



Available online at
ScienceDirect
www.sciencedirect.com

Elsevier Masson France
EM|consulte
www.em-consulte.com/en



Original article

The state of the art in European research on reducing social exclusion and stigma related to mental health: A systematic mapping of the literature



S. Evans-Lacko^{a,*}, E. Courtin^{b,1}, A. Fiorillo^{c,2}, M. Knapp^{b,3}, M. Luciano^{c,2}, A.-L. Park^{b,4},
 M. Brunn^{d,e,f,5}, S. Byford^{a,6}, K. Chevrel^{e,f,g,7}, A.K. Forsman^{h,i,8}, L. Gulacsi^j, J.M. Haro^{k,l,m,9},
 B. Kennelly^{n,10}, S. Knappe^{o,11}, T. Lai^{p,12}, A. Lasalvia^q, M. Miret^{r,13}, C. O'Sullivan^{s,14},
 C. Obradors-Tarragó^{k,l,15}, N. Rüsçh^{t,16}, N. Sartorius^{u,17}, V. Švab^v, J. van Weeghel^{w,18},
 C. Van Audenhove^{x,19}, K. Wahlbeck^{y,20}, A. Zlati^{z,21}, ROAMER Consortium, D. McDaid^{aa,22,23},
 G. Thornicroft^{ab,23}

^aHealth Service and Population Research Department, King's College London, Institute of Psychiatry, London, United Kingdom

^bLondon School of Economics, Houghton Street, WC2A 2AE London, United Kingdom

^cDepartment of Psychiatry, University of Naples SUN, Largo Madonna delle Grazie, 80134 Naples, Italy

^dFondation Fondamental, 94000 Créteil, France

^eUniversité Paris Diderot, Sorbonne Paris Cité, ECEVE, 75010 Paris, France

^fInserm, ECEVE, U1123, 75010 Paris, France

^gURC Eco Ile-de-France, DRCD, AP-HP, 75004 Paris, France

^hNational Institute for Health and Welfare (THL), Mental Health Promotion Unit, Hietalahdenkatu 2-4/L-talo, 65130 Vaasa, Finland

ⁱNordic School of Public Health NHV, Gothenburg, Sweden

^jDepartment of Health Economics, Corvinus University of Budapest, Fovam ter 8, 1098 Budapest, Hungary

^kParc Sanitari Sant Joan de Déu - CIBERSAM, Research and Development Unit, 42, c/Dr. Antoni Pujades, 08830 Sant Boi de Llobregat, Barcelona, Spain

^lCentro de Investigación Biomédica en Red de Salud Mental, CIBERSAM, Madrid, Spain

^mUniversitat de Barcelona, Barcelona, Spain

ⁿCairnes School of Business and Economics, National University of Ireland, Galway, Ireland

^oInstitute of Clinical Psychology and Psychotherapy, Technische Universität Dresden, Chemnitz Straße 46, 01187 Dresden, Germany

^pFourth view consulting, PO Box 38, Narva mnt 1, 10502 Tallinn, Estonia

^qDepartment of Public Health and Community Medicine, Section of Psychiatry, University of Verona, Verona, Italy

^rInstituto de Salud Carlos III, Centro de Investigación Biomédica en Red de Salud Mental, CIBERSAM, Department of Psychiatry, Universidad Autónoma de Madrid, Arzobispo Morcillo, 4, 28029 Madrid, Spain

* Corresponding author. Tel.: +44 20 7848 5076.

E-mail address: Sara.Evans-Lacko@kcl.ac.uk (S. Evans-Lacko).

¹ Tel.: +44 20 7852 3775.

² Tel.: +39 0815666531.

³ Tel.: +44 20 7955 6225.

⁴ Tel.: +44 20 7849 4665.

⁵ Tel.: +33 140 274 575.

⁶ Tel.: +44 20 7848 0043.

⁷ Tel.: +33 140 274 148.

⁸ Tel.: +358 6 323 1734.

⁹ Tel.: +34 93 600 26 85.

¹⁰ Tel.: +353 91 493093.

¹¹ Tel.: +49 351 463 39727.

¹² Tel.: +372 5666 3859.

¹³ Tel.: +34 91 497 27 16.

¹⁴ Tel.: +44 131 243 3800.

¹⁵ Tel.: +34 93 556 96 77.

¹⁶ Tel.: +49 731 500 62301/-00.

¹⁷ Tel.: +41 22 788 2331.

¹⁸ Tel.: +31 30 2931626.

¹⁹ Tel.: +0032 486 618484.

²⁰ Tel.: +358 400 659101.

²¹ Tel.: +40 752 123 674.

²² Tel.: +44 20 7955 6381.

²³ These authors contributed equally to this work.

<http://dx.doi.org/10.1016/j.eurpsy.2014.02.007>

0924-9338/© 2014 Elsevier Masson SAS. All rights reserved.

⁵ Mental Health Foundation, 18, Walker Street, EH3 7LP Edinburgh, United Kingdom

[†] Department of Psychiatry II, University of Ulm, Parkstrasse 11, 89073 Ulm, Germany

[‡] Association for the Improvement of Mental Health Programmes (AMH), 14, chemin Colladon, 1209 Geneva, Switzerland

[¶] University Ljubljana, Medical Faculty, Vrazov trg 2, 1000 Ljubljana, Slovenia

^{**} Phrenos Center of Expertise, Da Costakade 45, 3521 VS, Utrecht, The Netherlands

[×] KU Leuven LUCAS, Center for Care Research and Consultancy, Kapucijnenvoer 39, 3000 Leuven, Belgium

[‡] The Finnish Association for Mental Health, Maistraatinportti 4 A, 00240 Helsinki, Finland

^z Babes-Bolyai University, Sociology Department & Open Minds - Center for Mental Health Research, Mehedinti St, No 35, Apt 68, 400672 Cluj-Napoca, Romania

^{aa} London School of Economics, Houghton Street, WC2A 2AE London, United Kingdom

^{ab} Health Services and Population Research Department, King's College London, Institute of Psychiatry, Box P029, De Crespigny Park, SE5 8AF London, United Kingdom

ARTICLE INFO

Article history:

Received 17 January 2014

Received in revised form 16 February 2014

Accepted 19 February 2014

Available online 13 April 2014

Keywords:

Mental disorders

Stigmatization

Social marginalization

Social participation

Community psychiatry

Review

ABSTRACT

Stigma and social exclusion related to mental health are of substantial public health importance for Europe. As part of ROAMER (ROADmap for MEntal health Research in Europe), we used systematic mapping techniques to describe the current state of research on stigma and social exclusion across Europe. Findings demonstrate growing interest in this field between 2007 and 2012. Most studies were descriptive (60%), focused on adults of working age (60%) and were performed in Northwest Europe—primarily in the UK (32%), Finland (8%), Sweden (8%) and Germany (7%). In terms of mental health characteristics, the largest proportion of studies investigated general mental health (20%), common mental disorders (16%), schizophrenia (16%) or depression (14%). There is a paucity of research looking at mechanisms to reduce stigma and promote social inclusion, or at factors that might promote resilience or protect against stigma/social exclusion across the life course. Evidence is also limited in relation to evaluations of interventions. Increasing incentives for cross-country research collaborations, especially with new EU Member States and collaboration across European professional organizations and disciplines, could improve understanding of the range of underpinning social and cultural factors which promote inclusion or contribute toward lower levels of stigma, especially during times of hardship.

