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Treatment Outcomes for Eating Disorders in Sweden, 2012-2016 "Data from the National Quality Registry"

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2018-024179
Article Type:	Research
Date Submitted by the Author:	14-May-2018
Complete List of Authors:	Södersten, Per; Karolinska Institutet Brodin, Ulf; Karolinska Institutet, Sjöberg, Jennie; Mandometer Clinic Zandian, Modjtaba; Karolinska Institutet Bergh, Cecilia; Mandometer Clinic,
Keywords:	Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, PUBLIC HEALTH, STATISTICS & RESEARCH METHODS

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Treatment Outcomes for Eating Disorders in Sweden, 2012-2016

“Data from the National Quality Registry”

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3024 words (abstract, strengths and limitations, references, acknowledgements, and figure legends excluded)

35 references

5 figures

1 table

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Abstract

Objective To report the outcomes of eating disorders treatment in Sweden in 2012-2016.

Design The number of patients treated and the number of patients in remission at one year of follow-up at each clinic listed in the National Quality Registry for Eating Disorders Treatment were analyzed and compared with the published outcomes at three clinics that used survival analysis to estimate outcomes.

Setting All eating disorders clinics in Sweden.

Participants All patients treated at eating disorders clinics in Sweden.

Intervention Standard of care for eating disorders at most clinics and normalization of eating behaviour at three clinics.

Outcome measure Proportion of patients in remission at follow-up.

Results About 2600 patients were treated annually, fewer than half were followed-up, and the rate of remission was about 21% until 2014, decreasing to 14% in 2016. Outcomes differed amongst clinics and within clinics over time. There is no data on relapse in the registry. Rates of remission have been overestimated by excluding more than 50% of patients lost to follow-up. The published rate of remission at three clinics that treated 1200 patients in 1993-2011 was 27, 28, and 40% at one year of follow-up and 39, 68, and 82% when treatment was continued. The relapse rate was about 10% over five years of follow-up for these clinics.

Conclusions With the majority of patients lost to follow-up and no data on relapse in the National Quality Registry, it is difficult to estimate of the effects of the treatment of eating disorders in Sweden. Analysis of time to clinically significant events, including an extended

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period of follow-up, improves the quality of the estimates. Rates of remission have been publically overestimated, misleading health care policies. This is not a national problem as the effect of eating disorders treatment has been similarly overestimated internationally.

For peer review only

Strengths and limitations of this study

- This study has the strength of analyzing all patients treated, followed-up, and treated to remission at all eating disorders clinics over five years in Sweden.
- These outcomes are available in the National Quality Registry for Eating Disorders Treatment but have not been published in the scientific literature.
- Three clinics have published outcomes at three months intervals making comparisons between the outcomes in the registry possible.
- The study has the strength of showing that a time-to-event analysis improves compliance, thus facilitating estimation of outcomes.
- It is a limitation that whereas outcomes in the registry covered the years 2012-2016, the published outcomes covered the years 1993-2011.

Introduction

The National Quality Registries in Sweden have been developed starting in the 1970s and today there are about 100 registries, covering virtually all kinds of disease (1). The Swedish Association of Local Authorities and Regions (SALAR) and the Swedish Government recently agreed to strengthen the registries financially, pointing to their key role in the development of all aspects of health care, improving the quality of care, facilitating research, including international comparisons of outcomes, guiding health care policies, and making it possible for anyone to compare the outcomes of treatment at individual clinics (1,2). Indeed, the SALAR has a website for such comparisons (3).

The Swedish National Quality Registry for Eating Disorders Treatment, Riksät, was established in 1999 and has published 11 reports, written in Swedish, in 2001-2016 (4). Following the aims of the registries, the objective of Riksät is to “document the outcome of treatment” (quote from the first report in 2001). Thus, the important measures are the number of patients treated and the number of patients in remission at follow-up. These numbers are listed in Riksät but have not been analyzed and reported in the scientific literature. The first aim of the present study is to examine the rate of remission at the eating disorders clinics in Sweden. The second aim is to compare these remission rates with those that have been published separately by three Swedish clinics (5). The information in Riksät has been publicized nationally as demonstrating increasing rates of remission over the years to 56% in 2015 and that “70% of the patients are ‘cured’ within one year” (4,6). Because these outcomes are better than the outcomes reported in the scientific literature (7,8), it is important to examine their evidence basis. The third aim is to call attention to the fact that there are similar discrepancies between the published and internationally publicized outcomes of eating disorders treatment.

Methods

Riksät lists the number of patients treated each year and the number of patients in remission at follow-up one year after the start of treatment. Patients in remission from an eating disorder may fulfill the criteria for some other diagnosis. Riksät also reports changes in the patients' social functioning and their experiences of the treatment. These secondary measures improve as patients go into remission and will not be considered in this analysis. Hence, the protocol of Riksät includes two time points for assessment, there is no information on relapse.

Initially, Riksät reported the combined outcomes at the clinics across regions in Sweden, the reports published in 2009 and 2010 were incomplete, and no report was published in 2011. However, the outcomes at individual clinics were reported in 2012-2016. The number of patients treated at each clinic and the proportion of patients who were followed-up are listed in one set of tables in these reports. The number and the proportion of patients in remission at follow-up are listed in another set of tables. These numbers have been combined into one table (supplementary table) and used in the analysis.

Combined outcomes at all clinics

The numbers of patients treated and followed-up have been summarized for all clinics. The number of patients in remission has been related to the number of patients treated as well as to the number of patients followed-up in an attempt to explain the high remission rates publicized in Sweden.

Outcomes at individual clinics

In Riksät, the number of patients treated and the number of patients in remission were analyzed for clinics that had followed-up at least 20 patients in 2012-2013 and for clinics that

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3 had followed-up at least 10 patients in 2014-2016. Clinics that had followed-up fewer patients
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5 were combined to a category of “other clinics”. These data (supplementary table) have been
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7 analyzed to compare outcomes between clinics.
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11 If the treatment and the follow-up assessments are about the same at all clinics, the
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13 probability for remission should be the same in all clinics. This hypothesis, which can be
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15 formalized as: $H_0: P_i(\text{Remission}) = P_0(\text{Remission})$ for all clinics, $i=1, 2, 3, \dots, n$, was tested
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17 using a test for homogeneity of the data (9).
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21 Outcomes were compared amongst the three clinics in the Stockholm County Council,
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23 the Stockholm Centre for Eating Disorders (SCÄ), the Capio Centre for Eating Disorders
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25 (Capio), and the Mandometer Clinic (Mando). Each of these clinics had treated more patients
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27 to remission than any other clinic. The major difference in treatments amongst these clinics is
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29 that whilst Mando concentrates on normalizing the patients’ eating behaviour, SCÄ and Capio
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31 use standards of care, including cognitive behavioural therapy (CBT).
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34 **Published outcomes at three clinics**

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37 Mando reported the outcomes every third month of 1428 patients treated at six clinics in four
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39 countries over various periods of time in 1993-2011, and these data are available in the
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41 supplementary files of (5). Three of the clinics, located in Sweden, in Alingsås, Danderyd,
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43 and Huddinge, treated 1200 of these patients. The clinic in Huddinge, within the Stockholm
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45 County Council, is the oldest clinic and is referred to as Mando in this analysis. The
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47 probability of going into remission over consecutive three-month intervals up to 12 months at
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49 these clinics was estimated using a life-table approach to survival analysis (10). The rate of
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51 failure amongst censored patients was estimated to be 20%, yielding a conservative estimate
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53 of treatment outcomes.
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3 Whereas the probability of going into remission is an estimate of outcome, the
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5 proportion of patients in remission is the subsequently observed rate of remission. This
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7 analysis uses “the proportion of patients in remission” and “the rate of remission” expressed
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9 as percentage interchangeably (with no decimal points). The number of patients treated is
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11 related to the assessments after one year.
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13 14 **Results**

15 16 **Combined outcomes at all clinics**

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21 Figure 1 shows that the total number of patients treated at all clinics increased to about 2600
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23 in 2013, and remained relatively stable over the following years. The figure also shows that
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25 fewer than half the patients were typically followed-up and that the rate of remission was
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27 about 21% in 2012-2014, and decreased to 14% in 2016. The number of patients treated to
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29 remission increased from 477 in 2012 to 589 in 2014 and decreased to 358 in 2016.
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37 Figure 2 shows firstly, that the rate of remission at all clinics that followed-up their
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39 patients was less than 50% in 2012-2014, 29% in 2015, and 36% in 2016. Secondly, the
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41 figure shows that the rate of remission at clinics that had treated at least one patient to
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43 remission increased to 56% in 2015 and decreased to 54% in 2016. The second analysis thus
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45 excluded patients followed-up at clinics that did not treat a single patient to remission. The
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47 significance of these two calculations of remission rates is clarified in the Discussion.
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Outcomes at individual clinics

Because Riksät reported results for clinics that had followed-up at least 20 patients in 2012-2013 and for all clinics in 2014-2016, the number of clinics reporting their outcomes was lower in 2012-2013 (21 and 23) than in 2014-2016 (70, 64, and 59). However, it is possible to compare how many clinics had treated, followed-up, and treated at least 20 patients to remission in 2012-2016.

Figure 3 shows that more clinics had treated at least 20 patients in 2016 than in 2012. Whereas the clinics that had treated at least 20 patients in 2012 were selected for having followed them up, only 45% of the clinics followed-up at least 20 patients in 2016. About one in three of the clinics had treated at least 20 patients to remission in 2012 compared to about one in eight in 2016. The results in the other years fall in between the results in 2012 and 2016.

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Out of the 33 clinics that had treated at least 20 patients in 2016 (Figure 3, green bar at the very left), three (9%) had not followed-up any patients, and 21 (64%) had not treated a single patient to remission. These 21 clinics had treated a total of 857 patients, with a median (range) of 32 (20-98) patients/clinic.

SCÄ had treated about four times more patients annually (median: 715; range: 696-724) than Capio (175; 157-178) and Mando (123; 81-168), and followed-up about the same proportion of patients (43; 32-69%) as Capio (50; 48-65%) and Mando (43; 32-83%). These proportions are similar to the average proportions of follow-up at all clinics over these years (Figure 1).

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2
3 Figure 4 shows that Mando had treated a bigger proportion of patients to remission than
4 SCÄ and Capio in 2014-2016. Whilst the rate of remission was relatively stable at on average
5 36% at Mando over these three years, it decreased from 29% to 16% at SCÄ and from 30% to
6 14% at Capio. In 2016, the proportion of patients treated to remission at Mando (35%) was
7 about twice as big as the corresponding proportion at SCÄ (16%) and Capio (14%).
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17 **Test of homogeneity of outcomes between and within clinics**

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19 The probability of going into remission in 2012 was significantly different amongst the 17
20 clinics that had treated patients in all recorded years ($P \ll 0.001$; $\text{Chi}^2=80.2$, $\text{df}=16$). The
21 probability of going into remission was also significantly different amongst the five clinics
22 that had treated at least 100 patients in 2012 ($P < 0.001$; $\text{Chi}^2=23.7$, $\text{df}=4$). Analysis of the other
23 years gives similar results.
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33 Analysis of the results at SCÄ showed that the probability of going into remission was
34 significantly different over the years ($P \ll 0.001$; $\text{Chi}^2=46.3$, $\text{df}=4$). Analysis of the other
35 clinics gives similar results.
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40 **Outcomes at “other clinics”**

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43 Figure 5 shows that amongst the 2600 patients who were treated annually, the number of
44 patients treated at the “other clinics” increased to more than 1000 in the last two years. In
45 parallel, the proportion of patients who were followed-up and treated to remission at these
46 clinics decreased. Fewer than one in ten of the patients were treated to remission in the final
47 three years.
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Published outcomes at three clinics

Table 1 shows that the proportion of patients in remission at 12 months assessments was at least 27% and significantly different at the three Mando clinics, whose outcomes are published. Treatment continues after the 12 months at these clinics and the proportion of patients in remission increases after various, prolonged periods of time. Note that these clinics had been operating over various periods of time.

--- Please insert Table 1 about here ---

Discussion

About 2600 patients were treated annually at the eating disorders clinics in Sweden in 2012-2016, fewer than half were followed-up, and the proportion of patients treated to remission decreased from one in five in 2012 to less than one in seven in 2016. However, remission rates which are more than three times higher have been publicized nationally. These estimates were derived by excluding patients lost to follow-up and patients followed-up at clinics that did not treat patients to remission. In 2016, only four clinics treated 20 patients to remission, most clinics treated a small number of patients, followed-up a few, and treated only one patient in ten to remission. Outcomes varied significantly between clinics each year and within clinics over years. In addition, in 2016 more than half the 33 clinics that had treated on average 32 patients had failed to treat a single patient to remission; one of these clinics had treated 98 patients unsuccessfully.

Interpretation and comparison with published outcomes

Whilst these findings indicate that the procedures of treatment and follow-up differ amongst clinics in Sweden, a word of caution seems appropriate. For example, although outcomes

