Impact case study (REF3b)



Institution: King's College London (KCL)

Unit of Assessment: UoA4 – Psychology, Psychiatry & Neuroscience

Title of case study: 20: Reducing mental health stigma across England

1. Summary of the impact

Time to Change (TTC) is a national programme to reduce stigma and discrimination related to mental health. King's College London (KCL) researchers have conducted most of the original research that led to the intervention, had a major role in planning TTC with two leading mental health charities, Mind and Rethink Mental Illness, and have led the evaluation of the programme. That TTC is making a difference across England is evidenced by gradual positive changes in attitudes and behaviour. KCL measures are also being used by the UK Government and to evaluate anti-stigma campaigns in Denmark, New Zealand and Sweden.

2. Underpinning research

Stigma and discrimination against people with mental illness are widespread and severe, limit recovery from illness and reduce social inclusion. Research at Institute of Psychiatry, King's College London (KCL) has provided an international gold standard for working with mental health charities to create and apply evidence of cost-effectiveness of anti-stigma campaigns. Researchers include Prof Graham Thornicroft (1989-current, Professor of Community Psychiatry), Prof Paul McCrone (1992-current, Professor of Health Economics), Dr Diana Rose (2001-current, Reader in User-Led Research), Dr Vanessa Pinfold (1998-2003, Project Coordinator), Dr Sarah Clement (2008-present, Lecturer), Dr Claire Henderson (1999-2003, 2008-present, Clinical Senior Lecturer), Dr Elaine Brohan (2006-2012, PhD student) and Dr Evans-Lacko (2007-present, Lecturer).

KCL researchers develop and test interventions to address stigma: To reduce stigma-related attitudes and behaviour, and increase knowledge about mental illness, KCL researchers developed original interventions based on the principle of 'social contact' between people with and without experience of mental health problems as the most important active ingredient in anti-stigma interventions. In 2003, training workshops based on this principle demonstrated that for 109 police officers the mean attitude score improved significantly and 70% successfully reported more positive messages about mental illness at follow-up compared to baseline (1). Similar positive results were found in a study with 14 year old school students (2). In refining this approach for health professionals, a controlled trial with 110 medical students found a significant positive effect of factual content and personal testimonies training improved knowledge (3).

KCL researchers went on to develop, pilot and refine interventions suitable for the general population level. In the 'Time to Change Cambridge' pilot anti-stigma campaign, 410 interviews with members of the general population before, during and after the local prototype campaign activity showed significant and sustained positive changes for mental health-related knowledge items following the campaign. For instance there was a 24% increase in those agreeing with the statement "If a friend had a mental health problem, I know what advice to give them to get professional help." However, no significant changes were evident for attitudinal or behaviour related questions, highlighting a need to concentrate on improving this area when the campaign went live across England (4).

KCL researchers develop measures to assess stigma and discrimination: Stigma is comprised of three constructs: knowledge (ignorance), attitudes (prejudice) and behaviour (discrimination). Over the past 13 years, KCL researchers have developed a comprehensive set of scales to evaluate these concepts in anti-stigma campaigns. Development involved three studies with 532 adults who completed face-to-face or online interviews or surveys. The Mental Health Knowledge Schedule (MAKS) consists of stigma-related mental health knowledge domains (e.g. help seeking, recognition, employment) and items about knowledge of mental illnesses. Testing found it to be a brief and feasible measure (5). The Reported and Intended Behaviour Scale (RIBS) assesses reported (past and current) and intended (future) behavioural discrimination. The scale has high internal consistency, test-retest reliability and consensus validity, as rated by service users and international experts in stigma research (6).