© 2014 Elsevier Masson SAS. All rights reserved.

1. Introduction

Stigma and social exclusion related to mental health are of substantial public health importance in Europe. Experience of mental health problems early in life can be associated with a trajectory of exclusion and disadvantage, for example, through reduced participation in higher education, exclusion from civil society (including functions such as democratic participation), increased risk of contact with criminal justice systems, victimization, less access to physical healthcare, poverty and homelessness and reduced life expectancy [16,21,26,35,42,47]. Stigma and exclusion of these kinds can directly reduce well-being and can also have significant consequences in terms of lower participation in healthcare, higher rates of mortality, higher levels of self-stigma, lower levels of empowerment and higher rates of unemployment [14,40,43]. Employment rates for people with mental health problems, for instance, are lower than those of the overall population and lower than those for people with physical health problems [25,38].

These issues may intensify at times of macro-economic adversity, as currently experienced in many European and other countries. Stigma and social exclusion of marginalized groups may increase during times of economic recession and can result in increased exclusion of people with mental health problems [10], for example in relation to employment [1,15]. Although the evidence is from outside Europe, other research has shown how relative income-related disadvantages, in relation to prevalence of mental health problems and to suicide, widen during a recession [24]. Given that recession and a poor economic outlook may be associated with a decline in population mental health and depletion of social resources associated with resilience [19,34,46], there is likely to be an increasing proportion of the population feeling the impact of the economic hardship. Thus, there is an urgent need for evidence to help us understand the mechanisms of and evidence-based

solutions for decreasing stigma and social exclusion and to improving societal participation.

The importance of stigma and social exclusion was highlighted in a recent survey of 154 national associations/organizations of stakeholder groups in Europe, undertaken as part of the ROAMER (ROADmap for MEntal health Research in Europe) project. Stigma and discrimination were considered priorities across all stakeholder groups (i.e., trainee mental health professionals, psychiatrists, other mental health professionals, service users and/or carers and trainees) [17]. The ROAMER project, which was funded under the European Commission Seventh Framework Research Programme (FP7), aims to develop a comprehensive and integrated mental health research agenda oriented to translational research and aligned with the policies of the new EU long-term research programme Horizon 2020 [23]. One part of the ROAMER project focused on social and economic issues in relation to mental health and well-being across Europe. The research underpinning this paper was designed to inform the ROAMER mental health roadmap by describing the most recent, state of the art research in relation to stigma and social exclusion. Understanding what research achievements have already been made would also help to identify existing research gaps, to understand weaknesses in the field, and hence, to ascertain which research needs might be prioritized for the future.

The overarching objective of this study was to map current research on stigma and social exclusion in relation to mental health and well-being across Europe. We had three specific aims:

- to identify where in Europe (i.e., in which countries) research on stigma and social exclusion in relation to mental health and well-being is conducted;
- to describe the type of research on stigma and social exclusion in relation to mental health in Europe (e.g., methodology, type of disorder, age groups);

- to investigate the “main research” topics in the areas of stigma and social exclusion in relation to mental health in Europe (e.g., focus of research).

2. Materials and methods

In order to provide a broad overview of the scientific literature we employed systematic literature mapping techniques as outlined by published guidelines [7,13]. We used a broad set of search terms for:

- mental illness and well-being (in the title or abstract);
- referring to social exclusion/inclusion and stigma (in the title or abstract) (see [Appendix 1](#) for search terms used), and searched Pubmed and Psycinfo databases.

We focused on terms related to stigma, social exclusion and social inclusion to increase representation of research across different disciplines that may employ different terminology. The search terms were based on a bibliometric analysis used to assess mental health research funding in 2007 [6] and an earlier systematic mapping study of Social Exclusion and Mental Health Policy which covered the years 1948–2003 [12], both of which were supplemented with additional terms as recommended by scientific experts associated with the ROAMER project. To facilitate broad multidisciplinary thinking, the literature mapping strategy was presented to ROAMER scientific experts associated with the sub-project/work package devoted to social and economic issues as well as to all other ROAMER work packages, the scientific advisory board and the stakeholder advisory group. Recommendations from discussions at these meetings were incorporated into our mapping strategy.

2.1. Inclusion/exclusion criteria

As we aimed to identify the most recent “state of the art” research, studies had to be published in peer-reviewed journals between January 2007 and December 2012. This timeframe was established through consensus by the ROAMER consortium. The paper had to be an empirical paper and include an English language abstract. Review papers were excluded. The research must have been performed in a European Union (EU) country (including EU-28 countries and EU Candidate countries, i.e., Iceland, Montenegro, Serbia, The former Yugoslav Republic of Macedonia and Turkey) or the first author or corresponding author must have been based at a research institution in an EU country.

In regards to study outcomes, we reviewed papers using a two-stage process. First, we screened abstracts to be considered for full review if the main focus was related to mental health problems, well-being, stigma or social exclusion/inclusion. Articles which simply performed an evaluation of psychological or pharmacological treatments were excluded unless the treatments included a social component or measured an outcome which was, for example, related to stigma or human rights, or which was closely related to social exclusion (such as social relations, social functioning, or employment). Articles that investigated outcomes solely in relation to e.g., clinical symptoms or continuity of care were excluded. Where an abstract was found to meet the initial criteria, we then reviewed the full paper and included for final selection any paper where the primary or secondary outcome or the main determinant focused on stigma or social exclusion/inclusion.

2.2. Selection of studies

Four reviewers (SEL, EC, ML, AF) participated in the selection. Each of them independently screened an initial set of 200 abstracts.

Agreement for study exclusion between the authors ranged from 89–93%. Because of this high level of agreement, the remaining 4800 abstracts were divided between reviewers. Selected papers were then reviewed by the four reviewers (SEL, EC, ML, AF) independently to consider whether each retrieved paper met the inclusion criteria. Disparities in inclusion decisions were resolved through discussion. Reviewers did not contribute to inclusion decisions regarding studies in which they themselves were involved. Reference Manager was used to store all selected studies and extract relevant information into an SPSS database.

3. Results

The search on January 14, 2013 resulted in 11,078 articles from Medline and 16,047 articles from PsycINFO. When duplicates were removed, this resulted in 20,122 references. Although reviews themselves were not included, identified references were supplemented by recent systematic reviews of research related to social exclusion and mental health [9,11,37]. Of the total references, 5000 were randomly selected for review and data extraction. Three thousand eight hundred and eighty articles (78%) were excluded based on screening of the title and abstract. The remaining 1120 papers were reviewed using the full text version of the paper. Of those, 1023 were then excluded, as stigma/social exclusion was not considered to be the main focus of the paper. This resulted in 97 articles to be included in the systematic mapping (see [Fig. 1](#)) and the rest of this paper focuses on these articles.