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3 were significantly different over years at the biggest clinic (SCÄ), patients were treated to
4 remission all years, suggesting that a statistically significant within-clinic variation may be
5 less significant clinically. However, it seems unlikely that the decrease from a rate of
6 remission of about 30% in 2014 at this clinic to about half that rate two years later is a matter
7 of random variation. And the similar decrease in the rate of remission at another clinic in
8 these years (Capio) suggests that the procedures at these clinics also had deteriorated, at least
9 temporarily.
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19 Possible reasons for the variation in outcomes include changes in staffing, training of
20 staff, patient compliance to treatment, and the physical conditions in the clinics, factors that
21 affect outcomes in multicenter clinical trials (11). While the “study protocol” of the
22 multicenter trial aims at reducing the influence of these factors, there is no standard protocol
23 for the treatment of eating disorders. And although there is agreement that the treatment
24 guidelines for eating disorders should be followed, this consensus view has not yet improved
25 outcomes (12–18). For example, an attempt at implementing CBT, which is recommended in
26 all guidelines, in combination with antidepressant medication for the treatment of bulimia in
27 primary care in the U.S. resulted in a 70% dropout rate (19). A similar effort in general
28 practice in the U.K. found that out of 683 patients with a diagnosis of bulimia, about half of
29 the 272 patients who entered CBT completed the treatment, and although those patients
30 improved, they were not free of eating disorder symptoms after treatment (20). Compliance to
31 eating disorders treatment is a general problem, not a “Swedish” problem.
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48 The treatment at Mando was developed starting in 1993. A randomized controlled trial
49 demonstrated its effectiveness (21) and outcomes were subsequently reported for 1428
50 patients treated at six clinics in four countries (5). The combined rate of remission at these
51 clinics was about 75% in on average one year of treatment and the rate of relapse was about
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3 10% over five years of follow-up (5). Similar to Riksät, estimates were done amongst all
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5 patients entering treatment. However, far more patients were lost to follow-up at Riksät's one
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7 year time point of follow-up than to Mando's procedure of monitoring patients at three-
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9 months intervals throughout treatment and at 1, 2, 3, 6, 9, 12, 18, 24, 36, 48, and 60 months of
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11 follow-up (5). Despite the difference, the rate of remission at the Mando clinic in the
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13 Stockholm County Council was on average 33% in 2012-2016 according to the Riksät
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15 calculation, which is about half the estimated published 75% rate of remission after on
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17 average one year of treatment (5).
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21 Average remission rates should be viewed cautiously as outcomes at varied between
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23 clinics. Thus, the rate of remission at 12 months differed significantly at the three Mando
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25 clinics, yet it was higher than the average values reported for all clinics in each of the five
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27 years in Riksät. Differences in treatment methods between the Mando clinics and the other
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29 clinics may explain the differences in outcomes (8) and it is possible that outcomes will be
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31 more consistent at the Mando clinics once they have been operating for a longer period of
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33 time. For example, the Alingsås clinic had been treating patients for only two years and
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35 reached a rate of remission of only 39%. The variation in the rate for remission at 12 months
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37 at the Mando clinics in Amsterdam (16%), San Diego (52%), and Melbourne (25%) (5),
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39 support previous findings that international cultural and medical system differences also
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41 affect treatment outcomes (22). Thus, patients treated in San Diego improved rapidly, but they
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43 were often prevented from continuing in treatment because of the financial constraints of their
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45 insurance policies (5), a problem that would not affect patients in Sweden. It should be noted,
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47 however, that relatively few patients had been treated at these clinics.
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52 Dropout and relapse are significant events in the treatment of eating disorders (8,23),
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54 and neither these events, nor remission, should be expected to occur after a predetermined
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3 period of time such as at one year of follow-up as used in Riksät. It seems likely that this
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5 procedure explains why more than half the patients were lost to follow-up in Riksät. Practical
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7 approaches to survival analysis, including time-to-event analysis, are long available (10,24)
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9 and should be used in studies of outcomes of eating disorders treatment. The higher level of
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11 compliance at the Mando clinics (5) offers support for their value.
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15 Considering the difference between outcomes at Mando and the other Swedish clinics,
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17 including the fact that several hundred patients have been treated to remission, and that the
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19 rate of relapse has been reduced to 10% at the Mando clinics (5), a randomized controlled trial
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21 comparing outcomes at these clinics may be redundant; an attempt at a comparison (25), was
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23 fraught with problems (5). However, although the published literature indicates that
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25 differences in the characteristics of patients at admission do not explain the differences in
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27 remission rates (26), the possibility that such differences exist should be examined.
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31 The finding that the effects of eating disorders treatment have been overestimated in
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33 Sweden is similar to the international claim that CBT is “efficacious for a range of eating
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35 disorder presentations in the short and long-term” (18), publicized as: “Based on a solid
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37 empirical foundation, the transdiagnostic enhanced CBT approach will immediately become
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39 the gold standard for the treatment of eating disorders” (27), and “[the effect of CBT] is the
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41 most dramatic that we have seen in the literature ... [including] the potency ... and the
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43 impressive maintenance of change over the 19-months follow-up” (28). The published
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45 evidence does not support these claims (8,29–31) and evidence that the outcomes of CBT
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47 have been overestimated for the treatment of other disorders is gradually emerging (32,33).
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Implications for policy makers

Overestimations of the outcomes of the treatment for eating disorders in Sweden have been publicized over several years (4), including the claim that “70% of the patients are ‘cured’ within one year”, which is maintained on Sweden’s National Educational Radio Channel (6). These overstatements have misinformed health policy makers and can now be corrected.

In order to guide decisions on matters of health care, National and International Quality Registries must offer reliable information. Widely publicized “facts” need to be critically examined. Policy makers should be aware that once ill advised policies have been established, retrospectively controlling their evidence basis can be ineffective, and even strengthen the misguided policy (34,35).

Acknowledgements

We thank Sara Norring, Riksät, Anna Sandelin, the Centre of Registries Västra Götaland, and Fredrik Westander and Lale Björne-Fergéus, SALAR, for information on Riksät.

Transparency declaration: Södersten affirms that the manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

Ethics committee approval: The project was approved by the Regional Ethical Review Board of Stockholm (Dnr 2015/456-31).

Funding: This work was supported by The County Council of Stockholm grant number HNSV 15896, HSN 1502-0291, project 3252.

Role of the sponsor: The sponsor had no influence on the work.

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3 **Data sharing statement:** The data used for this analysis are available in a supplementary
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5 table.
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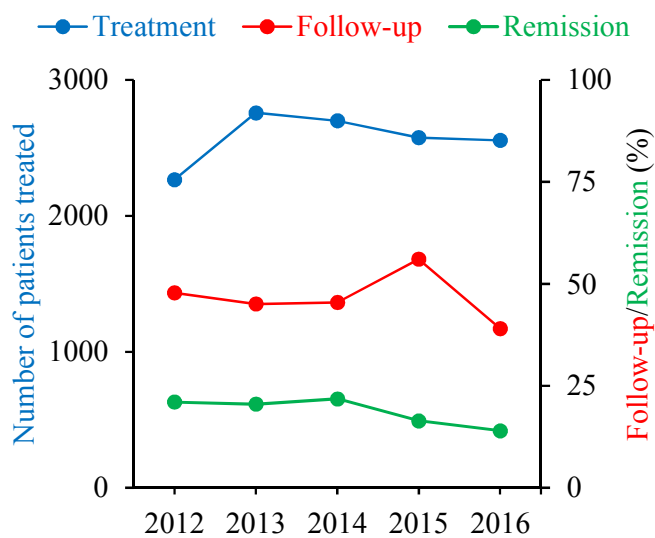
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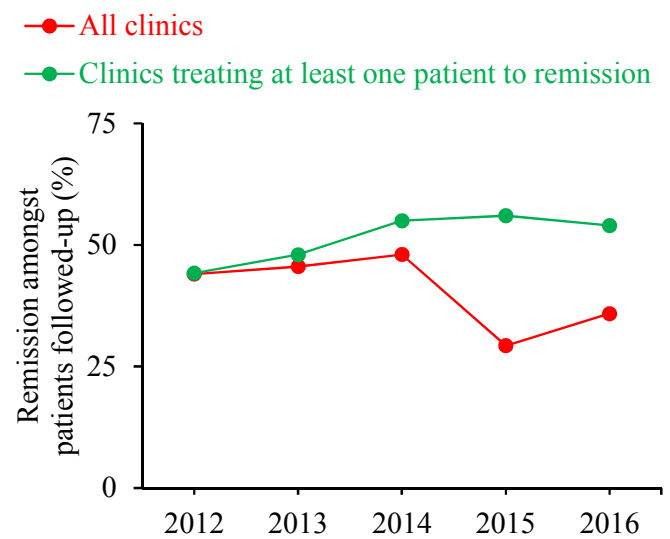
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Figure 1. Number of patients treated at all clinics in Sweden and proportion of patients followed-up and in remission one year later. The year on the x-axis indicates the year of follow-up, the corresponding number of patients starting their treatment the year before.



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Figure 2. Proportion of patients in remission at all clinics that followed-up their patients and at clinics that treated at least one patient to remission.



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Figure 3. Number of clinics that treated, followed-up, and treated at least 20 patients to remission and proportion of clinics that followed-up and treated at least 20 patients to remission in 2012 and 2016.

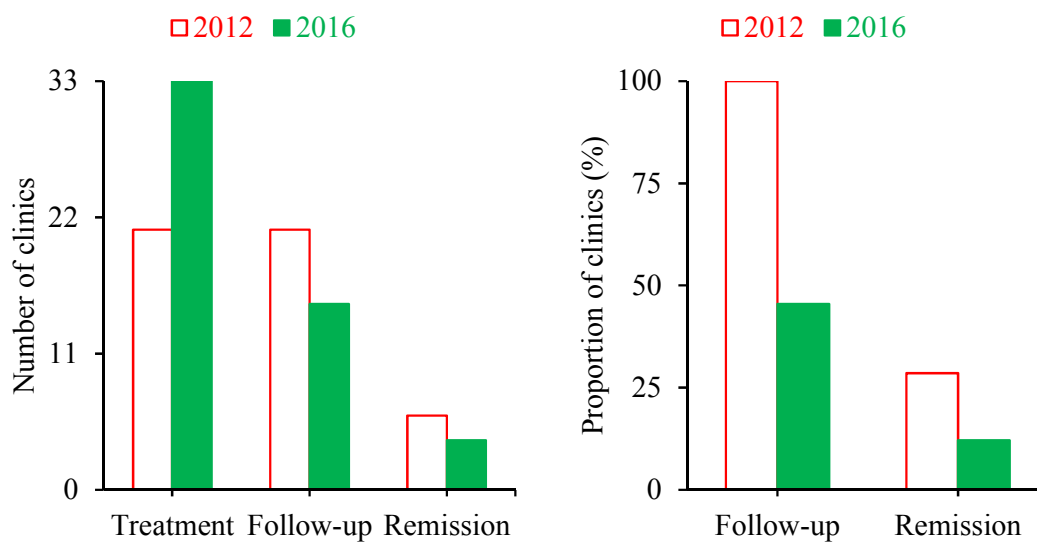
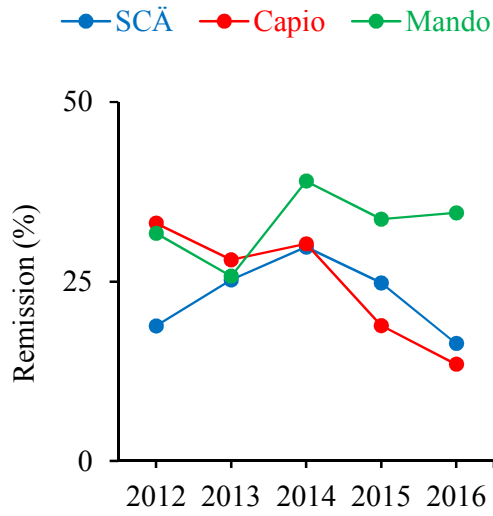


Figure 4. Proportion of patients treated to remission at the three clinics that treated more patients to remission than any other clinic.



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Figure 5. Number of patients treated at clinics that followed-up fewer than 10 patients and proportion of patients followed-up and in remission one year later. The year on the x-axis indicates the year of follow-up, the corresponding number of patients starting their treatment the year before.

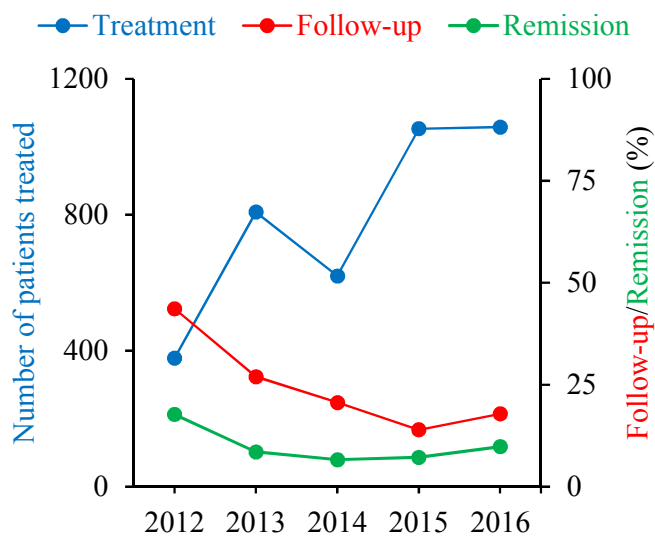


Table 1. Proportion of patients in remission at three Mando clinics.

<u>Outcome</u>	<u>Clinic</u>		
	<u>Alingsås</u>	<u>Danderyd</u>	<u>Huddinge</u>
Operation (years)	2	7	18
<u>12 months assessment</u>			
Patients in remission	13	72	219
Patients not in remission	36	107	552
Proportion in remission	27	40*	28
<u>Continued treatment (months)</u>			
Patients in remission	19	141	490
Patients not in remission	27	27	170
<u>Proportion in remission</u>	<u>39</u>	<u>82</u>	<u>68</u>

*P=0.0017 compared to Alingsås and Huddinge after P=0.0069 (overall difference).

Supplementary table.

Number of patients treated (Treat), followed-up (F-up), and in remission at follow-up (Rem) at eating disorders clinics in Sweden in 2012-2016. The three clinics in the Stockholm County Council are the Stockholm Centre for Eating Disorders (SCÄ, A01), Capio Centre for Eating Disorders (Capio, A04), and the Mandometer Clinic (Mando (B01). Other is the combination of all clinics that followed-up fewer than 20 patients in 2012-2013 and fewer than 10 patients in 2014-2016. Whilst most of the cells can be filled in, it is not possible to fill in all cells, because of the procedures of follow-up. The clinics are arranged from the maximal-minimal number of patients treated.

2012				2013				2014			
Clinic	Treat	F-up	Rem	Clinic	Treat	F-up	Rem	Clinic	Treat	F-up	Rem
A01	696	224	131	A01	710	305	179	A01	705	339	210
A04	157	93	52	A04	176	88	49	A04	162	77	49
B01	123	53	39	B01	168	54	43	B01	136	59	53
T01	120	50	21	T01	116	39	20	M10	105	36	20
M10	107	38	22	M10	111	36	22	T01	99	46	21
U02	90	23	9	O09	89	36	19	X02	85	40	22
O09	78	38	16	E12	83	41	28	H01	82	36	15
E12	66	25	14	Å04	63	35	21	U02	78	16	6
N05	49	26	11	H01	59	43	18	E12	72	38	23
R01	48	33	13	N02	58	30	7	N07	66	16	3
H01	44	44	12	O07	56	35	4	S02	63	1	0
D03	40	38	7	O03	44	44	6	O09	57	27	15
K08	36	24	12	M12	42	41	10	N02	55	32	15
O03	36	33	8	N05	39	26	3	C04	52	0	0
Å04	33	21	7	N07	39	21	1	O03	52	30	5
O07	31	31	5	C03	38	30	13	W11	49	11	0
W01	30	28	20	P04	33	32	9	O07	43	16	2
N02	29	28	1	W01	28	28	9	N05	40	16	8
N07	29	22	2	D03		12	3	C03	39	17	5
P04	26	26	0	K08		13	9	M52	39	20	11
C03	21	21	8	U02		12	5	P04	37	15	0
Other	378	165	67	Z02		13	8	Å02	33	27	14
				Å02		11	10	D03	31	11	0
Sum	2267	1084	477	Other	806	218	69	M03	30	7	0
								Å04	30	19	14
				Sum	2758	1243	565,9	R01	29	4	0
								Y06	29	0	0
								M12	26	15	7
								W04	26	8	0
								K08	25	13	9
								W01	24	9	0
								B03	20	4	0
								B05	19	1	0
								Z02	19	10	10
								Å12	19	4	0
								D08	18	10	8
								F01	17	10	0
								Y05	16	3	0
								O66	15	6	0