The stigma associated with mental health can lead to social marginalisation and low quality of life. KCL researchers transformed thinking in this field by emphasising the central importance of

Impact case study (REF3b)



discrimination i.e. the behavioural domain (7), and by developing a psychometrically validated measure to assess experienced discrimination. The **Discrimination and Stigma Scale (DISC)** was developed with the pioneering Service User Research Enterprise group at KCL (8). DISC has been used in large international studies including a cross-sectional survey in 27 countries of face-to-face interviews with 732 participants with schizophrenia showed that negative discrimination was experienced by 47% in making or keeping friends, by 43% from family members, by 29% in finding or keeping a job. Anticipated discrimination affected 64% in applying for work, training or education and 55% in looking for a close relationship. KCL researchers concluded that measures, such as disability discrimination laws, might not be effective without interventions to improve self-esteem of people with mental illness (9).

The media play an important role in perpetuating the stigma of mental illness and a KCL analysis of UK media coverage from 1992 to 2008 found that media coverage was not significantly improving (10) and that encouraging 'positive' reporting would be fruitful avenue for campaigners.

3. References to the research

- 1. Pinfold V, Huxley P, Thornicroft G, Farmer P, Toulmin H, Graham T. Reducing psychiatric stigma and discrimination: evaluating an educational intervention with the police force in England. Soc Psychiatry Psychiatr Epidemiol 2003; 38: 337-44. Doi: 10.1007/s00127-003-0641-4 (117 Scopus Citations).
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- 3. Kassam A, Glozier N, Leese M, Loughran J, Thornicroft G. A controlled trial of mental illness related stigma training for medical students. BMC Med Educ 2011;11:51. Doi: 10.1186/1472-6920-11-51 (7 Scopus Citations).
- 4. Evans-Lacko S, London J, Little K, Henderson C, & Thornicroft G. Evaluation of a brief antistigma campaign in Cambridge: do short-term campaigns work? BMC Public Health 2010;14;10:339. Doi: 10.1186/1471-2458-10-339 (17 Scopus Citations).
- Evans-Lacko S, Little K, Meltzer H, Rose D, Rhydderch D, Henderson C, Thornicroft G. Development and psychometric properties of the mental health knowledge schedule (MAKS), Can J Psychiatry 2010;55(7):440-8. Link: http://publications.cpa-apc.org/media.php?mid=996 (15 Scopus Citations).
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- 7. Thornicroft G, Rose D, Kassam A. Stigma: ignorance, prejudice or discrimination. British Journal of Psychiatry 2007; 190:192-3. (152 Scopus Citations).
- 8. Brohan E, Clement S, Rose D, Sartorius N, Slade M, Thornicroft G. Development and psychometric evaluation of the Discrimination and Stigma Scale (DISC). Psychiatry Res 2013; 208(1):33-40. Doi: 10.1016/j.psychres.2013.03.007. (1 Scopus Citation).
- 9. Thornicroft G, Brohan E, Rose D, Sartorius N, Leese M; INDIGO Study Group. Global pattern of experienced and anticipated discrimination against people with schizophrenia: a cross-sectional survey. Lancet 2009; 373:408-15. Doi: 10.1016/S0140-6736(08)61817-6 (146 Scopus Citations).
- 10. Goulden R, Corker E, Evans-Lacko S, Rose D, Thornicroft G, Henderson C. Newspaper coverage of mental illness in the UK, 1992-2008. BMC Public Health 2011 October 12; 11(1):796. Doi:10.1186/1471-2458-11-796 (3 Scopus citations)

Grants (PI: Graham Thornicroft)

- 2000-06: Lundbeck Stigma Phase 1-3 (3 grants in total £321,6000)
- 2004-06: Guy's and St Thomas' Charity Anti-stigma project (£160,923)
- 2006-09: Lundbeck Anti-Stigma Training and Evaluation Collaboration (£80,000)
- 2007-10: EU DG SANCO ASPEN stigma project (£195,028)
- 2007-11: Big Lottery, Comic Relief, Department of Health Time to Change (£1,874,957)
- 2007-12: National Institute for Health Research Programme Grant for Applied Research: SAPPHIRE (£2,000,000)



