Author’s response to reviews

Title: A first national survey of knowledge, attitudes and behaviours towards schizophrenia, bipolar disorder and autism in France

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Author’s response to reviews: see over
Re: A first national survey of mental health literacy and attitudes toward schizophrenia, bipolar disorder and autism in France

Dear Professor Ghaemi,

First apologies for the delays in the replies to the reviews of this paper– as you are now aware- we had some difficulty in accessing the referees’ reports.

Second, thank you for the reviews - both were useful and raised some important issues.

We have revised the paper and offered detailed responses to each reviewer in the attached documents. However, we feel we need to be clear that this study is a brief internet survey and did not attempt to test specific theories of ‘stigma’. We totally accept the important insights of the reviewers, but we have not tried to make our study look as if it was more sophisticated than it actually was-

As such the main changes we have undertaken aim to clarify that this is a basic study so we have -

1. made the title of the paper clearer and omitted the term mental health literacy (to avoid misleading readers that we may be testing a current theoretical model);

2. re-written the objectives (clarifying that this is partly a feasibility study looking at recruitment and representativeness of internet based surveys)

added a more detailed section in the discussion on study limitations to clarify weakness in the assessment tool we devised.

We emphasize that the referees quite rightly point out the weaknesses of our study-

a) It was not driven by current theories of stigma, but only explores components of knowledge attitudes and beliefs- (we have changed the title to make clear that our aims we simple)

b) The questionnaire we used was designed for the study (ie in French as allowing some trans-diagnostic comparisons)- it included ideas reported in other assessments rather than actually utilizing reliable and valid instruments currently available, also it does not use vignettes (which are known to reduce negative response biases)

c) The data analysis was relatively simple, and does not allow sophisticated modelling of the data nor associations to be revealed through path analysis

However, we believe we have undertaken a useful survey that is of interest to your readership; its main contributions to the literature are
a) It is the first such survey in France
b) It looks at spontaneous reporting of symptoms of mental disorders to see if people actually know the nature of problems encountered by individuals with schizophrenia - i.e. it explores ways in which people use terms (not just the term and not via vignettes)
c) It was a brief internet survey that obtained a large representative sample quickly and relatively easily - potentially accessing an important population (compared to postal or interview samples)
d) It focused on views 'trans-diagnostically' especially including for the first time childhood disorders and specifically naming bipolar disorders, rather than being a study that focused on schizophrenia and/or depression (the most widely used target groups)

Please find down below the answers to the questions raised by each of the referees.
We look forward to hearing your response regarding the possibility of publication in BMC.

Yours sincerely,

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RESPONSES TO REFEREES COMMENTS
1. Reviewer: John Read

Our responses to the reviewer and comments on changes to the text are detailed below.

1. The paper as written does not pay sufficient attention to the problems recently identified with the 'mental helath literacy' approach to stigma research. The main problem is that it had been thought that more 'information'/knowledge' will automatically improve attitudes, but we now know that much of the information promoted (especially medical/biological causal beliefs) is making attitudes worse and increasing fear and prejudice. See the Read et al paper (already cited but glossed over) and the more recent review by the lead researchers in this field Angermeyer et al. (attached) BJP 2011, 199:367-372.
We have first changes the title of our paper to clarify that in effect we accept the referee has made an important point that we have not specifically tested theories of mental health literacy.

We accept the ideas behind this comment entirely indeed our stance is very much that ‘information is not enough’ - As such we have made this more explicit within the text, adding additional comments in the introduction and the discussion. We also reference Read in our discussion of the limitations of our study.

In addition, with regard to biogenic explanations, we have noted in the introduction that this is important in the current study because there is not data on how individuals view genetic explanation in childhood mental disorders (as compared to adult). In the discussion we note that autism is more likely to be regarded as genetic than schizophrenia but does NOT attract such negative attitudes ie we believe we have added another level to this fascinating issue of biogenic explanations as age may also be relevant.

2 The current paper should highlight the finding that the French public (as is the case in over 20 countries -see Read et al 2006) prefer a psych-social view of schizophrenia to the bio-genetic one adoted by psychiatry, and relate that to the studies from other countries.

We have made some revision in the discussion and highlighted very clearly that the French negative views of schizophrenia mirror other countries- however, the results show that the French actually endorse alcohol and drug problems as a major risk factor and favour stress as the best explanation for bipolar disorders (we have further clarified this in the text to make it clear).