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2		E08	13	6	0
3		F02	13	12	3
4		M28	13	7	0
5		Å06	11	2	0
6		E09	9	2	0
7		I05	9	0	0
8		Y08	9	1	0
9		D14	8	0	0
10		Z05	8	0	0
11		G03	7	5	0
12		E06	6	0	0
13		E17	6	4	0
14		D06	5	0	0
15		I01	5	0	0
16		Å11	5	3	0
17		F04	4	2	0
18		F10	4	0	0
19		E11	3	0	0
20		E25	3	2	0
21		O46	3	3	0
22		E22	2	1	0
23		O01	2	0	0
24		B10	1	0	0
25		F07	1	0	0
26		F08	1	0	0
27		K09	1	0	0
28		O67	1	0	0
29		W13	1	0	0
30		Y07	1	0	0
31		Y10	1	0	0
32		Y11	1	0	0
33		I01	0	0	0
34		M37	0	0	0
35		M57	0	0	0
36		O27	0	0	0
37		O31	0	0	0
38		O35	0	0	0
39		O36	0	0	0
40		O37	0	0	0
41		O50	0	0	0
42		O72	0	0	0
43		Other		128	41
44		Sum	2699	1098	548
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2015

Clinic	Treat	F-up	Rem
A01	734	505	182
A04	175	113	33
O09	109	13	0
T01	106	36	0
B01	95	79	32
M10	95	42	15
H01	93	51	4
X02	83	7	0
S02	73	37	0
U02	73	14	0
N07	71	20	0
E12	59	49	20
N02	47	41	6
N05	45	5	0
M52	40	7	3
C04	36	0	0
O07	35	31	3
M03	34	5	0
Å04	34	14	7
D03	31	18	0
M12	31	9	0
O03	29	21	10
C03	26	13	11
Z02	26	13	9
M57	25	0	0
K08	23	16	0
B03	22	14	0
Å02	22	11	0
E08	18	10	0
O27	17	17	7
P04	17	0	0
W01	17	17	5
Y06	15	7	0
D08	14	2	0
G03	14	6	0
I05	13	0	0
O66	13	13	0
R01	13	6	0
Y05	13	2	0

2016

Clinic	Treat	F-up	Rem
A01	715	298	117
A04	178	95	24
T01	98	20	0
O09	85	40	0
X02	82	49	0
B01	81	43	28
O27	80	52	7
H01	77	23	6
M10	75	17	6
E12	67	35	7
C03	64	30	20
N07	64	1	0
U02	63	0	0
C04	49	0	0
O07	49	28	5
W11	44	2	0
N02	40	13	0
M52	36	34	0
N05	35	26	0
O03	35	24	8
S02	32	7	0
W01	31	29	11
Y06	31	5	0
Å04	30	12	10
M03	26	1	0
B03	23	1	0
D03	23	15	0
K08	23	13	0
L01	21	0	0
M37	21	1	0
Z02	21	6	0
E17	20	12	0
Å12	20	1	0
M28	19	7	0
R01	19	5	0
Å02	19	5	0
W04	17	6	0
O66	15	15	5
Y05	15	2	0

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2	D14	12	0	0	F01	13	0	0
3	W11	12	0	0	E09	11	0	0
4	E17	10	6	0	M12	10	3	0
5	W04	10	4	0	O72	9	1	0
6	Å06	10	8	0	B05	7	3	0
7	Å12	10	2	0	E08	7	3	0
8	E09	9	1	0	I05	7	0	0
9	B05	7	2	0	G03	6	2	0
10	L01	7	0	0	Z05	6	0	0
11	M28	7	1	0	Å06	6	4	0
12	Y08	6	1	0	D08	5	4	0
13	E06	5	0	0	E06	5	0	0
14	F02	5	0	0	I02	5	2	0
15	Å11	5	0	0	M57	5	0	0
16	I02	4	1	0	Y08	3	1	0
17	M37	4	4	0	F04	2	2	0
18	O72	4	1	0	O71	2	0	0
19	D06	2	0	0	E22	1	0	0
20	F01	2	2	0	Y11	1	0	0
21	F10	2	0	0	Å11	1	0	0
22	Y11	2	0	0	B10	0	0	0
23	B10	1	0	0	D06	0	0	0
24	E25	1	0	0	D14	0	0	0
25	F04	1	0	0	E25	0	0	0
26	Z05	1	0	0	F02	0	0	0
27	E11	0	0	0	F10	0	0	0
28	E22	0	0	0	P04	0	0	0
29	F07	0	0	0	E11	0	0	0
30	F08	0	0	0	F07	0	0	0
31	K09	0	0	0	F08	0	0	0
32	O01	0	0	0	K09	0	0	0
33	O46	0	0	0	O01	0	0	0
34	O67	0	0	0	O46	0	0	0
35	O71	0	0	0	O67	0	0	0
36	W13	0	0	0	W13	0	0	0
37	Y07	0	0	0	Y07	0	0	0
38	Y10	0	0	0	Y10	0	0	0
39	Other		147	76	Other			104
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41	Sum	2575	1444	423	Sum	2555	998	358
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BMJ Open

Treatment Outcomes for Eating Disorders in Sweden, 2012-2016 "Data from the National Quality Registry"

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2018-024179.R1
Article Type:	Research
Date Submitted by the Author:	11-Sep-2018
Complete List of Authors:	Södersten, Per; Karolinska Institutet Brodin, Ulf; Karolinska Institutet, Sjöberg, Jennie; Mandometer Clinic Zandian, Modjtaba; Karolinska Institutet Bergh, Cecilia; Mandometer Clinic,
Primary Subject Heading:	Public health
Secondary Subject Heading:	Health policy
Keywords:	Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, PUBLIC HEALTH, STATISTICS & RESEARCH METHODS

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Treatment Outcomes for Eating Disorders in Sweden, 2012-2016

“Data from the National Quality Registry”

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4333 words excluding abstract, strengths and limitations, references, acknowledgements, and

figure legends

51 references

5 figures

2 tables

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Abstract

Objective To report the outcomes of eating disorders treatment in Sweden in 2012-2016.

Design The number of patients treated and the number of patients not fulfilling an eating disorders diagnosis (remission) at one year of follow-up at the clinics listed in the National Quality Registry for Eating Disorders Treatment were analyzed. The published outcomes at three clinics, that used survival analysis to estimate outcomes, were compared with their outcomes in the registry. Outcomes at the three biggest clinics were compared.

Setting All eating disorders clinics.

Participants All patients treated at eating disorders clinics.

Intervention Cognitive behavioural therapy at most clinics and normalization of eating behaviour at the three clinics with published outcomes.

Outcome measure Proportion of patients in remission.

Results About 2600 patients were treated annually, fewer than half were followed-up, and remission rates decreased from 21% in 2014 to 14% in 2016. Outcomes, which differed amongst clinics and within clinics over time, have been publically overestimated by excluding patients lost to follow-up. The published estimated rate of remission at three clinics that treated 1200 patients in 1993-2011 was 27, 28, and 40% at one year of follow-up. The average rate of remission over the three last years at the biggest of these clinics was 36%, but decreased from 29 and 30% to 16 and 14% at the two other of the biggest clinics.

Conclusions With more than half the patients lost to follow-up and no data on relapse in the National Quality Registry, it is difficult to estimate the effects of eating disorders treatment in

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3 Sweden. Analysis of time to clinically significant events, including an extended period of
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5 follow-up, has improved the quality of the estimates at three clinics. Overestimation of
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7 remission rates has misled health care policies. The effect of eating disorders treatment has
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9 also been overestimated internationally.
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Strengths and limitations of this study

- This study has the strength of analyzing all patients treated, followed-up, and treated to remission at all eating disorders clinics over five years in Sweden.
- These outcomes are available in the National Quality Registry for Eating Disorders Treatment but have not been published in the scientific literature.
- Three clinics have published outcomes at three-month intervals making it possible to compare these outcomes with their outcomes in the registry.
- The study has the strength of showing that a time-to-event analysis improves compliance, facilitating estimation of outcomes.
- It is a limitation that whereas outcomes in the registry covered the years 2012-2016, the published outcomes at the three clinics covered the years 1993-2011.

INTRODUCTION

The National Quality Registries in Sweden have been developed starting in the 1970s and today there are about 100 registries, covering virtually all kinds of disease (1). The Swedish Association of Local Authorities and Regions (SALAR) and the Swedish Government recently agreed to strengthen the registries financially, pointing to their key role in the development of all aspects of health care, improving the quality of care, facilitating research, including international comparisons of outcomes, guiding health care policies, and making it possible for anyone to compare the outcomes of treatment at individual clinics (1,2). Indeed, the SALAR has a website for such comparisons (3).

The Swedish National Quality Registry for Eating Disorders Treatment, Riksät, was established in 1999 and has published 11 reports, written in Swedish, in 2001-2016 (4). Following the aims of the registries, the objective of Riksät is to “document the outcome of treatment” (quote from the first report in 2001). Thus, the important measures are the number of patients treated and the number of patients in remission at follow-up. These numbers are listed in Riksät but have not been analyzed and reported in the scientific literature. The first aim of the present study is to examine the rate of remission at all eating disorders clinics in Sweden.

The results in Riksät have been publicized nationally as demonstrating increasing rates of remission over the years to 56% in 2015 and that “70% of the patients are ‘cured’ within one year” (4,5). Because these outcomes are better than the outcomes reported in the scientific literature (6,7), the second aim of this study is to examine their evidence basis.

There are three clinics in Sweden, that have published outcomes (8). Because these clinics (Mandometer Clinics) also report to Riksät it is possible to compare their published

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3 outcomes with their outcomes in Riksät. The biggest of the three Mandometer clinics is the
4 clinic in the County Council of Stockholm (Mando). The third aim of this study is to compare
5 the outcomes at Mando with the outcomes at the two other of the biggest clinics in Sweden,
6 the Stockholm Centre for Eating Disorders (SCED) and the Capio Centre for Eating Disorders
7 (Capio).
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14 The fourth aim of this study is to call the attention of policy makers to the fact that
15 outcomes of eating disorders treatment have been overestimated not only in Sweden but in
16 other countries as well.
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22 **METHODS**

23 **Patients and diagnostic procedures**

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25 Riksät lists the number of patients entering treatment each year and the number of patients
26 followed-up one year later, although the exact time of follow-up is not mentioned. More than
27 90% of the patients entering treatment at the specialist clinics are listed in the registry, but
28 patients that are treated at general psychiatric units may not be listed. Whilst there is no
29 information on how many these patients might be, most patients treated are listed in the
30 registry. There is no information on long term outcome, including relapse.
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42 At the beginning of treatment and at follow-up the patients completed the Eating
43 Disorders Examination Questionnaire (EDE-Q), which measures eating disorders symptoms
44 (9), and the Clinical Impairment Assessment (CIA), which measures psychosocial functioning
45 as a consequence of the eating disorder (10). The EDE-Q was used for patients older than 10
46 years and the CIA was used for patients older than 18 years. A semistructured interview was
47 used for children and adults to determine overall psychiatric symptoms and social functioning
48 (see e.g., (11)). Using these procedures, the patients were diagnosed with Anorexia Nervosa,
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3 Bulimia Nervosa, Eating Disorder Not Otherwise Specified, or Binge Eating Disorder relying
4 on the criteria in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (12).
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6 Patients who no longer fulfilled the diagnostic criteria for an eating disorder were listed as in
7 remission. About 4-5% of the patients in the yearly reports had been treated before when
8 entering treatment.
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14 Riksät reports changes in the patients' social functioning and their experiences of the
15 treatment, and these secondary measures improve in parallel as patients go into remission but
16 will not be considered in this analysis.
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22 Whilst Riksät thus includes two time points for assessment, the Mandometer clinics
23 have developed a treatment in which the patients are assessed at three-month intervals and
24 followed-up 1, 2, 3, 6, 9, 12, 18, 24, 36, 48, and 60 months after remission. The procedures,
25 including the criteria for inclusion, exclusion, and remission were published in 2002 (13), and
26 have been re-published many times (e.g., (8)); another description may be redundant. The
27 Mandometer clinics also report their outcomes to Riksät.
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36 **Treatments**

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39 The 2012-2014 Riksät reports did not specify the treatments used beyond mentioning that
40 these were guided by "the principles of cognitive behavioural therapy" (CBT) and that they
41 could be used with individual patients or with groups of patients. Medical intervention was
42 used for monitoring and restoring physical health and psychopharmacology was also used,
43 absence of evidence of their efficiency was pointed out. The 2015-2016 reports provide
44 details on treatments. Thus, CBT was used with on average 52% of the children and with 72%
45 of the adults, psychodynamic therapy was used with on average 21% of the children and with
46 24% of the adults, and family-based therapies were used with on average 38% of the children.
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3 The treatment developed at the Mandometer clinics was described in 1996 (14), re-published
4 some years on (8,13), and because it has since been described in several other papers, another
5 description may be redundant. Suffice it to say that an important intervention is teaching
6 patients how to eat normally using real time visual feedback on how much food to eat and
7 how quickly to eat it. A video of how this method works was published recently (15). In
8 addition, the patients are provided with warmth, that exerts an anxiolytic effect in 30 minutes
9 (16), their physical activity is reduced, and they are assisted in restarting their social
10 interactions (13). Interestingly, re-establishing normal eating behaviour is also the most
11 important intervention in CBT, although it is not clear how this is achieved (7).
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23 **Description of outcomes**

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26 Initially, Riksät reported the combined outcomes at the clinics across regions in Sweden, the
27 reports published in 2009 and 2010 were incomplete, and no report was published in 2011.
28
29 However, the outcomes at individual clinics were reported in 2012-2016. The number of
30 patients treated at each clinic and the proportion of patients who were followed-up are listed
31 in one set of tables in these reports. The number and the proportion of patients in remission at
32 follow-up are listed in another set of tables. These numbers have been combined into one
33 table (supplementary table) and used in the analysis.
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43 **Combined outcomes at all clinics**

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46 The numbers of patients treated, followed-up, and treated to remission have been summarized
47 for all clinics. The number of patients in remission has been related to the number of patients
48 treated as well as to the number of patients followed-up in an attempt to explain the high
49 remission rates publicized in Sweden.
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3 If the treatment and the follow-up assessments are about the same at all clinics, the
4 probability for remission should be the same in all clinics. This hypothesis, which can be
5 formalized as: $H_0: P_i(\text{Remission}) = P_0(\text{Remission})$ for all clinics, $i=1, 2, 3, \dots, n$, was tested
6 using a test for homogeneity of the data (17).
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12 In 2012-2013 Riksät listed the number of clinics that treated and followed-up at least 20
13 patients. The number of patients treated to remission at these clinics was listed in 2012, but in
14 2013 the number of patients treated to remission included clinics that had followed-up at least
15 10 children or 10 adult patients. In 2014-2016 the number of patients treated, followed-up,
16 and treated to remission was listed for all clinics. Using these data (supplementary table), the
17 number of clinics following-up at least 20 patients have been analyzed. Outcomes at clinics
18 following-up fewer than 10 patients have also been analyzed.
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28 **Published outcomes at Mandometer clinics**

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31 Mandometer clinics have published the outcomes of 1428 patients treated at six clinics in four
32 countries over various periods of time in 1993-2011, and these data are available in the
33 supplementary files of (8). The three Swedish clinics, in Alingsås, Danderyd, and Huddinge,
34 treated 1200 of these patients. The clinic in Huddinge, within the Stockholm County Council,
35 is the oldest clinic and is referred to as Mando in this analysis. The probability of going into
36 remission over consecutive three-month intervals up to 12 months at these clinics was
37 estimated using a life-table approach to survival analysis (18). The rate of failure amongst
38 censored patients was estimated to be 20%, yielding a conservative estimate of treatment
39 outcomes. This analysis allows comparison between these published outcomes and the
40 outcomes for the same clinics listed in Riksät.
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54 **Outcomes at individual clinics**

Outcomes were compared amongst SCED, Capio, and Mando.