4. Details of the impact

Tracking progress of Time to Change (TTC): TTC, launched in January 2009, is England's biggest ever programme to tackle stigma and discrimination against people with mental health problems (1a). TTC includes a social marketing campaign and both large-scale and locally-based initiatives aiming to bring together people with and without experience of mental illness. King's College London (KCL) research greatly contributed to the development of TTC from initiation of the first phase in 2008, led by the mental health charities Mind and Rethink Mental Illness (1b). KCL's Institute of Psychiatry continues to be TTC's evaluation partner, collaborating with TTC to track the progress and impact of the campaign and to allow the charities to improve their interventions (1c). Between 2009 and 2011, KCL and Rethink Mental Illness carried out a series of national phone surveys using the DISC scale with 3,579 mental health service users. They found high levels of experiences of discrimination in the previous 2 months, that significantly reduced over the first 4 years of the TTC programme (91% in 2008, 88% in 2011) (1d,e).

KCL research influences Time to Change campaigns: A KCL-led TTC survey of nearly 7,000 people using the KCL measures (MAKS and RIBS) indicated that for 2009-12 there were improvements in intended behaviour and a positive trend in attitudes. They also showed that social contact, the core active ingredient to reduce stigma, is increasing. In 2008, 52.5% of the general population sample stated they did not know anyone with a mental illness compared to 37.7% in 2012 (2a). KCL evaluations of TTC social marketing campaigns shows consistently positive relationships between campaign awareness and more favourable knowledge, attitudes and intended behaviour, such as 'willingness to live with someone with a mental health problem' (2b). These were key areas of focus highlighted by previous KCL research (Evans-Lacko S et al. 2010)

KCL's evaluation of TTC media campaigns offers insights that then allow TTC to target audiences more specifically for each phase of the programme. In their 2012 project report, TTC state that "the evidence from KCL research that...some bursts had more impact with Black and Minority Ethnic audiences while some had less [made it] possible to adapt the number of radio ads aired and media buying to resonate better with [this] audience" (2c). KCL research (Pinfold V 2003, Kassam A 2011) highlighting the strength of the association between outcomes and social contact influenced the messaging of later campaign bursts and TTC's social contact programme. By July 2013, more than 41,000 people had pledged via the TTC website to help end prejudice and more than 119,000 people 'like' the TTC Facebook page. A KCL survey on these Facebook fans found that "social media empowered people to speak out about their mental health and challenge stigma and discrimination." As a result the project was able to count people engaged through Facebook and Twitter towards its targets (2c). Research by KCL (Goulden R, 2011) also led to the inclusion of a media target in the TTC campaign. Indeed, KCL analysis showed that press coverage of mental illness had improved over the course of the campaign, with TTC achieving a higher proportion of anti-stigmatising coverage (2d). Since then, TTC has held events for journalists on coverage of mental health. Building on KCL research (Pinfold 2003, Kassam 2011), TTC's Education Not Discrimination (END) project, run by Rethink Mental Illness, targets medical students and trainee teachers (2e). The intervention produced short-term improvements in stigmarelated knowledge, attitudes and intended behaviour (2f).

Contribution of KCL to TTC's sustainability and Department of Health measures: In 2010 TTC cited KCL's evaluation findings in its bid to the Department of Health (DH) for continued funding (3a). In 2011, the DH announced £16m funding for TTC Phase 2 (3b) and the work of TTC was commended during the Mental Health debate on June 14th 2012, during which four MPs disclosed their experiences of mental health problems (3c). In 2011, the Government, in its 'No health without mental health' strategy, pledged to work with TTC "to agree the best ways to assess improvements over the lifetime of this strategy" (3d). In the subsequent 'Implementation Framework' for this strategy the three main components of KCL's evaluation of TTC Phase 2 are listed as the methods of assessing progress towards the objective in the strategy that "fewer people will experience stigma and discrimination." KCL staff liaised with the DH on inclusion of KCL measures in its national Dashboard assessing progress towards this objective. Implementing the strategy will include encouraging "a range of organisations [to] sign up to the TTC Campaign, to raise the profile of mental health and to address stigma among staff" (3e). KCL research

Impact case study (REF3b)



evaluating the Cambridge pilot trial (Evans-Lacko S et al 2010) is also cited in the evidence supporting the Government's commitment to reducing mental health stigma (3f).