3 It would be important to use the important data gathered in this study to actually analyse the hypothesis (supported by many previous studies) that genetic causal beliefs are related to negative attitudes (eg about recovery, ability to live in society etc), and whether psychosocial explanations are realted to more postive attitudes. This is the core ‘debate’ in the literature at the moment with enormous implicatoins for destigmatisation programmes.

We accept that this would be of interest but unfortunately the way the data were gathered does not allow us to employ more sophisticated path analysis and also - we wish to be clear this was partly a feasibility study and a first attempt to see if a brief internet programme was possible- hence we do not wish to pursue more analyses of the data, but rather use this study to help the design of a further better study in the future.

4. The methods section has inadequate information about the details of the interview schedule/questionnaire. eg what is considered ‘knowledge’ /examples of mental health literacy?(and how was that decided? by whom?) list the adjectives from which respondents selected

See also responses to the other referee - We have added more information on the design of the study - especially highlighting why a brief questionnaire was used drawing from the literature and not using established questionnaires.

The survey instrument comprised of 21 items designed to capture data on themes examined in previously published questionnaires exploring stigma, prejudice and discrimination (Angermeyer & Matschinger, 2003; Corrigan et al, 2001a; ibid, 2002; Jorm, 2000; Link et al, 1999; ibid, 2004; Wolff et al, 1996). The questions targeted key domains such as mental health literacy (n=8), attitudes (n=5) and behaviours (n=4)
towards those with mental disorders and familiarity with mental disorders (n=4). Knowledge questions included views of the likely prevalence of mental disorders in the general population, causal attributions (e.g., views of risk factors such as genetic vulnerability, external stressors, etc.) and beliefs about controllability (by the individual themselves or via different treatment), stability, and predictability. Attitudes and behaviours were explored by questions that assessed terminology used to describe mental disorders, and reactions such as avoidance or social distancing. Familiarity questions explored issues such as personal or family experiences of mental disorders and predictions about future vulnerability (factors that may act as modifiers of reactions); these were supplemented by questions that explored views on likely help-seeking and probability of self-disclosure. Socio-demographic factors associated with knowledge of, and attitudes and behaviours towards those with mental disorders were also examined.

The item format included forced-choice (yes/no/don’t know) questions, rank ordering of statements or Likert scale ratings. Respondents were also asked to endorse adjectives, verbs or expressions (from a list provided) that describe responses to mental disorders in general and then individuals with mental disorders specifically. The responses were then further classified (e.g., ‘anger’, ‘pity’, ‘fear’, etc.) to allow the identification of themes such as sympathetic, empathic, or prejudicial. Likewise some questions about predicted behaviours (e.g., would the respondent be prepared to work alongside someone with bipolar disorder, schizophrenia, or autism) assessed differences in reaction to or degree of discrimination towards each disorder. To aid understanding, we employed the term manic depression rather than bipolar disorders as this is more familiar to and more commonly used by the lay public.

We have expanded a little on the other issues but acknowledge there is a weakness in the study in that the questions were designed by the senior author and then agreed with the other contributors and whilst they drew on the literature, the item selection aimed to cover adult and childhood disorders. This is now discussed more fully in the study limitations—

…The main study limitation is however that in order to make this a brief, internet-based questionnaire, we have used the concepts and ideas prevalent in the literature, but did not use a set of previously validated reliable questionnaires, also some concepts needed to be translated into French (which in some cases may change the subtlety of the original meaning e.g., whether a person is described as being ‘able to work’ as opposed to ‘unable to work’). Hence, there may be issues in the nature of the questionnaire that will reduce our ability to compare some of the findings with other studies. Also, we used diagnostic labels in some instances instead of case vignettes which will affect the views expressed or items endorsed (Read et al., 2006).

5. Similarly the Results are not presented in sufficient detail throughout. As noted above, we only collated simple response data from this internet survey, but we have learnt that we need to do more in terms of data collection and the organization of the data to allow more sophisticated analysis more clearly informed by theoretical models in the future. We do not feel we can add much more as we give the results as obtained.

6. Discussion
The limitations section must acknowledge that using a diagnostic label (vs an unlabelled vignette) (i) increases biological causal beliefs and (ii) increases prejudice/stigma (see Read et al). This is very important. We have added additional comments in the introduction. We have also clarified in the discussion the interesting finding (noted by the other referee) that using the diagnostic terms, but then asking individuals to identify the actual characteristics may be seen as an alternative to vignettes. 