Patient and public involvement

This study is an analysis of patient data in a registry and those patients did not participate in the analysis. The results will be openly available at mandometer.com.

RESULTS

Patient characteristics

The characteristics of the patients at the start of treatment were stable over all years and measures of variability are therefore not included. The average proportion of males was 4.6%, the average proportion of children and adolescents, who were <18 years old, was 29%. The age, obviously, was variable and the average mean (SD) age of all patients was 23.1 (8.9) years. The proportion of the various eating disorders diagnoses was also stable over the years and average values are presented in Table 1.

Table 1. Diagnoses amongst patients entering treatment for eating disorders in Sweden in 2012-2016. There were about 2600 patient each year and the proportions are averaged over these years. Children were <18 years old.

<u>Diagnosis</u>	<u>Proportion (%)</u>	
	<u>Children</u>	<u>Adults</u>
Anorexia Nervosa	39	20
Bulimia Nervosa	8	32
Eating Disorder Not Otherwise Specified	45	37

Binge Eating Disorder	1	6
Other*	7	5

*Not specified.

Combined outcomes at all clinics

Figure 1 shows that the total number of patients treated at all clinics increased to about 2600 in 2013, and remained relatively stable over the following years. The figure also shows that fewer than half the patients were typically followed-up a year later and that the rate of remission was about 21% in 2012-2014, and decreased to 14% in 2016. The number of patients treated to remission increased from 477 in 2012 to 589 in 2014 and decreased to 358 in 2016. There is no information on possible differences in the number of patients in remission related to the diagnosis at the start of treatment.

--- Please insert Figure 1 about here ---

Figure 2 shows firstly, that the rate of remission at all clinics that followed-up their patients was less than 50% in 2012-2014, 29% in 2015, and 36% in 2016. Secondly, the figure shows that the rate of remission at clinics that had treated at least one patient to remission increased to 56% in 2015 and decreased to 54% in 2016. The second analysis thus excluded patients followed-up at clinics that did not treat a single patient to remission. The significance of these two calculations of remission rates is clarified in the Discussion.

--- Please insert Figure 2 about here ---

Variability in outcomes

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3 The probability of going into remission in 2012 was significantly different amongst the 17
4 clinics that had treated patients in all recorded years ($P < 0.001$; $\text{Chi}^2 = 80.2$, $\text{df} = 16$). The
5 probability of going into remission was also significantly different amongst the five clinics
6 that had treated at least 100 patients in 2012 ($P < 0.001$; $\text{Chi}^2 = 23.7$, $\text{df} = 4$). Analysis of the other
7 years gives similar results.
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14 Analysis of the results at SCED showed that the probability of going into remission was
15 significantly different over the years ($P < 0.001$; $\text{Chi}^2 = 46.3$, $\text{df} = 4$). Analysis of the other
16 clinics gives similar results.
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21 22 **Combined outcomes at clinics that followed-up at least 20 patients**

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24 Because Riksät reported on clinics that had followed-up at least 20 patients in 2012-2013 and
25 for all clinics in 2014-2016, the number of clinics reporting their outcomes was lower in
26 2012-2013 (21 and 23) than in 2014-2016 (70, 64, and 59). However, it is possible to compare
27 how many clinics had treated, followed-up, and treated at least 20 patients to remission in
28 2012-2016.
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37 Figure 3 shows that more clinics had treated at least 20 patients in 2016 than in 2012.
38 Whereas the clinics that had treated at least 20 patients in 2012 were selected for having
39 followed them up, only 45% of these clinics followed-up at least 20 patients in 2016. About
40 one in three of these clinics had treated at least 20 patients to remission in 2012 compared to
41 about one in eight in 2016. The results in the other years fall in between the results in 2012
42 and 2016.
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3 Out of the 33 clinics that had treated at least 20 patients in 2016 (Figure 3, green bar at
4 the very left), three (9%) had not followed-up any patient, and 21 (64%) had not treated a
5 single patient to remission. These 21 clinics had treated a total of 857 patients, with a median
6 (range) of 32 (20-98) patients/clinic.
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11 12 **Combined outcomes at clinics that followed-up fewer than 10 patients**

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15 Figure 4 shows that amongst the about 2600 patients who were treated annually in 2013-2016,
16 the number of patients treated at clinics that followed-up fewer than 10 patients increased to
17 more than 1000 in the last two years. In parallel, the proportion of patients who were
18 followed-up and treated to remission at these clinics decreased. Fewer than one in ten of the
19 patients were treated to remission in the final three years. Please note that the values for 2012
20 include clinics that followed up fewer than 20 patients. Clinics following-up fewer than 10
21 patients were not reported separately this year.
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32 --- Please insert Figure 4 about here ---
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35 **Published outcomes at Mandometer clinics**

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38 Table 2 shows that the proportion of patients in remission at 12 months assessments was at
39 least 27% and significantly different at the three Mandometer clinics, whose outcomes are
40 published. Treatment continues after the 12 months at these clinics and the proportion of
41 patients in remission increases after various, prolonged periods of time. Please note that these
42 clinics had been operating over various periods of time.
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Table 1. Proportion of patients in remission at Mandometer clinics.

Outcome	Clinic		
	Alingsås	Danderyd	Mando
Operation (years)	2	7	18
<u>12 months assessment</u>			
Patients in remission	13	72	219
Patients not in remission	36	107	552
Proportion in remission	27	40*	28
<u>Continued treatment (months)</u>			
Patients in remission	19	141	490
Patients not in remission	27	27	170
<u>Proportion in remission</u>	<u>39</u>	<u>82</u>	<u>68</u>

*P=0.0017 compared to Alingsås and Mando after P=0.0069 (overall difference).

It may be mentioned that the time to remission depends on the diagnosis at admission, with the longest time to remission for patients with anorexia nervosa (8).

Outcomes at the three biggest clinics

SCED had treated about four times more patients annually (median: 715; range: 696-724) than Capiro (175; 157-178) and Mando (123; 81-168), and followed-up about the same proportion of patients (43; 32-69%) as Capiro (50; 48-65%) and Mando (43; 32-83%). These proportions are similar to the average proportions of follow-up at all clinics over these years (Figure 1).

Figure 5 shows that Mando had treated a bigger proportion of patients to remission than SCED and Capiro in 2014-2016. Whilst the rate of remission was relatively stable at on average 36% at Mando over these three years, it decreased from 29% to 16% at SCED and from 30% to 14% at Capiro. In 2016, the proportion of patients treated to remission at Mando (35%) was about twice as big as the corresponding proportion at SCED (16%) and Capiro (14%).

--- Please insert Figure 5 about here ---

DISCUSSION

Patient characteristics, diagnostic procedures, and treatments

The characteristics of the patients, who have been treated for eating disorders in Sweden, including the proportion of males and children, age and diagnosis, have been relatively stable in recent years and are similar to the characteristics of eating disorders patients in other countries (19). It is worth noting that whilst a minority of the patients were diagnosed with Binge Eating Disorder, that disorder is now the most common eating disorder (20). Although the diagnostic procedures may differ amongst clinics (19), most of the procedures used in Sweden have been developed in other countries. In addition, the treatments used in Sweden,

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3 including CBT, psychodynamic therapy, and family therapy, as well as medical and
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5 psychopharmacological interventions aiming at restoring physical and mental health are the
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7 same as those recommended in the guidelines and used in most countries (19,21–26). The
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9 treatment at the Mandometer clinics differs in that an important intervention is the
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11 normalization of eating behaviour using real time visual feedback on how to eat as described
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13 many times and most recently by video (15). The differences and similarities amongst the
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15 Mandometer treatment and CBT have been described in detail recently, including the
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17 differences in outcomes (7).
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21 **Outcomes in Sweden**

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24 About 2600 patients were treated annually at the eating disorders clinics in Sweden in 2012-
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26 2016, fewer than half were followed-up, and the proportion of patients treated to remission
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28 decreased from one in five in 2012 to less than one in seven in 2016. However, remission
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30 rates which are more than three times higher have been publicized nationally. These estimates
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32 were derived by excluding patients lost to follow-up and patients followed-up at clinics that
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34 did not treat patients to remission. In 2016, only four clinics treated 20 patients to remission;
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36 most clinics treated a small number of patients, followed-up a few, and treated only one
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38 patient in ten to remission. Outcomes varied significantly between clinics each year and
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40 within clinics over years. In addition, in 2016 more than half the 33 clinics that had treated on
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42 average 32 patients had failed to treat a single patient to remission; one of these clinics had
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44 treated 98 patients unsuccessfully.
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49 **Interpretation and comparison with published outcomes**

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52 Whilst these findings indicate that the procedures of treatment and follow-up differ amongst
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54 clinics in Sweden, a word of caution seems appropriate. For example, although outcomes
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3 were significantly different over years at the biggest clinic (SCED), patients were treated to
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5 remission all years, suggesting that a statistically significant within-clinic variation may be
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7 less significant clinically. However, it seems unlikely that the decrease from a rate of
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9 remission of about 30% in 2014 at this clinic to about half that rate two years later is a matter
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11 of random variation. And the similar decrease in the rate of remission at another clinic in
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13 these years (Capiro) suggests that the procedures at these clinics had deteriorated, at least
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15 temporarily.
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19 Possible reasons for the variation in outcomes include changes in staffing, training of
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21 staff, patient compliance to treatment, and the physical conditions in the clinics, factors that
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23 affect outcomes in multicenter clinical trials (27). Whilst the “study protocol” of the
24
25 multicenter trial aims at reducing the influence of these factors, there is no standard protocol
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27 for the treatment of eating disorders. And although there is agreement that the treatment
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29 guidelines for eating disorders should be followed, this consensus view has not yet improved
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31 outcomes (21–23,25,28–30). For example, an attempt at implementing CBT, which is
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33 recommended in all guidelines, in combination with antidepressant medication for the
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35 treatment of bulimia nervosa in primary care in the U.S. resulted in a 70% dropout rate (31).
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37 A similar effort in general practice in the U.K. found that out of 683 patients with a diagnosis
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39 of bulimia, about half of the 272 patients who entered CBT completed the treatment, and
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41 although those patients improved, they were not free of eating disorders symptoms after
42
43 treatment (32). A recent study aiming to implement CBT for anorexia nervosa in general
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45 practice produced similar results. Thus, out of 257 patient referrals, 44 patients started in
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47 treatment and 22 completed the treatment (33), findings that were replicated in another recent
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49 study (34). Compliance is thus a general problem in the treatment of eating disorders, not a
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51 “Swedish” problem, but it can be improved as discussed below.
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3 Whether these factors are causally related to the decrease in remission rates in 2015-
4 2016 remains to be determined. But it may be of some significance that as the number of
5 patients treated at clinics that treated fewer than ten patients to remission increased, the
6 proportion of patients followed-up and treated to remission decreased (Figure 4). And when
7 the number of patients followed-up at all clinics increased in 2015, there was a marked
8 decrease in the proportion of patient treated to remission (Figures 1 and 2).
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17 The Mandometer treatment was developed starting in 1993, a theoretical framework and
18 preliminary findings were reported in 1996 (14,35). A randomized controlled trial
19 demonstrated its effectiveness and outcomes for 1428 patients treated at six clinics in four
20 countries were subsequently reported (8,13). The combined rate of remission at these clinics
21 was estimated to be about 75% in on average one year of treatment and the rate of relapse was
22 estimated to be about 10% over five years of follow-up (8). Similar to Riksät, estimates were
23 done amongst all patients entering treatment. However, far more patients were lost to follow-
24 up at Riksät's one year time point of follow-up than to Mandometer's procedure of
25 monitoring patients at three-month intervals throughout treatment and at 1, 2, 3, 6, 9, 12, 18,
26 24, 36, 48, and 60 months of follow-up (8). Despite the difference, the rate of remission at the
27 Mando clinic in the Stockholm County Council was on average 33% in 2012-2016 according
28 to the Riksät calculation, which is about half the estimated published 75% rate of remission
29 after on average one year of treatment (8).
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46 Average remission rates should be viewed cautiously as outcomes varied between
47 clinics. Thus, the published rate of remission at 12 months differed significantly at the three
48 Mandometer clinics, yet it was higher than the average values reported for all clinics in each
49 of the five years in Riksät. Differences in treatment methods between the Mandometer clinics
50 and the other clinics may explain the differences in outcomes (7) and it is possible that
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3 outcomes will be more consistent at the Mandometer clinics once they have been operating
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5 for a longer period of time. For example, the Alingsås clinic had been treating patients for
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7 only two years and reached a rate of remission of only 39%. The variation in the rate of
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9 remission at 12 months at the Mandometer clinics in Amsterdam (16%), San Diego (52%),
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11 and Melbourne (25%) (8), support previous findings that international cultural and medical
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13 system differences also affect treatment outcomes (36). Thus, patients treated in San Diego
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15 improved rapidly, but they were often prevented from continuing in treatment because of the
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17 financial constraints of their insurance policies (8), a problem that would not affect patients in
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19 Sweden. It should be noted that relatively few patients had been treated at these clinics.
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23 Dropout and relapse are significant events in the treatment of eating disorders (7,37,38),
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25 and neither these events, nor remission, should be expected to occur after a predetermined
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27 period of time such as at one year of follow-up as used in Riksät. Also, the precise time for
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29 follow-up is not mentioned. It seems likely that this procedure explains why more than half
30
31 the patients were lost to follow-up in Riksät. Practical approaches to survival analysis,
32
33 including time-to-event analysis, are long available (18,39) and should be used in studies of
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35 outcomes of eating disorders treatment. The higher level of compliance at the Mandometer
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37 clinics (8) offers support for their value.
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41 Considering the difference between outcomes at Mando and the other Swedish clinics,
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43 including the fact that several hundred patients have been treated to remission, and that the
44
45 rate of relapse has been reduced to an estimated 10% at the Mando clinics, a randomized
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47 controlled trial comparing outcomes at these clinics may be redundant; an attempt at a
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49 comparison (40), was fraught with problems (8). The major treatment in Swedish clinics is
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51 CBT and a detailed analysis showed that the remission rates after CBT are lower than those
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53 after Mandometer treatment (7). Psychodynamic therapy is also used in Swedish clinics,
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3 although outcomes of this therapy are inferior to those of CBT (41). Similarly, the use of
4 family-based therapies with children in Sweden as in other countries, probably does not
5 explain the differences in outcomes. But differences in patient characteristics at admission
6 may contribute to differences in treatment outcomes and even if the published literature
7 indicates that they do not (42), the possibility that such differences exist should be examined.
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13 14 15 **Implications for policy makers**

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18 Overestimations of the outcomes of the treatment for eating disorders in Sweden have been
19 publicized over several years (4), including the claim that “70% of the patients are ‘cured’
20 within one year”, which is maintained on Sweden’s National Educational Radio Channel (5).
21 This is similar to the international claim that CBT is “efficacious for a range of eating
22 disorder presentations in the short and long-term” (30), publicized as: “Based on a solid
23 empirical foundation, the transdiagnostic enhanced CBT approach will immediately become
24 the gold standard for the treatment of eating disorders” (43), and “[the effect of CBT] is the
25 most dramatic that we have seen in the literature ... [including] the potency ... and the
26 impressive maintenance of change over the 19-months follow-up” (44). The published
27 evidence does not support these claims (7,45–47) and evidence that the outcomes of CBT
28 have been overestimated for the treatment of other disorders is gradually emerging (48,49).
29 These overstatements have misinformed health policy makers and can now be corrected.
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45 In order to guide decisions on matters of health care, National and International Quality
46 Registries must offer reliable information. Widely publicized “facts” need to be critically
47 examined. Policy makers should be aware that once ill advised policies have been established,
48 retrospectively controlling their evidence basis can be ineffective, and even strengthen the
49 misguided policy (50,51).
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Acknowledgements

We thank Sara Norring, Riksät, Anna Sandelin, the Centre of Registries Västra Götaland, and Fredrik Westander and Lale Björne-Fergéus, SALAR, for information on Riksät.