Further use of KCL measures: In collaboration with KCL, in 2010 DISC was adapted for use in New Zealand as part of the government's 'Like Minds Like Mine' national anti-stigma campaign to survey 1,135 mental health service users. The authors highlight how the model provided by KCL was the only similar project in the world they could identify (4a). Additionally, MAKS, RIBS and DISC are being used to evaluate Sweden's anti-stigma campaign (4b) and DISC is being used by the company Ethnos to conduct a TTC-commissioned survey of mental health related discrimination among 750 Black and Minority Ethnic people with mental health problems (4c).

5. Sources to corroborate the impact

1) Time to Change

- a. Website: http://www.time-to-change.org.uk/
- b. KCL paper's being cited as essential to TTC: http://www.time-to-change.org.uk/research-reports-publications/campaign
- c. Examples of KCL's role in TTC:
- http://www.time-to-change.org.uk/legacy
- http://www.time-to-change.org.uk/sites/default/files/Background%20and%20achievements.pdf
- d. Henderson C, et al. Psychiatr Serv. 2012;63(5):451-7. Doi: 10.1176/appi.ps.201100422
- e. Corker E, et al. Br J Psychiatry Suppl 2013;55:s58-63. Doi: 10.1192/bjp.bp.112.112912

2) Time to Change campaigns

- a. Evans-Lacko S, et al. Br J Psychiatry Suppl 2013;55:s51-7. Doi: 0.1192/bjp.bp.112.112979
- b. Evans-Lacko S, et al. Br J Psychiatry Suppl 2013;55:s77-88. Doi: 10.1192/bjp.bp.113.126672
- c. TTC Projects 2012 (pgs 3, 5, 6): http://www.time-to-change.org.uk/sites/default/files/The%20Time%20to%20Change%20projects.pdf
- d. Thornicroft A, et al. Br J Psychiatry Suppl 2013;55:s-64-s69. Doi:10.1192/bjp.bp.112.112920
- e. Education Not Discrimination: http://www.time-to-change.org.uk/about-us/end
- f. Friedrich B, et al. Br J Psychiatry Suppl 2013;55:s89-94. Doi: 10.1192/bjp.bp.112.114017

3) Contribution of KCL to TTC's sustainability and Department of Health measure

- a. Sustaining the Change. TTC Phase 2 (2011-2015): http://www.time-to-change.org.uk/blog/sustaining-change-our-plans-future
- b. Government funding for TTC phase 2: https://www.gov.uk/government/news/20-million-to-knock-down-mental-health-stigma
- c. Mental Health debate. 14.6.2012: http://www.publications.parliament.uk/pa/cm201213/cmhansrd/cm120614/debtext/120614-0002.htm#12061445000002
- d. Department of Health: No health without mental health (pgs 13, 29, 31): https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213761/dh_1240 58.pdf
- e. DoH: No health without mental health: implementation framework (p15): http://www.dh.gov.uk/health/files/2012/07/No-Health-Without-Mental-Health-Implementation-Framework-Report-accessible-version.pdf
- f. Supplementary note to the No Health Without Mental Health Impact Assessment, to accompany publication of an Implementation Framework (Annex D)

 https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216871/Mental-Health-Implementation-Framework-Impact-Assessment-supplementary-note.pdf

5) Further use of KCL measures

- a. Discrimination reported by users of mental health services: 2010 survey. Research report for ministry of health July 2011 (pg 18): http://www.likeminds.org.nz/file/downloads/pdf/file_100.pdf
- b. Hansson L, et al. Nord J Psychiatry. 2013 Mar 13. Doi:10.3109/08039488.2013.775339
- c. Ethnos survey: http://www.manchestercommunitycentral.org/news/bme-mental-health-survey-%E2%80%93-volunteers-needed-0