We suggest that vignettes get at general attitudes and understanding, what is interesting about our question is that we examine what people know about the experiences of individuals with the label - which is a slightly different approach.

With regard to biological beliefs increasing stigma - we have added a comment on this as our study is not totally consistent (see the comments on autism above)- so as noted we have noted…

This finding is especially interesting given the fact that there is increasing concern that messages regarding the biogenic nature of mental disorders may have increased rather than decreased negative views of adult mental disorders- this effect was not observed in our study with regard to a major childhood disorder, possibly suggesting that age of individuals with a disorder may influence levels of stigma.

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Our responses to the reviewer and comments on changes to the text are detailed below.

(1) The research question – exploring knowledge, attitudes and behaviours – is clearly stated. To actually add to current knowledge of mental-health related stigma, however, contemporary survey research on mental health problems needs to be based on a clear theoretical model of the stigma concept, testing the specific associations hypothesized (e.g. between the use of labels and emotional reactions; attitudes and behaviour, familiarity and social distance, etc.) The authors do take several components of stigma theories (Thornicroft et al. 2007, Corrigan et al. 2003) into account. What is missing, however, are clear hypotheses on how these components are interrelated, drawing on previous findings.

We acknowledge that this is an important topic, but feel our study was rather more basic and was not in reality designed in a way that allows us to test these different issues.

We have therefore made this clearer by changing the title of the paper and also adding simpler objectives regarding what we have done. We feel this is more sensible as to do otherwise would potentially suggest that the authors were undertaking a more sophisticated study than they actually have undertaken.

(2) As a result, authors present a variety of interesting findings which may appear somewhat unstructured, thus obstructing the reader's view for the study's key findings. For example, the comparison of respondents' associations with diagnostic labels in contrast with the portrayal of individuals suffering from particular illnesses, showing a significant decrease in negative labelling when a disorder was associated with a personal history, strikes me an original contribution.

In a similar vein, deepening the understanding of mental health literacy beyond the recognition of diagnostic labels by asking respondents to actually describe characteristics of the respective illness (p. 8, lines 3-5 from the bottom), may add to our knowledge on the level of information required to improve help-seeking. The fact that stigma varies between different disorders, with schizophrenia associated with the most negative attitudes, however, has widely been established in previous research.

We have clarified the objectives of the study, made clearer that the emphasis in on differences between childhood and adult disorders, and reduced the discussion of negative views of schizophrenia (which we accept are not novel)- simply emphasizing that France is similar to elsewhere.

(3) The breadth rather than depth of findings may also reflect the methods of data collection. It appears that authors developed their own 21-item questionnaire, combining items from a wide range of established instruments to measure stigma and its components (see p. 6, last paragraph). What remains unclear, on the other hand, is i. an overview of the 8 mental health literacy, 5 attitude, 4 behaviour and 4 familiarity items used in the study, e.g. in a table ii, the motivation behind using a combination of items rather than choosing a validated measure (e.g. Link et al.'s Social Distance Scale, Corrigan et al.'s
Attribution Questionnaire, established semantic differentials for assessing stereotypes, etc.), or a combination thereof. The motivation behind selecting particular items as opposed to others. The internal consistency of the 4 different constructs measured. As a result of their choice, authors mainly present descriptive data (frequencies and ranked frequencies), basing their analysis on individual items rather than clearly defined constructs. A related problem may be the use of inconsistent response formats across the questionnaire (dichotomous questions, Likert-scales, ranking scales), which may affect response behavior and complicates data analysis.

We have added a section to the methods. The survey instrument comprised of 21 items designed to capture data on themes examined in previously published questionnaires exploring stigma, prejudice and discrimination (Angermeyer & Matschinger, 2003; Corrigan et al, 2001a; ibid, 2002; Jorm, 2000; Link et al, 1999; ibid, 2004; Wolff et al, 1996). The questions targeted key domains such as mental health literacy (n=8), attitudes (n=5) and behaviors (n=4) towards those with mental disorders and familiarity with mental disorders (n=4). Knowledge questions included views of the likely prevalence of mental disorders in the general population, causal attributions (eg views of risk factors such as genetic vulnerability, external stressors, etc) and beliefs about controllability (by the individual themselves or via different treatment), stability and predictability. Attitudes and behaviors were explored by questions that assessed terminology used to describe mental disorders, and reactions such as avoidance or social distancing. Familiarity questions explored issues such as personal or family experiences of mental disorders and predictions about future vulnerability (factors that may act as modifiers of reactions); these were supplemented by questions that explored views on likely help-seeking and probability of self-disclosure. Socio-demographic factors associated with knowledge of, and attitudes and behaviors towards those with mental disorders were also examined.