3.1. Geographic region

The majority of studies (in this case we use the term study to refer to each paper, even though some may have included multiple studies in one paper) took place in Northwestern Europe, primarily in the United Kingdom (32%), followed by Finland (8%) and Sweden (8%) and Germany (7%). When we adjusted for population size (see [Fig. 2](#)), however, Finland had the highest number of publications per capita (1.49 publications per million inhabitants), followed by Slovenia (1.43), Sweden (0.85), Denmark (0.54) and the UK (0.50). Only a small proportion of studies (8%) included a site outside of Europe.

3.2. Study characteristics

We investigated the number of published articles over each year and we found that the number of papers has grown over time (see [Fig. 3](#)) with the largest number of studies being published in 2012 ($n = 22$). Prior to that, there was a gradual increase in the number of publications leading up to 2012. A brief comparison with the total number of publications on mental health problems using MESH terms for mental disorders in Pubmed shows an increase in research interest for both mental disorders in general and the social exclusion or stigma associated with these disorders. It should however be noted that studies focusing on stigma or social exclusion still constitute only a very small proportion of the mental health research (0.035% in 2007 to 0.054% in 2012).

Most of the studies analyzed primary data collected for the purpose of the study (65%), while about one third (34%) used secondary data. In terms of study design, most studies employed a cross-sectional design (56%) and another one quarter (24%) used a longitudinal design, usually based on existing cohort or registry data. A small proportion of studies performed qualitative research (11%); although mixed-methods designs were also considered, we did not find any articles using this approach. The smallest category comprised studies that used a randomized controlled trial or a controlled pre/post study design (9%).

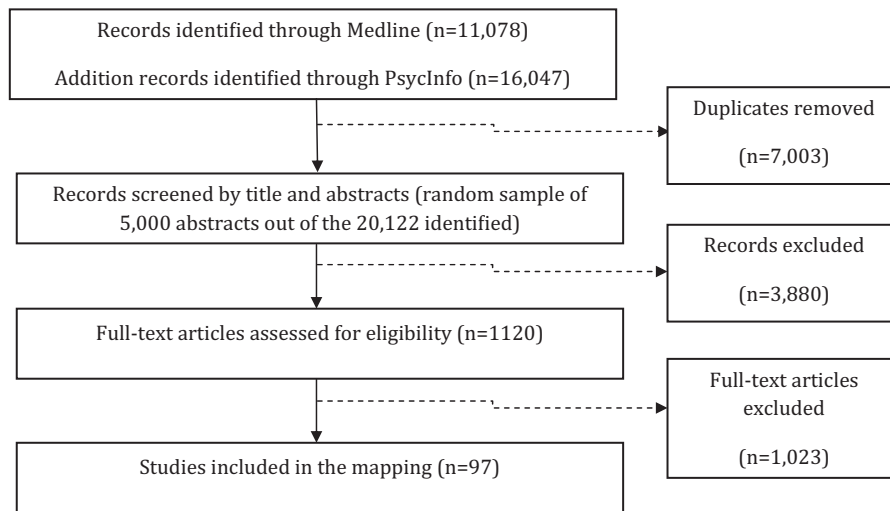


Fig. 1. Flow diagram showing study selection process.

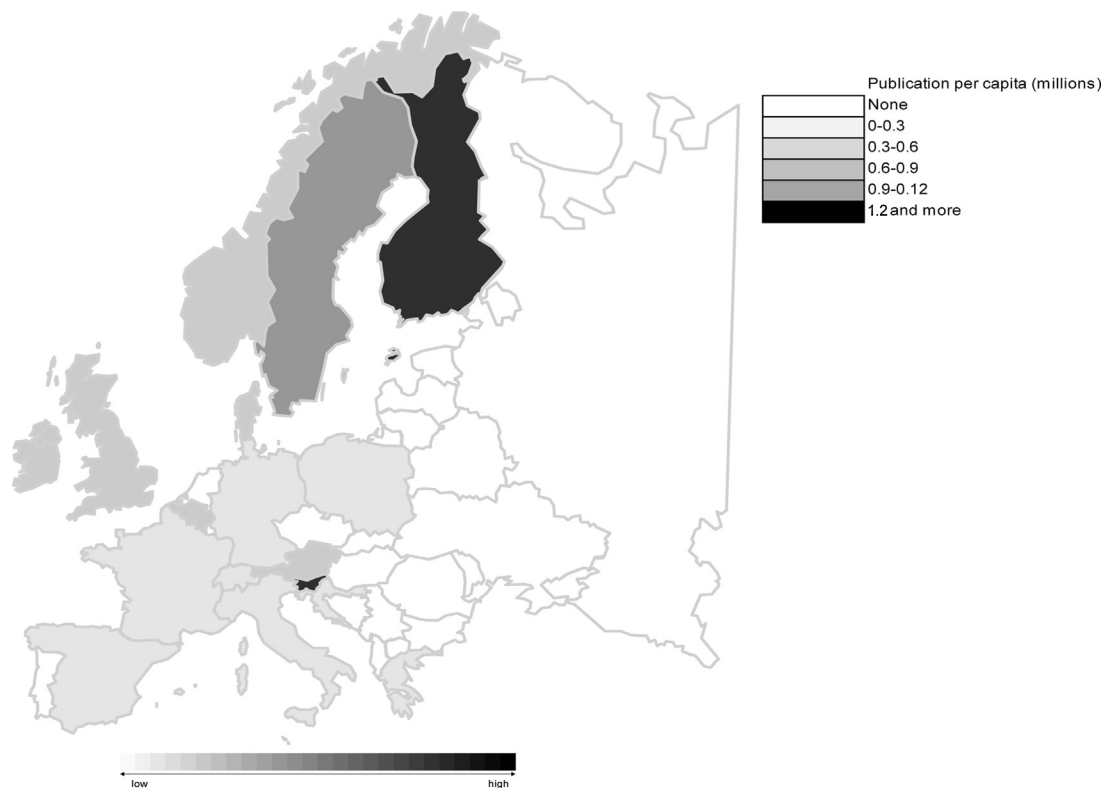


Fig. 2. Geographic distribution of research by country and size of population.

3.3. Study sample characteristics

Regarding sample composition, we characterized each study according to representation of gender, age group and mental health condition of study participants. The majority of studies included both (47%) or unspecified genders (47%), with only a small number focused on a specific gender (5% included females only). Regarding the age of study participants, the majority of studies focused on adults of working age (60%) with only a small number focused on children (6%), adolescents (1%), older adults (4%) or multiple age groups (other than children and adolescents) (5%). One quarter (25%) of studies did not specify the age group.

In terms of clinical or mental health-related characteristics, most studies referred to mental health broadly (20%) or common mental disorders without focusing on a specific mental illness (17%). Schizophrenia (16%) and depression (13%) were the only mental disorders for which there was a particular focus in the stigma and social exclusion literature (see [Table 1](#)).