Transparency declaration

Södersten affirms that the manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

Ethics approval

The project was approved by the Regional Ethical Review Board of Stockholm (Dnr 2015/456-31).

Authors

Södersten examined the registry data in detail over the last two years. He reviewed his examinations for all authors at regular intervals during the examination period. He is responsible for the overall content as guarantor and assumes responsibility for all aspects of the work. All data used for the analysis are included as a supplementary table to this submission, which all authors are happy to share with other researchers.

Brodin is medical statistician and has performed all statistical analyses and reviewed these for all authors at regular intervals during the examination period.

Sjöberg is clinical director of the Mandometer Clinic in Alingsås and responsible for treatment and data collection and reporting to the registry in 2012-2016.

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3 Zandian is clinical quality controller and has been responsible for data collection and
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5 reporting to the registry in 2012-2016.
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8 Bergh is clinical director for the Mandometer Clinic in Huddinge and responsible for
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10 treatment at all Mandometer clinics.
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13 All authors have seen and reviewed several versions of the manuscript and agreed to its final
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15 version.
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17
18 Södersten is: “the corresponding author and attests that all listed authors meet authorship
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20 criteria and that no others meeting the criteria have been omitted”.
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23 24 **Contributorship**

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26
27 Åsa Lundqvist BA of the Mandometer Clinic in Stockholm has been contact person with the
28
29 Rikät registry staff over the years 2012-2016. Ms Lundqvist supervised the reporting of data
30
31 to the registry and is in charge of the follow-up programme of the Mandometer Clinic.
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34 35 **Competing interests**

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37
38 Complete openness concerning financial arrangements is intended here. Brodin, Sjöberg and
39
40 Zandian declare that they have no financial interests related to this study. Our research is
41
42 carried out at the Karolinska Institute, where Södersten is a professor em. The research is
43
44 translated clinically by Mando Group AB, a company started by Södersten and Bergh, who
45
46 have 47.5% of the stock each. Professor Michael Leon of the University of California at
47
48 Irvine has 5%. Mando Group AB contracts with the County Council of Stockholm every fifth
49
50 year to treat patients with eating disorders. Mando Groups AB signed its first contract in 1997
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52 with the County Council of Stockholm and, since then, its treatment is one of the standards of
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54 care offered to the citizens of Stockholm. This arrangement is the same as when the County
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3 Council of Stockholm contracts with its own clinics to treat patients with all kinds of disease,
4 including eating disorders. That is to say, the County Council of Stockholm provides eating-
5 disorder services to the citizens of Stockholm both through a clinic of its own and through
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7 Mando Group AB. There is a third provider of care for patients with eating disorders in
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9 Stockholm, which is a private clinic. All health care in Sweden is funded through the tax
10
11 system; private pay is extremely uncommon. It should be added firstly, that Mando Group AB
12
13 is in compliance with the recommendation of the International Committee of Medical Journal
14
15 Editors on “Author Responsibilities-Conflicts of Interest”
16
17 [http://www.icmje.org/recommendations/browse/roles-and-responsibilities/author-](http://www.icmje.org/recommendations/browse/roles-and-responsibilities/author-responsibilities--conflicts-of-interest.html)
18
19 [responsibilities--conflicts-of-interest.html](http://www.icmje.org/recommendations/browse/roles-and-responsibilities/author-responsibilities--conflicts-of-interest.html). Secondly, it should also be added that all profit
20
21 that Mando Group AB has made has been re-invested in research and development and that
22
23 there have been no dividends to stock owners. All of the above is declared in all manuscript
24
25 submissions and thus far, journals have judged it necessary to publish only some of the
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27 details. It seems, however, that the potential ethical problem when scientists translate their
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29 research findings into the clinic in a company is not unlike that which arises when any
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31 scientist, in an academic setting is developing a theory and needs further economic funding
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33 for her/his work and may receive recognition and financial benefits for the work. The
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35 incentive is, in part, economic in this case as well and the ethical “problem” is similar in both
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37 cases. However, the more important incentive is the improvement of the treatment of patients
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39 with eating disorders. We are researchers working in an academic setting and like many other
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41 medical research institutes today, the Karolinska Institute encourages scientists to translate
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43 their research into the clinic in companies that aim to generate financial profits to be used for
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45 research and development (see:
46
47 http://ki.se.proxy.kib.ki.se/sites/default/files/summary_strategy2018.pdf).

54 55 **Funding**

1
2
3 This work was supported by The County Council of Stockholm grant number HNSV 15896,
4
5 HSN 1502-0291, project 3252.
6
7

8 **Role of the sponsor**

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11 The sponsor had no influence on the work.
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14 **Data sharing statement**

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17 The data used for this analysis are available in a supplementary table.
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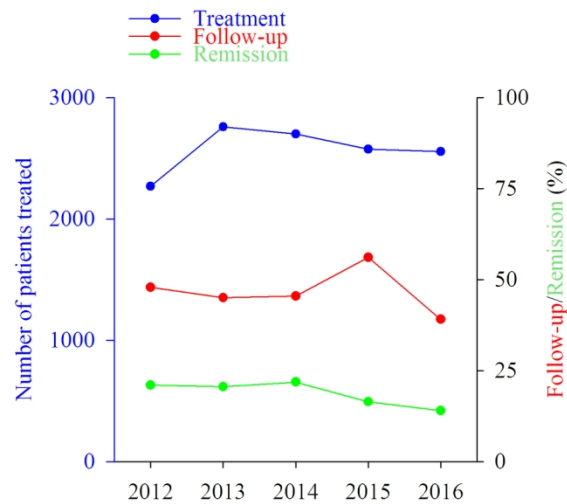


Figure 1. Number of patients treated at all clinics in Sweden and proportion of patients followed-up and in remission one year later. The year on the x-axis indicates the year of follow-up, the corresponding number of patients starting their treatment the year before.

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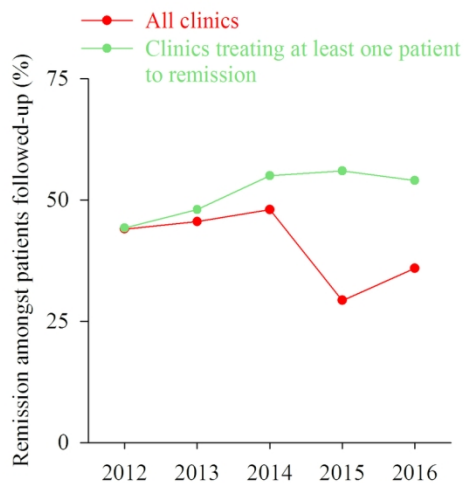


Figure 2. Proportion of patients in remission at all clinics that followed-up their patients and at clinics that treated at least one patient to remission.

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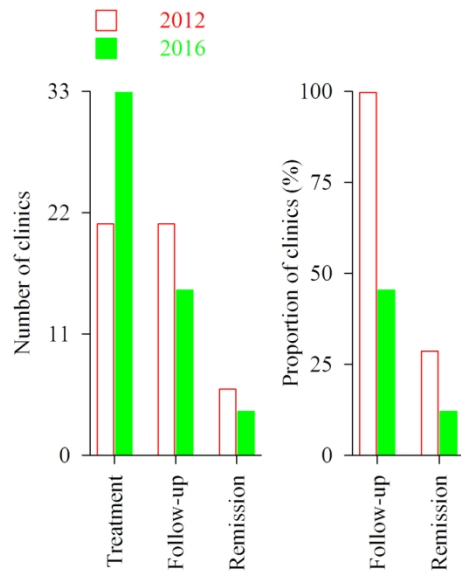


Figure 3. Number of clinics that treated, followed-up, and treated at least 20 patients to remission and proportion of clinics that followed-up and treated at least 20 patients to remission in 2012 and 2016.

127x180mm (300 x 300 DPI)

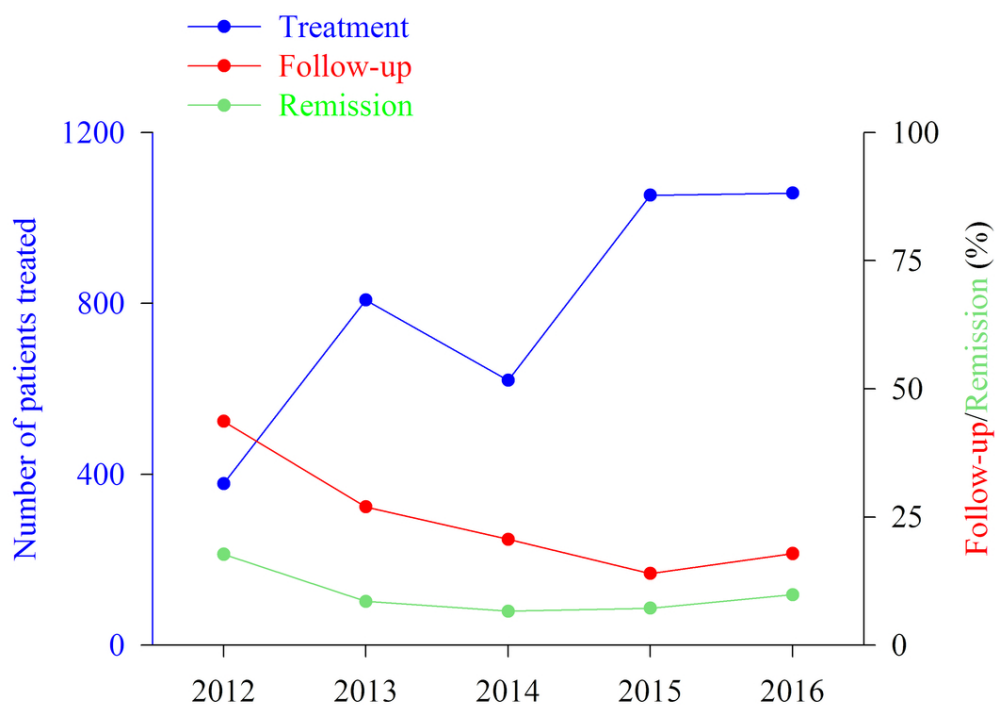


Figure 4. Number of patients treated at clinics that followed-up fewer than 10 patients (2013-2016) or 20 patients (2012) and proportion of patients followed-up and in remission one year later. The year on the x-axis indicates the year of follow-up, the corresponding number of patients starting their treatment the year before.

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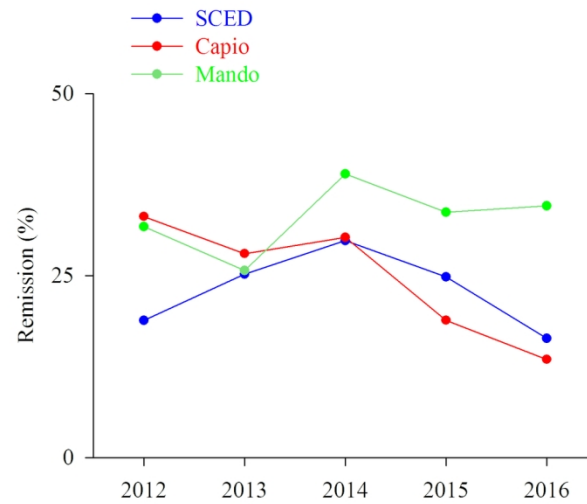


Figure 5. Proportion of patients treated to remission at the three clinics that treated more patients to remission than any other clinic, the Stockholm Centre for Eating Disorders (SCED), the Capiro Centre for Eating Disorders (Capiro), and the Mandometer Clinic in Stockholm (Mando).

127x180mm (300 x 300 DPI)

Supplementary table.

Number of patients treated (Treat), followed-up (F-up), and in remission at follow-up (Rem) at eating disorders clinics in Sweden in 2012-2016. The three clinics in the Stockholm County Council are the Stockholm Centre for Eating Disorders (SCED, A01), Caphio Centre for Eating Disorders (Caphio, A04), and the Mandometer Clinic (Mando (B01). Other is the combination of all clinics that followed-up fewer than 20 patients in 2012-2013 and fewer than 10 patients in 2014-2016.

Whilst most of the cells can be filled in, it is not possible to fill in all cells, because of the procedures of follow-up. The clinics are arranged from the maximal-minimal number of patients treated.