The item format included forced-choice (yes/no/don’t know) questions, rank ordering of statements or Likert scale ratings. Respondents were also asked to endorse adjectives, verbs or expressions (from a list provided) that describe responses to mental disorders in general and then individuals with mental disorders specifically. The responses were then further classified (eg ‘anger’, ‘pity’, ‘fear’, etc) to allow the identification of themes such as sympathetic, empathic or prejudicial. Likewise some questions about predicted behaviors (eg would the respondent be prepared to work alongside someone with bipolar disorder, schizophrenia or autism) assessed differences in reaction to or degree of discrimination towards each disorder. To aid understanding, we employed the term manic depression rather than bipolar disorders as this is more familiar to and more commonly used by the lay public.

(4) In the method section, authors describe having carried out least-square regression analysis to simultaneously assess the relationship of “... demographic variables or familiarity with mental disorders with different levels of awareness or tolerance among the public” (p.8, lines 3-5). However, neither is the regression model with its dependent and independent variables specified, nor are the results of the models tested reported in a table.
We have excluded the comments on regression models as they are not relevant.

(5) A further question is raised by the selection of stimuli for the three disorders studied. Explicitly, authors state that they “...employed the term manic depression rather than bipolar disorders as this is more familiar to and more commonly used by the lay public” (p. 7, lines 3-6 from bottom of page). One may wonder what this assessment is based on. Have authors conducted a pre-test, or are they referring to previous research on diagnostic labelling of vignettes describing typical symptoms of bi-polar disorder? An indication that the above assumption may have affected study results is given by the authors themselves: “Intriguingly, individuals ranked bi-polar disorder as the second most likely future mental health problem (after depression), ahead of other common mental disorders, perhaps indicating that in the public’s mind, bipolar is more like unipolar disorders...... rather than... (having) many similarities with psychoses” (p. 12, lines 14-18). This result may not reflect “the public’s mind” (yet another assumption), but rather result from the label “manic depression”, which may have suggested similarity with depression.

We feel we may have confused the issue - by offering both terms - It is true that in France manic depression is a widely used term but the descriptions in the questionnaire are of bipolar disorders and we have decided that it may be simpler to exclude this discussion from the text rather than overcomplicate the paper.

(6) Please specify in more detail how you obtained responses on associations with diagnostic labels (characteristics typical of diagnostic categories) as well as how you asked for descriptors of mental disorders as opposed to individuals with a mental disorder. Did you use open-ended questions? What procedure was applied to code open responses?

See the response to item 3 on the methods and responses to referee 1 - the question asked if individuals knew the terms and then the next question asked then to describe characteristics of the disorder. The questions on adjectives were open ended and then themes were coded.

(7) Regarding public views about the effectiveness of different treatment options (p. 9, lines 14-18), it would be of interest to see how particular treatment approaches were ranked according to the disorder enquired, in the same fashion as reported for the expected course of the different disorders in Table 2. What kinds of treatments were actually enquired? As it stands, only medication and psychotherapies are mentioned in the manuscript. Also, have authors differentiated effectiveness ratings according to the three disorders studied?

The results section gives the views of effectiveness by disorder and shows that treatments for schizophrenia are regarded as less effective. Treatments were only given in very broad terms ie therapies/medications

(8) Another question arises as to how the three disorders were compared. Did all respondents answer all questions about three disorders, or was there a random selection of subsamples which were presented with the questionnaire for one disorder each?

We have clarified the description in the first section of the results -
Basically the response rate was very very high - with 916 fully complete questionnaires or with replies that allowed analysis - we use % throughout to demonstrate proportion rather than numbers of responses per item.

There was no evidence of response biases, but we do note in the discussion that the rate of self-report of mental health problems may hint at under-reporting on this issue - and we comment that the respondents do acknowledge that they are reluctant to self-disclose to others - so we think this is a reasonable hypothesis.