3.4. Type of research performed

We characterized studies in terms of the type of study (i.e., what were the study aims) (see [Table 2](#)), study design and also in terms of the focus of the research.

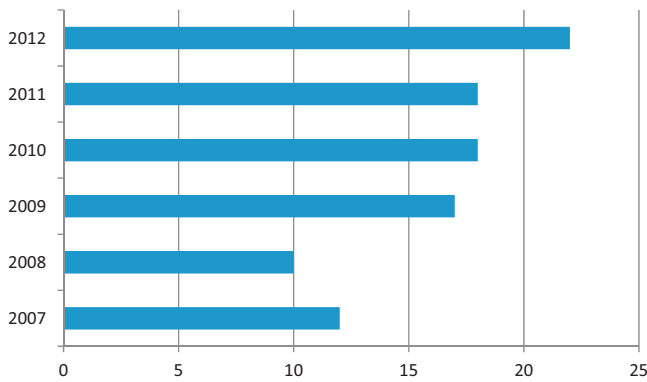


Fig. 3. Number of studies by year of publication.

When categorizing the type of study, we used an adapted version of the Health Research Classification System of the UK Clinical Research Collaboration [22]. Most of the articles included in the mapping aimed at screening at-risk populations (40%) or were underpinning research (25%). A related finding is that the majority of studies (60%) were descriptive and just under one third (29%) aimed to identify mechanisms. Only a small number of

Table 1
Mental health content reported in the articles included in the mapping.

Mental health content ^a	Frequency	Percent (%)
Mental health	19	19.7
Unspecified mental disorder or common mental disorder	17	17.5
Schizophrenia and non-affective psychosis	16	16.5
Depressive disorders	13	13.4
Unspecified	12	12.4
More than one disorder ^b	11	11.3
Trauma- and stressor-related Disorders	2	2.1
Other disorders ^c	2	2.1
Bipolar disorders	1	1
Anxiety disorders	1	1
Dementia	1	1
Autism and other neurodevelopmental disorders	1	1
Mental state	1	1
Total	97	100

^a Other potential mental health contents searched for but not reported here because no article focusing on this disorder was found include: psychiatric comorbidity; mental capacity; mental confusion; mental disability; disruptive, impulse control and conduct disorder; sexual dysfunctions; eating disorders; neurocognitive disorders; mental retardation; substance use and addictive disorders; elimination disorders; personality disorders; dissociative disorders; and somatic symptom disorders.

^b E.g. depression and psychological distress.

^c E.g. suicidal ideation.

Table 2
Overview of the types of studies included in the mapping^a.

Type of study ^a	Frequency	Percent (%)
Detection, screening and diagnosis	39	40.3
Underpinning research	24	24.7
Health and social care services research	16	16.5
Evaluation of treatments and therapeutic interventions	7	7.2
Management of diseases and conditions	6	6.2
Prevention of disease and condition, and promotion of well-being	4	4.1
Development of treatments and therapeutic interventions	1	1
Total	97	100

^a Another category – etiology – was included but not reported here as none of study conducted this type of research.

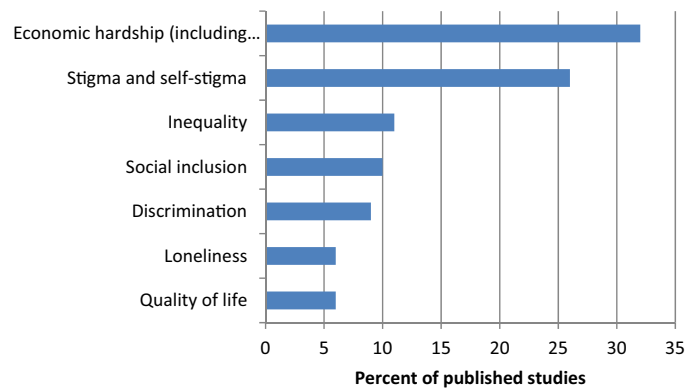


Fig. 4. Focus of the research.

studies (11%) looked at intervention development and/or evaluated interventions. In terms of the focus of the research (i.e., what are the main research topics in relation to research on stigma and social exclusion related to mental health and well-being in Europe), we identified seven main topics of study (see Fig. 4). These categories were developed inductively based on the broad categories reflected in the identified published studies. The most common focus of the research was on employment-related difficulties, and this represented 32% of studies. This was followed by research focused on stigma and self-stigma (26%), inequality (11%), social exclusion (10%), discrimination (9%), loneliness (6%) and quality of life (6%).

We also investigated the research topics by age group and found that the distribution of age groups varied by research topic (see Fig. 5). Though possibly self-evident, research pertaining to employment-related difficulties and to discrimination did not include any studies focused on children, adolescents or older adults. Research on loneliness was the category with the most research on older adults. Research on quality of life was the most equally distributed across age groups.

Finally, we examined whether published studies included a formal definition of the social issue being studied in order to better understand the theoretical underpinnings of the studies. There were 32% of the articles that included in the mapping provided a formal definition. Comparatively more studies focusing on stigma included a definition of the issue being considered. When explicitly defined, Goffman’s seminal definition of stigma as “an attribute that is deeply discrediting and that reduces the bearer from a whole and usual person to a tainted, discounted one” [20] was often quoted. In recent years, Link, Phelan and colleagues have revisited this definition to reflect advances in stigma research. Their definition distinguishes between five main components of stigma (labeling, stereotyping, separation, status loss, and discrimination) [32,33] and was used in the majority of the studies that included a definition.

4. Discussion

Overall, this systematic mapping of research on stigma and social exclusion in relation to mental health and well-being across Europe shows growing interest in this field in recent years. The growth might not be specific for stigma and social exclusion research as there were similar findings in literature mapping related to public mental health and well-being [36], and also Leeuwen [30] found growth in publications in social psychology. The systematic mapping methodology allowed us to take stock of a representative proportion of available evidence and to better understand what is known about social and economic impacts of

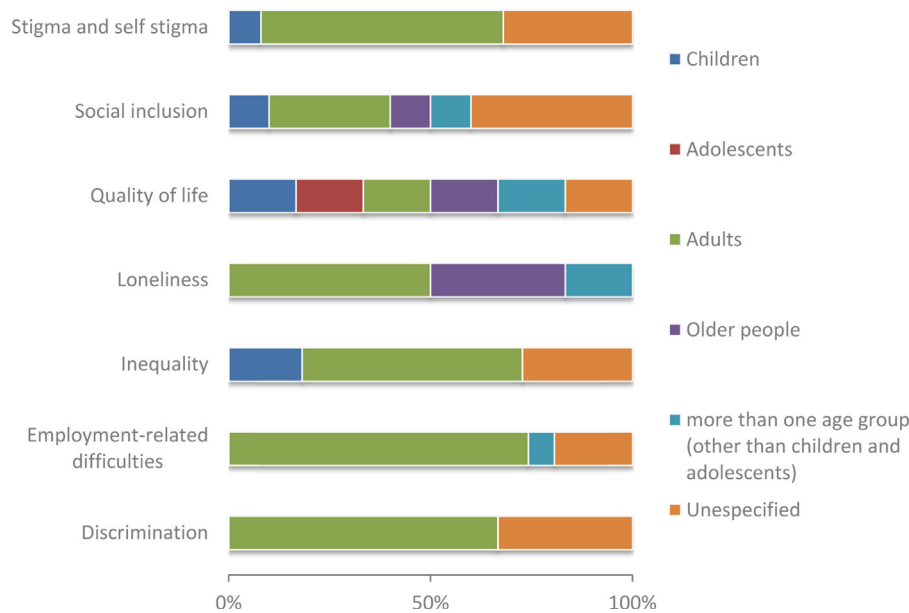


Fig. 5. Study focus by age group.

social exclusion and stigma across the life course. Moreover, this strategy also allowed us to identify geographical disparity in research in Europe and gaps in the evidence base and how these might be filled [7,31].