2012				2013				2014			
Clinic	Treat	F-up	Rem	Clinic	Treat	F-up	Rem	Clinic	Treat	F-up	Rem
A01	696	224	131	A01	710	305	179	A01	705	339	210
A04	157	93	52	A04	176	88	49	A04	162	77	49
B01	123	53	39	B01	168	54	43	B01	136	59	53
T01	120	50	21	T01	116	39	20	M10	105	36	20
M10	107	38	22	M10	111	36	22	T01	99	46	21
U02	90	23	9	O09	89	36	19	X02	85	40	22
O09	78	38	16	E12	83	41	28	H01	82	36	15
E12	66	25	14	Å04	63	35	21	U02	78	16	6
N05	49	26	11	H01	59	43	18	E12	72	38	23
R01	48	33	13	N02	58	30	7	N07	66	16	3
H01	44	44	12	O07	56	35	4	S02	63	1	0
D03	40	38	7	O03	44	44	6	O09	57	27	15
K08	36	24	12	M12	42	41	10	N02	55	32	15
O03	36	33	8	N05	39	26	3	C04	52	0	0
Å04	33	21	7	N07	39	21	1	O03	52	30	5
O07	31	31	5	C03	38	30	13	W11	49	11	0
W01	30	28	20	P04	33	32	9	O07	43	16	2
N02	29	28	1	W01	28	28	9	N05	40	16	8
N07	29	22	2	D03		12	3	C03	39	17	5
P04	26	26	0	K08		13	9	M52	39	20	11
C03	21	21	8	U02		12	5	P04	37	15	0
Other	378	165	67	Z02		13	8	Å02	33	27	14
				Å02		11	10	D03	31	11	0
Sum	2267	1084	477	Other	806	218	69	M03	30	7	0
								Å04	30	19	14
				Sum	2758	1243	566	R01	29	4	0
								Y06	29	0	0
								M12	26	15	7
								W04	26	8	0
								K08	25	13	9
								W01	24	9	0
								B03	20	4	0
								B05	19	1	0
								Z02	19	10	10
								Å12	19	4	0
								D08	18	10	8
								F01	17	10	0
								Y05	16	3	0
								O66	15	6	0

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2		E08	13	6	0
3		F02	13	12	3
4		M28	13	7	0
5		Å06	11	2	0
6		E09	9	2	0
7		I05	9	0	0
8		Y08	9	1	0
9		D14	8	0	0
10		Z05	8	0	0
11		G03	7	5	0
12		E06	6	0	0
13		E17	6	4	0
14		D06	5	0	0
15		I01	5	0	0
16		Å11	5	3	0
17		F04	4	2	0
18		F10	4	0	0
19		E11	3	0	0
20		E25	3	2	0
21		O46	3	3	0
22		E22	2	1	0
23		O01	2	0	0
24		B10	1	0	0
25		F07	1	0	0
26		F08	1	0	0
27		K09	1	0	0
28		O67	1	0	0
29		W13	1	0	0
30		Y07	1	0	0
31		Y10	1	0	0
32		Y11	1	0	0
33		I01	0	0	0
34		M37	0	0	0
35		M57	0	0	0
36		O27	0	0	0
37		O31	0	0	0
38		O35	0	0	0
39		O36	0	0	0
40		O37	0	0	0
41		O50	0	0	0
42		O72	0	0	0
43		Other		128	41
44		Sum	2699	1098	548
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2015

Clinic	Treat	F-up	Rem
A01	734	505	182
A04	175	113	33
O09	109	13	0
T01	106	36	0
B01	95	79	32
M10	95	42	15
H01	93	51	4
X02	83	7	0
S02	73	37	0
U02	73	14	0
N07	71	20	0
E12	59	49	20
N02	47	41	6
N05	45	5	0
M52	40	7	3
C04	36	0	0
O07	35	31	3
M03	34	5	0
Å04	34	14	7
D03	31	18	0
M12	31	9	0
O03	29	21	10
C03	26	13	11
Z02	26	13	9
M57	25	0	0
K08	23	16	0
B03	22	14	0
Å02	22	11	0
E08	18	10	0
O27	17	17	7
P04	17	0	0
W01	17	17	5
Y06	15	7	0
D08	14	2	0
G03	14	6	0
I05	13	0	0
O66	13	13	0
R01	13	6	0
Y05	13	2	0

2016

Clinic	Treat	F-up	Rem
A01	715	298	117
A04	178	95	24
T01	98	20	0
O09	85	40	0
X02	82	49	0
B01	81	43	28
O27	80	52	7
H01	77	23	6
M10	75	17	6
E12	67	35	7
C03	64	30	20
N07	64	1	0
U02	63	0	0
C04	49	0	0
O07	49	28	5
W11	44	2	0
N02	40	13	0
M52	36	34	0
N05	35	26	0
O03	35	24	8
S02	32	7	0
W01	31	29	11
Y06	31	5	0
Å04	30	12	10
M03	26	1	0
B03	23	1	0
D03	23	15	0
K08	23	13	0
L01	21	0	0
M37	21	1	0
Z02	21	6	0
E17	20	12	0
Å12	20	1	0
M28	19	7	0
R01	19	5	0
Å02	19	5	0
W04	17	6	0
O66	15	15	5
Y05	15	2	0

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2	D14	12	0	0	F01	13	0	0
3	W11	12	0	0	E09	11	0	0
4	E17	10	6	0	M12	10	3	0
5	W04	10	4	0	O72	9	1	0
6	Å06	10	8	0	B05	7	3	0
7	Å12	10	2	0	E08	7	3	0
8	E09	9	1	0	I05	7	0	0
9	B05	7	2	0	G03	6	2	0
10	L01	7	0	0	Z05	6	0	0
11	M28	7	1	0	Å06	6	4	0
12	Y08	6	1	0	D08	5	4	0
13	E06	5	0	0	E06	5	0	0
14	F02	5	0	0	I02	5	2	0
15	Å11	5	0	0	M57	5	0	0
16	I02	4	1	0	Y08	3	1	0
17	M37	4	4	0	F04	2	2	0
18	O72	4	1	0	O71	2	0	0
19	D06	2	0	0	E22	1	0	0
20	F01	2	2	0	Y11	1	0	0
21	F10	2	0	0	Å11	1	0	0
22	Y11	2	0	0	B10	0	0	0
23	B10	1	0	0	D06	0	0	0
24	E25	1	0	0	D14	0	0	0
25	F04	1	0	0	E25	0	0	0
26	Z05	1	0	0	F02	0	0	0
27	E11	0	0	0	F10	0	0	0
28	E22	0	0	0	P04	0	0	0
29	F07	0	0	0	E11	0	0	0
30	F08	0	0	0	F07	0	0	0
31	K09	0	0	0	F08	0	0	0
32	O01	0	0	0	K09	0	0	0
33	O46	0	0	0	O01	0	0	0
34	O67	0	0	0	O46	0	0	0
35	O71	0	0	0	O67	0	0	0
36	W13	0	0	0	W13	0	0	0
37	Y07	0	0	0	Y07	0	0	0
38	Y10	0	0	0	Y10	0	0	0
39	Other		147	76	Other			104
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41	Sum	2575	1444	423	Sum	2555	998	358
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BMJ Open

Treatment Outcomes for Eating Disorders in Sweden, 2012-2016 "Data from the National Quality Registry"

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2018-024179.R2
Article Type:	Research
Date Submitted by the Author:	16-Oct-2018
Complete List of Authors:	Södersten, Per; Karolinska Institutet Brodin, Ulf; Karolinska Institutet, Sjöberg, Jennie; Mandometer Clinic Zandian, Modjtaba; Karolinska Institutet Bergh, Cecilia; Mandometer Clinic,
Primary Subject Heading:	Public health
Secondary Subject Heading:	Health policy
Keywords:	Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, PUBLIC HEALTH, STATISTICS & RESEARCH METHODS

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Treatment Outcomes for Eating Disorders in Sweden, 2012-2016

“Data from the National Quality Registry”

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4367 words excluding abstract, strengths and limitations, references, acknowledgements, and

figure legends

52 references

5 figures

2 tables

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For peer review only

Abstract

Objective To report the outcomes of eating disorders treatment in Sweden in 2012-2016.

Design The number of patients treated and the number of patients not fulfilling an eating disorders diagnosis (remission) at one year of follow-up at the clinics listed in the National Quality Registry for Eating Disorders Treatment were analyzed. The published outcomes at three clinics, that used survival analysis to estimate outcomes, were compared with their outcomes in the registry. Outcomes at the three biggest clinics were compared.

Setting All eating disorders clinics.

Participants All patients treated at eating disorders clinics.

Intervention Cognitive behavioural therapy at most clinics and normalization of eating behaviour at the three clinics with published outcomes.

Outcome measure Proportion of patients in remission.

Results About 2600 patients were treated annually, fewer than half were followed-up, and remission rates decreased from 21% in 2014 to 14% in 2016. Outcomes, which differed amongst clinics and within clinics over time, have been publically overestimated by excluding patients lost to follow-up. The published estimated rate of remission at three clinics that treated 1200 patients in 1993-2011 was 27, 28, and 40% at one year of follow-up. The average rate of remission over the three last years at the biggest of these clinics was 36%, but decreased from 29 and 30% to 16 and 14% at the two other of the biggest clinics.

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3 **Conclusions** With more than half the patients lost to follow-up and no data on relapse in the
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5 National Quality Registry, it is difficult to estimate the effects of eating disorders treatment in
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7 Sweden. Analysis of time to clinically significant events, including an extended period of follow-
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9 up, has improved the quality of the estimates at three clinics. Overestimation of remission rates
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11 has misled health care policies. The effect of eating disorders treatment has also been
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13 overestimated internationally.
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Strengths and limitations of this study

- This study has the strength of analyzing all patients treated, followed-up, and treated to remission at all eating disorders clinics over five years in Sweden.
- These outcomes are available in the National Quality Registry for Eating Disorders Treatment but have not been published in the scientific literature.
- Three clinics have published outcomes at three-month intervals making it possible to compare these outcomes with their outcomes in the registry.
- The study has the strength of showing that a time-to-event analysis improves compliance, facilitating estimation of outcomes.
- It is a limitation that whereas outcomes in the registry covered the years 2012-2016, the published outcomes at the three clinics covered the years 1993-2011.

INTRODUCTION

The National Quality Registries in Sweden have been developed starting in the 1970s and today there are about 100 registries, covering virtually all kinds of disease (1). The Swedish Association of Local Authorities and Regions (SALAR) and the Swedish Government recently agreed to strengthen the registries financially, pointing to their key role in the development of all aspects of health care, improving the quality of care, facilitating research, including international comparisons of outcomes, guiding health care policies, and making it possible for anyone to compare the outcomes of treatment at individual clinics (1,2). Indeed, the SALAR has a website for such comparisons (3).

The Swedish National Quality Registry for Eating Disorders Treatment, Riksät, was established in 1999 and has published 11 reports, written in Swedish, in 2001-2016 (4). Following the aims of the registries, the objective of Riksät is to “document the outcome of treatment” (quote from the first report in 2001). Thus, the important measures are the number of patients treated and the number of patients in remission at follow-up. These numbers are listed in Riksät but have not been analyzed and reported in the scientific literature. The first aim of the present study is to examine the rate of remission at all eating disorders clinics in Sweden.

The results in Riksät have been publicized nationally as demonstrating increasing rates of remission over the years to 56% in 2015 and that “70% of the patients are ‘cured’ within one year” (4,5). Because these outcomes are better than the outcomes reported in the scientific literature (6,7), the second aim of this study is to examine their evidence basis.

There are three clinics in Sweden, that have published outcomes (8). Because these clinics (Mandometer Clinics) also report to Riksät it is possible to compare their published outcomes

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3 with their outcomes in Riksät. The biggest of the three Mandometer clinics is the clinic in the
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5 County Council of Stockholm (Mando). The third aim of this study is to compare the outcomes at
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7 Mando with the outcomes at the two other of the biggest clinics in Sweden, the Stockholm Centre
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9 for Eating Disorders (SCED) and the Capio Centre for Eating Disorders (Capio).
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13 The fourth aim of this study is to call the attention of policy makers to the fact that
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15 outcomes of eating disorders treatment have been overestimated not only in Sweden but in other
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17 countries as well.
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21 **METHODS**

22 **Patients and diagnostic procedures**

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25 Riksät lists the number of patients entering treatment each year and the number of patients
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27 followed-up one year later, although the exact time of follow-up is not mentioned. More than
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29 90% of the patients entering treatment at the specialist clinics are listed in the registry, but
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31 patients that are treated at general psychiatric units may not be listed. Whilst there is no
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33 information on how many these patients might be, most patients treated are listed in the registry.
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36 There is no information on long term outcome, including relapse.
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43 At the beginning of treatment and at follow-up the patients completed the Eating Disorders
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45 Examination Questionnaire (EDE-Q), which measures eating disorders symptoms (9), and the
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47 Clinical Impairment Assessment (CIA), which measures psychosocial functioning as a
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49 consequence of the eating disorder (10). The EDE-Q was used for patients older than 10 years
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51 and the CIA was used for patients older than 18 years. A semistructured interview was used for
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53 children and adults to determine overall psychiatric symptoms and social functioning (see e.g.,
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3 (11)). Using these procedures, the patients were diagnosed with Anorexia Nervosa, Bulimia
4 Nervosa, Eating Disorder Not Otherwise Specified, or Binge Eating Disorder relying on the
5 criteria in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (12). Patients
6 who no longer fulfilled the diagnostic criteria for an eating disorder were listed as in remission.
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8 About 4-5% of the patients in the yearly reports had been treated before when entering treatment.
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16 Riksät reports changes in the patients' social functioning and their experiences of the
17 treatment, and these secondary measures improve in parallel as patients go into remission but will
18 not be considered in this analysis.
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24 Whilst Riksät thus includes two time points for assessment, the Mandometer clinics have
25 developed a treatment in which the patients are assessed at three-month intervals and followed-up
26 1, 2, 3, 6, 9, 12, 18, 24, 36, 48, and 60 months after remission. The procedures, including the
27 criteria for inclusion, exclusion, and remission were published in 2002 (13), and have been re-
28 published many times (e.g., (8)); another description may be redundant. The Mandometer clinics
29 also report their outcomes to Riksät.
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38 39 **Treatments**

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42 The 2012-2014 Riksät reports did not specify the treatments used beyond mentioning that these
43 were guided by “the principles of cognitive behavioural therapy” (CBT) and that they could be
44 used with individual patients or with groups of patients. Medical intervention was used for
45 monitoring and restoring physical health and psychopharmacology was also used, absence of
46 evidence of their efficiency was pointed out. The 2015-2016 reports provide details on
47 treatments. Thus, CBT was used with on average 52% of the children and with 72% of the adults,
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49 psychodynamic therapy was used with on average 21% of the children and with 24% of the
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3 adults, and family-based therapies were used with on average 38% of the children. The treatment
4 developed at the Mandometer clinics was described in 1996 (14), re-published some years on
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6 (8,13), and because it has since been described in several other papers, another description may
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8 be redundant. Suffice it to say that an important intervention is teaching patients how to eat
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10 normally using real time visual feedback on how much food to eat and how quickly to eat it. A
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12 video of how this method works was published recently (15). In addition, the patients are
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14 provided with warmth, that exerts an anxiolytic effect in 30 minutes (16), their physical activity
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16 is reduced, and they are assisted in restarting their social interactions (13). Interestingly, re-
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18 establishing normal eating behaviour is also the most important intervention in CBT, although it
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20 is not clear how this is achieved (7).
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27 **Description of outcomes**

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31 Initially, Riksät reported the combined outcomes at the clinics across regions in Sweden, the
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33 reports published in 2009 and 2010 were incomplete, and no report was published in 2011.
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36 However, the outcomes at individual clinics were reported in 2012-2016. The number of patients
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38 treated at each clinic and the proportion of patients who were followed-up are listed in one set of
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40 tables in these reports. The number and the proportion of patients in remission at follow-up are
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42 listed in another set of tables. These numbers have been combined into one table (supplementary
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44 table) and used in the analysis.
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48 **Combined outcomes at all clinics**

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51 The numbers of patients treated, followed-up, and treated to remission have been summarized for
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53 all clinics. The number of patients in remission has been related to the number of patients treated
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3 as well as to the number of patients followed-up in an attempt to explain the high remission rates
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5 publicized in Sweden.
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9 If the treatment and the follow-up assessments are about the same at all clinics, the
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11 probability for remission should be the same in all clinics. This hypothesis, which can be
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13 formalized as: $H_0: P_i(\text{Remission}) = P_0(\text{Remission})$ for all clinics, $i=1, 2, 3, \dots, n$, was tested using
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15 a test for homogeneity of the data (17).
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19 In 2012-2013 Riksät listed the number of clinics that treated and followed-up at least 20
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21 patients. The number of patients treated to remission at these clinics was listed in 2012, but in
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23 2013 the number of patients treated to remission included clinics that had followed-up at least 10
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25 children or 10 adult patients. In 2014-2016 the number of patients treated, followed-up, and
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27 treated to remission was listed for all clinics. Using these data (supplementary table), the number
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29 of clinics following-up at least 20 patients have been analyzed. Outcomes at clinics following-up
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31 fewer than 10 patients have also been analyzed.
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36 **Published outcomes at Mandometer clinics**

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40 Mandometer clinics have published the outcomes of 1428 patients treated at six clinics in four
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42 countries over various periods of time in 1993-2011, and these data are available in the
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44 supplementary files of (8). The three Swedish clinics, in Alingsås, Danderyd, and Huddinge,
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46 treated 1200 of these patients. The clinic in Huddinge, within the Stockholm County Council, is
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48 the oldest clinic and is referred to as Mando in this analysis. The probability of going into
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50 remission over consecutive three-month intervals up to 12 months at these clinics was estimated
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52 using a life-table approach to survival analysis (18). The rate of failure amongst censored patients
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54 was estimated to be 20%, yielding a conservative estimate of treatment outcomes. This analysis
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allows comparison between these published outcomes and the outcomes for the same clinics listed in Riksät.