(9) The comparison between mental disorders in childhood as opposed to adulthood stated as a research objective was not specifically undertaken. Also, theories as to why there might be differences between attitudes about mental health problems in children and adults are not evident in the manuscript.

We have clarified the objectives and also clarified in the results section that we compare results of findings regarding eg risk factors/treatment and familiarity etc

(10) The discussion starts with a lengthy summary of findings, which is largely redundant.

We have shortened this to highlight only important significant findings and also the section in the final paragraphs regarding implications of the schizophrenia findings have been reduced.

(11) Study limitations are spelt out clearly when it comes to sampling procedures and the representativeness of the study sample. However, authors should be more explicit about limitations arising from the assessment instrument, the variation in response categories and the diagnostic labels used as stimuli for the knowledge, attitude and behaviour items. In addition, they may wish to produce stronger arguments for what their study adds, in addition to being the first survey into mental health literacy in France.

We have added a further comment on the instrument and on the issue of item design influencing possible responses.

We have not expanded further on what this study adds, except to end with a note that a strategy aimed at the public needs to consider what can be generic interventions and the notion that there may need to be disorder-specific strategies.

(12) Implications of findings for interventions to enhance mental health literacy are well-founded in the results presented as well as partly innovative in that they i. emphasize the role of personal testimonials, i.e. improving attitudes towards individuals rather than towards a particular disorder, and ii. underline the necessity to differentiate communication strategies for specific disorders rather than addressing mental illness in general.

On the other hand, the step-wise approach proposed in the concluding paragraph once more suggests a lack of conceptual clarity: it appears to seek instilling adequate clinical knowledge about bi-polar disorder (What about the other two disorders studied?) in the public, as the authors put it: “....building upon knowledge and more benign attitudes, then gradually making the link between the more severe aspects of the this disorder and psychoses in general, with a view to identifying with schizophrenia.” (p.15, final paragraph) This seems counter-intuitive: One may wonder how this strategy is supposed to contribute to improving public attitudes of bi-polar disorder, as the current paper and previous research clearly
demonstrate that schizophrenia is associated with markedly more negative stereotypes and a stronger desire for social distance than most other mental health problems, except for alcoholism and substance abuse. It appears that authors do not clearly distinguish between public health education aimed to approximate lay and clinical knowledge, and reducing stigma towards individuals suffering from mental health problems. While they address the potentially conflicting results of mental health literacy campaigns (negative stereotypes of schizophrenia prevail despite education efforts (p. 13); unexpected consequences of promoting a 'biogenic' aetiological model (p. 3)), they appear to go on proposing this very strategy. Here, authors may wish to envisage other intervention approaches that have proven effective in previous evaluation studies, such as arts festivals (Quinn, Shulman, Knifton, & Byrne, 2010) or school level interventions with children and young people (Conrad et al., 2009; Schulze, Richter-Welting, Matschinger, & Angermeyer, 2003; Tobler et al., 2000; Weist, Nabors, Myers, & Armburster, 2000), which build on facilitating personal contact with individuals who have had a mental health problem rather than exclusively informing about clinical syndromes. We have revised our discussion of these issues—clarifying that we do not think information alone is sufficient, furthermore we have used some of the helpful references provided by this reviewer to emphasize the idea of interactive approaches and those that make individuals with problems visible as being useful ways forward.

Minor essential revisions:

(1) Presentation of results:
Caption of Table 2 should specify that it reports results of ranking different categories. Otherwise readers would expect a complete overview of the distribution of answers and the different response categories, e.g. yes, no, and don’t know.
We have added a line under table 2 to clarify and referred readers to the text as well.

(2) There are inconsistencies in the labels used for stereotypes in the results section of the text (...most likely to be able to work; bottom of page 10) and in Figure 1 (unable to work/unable to live in society). Authors should make explicit how the relevant stereotypes were actually enquired, i.e. give the wording to show whether they measured a positive or negative stereotype. The phrasing of questions and scaling of responses has been shown to significantly affect responses, with significantly less endorsement for negative responses and more endorsement of positive responses. (Porst, 1998)
- the items are written able/unable/don’t know…

(3) Introduction:
In the introduction (p. 4, lines 10-12) it is stated that “...the majority of studies utilizing these theories conceptualize ‘mental disorder’ as a single entity or only focus on schizophrenia”. Please give sources for this statement.
This is our reading of the literature - which we believe to be accurate - so we cannot give a reference.