In terms of geographical representation, the mapping suggests that publications in relation to stigma and social exclusion are unequally distributed across European countries with most publications being from Northwestern Europe and relatively few from countries that have joined the EU since 2004, with the notable exception of Slovenia. Although we identified publications from Central and Eastern Europe, there was a substantial disparity in publications per capita in Western Europe compared to Central/Eastern Europe. It could be that this is linked to the very active role in health policy that Slovenia had during its 2008 EU presidency, including events such as the high level conference “Together for Mental Health and Well-being”. This provides a potential example of how institutions such as the rotating EU presidency could allow smaller or newer member states to gain momentum in certain areas, thereby beginning to reduce geographical inequalities. The low proportion of publications from countries that have joined the EU since 2004 is, however, not a novel finding as previous studies have shown a similar distribution, at least in terms of a low proportion of research in Eastern Europe [8]. Although the rotating presidency may be a helpful influence, it is not likely to be practicable for all countries and there may be other EU funding incentives that could be tailored to develop research capacity as well as further training and collaborative opportunities. Interestingly, the geographical distribution of research corresponds to the geographical distribution of stigma and discrimination, as measured in recent publications in that there is greater stigma in places with less research on the topic [28,44]. Thus, it could be that recognition and prioritization of stigma and social exclusion at the policy level and among researchers are important across many countries.

In recent years European networks focused on social issues in relation to mental illness and well-being have formed to facilitate research in this area across Europe. These include: the Anti-Stigma Programme European Network (ASPEN, <http://www.antistigma.eu/>), the European Network for Mental Health Service Evaluation (ENMESH, <http://www.enmesh.eu/>), Adapting

European Health Systems to Diversity (ADAPT, http://www.cost.eu/domains_actions/isch/Actions/IS1103) and the Mental Health: European Economic Network (MHEEN, <http://www.mhe-sme.org/mheen.html>). These networks generate opportunities to include a more diverse range of countries in research (all networks involved new member states), provide links to research which has not yet been published in peer-reviewed journals and may also help to “institutionalize memory” as individuals (e.g., researchers, policy-makers and other officials) move on. Nevertheless, a gap may still exist in terms of leadership on publications and research focused in countries currently lacking a research base. This is important as greater geographic diversity could help us to better understand the mechanisms and consequences of stigma and social exclusion across different cultural, economic and legal systems. There were only a small number of studies identified which included countries outside of Europe; however, there are some good examples of broad international networks such as International Study of Discrimination Stigma Outcomes (INDIGO) which are led by European researchers and are publishing work in the field. [28,44].

The mapping also identified a paucity of research on specific population sub-groups. Most research conducted focused on adults of working age. Previous reviews have also demonstrated a lack of research on stigma among children and adolescents [33]. A recent Cochrane review of mass media interventions identified none that were focused on children or adolescents [9]. This is important as early experiences of stigma and/or social exclusion among young people may lead to a cycle of social exclusion and disadvantage that is difficult to break later in life [29,41,48]. The mapping also highlighted gaps in relation to older people, a rapidly growing demographic group across Europe where loneliness has been identified as an important factor for mental health problems and decreased well-being [2,5,45]. Other research related to ROAMER has found a similar under-representation of older people in other related research areas, such as public mental health. There was also limited research in terms of other ethnic and religious minority groups including vulnerable population such as Roma, refugees or displaced people; and the relevance of this could be driven by the country in which the research was based. In terms of mental health conditions, most research focused on mental health

generally or common mental disorders. Schizophrenia was an exception and was the mental health condition associated with the greatest number of publications. Although depression was also prominent in the literature, other disorders received little attention.

In terms of the type of research, overall the papers were characterized by descriptive research with few studies of interventions or mechanisms. Advances in the field of mental health stigma and social exclusion will require a move from descriptive approaches of the phenomenon to analyses of underlying social mechanisms, which could form the basis for future interventions to reduce stigma and promote inclusion.

Most research used primary data and employed cross-sectional designs. One implication is that further longitudinal research is needed to unravel the complex relationships between mental health problems, stigma and exclusion over the life course. The review shows that there is at the moment no conclusive evidence on causal links, which would provide a good basis for the design of interventions in that area. Study design varied by research focus, with for instance a larger proportion of intervention studies in the area of stigma. It is possible that opportunities for interrogation of existing cohort studies or registries may be considered further as administrative databases in health and social care exist in many European countries and offer possibilities for analysis of large longitudinal data sets. Further consideration of data linkage and the inclusion of validated stigma and or social exclusion-related questions [4] in cohort studies would also aid future research planning. This would also be important for the promotion and integration of multidisciplinary research on the determinants of stigma and social exclusion.

The mapping identified little published work on interventions. There is a growing number of national and regional initiatives in Europe for reducing stigma and promoting social inclusion [3,39]. However, despite the existence of interventions and social policy mechanisms that have been introduced to alleviate stigma and social exclusion across Europe, few of these initiatives are evaluated and much of the information is only available in local languages [3]. Moreover, evaluations of many existing interventions lack robust methods [9] that limits the conclusions that can be drawn about the most effective ways to reduce stigma and improve social inclusion of people with mental health problems.

Our review also noted that most published research did not include a formal definition of the terms used. Interventions which did refer to a theoretical model of stigma and cite a definition mainly referred to Goffman and or Link [20,32,33]. Although we have a long history around the development of social psychological and sociological understanding of stigma processes, there seems to be a disconnect between application of theory in relation to development and evaluation of interventions to reduce stigma and social exclusion. It may be that theoretical research could be further exploited in order to introduce a stronger theoretical base to intervention work. Additionally, clarifying the meaning and use of concepts in stigma and social exclusion research has practical implications for measurement of social outcomes in the area of mental health.

4.1. *Strengths and limitations*

This systematic mapping review covered a broad range of scientific papers and investigated a wide range of outcomes. Nevertheless, our review was limited in that it only included papers with English language abstracts and we did not perform an assessment of the quality of the studies. Covering such a broad area of research resulted in a very large number of abstracts to be retrieved and thus we were only able to review a random subsample of publications, even though this was still quite a large

sample of 5000 papers. As we did not review all studies, it is possible that there may be some countries with a small number of studies which were missed from our review and thus, we lacked the statistical power to test and examine some more finely grained sub-questions. Additionally, as we were focused on mapping scientific publications, we did not include grey literature or doctoral theses; the inclusion of these sources may have generated different patterns of activity as certain countries or disciplines may have different traditions in relation to the publication of research findings in books or monographs. Using a random sample of a large number of studies, however, should have led to a representative set of papers in terms of the study characteristics and geographic patterns.

