards antidepressants, which were viewed by many as addictive (38, 40). Two thirds of general practitioners surveyed were aware of the campaign and between 25–40% had changed their practice as a result (36, 39).

‘Changing Minds: Every Family in the Land’

This campaign produced nine key outputs (56). The results of national surveys of public opinions conducted before and after the campaign showed that the public’s ability to recognise the nature of and differences between mental illnesses had not significantly improved (41).

‘Time to Change’

Phase 1 of TTC (2007–11) consisted of a number of interventions, including: a social marketing campaign; programmes for specific target groups including medical students and trainee teachers and employers; local anti-discrimination initiatives; exercise programmes for people with mental health problems to promote social contact; social contact events organised by a range of stakeholders; and the use of social media such as Twitter and Facebook. Findings showed that, across England, there were significant improvements in intended behaviour and a positive (but non-significant; p=0.08) trend in attitudes towards mental illness (43). There was a significant (3%) increase in the proportion of service users who reported having experienced no discrimination during the previous year (42). Finally, a significant improvement in employment-related attitudes (as indicated by a significant reduction in the proportion of employers who endorsed the view that people with mental health problems are less reliable than other employees and that employees with mental health problems are unlikely to ever fully recover) was observed amongst senior employers between 2006 and 2010 (45). However, there was no decrease in stigmatising newspaper articles during the campaign period (57) and nor was there...
a change in the discrimination and stigmatising attitudes displayed health care workers. Finally, 87% of service users surveyed had still experienced some form of discrimination in the preceding 12 months (45).

‘Don’t Bottle It Up’

The British Army has recently made substantial efforts to reduce stigma amongst soldiers, in particular a multi-faceted campaign called “Don’t Bottle It Up” has used mixed media delivery methods in an attempt to reach personnel of all ranks. This campaign is ongoing at the time of writing and formal assessment of the impact of the programme has yet to be conducted. Military researchers have reported a sustained (although modest) reduction in levels of reported stigma over time, although the outcome data pre-date the introduction of the ‘don’t bottle it up’ campaign, (58). Reported stigma was twice as prevalent amongst troops on deployment than amongst those who were surveyed immediately after leaving a combat zone (47).

Discussion

Our scoping review identified anti-stigma campaigns in 21 European countries and regions. Many other campaigns have been conducted in other countries, but descriptions of many of these are not easily available because a) there are no academic publications describing them, b) descriptions exist only in local languages or c) both (4). In most studies that included an evaluation component, the results were mixed. For some, there was little evidence of a significant general stigma reduction effect whilst, for others, positive effects tended to vary by sub-population or were related to specific attitudes or behaviours. As such, the evidence to support the efficacy of population-level interventions is available from only a few European countries, along with a similarly small number of non-European countries (59, 60). Perhaps the best evidence is from Australia, where different levels of campaign uptake in different states have allowed firmer conclusions about the impact of the BeyondBlue programme (59).

Conclusions and recommendations

Despite numerous anti-stigma campaigns being conducted recently in Europe, at the time of writing, the potential to learn from them is not being realised fully. Several recommendations can be made to build on to those above. For countries in which no anti-stigma campaigns were identified, consideration should be given to Professor Sartorius’ statement that successful campaigns can be implemented in any country or region (49). By consulting people with mental illnesses about the priority target groups for a campaign, the most effective use can be made of scarce resources. The use of social contact in ways that have been shown to be effective should be considered, especially in campaigns where adults are the target group; for adolescents there should be a stronger emphasis on education (15). Messaging that include biological causal explanations is best avoided (16), while those that encourage social contact and convey the meaning of personal recovery are more likely to have a positive impact (13). As an example of a low cost strategy that provides virtual social contact as well as being a vehicle for education and protest, the effect of social media (such as a Twitter feed or Facebook page), deserves more attention as this is missing from all campaign evaluations so far.

For countries in which campaigns have been implemented but not evaluated, it is imperative that evaluation is considered as an integral part of all stigma-reduction campaigns and the findings disseminated widely; this includes publishing findings in English. Such evaluations serve several purposes: to guide the development of the campaign as it progresses; to help planners to make informed decisions about future anti-stigma campaigns; to gather support from service users and other stakeholders where they also observe positive results; and to add to the existing knowledge base for use in other countries. It is important that lessons learned – both informally and via formal evaluations – are shared with other countries. This is one goal of the Global Alliance Against Stigma, a consortium of 16 countries (including 11 from Europe) dedicated to eradicating the stigma associated with mental illness (for further details, contact Karen Wilson: k.wilson@time-to-change.org.uk). To further build on the recommendations above, a valuable next step for this alliance would be to make available a summary of what has been learned, so that information on how to conduct a successful campaign and what to include/exclude is freely accessible. In this way, stigma and discrimination can be further reduced (30).

Conflict of interest

R. Borschmann has no interests to declare.
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N. Jones has no interests to declare.
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