Outcomes at individual clinics

Outcomes were compared amongst SCED, Capio, and Mando.

Patient and public involvement

This study is an analysis of patient data in a registry and those patients did not participate in the analysis. The results will be openly available at mandometer.com.

RESULTS

Patient characteristics

The characteristics of the patients at the start of treatment were stable over all years and measures of variability are therefore not included. The average proportion of males was 4.6%, the average proportion of children and adolescents, who were <18 years old, was 29%. The age, obviously, was variable and the average mean (SD) age of all patients was 23.1 (8.9) years. The proportion of the various eating disorders diagnoses was also stable over the years and average values are presented in Table 1.

Table 1. Diagnoses amongst patients entering treatment for eating disorders in Sweden in 2012-2016. There were about 2600 patient each year and the proportions are averaged over these years. Children were <18 years old.

Proportion (%)

<u>Diagnosis</u>	<u>Children</u>	<u>Adults</u>
Anorexia Nervosa	39	20
Bulimia Nervosa	8	32
Eating Disorder Not Otherwise Specified	45	37
Binge Eating Disorder	1	6
<u>Other*</u>	<u>7</u>	<u>5</u>

*Not specified.

Combined outcomes at all clinics

Figure 1 shows that the total number of patients treated at all clinics increased to about 2600 in 2013, and remained relatively stable over the following years. The figure also shows that fewer than half the patients were typically followed-up a year later and that the rate of remission was about 21% in 2012-2014, and decreased to 14% in 2016. The number of patients treated to remission increased from 477 in 2012 to 589 in 2014 and decreased to 358 in 2016. There is no information on possible differences in the number of patients in remission related to the diagnosis at the start of treatment.

--- Please insert Figure 1 about here ---

Figure 2 shows firstly, that the rate of remission at all clinics that followed-up their patients was less than 50% in 2012-2014, 29% in 2015, and 36% in 2016. Secondly, the figure shows that

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3 the rate of remission at clinics that had treated at least one patient to remission increased to 56%
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5 in 2015 and decreased to 54% in 2016. The second analysis thus excluded patients followed-up at
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7 clinics that did not treat a single patient to remission. The significance of these two calculations
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9 of remission rates is clarified in the Discussion.
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16 **Variability in outcomes**

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20 The probability of going into remission in 2012 was significantly different amongst the 17 clinics
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22 that had treated patients in all recorded years ($P < 0.001$; $\text{Chi}^2 = 80.2$, $\text{df} = 16$). The probability of
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24 going into remission was also significantly different amongst the five clinics that had treated at
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26 least 100 patients in 2012 ($P < 0.001$; $\text{Chi}^2 = 23.7$, $\text{df} = 4$). Analysis of the other years gives similar
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28 results.
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33 Analysis of the results at SCED showed that the probability of going into remission was
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35 significantly different over the years ($P < 0.001$; $\text{Chi}^2 = 46.3$, $\text{df} = 4$). Analysis of the other clinics
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37 gives similar results.
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41 **Combined outcomes at clinics that followed-up at least 20 patients**

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44 Because Riksät reported on clinics that had followed-up at least 20 patients in 2012-2013 and for
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46 all clinics in 2014-2016, the number of clinics reporting their outcomes was lower in 2012-2013
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48 (21 and 23) than in 2014-2016 (70, 64, and 59). However, it is possible to compare how many
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50 clinics had treated, followed-up, and treated at least 20 patients to remission in 2012-2016.
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3 Figure 3 shows that more clinics had treated at least 20 patients in 2016 than in 2012.

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5 Whereas the clinics that had treated at least 20 patients in 2012 were selected for having followed
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7 them up, only 45% of these clinics followed-up at least 20 patients in 2016. About one in three of
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9 these clinics had treated at least 20 patients to remission in 2012 compared to about one in eight
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11 in 2016. The results in the other years fall in between the results in 2012 and 2016.
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19 Out of the 33 clinics that had treated at least 20 patients in 2016 (Figure 3, green bar at the
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21 very left), three (9%) had not followed-up any patient, and 21 (64%) had not treated a single
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23 patient to remission. These 21 clinics had treated a total of 857 patients, with a median (range) of
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25 32 (20-98) patients/clinic.
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28 29 **Combined outcomes at clinics that followed-up fewer than 10 patients**

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33 Figure 4 shows that amongst the about 2600 patients who were treated annually in 2013-2016,
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35 the number of patients treated at clinics that followed-up fewer than 10 patients increased to more
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37 than 1000 in the last two years. In parallel, the proportion of patients who were followed-up and
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39 treated to remission at these clinics decreased. Fewer than one in ten of the patients were treated
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41 to remission in the final three years. Please note that the values for 2012 include clinics that
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43 followed up fewer than 20 patients. Clinics following-up fewer than 10 patients were not reported
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45 separately this year.
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53 54 **Published outcomes at Mandometer clinics**

Table 2 shows that the proportion of patients in remission at 12 months assessments was at least 27% and significantly different at the three Mandometer clinics, whose outcomes are published. Treatment continues after the 12 months at these clinics and the proportion of patients in remission increases after various, prolonged periods of time. Please note that these clinics had been operating over various periods of time.

Table 1. Proportion of patients in remission at Mandometer clinics.

	Clinic		
Outcome	Alingsås	Danderyd	Mando
Operation (years)	2	7	18
<u>12 months assessment</u>			
Patients in remission	13	72	219
Patients not in remission	36	107	552
Proportion in remission	27	40*	28
<u>Continued treatment (months)</u>			
Patients in remission	19	141	490
Patients not in remission	27	27	170

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3 Proportion in remission 39 82 68
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6 *P=0.0017 compared to Alingsås and Mando after P=0.0069 (overall difference).
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10 It may be mentioned that the time to remission depends on the diagnosis at admission, with
11 the longest time to remission for patients with anorexia nervosa (8).
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15 16 17 18 19 20 21 22 **Outcomes at the three biggest clinics**

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26 SCED had treated about four times more patients annually (median: 715; range: 696-724) than
27 Capiro (175; 157-178) and Mando (123; 81-168), and followed-up about the same proportion of
28 patients (43; 32-69%) as Capiro (50; 48-65%) and Mando (43; 32-83%). These proportions are
29 similar to the average proportions of follow-up at all clinics over these years (Figure 1).
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36 Figure 5 shows that Mando had treated a bigger proportion of patients to remission than
37 SCED and Capiro in 2014-2016. Whilst the rate of remission was relatively stable at on average
38 36% at Mando over these three years, it decreased from 29% to 16% at SCED and from 30% to
39 14% at Capiro. In 2016, the proportion of patients treated to remission at Mando (35%) was about
40 twice as big as the corresponding proportion at SCED (16%) and Capiro (14%).
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52 **DISCUSSION**

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Patient characteristics, diagnostic procedures, and treatments

The characteristics of the patients, who have been treated for eating disorders in Sweden, including the proportion of males and children, age and diagnosis, have been relatively stable in recent years and are similar to the characteristics of eating disorders patients in other countries (19). It is worth noting that whilst a minority of the patients were diagnosed with Binge Eating Disorder, that disorder is now the most common eating disorder (20). Although the diagnostic procedures may differ amongst clinics (19), most of the procedures used in Sweden have been developed in other countries. In addition, the treatments used in Sweden, including CBT, psychodynamic therapy, and family therapy, as well as medical and psychopharmacological interventions aiming at restoring physical and mental health are the same as those recommended in the guidelines and used in most countries (19,21–26). The treatment at the Mandometer clinics differs in that an important intervention is the normalization of eating behaviour using real time visual feedback on how to eat as described many times and most recently by video (15). The differences and similarities amongst the Mandometer treatment and CBT have been described in detail recently, including the differences in outcomes (7).

Outcomes in Sweden

About 2600 patients were treated annually at the eating disorders clinics in Sweden in 2012–2016, fewer than half were followed-up, and the proportion of patients treated to remission decreased from one in five in 2012 to less than one in seven in 2016. However, remission rates which are more than three times higher have been publicized nationally. These estimates were derived by excluding patients lost to follow-up and patients followed-up at clinics that did not treat patients to remission. In 2016, only four clinics treated 20 patients to remission; most clinics

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3 treated a small number of patients, followed-up a few, and treated only one patient in ten to
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5 remission. Outcomes varied significantly between clinics each year and within clinics over years.
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7 In addition, in 2016 more than half the 33 clinics that had treated on average 32 patients had
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9 failed to treat a single patient to remission; one of these clinics had treated 98 patients
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11 unsuccessfully.
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15 **Interpretation and comparison with published outcomes**

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19 Whilst these findings indicate that the procedures of treatment and follow-up differ amongst
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21 clinics in Sweden, a word of caution seems appropriate. For example, although outcomes were
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23 significantly different over years at the biggest clinic (SCED), patients were treated to remission
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25 all years, suggesting that a statistically significant within-clinic variation may be less significant
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27 clinically. However, it seems unlikely that the decrease from a rate of remission of about 30% in
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29 2014 at this clinic to about half that rate two years later is a matter of random variation. And the
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31 similar decrease in the rate of remission at another clinic in these years (Capiro) suggests that the
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33 procedures at these clinics had deteriorated, at least temporarily.
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39 Possible reasons for the variation in outcomes include changes in staffing, training of staff,
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41 patient compliance to treatment, and the physical conditions in the clinics, factors that affect
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43 outcomes in multicenter clinical trials (27). Whilst the “study protocol” of the multicenter trial
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45 aims at reducing the influence of these factors, there is no standard protocol for the treatment of
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47 eating disorders. And although there is agreement that the treatment guidelines for eating
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49 disorders should be followed, this consensus view has not yet improved outcomes (21–23,25,28–
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51 30). For example, an attempt at implementing CBT, which is recommended in all guidelines, in
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53 combination with antidepressant medication for the treatment of bulimia nervosa in primary care
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3 in the U.S. resulted in a 70% dropout rate (31). A similar effort in general practice in the U.K.
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5 found that out of 683 patients with a diagnosis of bulimia, about half of the 272 patients who
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7 entered CBT completed the treatment, and although those patients improved, they were not free
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9 of eating disorders symptoms after treatment (32). A recent study aiming to implement CBT for
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11 anorexia nervosa in general practice produced similar results. Thus, out of 257 patient referrals,
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13 44 patients started in treatment and 22 completed the treatment (33), findings that were replicated
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15 in another recent study (34). Compliance is thus a general problem in the treatment of eating
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17 disorders, not a “Swedish” problem, but it can be improved as discussed below.
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23 Whether these factors are causally related to the decrease in remission rates in 2015-2016
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25 remains to be determined. But it may be of some significance that as the number of patients
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27 treated at clinics that treated fewer than ten patients to remission increased, the proportion of
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29 patients followed-up and treated to remission decreased (Figure 4). And when the number of
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31 patients followed-up at all clinics increased in 2015, there was a marked decrease in the
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33 proportion of patient treated to remission (Figures 1 and 2).
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38 The Mandometer treatment was developed starting in 1993, a theoretical framework and
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40 preliminary findings were reported in 1996 (14,35). A randomized controlled trial demonstrated
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42 its effectiveness and outcomes for 1428 patients treated at six clinics in four countries were
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44 subsequently reported (8,13). The combined rate of remission at these clinics was estimated to be
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46 about 75% in on average one year of treatment and the rate of relapse was estimated to be about
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48 10% over five years of follow-up (8). Similar to Riksät, estimates were done amongst all patients
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50 entering treatment. However, far more patients were lost to follow-up at Riksät’s one year time
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52 point of follow-up than to Mandometer’s procedure of monitoring patients at three-month
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54 intervals throughout treatment and at 1, 2, 3, 6, 9, 12, 18, 24, 36, 48, and 60 months of follow-up
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3 (8). Despite the difference, the rate of remission at the Mando clinic in the Stockholm County
4 Council was on average 33% in 2012-2016 according to the Riksät calculation, which is about
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6 half the estimated published 75% rate of remission after on average one year of treatment (8).
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11 Average remission rates should be viewed cautiously as outcomes varied between clinics.
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13 Thus, the published rate of remission at 12 months differed significantly at the three Mandometer
14 clinics, yet it was higher than the average values reported for all clinics in each of the five years
15 in Riksät. Differences in treatment methods between the Mandometer clinics and the other clinics
16 may explain the differences in outcomes (7) and it is possible that outcomes will be more
17 consistent at the Mandometer clinics once they have been operating for a longer period of time.
18 For example, the Alingsås clinic had been treating patients for only two years and reached a rate
19 of remission of only 39%. The variation in the rate of remission at 12 months at the Mandometer
20 clinics in Amsterdam (16%), San Diego (52%), and Melbourne (25%) (8), support previous
21 findings that international cultural and medical system differences also affect treatment outcomes
22 (36). Thus, patients treated in San Diego improved rapidly, but they were often prevented from
23 continuing in treatment because of the financial constraints of their insurance policies (8), a
24 problem that would not affect patients in Sweden. It should be noted that relatively few patients
25 had been treated at these clinics.
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44 Dropout and relapse are significant events in the treatment of eating disorders (7,37,38),
45 and neither these events, nor remission, should be expected to occur after a predetermined period
46 of time such as at one year of follow-up as used in Riksät. Also, the precise time for follow-up is
47 not mentioned. It seems likely that this procedure explains why more than half the patients were
48 lost to follow-up in Riksät. Practical approaches to survival analysis, including time-to-event
49 analysis, are long available (18,39) and should be used in studies of outcomes of eating disorders
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3 treatment. The higher level of compliance at the Mandometer clinics (8) offers support for their
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5 value.
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9 Considering the difference between outcomes at Mando and the other Swedish clinics,
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11 including the fact that several hundred patients have been treated to remission, and that the rate of
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13 relapse has been reduced to an estimated 10% at the Mando clinics, a randomized controlled trial
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15 comparing outcomes at these clinics may be redundant; an attempt at a comparison (40), was
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17 fraught with problems (8). The major treatment in Swedish clinics is CBT and a detailed analysis
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19 showed that the remission rates after CBT are lower than those after Mandometer treatment (7).
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21 Psychodynamic therapy is also used in Swedish clinics, although outcomes of this therapy are
22
23 inferior to those of CBT (41). Similarly, the use of family-based therapies with children in
24
25 Sweden as in other countries, probably does not explain the differences in outcomes. Differences
26
27 in patient characteristics at admission may contribute to differences in treatment outcomes and
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29 the possibility that such differences exist should be examined, although the published literature
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31 indicates that they do not (42). Also, there are no differences in the Swedish referral system such
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33 that more severely ill patients at one of the clinics might explain differences in outcomes.
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40 **Implications for policy makers**