5. **Conclusion**

The current social and economic circumstances in Europe highlight the social challenges of improving population mental health and well-being during times of hardship, particularly as these are periods during which the impact of stigma and social exclusion may be exacerbated. Our findings suggest that there has been a growth in research on stigma and social exclusion across Europe in recent years, which has helped decision-makers and citizens more generally gain a better understanding of the characteristics of individuals and populations which are associated with greater or less stigma and social inclusion. More research is needed on the mechanisms of reducing stigma and social exclusion, in addition to factors which might promote resilience or protect against stigma and social exclusion across the life course. In relation to mechanisms, we need greater connection between application of theory on development and evaluation of intervention, in addition to more robust evaluation of interventions to understand the most effective ways of promoting inclusion and reducing stigma across individuals and populations. Currently, research around stigma and social exclusion is unequally distributed across Europe and little research exists to contextualize these issues globally. Increasing incentives for cross-country research collaborations, especially with new EU Member States and with collaborations outside Europe, could help improve understanding of the diverse range of underpinning social and cultural factors which promote inclusion or contribute toward lower levels of stigma, especially during times of hardship. Additionally, collaboration across various European professional organizations and across a range of scientific disciplines could facilitate more diverse networks, and potentially promote creative approaches and more translation of research theory into practice. Europe is uniquely placed and may have a comparative advantage to research in comparison to other parts of the world as the heterogeneity in economic circumstances, population characteristics, and social-welfare/protection systems allows for interesting comparisons across countries. Incorporation of stigma measures in cohort or panel studies could help elucidate mechanisms and explore associations, while also facilitating natural experiments as a basis for evaluating policies or interventions which are introduced unevenly either over time [27] or across different cultural or other contexts. Proxy measures of social inclusion and exclusion are available in administrative databases, and measures to promote access and analyses of “big data” need to be fostered. Finally, cross-country collaborations and interdisciplinary collaborations should create opportunities for research which makes use of the rich theoretical frameworks that have been developed over time and evaluates them in real world settings.

Disclosure of interest

SEL received consulting fees from Lundbeck. The other authors declare that they have no conflict of interest.

Acknowledgements

The research within the ROAMER Project leading to these results has received funding from the European Union Seventh Framework Program (FP7/2007-2013) under Grant Agreement n° 282586.

Appendix 1. Systematic mapping search terms

Social exclusion search terms (title or abstract)

(Social exclusion OR socially excluded OR social isolation OR socially isolated OR social rejection OR socially rejected OR (social adj3 disadvantage) OR (social adj3 disadvantages) OR (social adj3 disadvantaged) OR social alienation OR (socially inactive) OR (social adj3 inactivity) OR (social adj3 inactive) OR (social adj3 inaction) OR social outcast OR underclass OR social distance OR social hierarchy OR anomie OR vulnerable populations OR underprivileged OR Social inclusion OR socially included OR social capital OR social cohesion OR Social engagement OR socially engaged OR social involvement OR socially involved OR Social participation OR social cohesion OR social capital OR Social environment OR social insurance OR social protection OR social security OR social support OR social welfare OR social well-being OR social well-being OR support networks OR welfare benefit OR welfare rights OR minimum income OR minimum wage Social adjustment OR social interaction OR social interactions OR social justice OR social networks OR social adaptation OR Interpersonal relations OR social interaction OR social responsibility OR Social responsibilities OR right to treatment OR Inequity OR disparity OR disparities OR unfair treatment OR differential treatment OR social discrimination OR prejudice OR Social characteristics OR shame OR stigma OR stigmatise OR stigmatizing OR stigmatization OR stigmatization OR social perception OR stereotype OR stereotyping OR

Barriers or barrier OR social class OR right to treatment OR social segregation OR

Community participation OR community support OR community networks OR community

mental health services OR (Neighbourhood AND support) OR (neighborhood support) OR

(Friends AND support) OR friendship OR Family life OR family relations OR family relationships OR family relationship OR partner OR communication OR family support OR Marriage OR divorce OR marital status OR Civil rights OR human rights OR basic rights OR

Rights AND (freedom OR move OR movement) OR food OR starvation OR starving OR

Hunger OR Political rights OR vote OR voting OR voice OR voicing OR politically active OR politically inactive OR politically engaged OR political engagement OR autonomy OR

Patient rights OR (rights AND health) OR (rights AND physical health) OR (rights AND

somatic health) OR (rights AND healthcare) OR standard of care OR living will OR poor

healthcare OR professional patient relationship OR right to treatment OR

Data protection OR access to information OR informed consent OR community networks

OR confidentiality OR (Patient adj3 access adj3 medical records) OR

Consent to treatment OR forced treatment OR cruel treatment OR inhuman treatment OR

inhumane treatment OR degrading treatment OR Involuntary admission OR involuntary interventions OR involuntary treatment OR (involuntary AND medication) OR coercion OR coerce OR threat OR threaten OR refuse to treatment OR treatment refusal OR

Maltreatment OR maltreat OR persecution OR persecute OR punishment OR punish Rights AND (child bearing OR pregnant OR pregnancy OR parenting OR abortion) OR

unwanted pregnancy OR Access AND (social services OR public services OR mental health services OR public facilities) OR Socio-economic factors OR economically inactive OR (gap adj3 income) OR (socio-economic adj3 inequalities) OR (socio-economic adj3 inequality) OR (social adj3 inequalities) OR (social adj3 inequality) OR Low income OR (income adj3 inequality) OR (income adj3 inequalities) OR (poor adj3 community) OR (poor adj3 family) OR (poor adj3 families) OR (poor adj3 household) OR (poor adj3 households) OR (poor adj3 neighbourhood) OR (poor adj3 neighborhood) OR poor adj3 community OR (poor adj3 income) OR (poor adj3 money) OR deprivation OR deprive OR low earning OR poverty OR low wage OR low wages OR (Practice adj3 monitor) OR (quality adj3 care) OR (quality adj3 services) OR (complain and services) OR treatment guidelines OR admission principles OR

Poor housing OR residence characteristics OR (poor AND accommodation AND standard)

OR (rights adj3 ownership) OR (rights adj3 assets) OR (poor housing) OR (poor

adj3 shelter) OR housing conditions OR living conditions OR rights adj3 treatment OR

Homeless or homelessness OR (Access AND education) OR job and training OR (rights adj3 education) OR basic skill OR basic skills OR continuing education OR education OR poor education OR qualification OR illiteracy OR adult education OR educational status OR educational achievement OR special education OR Labour market OR labor market OR employment OR labour force OR labor force OR workforce OR employment OR employed

Unemployed OR unemployment OR Occupations OR (Job AND flexibility) OR (flexible AND job) OR (work AND voluntary) OR paid job OR paid work OR working conditions OR lonel*)

Mental illness and mental health and well-being search terms (title or abstract)

((“drug abuse” OR “drug addict” OR “drug addicts” OR “drug addiction” OR “drug addicted” OR “drug dependent” OR “drug dependence” OR “drug withdrawal” OR “drug abuse”) OR (“addictive disease” OR “addictive disorder”) OR (“alcoholic patient” OR “alcoholic subject” OR alcoholism OR “alcohol dependent” OR “alcohol dependence” OR “fetal alcohol” OR “prenatal alcohol” OR “chronic ethanol” OR “chronic* alcohol” OR “alcohol withdrawal” OR “ethanol withdrawal”) OR (“caffeine dependent” OR “caffeine dependence” OR “caffeine addiction” OR (caffeine AND addict*) OR “caffeine withdrawal”) OR (((cocaine OR heroin OR cannabis OR mdma OR ecstasy OR morphine*) AND (abuse OR depend* OR dependent* OR dependence* OR addict* OR addicts OR addicted OR addiction* OR withdrawal)) OR methadone) OR (addiction OR addictive OR “substance abuse” OR “withdrawal syndrome” OR psychoactive*) OR ((schizophrenia OR schizophrenic) OR Schizotyp* OR ((Delusional OR paranoid) AND disorder*) OR hallucination* OR Psychotic OR Schizoaffective OR psychosis) OR (((manic OR bipolar OR mood) AND disorder*) OR (depressive AND (disorder* OR episode*)) OR “depressive symptom” OR hypomania OR mania* OR ((major OR psychotic OR disorder*) AND depression) OR “suicide attempt” OR suicidal* OR cyclothymia OR Dysthymia) OR (((anxiety OR panic OR “Obsessive-compulsive” OR adjustment OR conversion OR dissociative OR Somatoform OR Somatization OR neurotic) AND disorder*) OR (“hypochondriasis” OR “body dysmorphic disorder” OR “pain disorder”) OR agoraphobia OR “social phobia” OR “Post-traumatic stress” OR “stress disorder”) OR (“Eating disorder” OR “Anorexia nervosa” OR “Bulimia nervosa” OR “sleep disturbance” OR (sexual AND (disorder* OR dysfunction)) OR ((postnatal OR postpartum) AND depression) OR ((antidepressant* OR laxative* OR analgesic* OR psychotropic* OR vitamin* OR steroids

OR hormone*) AND abuse)) OR (((insomnia OR sleepiness OR "sleep disturbance") NOT (apnea OR "side effect*" OR parkinson* OR alzheimer OR neurodegenerat* OR cancer OR obesity OR obese*)) OR (hypersomnia NOT narcolepsy) OR ((sleep OR night) AND terror*) OR nightmare*) OR ((disorder* AND (personality OR identity OR impulse* OR impulsive* OR impulsivity)) OR asocial OR antisocial OR psychopathic OR anxious OR narcissi* OR "Pathological gambling" OR pyromania* OR Trichotillomania OR Psychosexual OR ("Munchhausen syndrome")) OR ("Pervasive developmental disorder*" OR autism OR autistic* OR "Rett* syndrome" OR "Asperger* syndrome") OR (((Hyperkinetic OR Conduct OR Emotional OR tic) AND disorder*) OR (anxiety AND (separation OR phobic OR social)) OR (hyperactivity AND (disorder* OR syndrome)) OR "Tourette syndrome" OR "Tourette's syndrome") OR ((Mental AND (disorder* OR illness OR health)) OR "psychological distress" OR "psychiatric disorder") OR (Nervousness OR "nervous tension" OR Irritability)) OR anorexia OR (neurosis OR neuroses OR psychoses) OR (("mental confusion*") OR ("mental disability*") OR ("mental capacity*") OR ((psychiatric OR mental) AND (comorbidity OR comorbid)) OR psychiatry OR psychology))

References

- [1] Angermeyer MC, Matschinger H, Schomerus G. Public attitudes towards people with depression in times of uncertainty: results from three population surveys in Germany. *Soc Psychiatry Psychiatr Epidemiol* 2013;48(9):1513–8.
- [2] Barg FK, Huss-Ashmore R, Wittink MN, Murray GF, Bogner HR, Gallo JJ. A mixed-methods approach to understanding loneliness and depression in older adults. *J Gerontol B Psychol Sci Soc Sci* 2006;61(6):S329–39.
- [3] Beldie A, den Boer JA, Brain C, Constant E, Figueira ML, Filipic I, et al. Fighting stigma of mental illness in midsize European countries. *Soc Psychiatry Psychiatr Epidemiol* 2012;47(Suppl. 1):1–38.
- [4] Brohan E, Slade M, Clement S, Thornicroft G. Experiences of mental illness stigma, prejudice and discrimination: a review of measures. *BMC Health Serv Res* 2010;10:80.
- [5] Cattan M, White M, Bond J, Learmouth A. Preventing social isolation and loneliness among older people: a systematic review of health promotion interventions. *Ageing and Society* 2005;25:41–67.
- [6] Chevreur K, McDaid D, Farmer CM, Prigent A, Park AL, Leboyer M, et al. United and nonprofit funding for research on mental disorders in France, the United Kingdom, and the United States. *J Clin Psychiatry* 2012;73(7):e906–12.
- [7] Clapton J, Rutter D, Sharif N. Systematic mapping guidance. London: Social Care Institute for Excellence; 2009.
- [8] Clarke A, Gatineau M, Grimaud O, Royer-Devaux S, Wyn-Roberts N, Le B. I, et al. A bibliometric overview of public health research in Europe. *Eur J Public Health* 2007;17(Suppl. 1):43–9.
- [9] Clement S, Lassman F, Barley E, Evans-Lacko S, Williams P, Yamaguchi S, et al. Mass media interventions for reducing mental health-related stigma. *Cochrane Database Syst Rev* 2013;7 [CD009453].
- [10] Corker E, Hamilton S, Henderson C, Weeks C, Pinfold V, Rose D, et al. Experiences of discrimination among people using mental health services in England 2008–2011. *Br J Psychiatry Suppl* 2013;55:s58–63.
- [11] Corrigan PW, Morris SB, Michaels PJ, Rafacz JD, Rusch N. Challenging the public stigma of mental illness: a meta-analysis of outcome studies. *Psychiatr Serv* 2012.
- [12] Curran C, Burchardt T, Knapp M, McDaid D, Li B. Challenges in multidisciplinary systematic reviewing: a study on social exclusion and mental health policy. *Soc Policy Adm* 2007;41(3):289–312.
- [13] Evidence for Policy and Practice Information and Co-ordinating Centre. EPPI-Centre methods for conducting systematic reviews. University of London; 2010.
- [14] Evans-Lacko S, Brohan E, Mojtabai R, Thornicroft G. Association between public views of mental illness and self-stigma among individuals with mental illness in 14 European countries. *Psychol Med* 2012;16:1–13.
- [15] Evans-Lacko S, Knapp M, McCrone P, Thornicroft G, Mojtabai R. The mental health consequences of the recession: economic hardship and employment of people with mental health problems in 27 European countries. *PLoS One* 2013;8(7):e69792.
- [16] Fazel S, Khosla V, Doll H, Geddes J. The prevalence of mental disorders among the homeless in western countries: systematic review and meta-regression analysis. *PLoS Med* 2008;5(12):e225.
- [17] Fiorillo A, Luciano M, Del Vecchio V, Sampogna G, Obradors-Tarragó C, Maj M, et al. Priorities for mental health research in Europe: a survey among national stakeholders' associations within the ROAMER project. *World Psychiatry* 2013;12(2):165–70.
- [18] Gili M, Roca M, Basu S, McKee M, Stuckler D. The mental health risks of economic crisis in Spain: evidence from primary care centres, 2006 and 2010. *Eur J Public Health* 2013;23(1):103–8.
- [19] Goffman E. *Stigma: notes on the management of spoiled identity*. Englewood Cliffs, NJ: Prentice-Hall; 1963.
- [20] Goodman A, Joyce R, Smith JP. The long shadow cast by childhood physical and mental problems on adult life. *Proc Natl Acad Sci U S A* 2011;108(15):6032–7.
- [21] Health Research Classification System of the UK Clinical Research Collaboration. UK Clinical Research Collaboration; <http://www.ukcrcl.org/researchcoordination/classificationsystem/>.
- [22] Haro J, Ayuso-Mateos JL, Biter I, Demotes-Mainard J, Leboyer M, Lewis S, et al. ROAMER: a European Roadmap for mental health research. *Int J Methods of Psychiatr Res* 2014;23(Suppl 1):1–13.
- [23] Hong J, Knapp M, McGuire A. Income-related inequalities in the prevalence of depression and suicidal behaviour: a 10-year trend following economic crisis. *World Psychiatry* 2011;10(1):40–4.
- [24] Kilian R, Becker T. Macro-economic indicators and labour force participation of people with schizophrenia. *J Ment Health* 2007;16(2):211–22.
- [25] Knapp M, King D, Healey A, Thomas C. Economic outcomes in adulthood and their associations with antisocial conduct, attention deficit and anxiety problems in childhood. *J Ment Health Policy Econ* 2011;14(3):137–47.
- [26] Lanfredi M, Rossi G, Rossi R, Van BT, Thornicroft G, Quinn N, et al. Depression prevention and mental health promotion interventions: is stigma taken into account? An overview of the Italian initiatives. *Epidemiol Psychiatr Sci* 2013;22(4):363–74.
- [27] Lasalvia A, Zoppi S, Van Bortel T, Bonetto C, Cristofalo D, Wahlbeck K, et al. Global pattern of experienced and anticipated discrimination reported by people with major depressive disorder: a cross-sectional survey. *Lancet* 2013;381(9860):55–62. <http://www.ncbi.nlm.nih.gov/pubmed/23083627>.
- [28] Lasalvia A, Zoppi S, Bonetto C, Tosato S, Zanatta G, Cristofalo D, et al. The role of experienced and anticipated discrimination in everyday life of people with first-episode psychosis. *Psychiatr Serv* 2014.
- [29] Leeuwen T. Publication trends in social psychology journals: A long-term bibliometric analysis. *Eur J Soc Psychol* 2013;43(1):9–11.
- [30] Leone T, Coast E, Narayanan S, de Graft AA. Diabetes and depression comorbidity and socio-economic status in low and middle income countries (LMICs): a mapping of the evidence. *Global Health* 2012;8:39.
- [31] Link BG, Struening EL, Neese-Todd S, Asmussen S, Phelan JC. Stigma as a barrier to recovery: The consequences of stigma for the self-esteem of people with mental illnesses. *Psychiatr Serv* 2001;52(12):1621–6.
- [32] Link BG, Yang LH, Phelan JC, Collins PY. Measuring mental illness stigma. *Schizophr Bull* 2004;30(3):511–41.
- [33] McDaid D, Quaglio G, Correia de CA, Dario C, Van WL, Karapiperis T, et al. Health protection in times of economic crisis: challenges and opportunities for Europe. *J Public Health Policy* 2013;34(4):489–501.
- [34] McLeod JD, Fettes DL. Trajectories of failure: the educational careers of children with mental health problems. *AJS* 2007;113(3):653–701.
- [35] Miret M, Marchena C, Caballero F, Obradors-Tarrago C, Haro J, Ayuso-Mateos JL. A systematic mapping of well-being research in Europe; [submitted] 2014.
- [36] Mittal D, Sullivan G, Chekuri L, Allee E, Corrigan PW. Empirical Studies of Self-Stigma Reduction Strategies: A Critical Review of the Literature. *Psychiatr Serv* 2012.
- [37] OECD. Sick on the job: myths and realities about mental health and work; 2012. <http://dx.doi.org/10.1787/9789264124523-en>.
- [38] Quinn N, Knifton L, Goldie I, Van BT, Dowds J, Lasalvia A, et al. Nature and impact of European anti-stigma depression programmes. *Health Promot Int* 2013.
- [39] Rusch N, Corrigan PW, Wassel A, Michaels P, Larson JE, Olschewski M, et al. Self-stigma, group identification, perceived legitimacy of discrimination and mental health service use. *Br J Psychiatry* 2009;195(6):551–2.
- [40] Rusch N, Heekeren K, Theodoridou A, Dvorsky D, Muller M, Paust T, et al. Attitudes towards help-seeking and stigma among young people at risk for psychosis. *Psychiatr Res* 2013;210(3):1313–5.
- [41] Ten HM, de GR, van WJ, van DS. The association between common mental disorders and violence: to what extent is it influenced by prior victimization, negative life events and low levels of social support? *Psychol Med* 2013;4:1–14.
- [42] Thornicroft G, Shunned. *Discrimination against People with Mental Illness*. Oxford: Oxford University Press; 2006.
- [43] Thornicroft G, Brohan E, Rose D, Sartorius N, Leese M. Global pattern of experienced and anticipated discrimination against people with schizophrenia: a cross-sectional survey. *Lancet* 2009;373(9661):408–15.
- [44] Victor C, Scambler S, Bowling A, Bond J. The prevalence of, and risk factors for, loneliness in later life: a survey of older people in Great Britain. *Ageing Soc* 2005;25(3):357–75.
- [45] Wahlbeck K, Awolin M. The impact of economic crises on the risk of depression and suicide: a literature review. European Commission; 2009.
- [46] Wahlbeck K, Westman J, Nordentoft M, Gissler M, Laursen TM. Outcomes of Nordic mental health systems: life expectancy of patients with mental disorders. *Br J Psychiatry* 2011;199(6):453–8.
- [47] Yap MB, Reavley NJ, Jorm AF. The associations between psychiatric label use and young people's help-seeking preferences: results from an Australian national survey. *Epidemiol Psychiatr Sci* 2013;25:1–9.