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43 Overestimations of the outcomes of the treatment for eating disorders in Sweden have been
44
45 publicized over several years (4), including the claim that “70% of the patients are `cured` within
46
47 one year”, which is maintained on Sweden’s National Educational Radio Channel (5). This is
48
49 similar to the international claim that CBT is “efficacious for a range of eating disorder
50
51 presentations in the short and long-term” (30), publicized as: “Based on a solid empirical
52
53 foundation, the transdiagnostic enhanced CBT approach will immediately become the gold
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3 standard for the treatment of eating disorders” (43), and “[the effect of CBT] is the most dramatic
4
5 that we have seen in the literature ... [including] the potency ... and the impressive maintenance
6
7 of change over the 19-months follow-up” (44). The published evidence does not support these
8
9 claims (7,45–47) and evidence that the outcomes of CBT have been overestimated for the
10
11 treatment of other disorders is gradually emerging (48,49). These overstatements have
12
13
14
15 misinformed health policy makers and can now be corrected.
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18 The importance of the National Quality Registries in guiding health care policies in Sweden
19
20 was recently re-emphasized (50). In order to guide decisions on matters of health care, national
21
22 and international registries must offer reliable information. Widely publicized “facts” need to be
23
24 critically examined. Policy makers should be aware that once ill advised policies have been
25
26 established, retrospectively controlling their evidence basis can be ineffective, and even
27
28 strengthen the misguided policy (51,52).
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33 **Acknowledgements**

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36 We thank Sara Norring, Riksät, Anna Sandelin, the Centre of Registries Västra Götaland, and
37
38 Fredrik Westander and Lale Björne-Fergéus, SALAR, for information on Riksät.
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42 **Transparency declaration**

43
44
45 Södersten affirms that the manuscript is an honest, accurate, and transparent account of the study
46
47 being reported; that no important aspects of the study have been omitted; and that any
48
49 discrepancies from the study as planned (and, if relevant, registered) have been explained.
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53 **Ethics approval**

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3 The project was approved by the Regional Ethical Review Board of Stockholm (Dnr 2015/456-
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5 31).
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7

8 **Authors**

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10
11 Södersten examined the registry data in detail over the last two years. He reviewed his
12
13 examinations for all authors at regular intervals during the examination period. He is responsible
14
15 for the overall content as guarantor and assumes responsibility for all aspects of the work. All
16
17 data used for the analysis are included as a supplementary table to this submission, which all
18
19 authors are happy to share with other researchers.
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23
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25 Brodin is medical statistician and has performed all statistical analyses and reviewed these for all
26
27 authors at regular intervals during the examination period.
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30
31 Sjöberg is clinical director of the Mandometer Clinic in Alingsås and responsible for treatment
32
33 and data collection and reporting to the registry in 2012-2016.
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37 Zandian is clinical quality controller and has been responsible for data collection and reporting to
38
39 the registry in 2012-2016.
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42
43 Bergh is clinical director for the Mandometer Clinic in Huddinge and responsible for treatment at
44
45 all Mandometer clinics.
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49 All authors have seen and reviewed several versions of the manuscript and agreed to its final
50
51 version.
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55 Södersten is: “the corresponding author and attests that all listed authors meet authorship criteria
56
57 and that no others meeting the criteria have been omitted”.
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Contributorship

Åsa Lundqvist BA of the Mandometer Clinic in Stockholm has been contact person with the Rikät registry staff over the years 2012-2016. Ms Lundqvist supervised the reporting of data to the registry and is in charge of the follow-up programme of the Mandometer Clinic.

Competing interests

Complete openness concerning financial arrangements is intended here. Brodin, Sjöberg and Zandian declare that they have no financial interests related to this study. Our research is carried out at the Karolinska Institute, where Södersten is a professor em. The research is translated clinically by Mando Group AB, a company started by Södersten and Bergh, who have 47.5% of the stock each. Professor Michael Leon of the University of California at Irvine has 5%. Mando Group AB contracts with the County Council of Stockholm every fifth year to treat patients with eating disorders. Mando Groups AB signed its first contract in 1997 with the County Council of Stockholm and, since then, its treatment is one of the standards of care offered to the citizens of Stockholm. This arrangement is the same as when the County Council of Stockholm contracts with its own clinics to treat patients with all kinds of disease, including eating disorders. That is to say, the County Council of Stockholm provides eating-disorder services to the citizens of Stockholm both through a clinic of its own and through Mando Group AB. There is a third provider of care for patients with eating disorders in Stockholm, which is a private clinic. All health care in Sweden is funded through the tax system; private pay is extremely uncommon. It should be added firstly, that Mando Group AB is in compliance with the recommendation of the International Committee of Medical Journal Editors on “Author Responsibilities-Conflicts of Interest” <http://www.icmje.org/recommendations/browse/roles-and-responsibilities/author->

responsibilities--conflicts-of-interest.html. Secondly, it should also be added that all profit that Mando Group AB has made has been re-invested in research and development and that there have been no dividends to stock owners. All of the above is declared in all manuscript submissions and thus far, journals have judged it necessary to publish only some of the details. It seems, however, that the potential ethical problem when scientists translate their research findings into the clinic in a company is not unlike that which arises when any scientist, in an academic setting is developing a theory and needs further economic funding for her/his work and may receive recognition and financial benefits for the work. The incentive is, in part, economic in this case as well and the ethical “problem” is similar in both cases. However, the more important incentive is the improvement of the treatment of patients with eating disorders. We are researchers working in an academic setting and like many other medical research institutes today, the Karolinska Institute encourages scientists to translate their research into the clinic in companies that aim to generate financial profits to be used for research and development (see: http://ki.se.proxy.kib.ki.se/sites/default/files/summary_strategy2018.pdf).

Funding

This work was supported by The County Council of Stockholm grant number HNSV 15896, HSN 1502-0291, project 3252.

Role of the sponsor

The sponsor had no influence on the work.

Data sharing statement

The data used for this analysis are available in a supplementary table.

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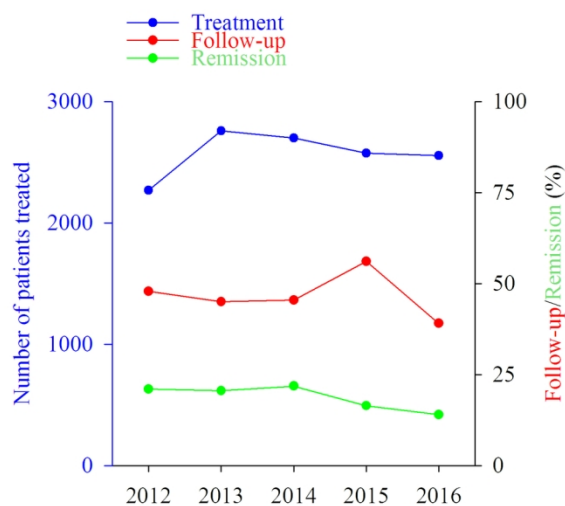


Figure 1. Number of patients treated at all clinics in Sweden and proportion of patients followed-up and in remission one year later. The year on the x-axis indicates the year of follow-up, the corresponding number of patients starting their treatment the year before.

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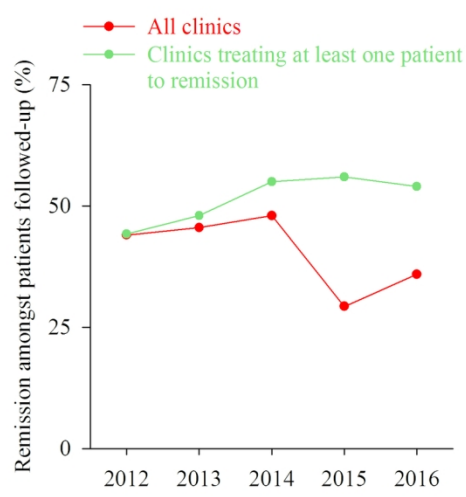


Figure 2. Proportion of patients in remission at all clinics that followed-up their patients and at clinics that treated at least one patient to remission.

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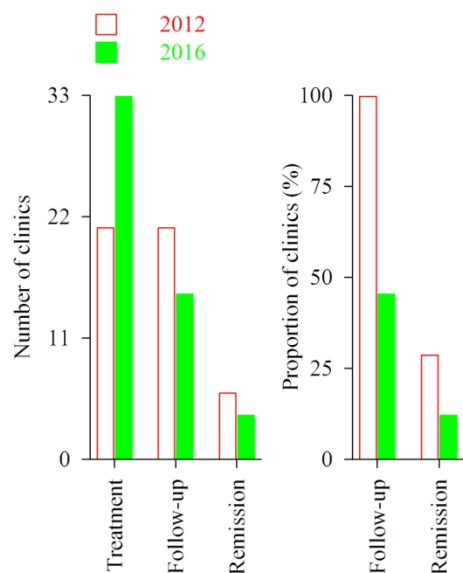


Figure 3. Number of clinics that treated, followed-up, and treated at least 20 patients to remission and proportion of clinics that followed-up and treated at least 20 patients to remission in 2012 and 2016.

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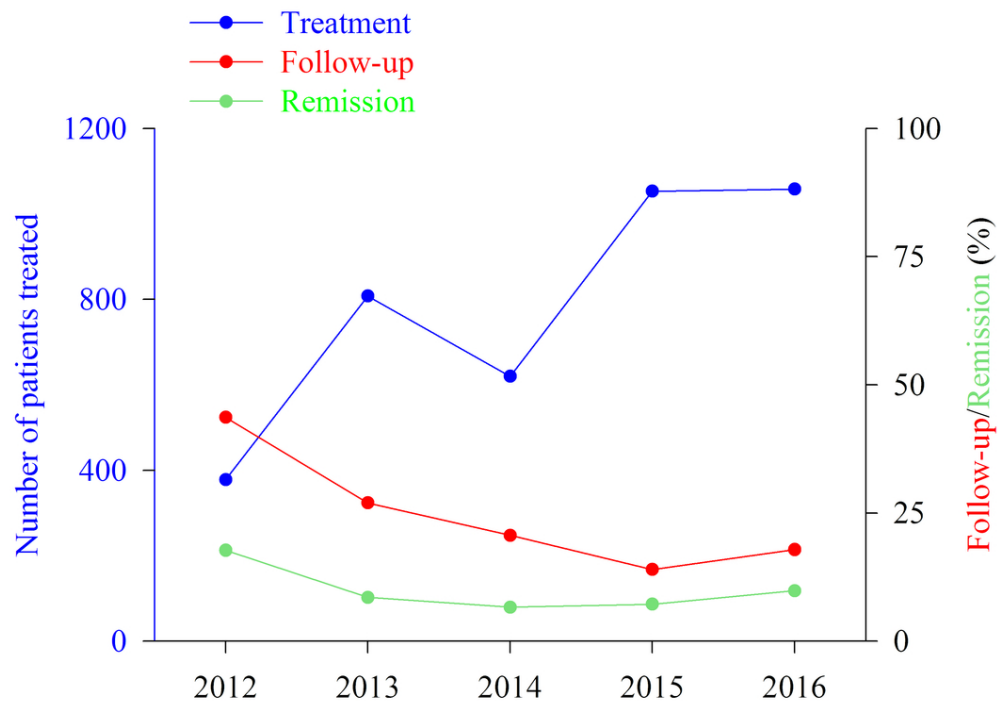


Figure 4. Number of patients treated at clinics that followed-up fewer than 10 patients (2013-2016) or 20 patients (2012) and proportion of patients followed-up and in remission one year later. The year on the x-axis indicates the year of follow-up, the corresponding number of patients starting their treatment the year before.

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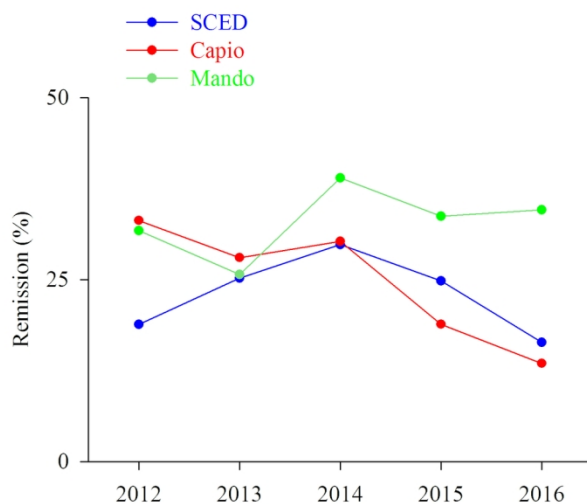


Figure 5. Proportion of patients treated to remission at the three clinics that treated more patients to remission than any other clinic, the Stockholm Centre for Eating Disorders (SCED), the Capiro Centre for Eating Disorders (Capiro), and the Mandometer Clinic in Stockholm (Mando).

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Supplementary table.

Number of patients treated (Treat), followed-up (F-up), and in remission at follow-up (Rem) at eating disorders clinics in Sweden in 2012-2016. The three clinics in the Stockholm County Council are the Stockholm Centre for Eating Disorders (SCED, A01), Caphio Centre for Eating Disorders (Caphio, A04), and the Mandometer Clinic (Mando (B01). Other is the combination of all clinics that followed-up fewer than 20 patients in 2012-2013 and fewer than 10 patients in 2014-2016.

Whilst most of the cells can filled in, it is not possible to fill in all cells, because of the procedures of follow-up. The clinics are arranged from the maximal-minimal number of patients treated.

2012				2013				2014			
Clinic	Treat	F-up	Rem	Clinic	Treat	F-up	Rem	Clinic	Treat	F-up	Rem
A01	696	224	131	A01	710	305	179	A01	705	339	210
A04	157	93	52	A04	176	88	49	A04	162	77	49
B01	123	53	39	B01	168	54	43	B01	136	59	53
T01	120	50	21	T01	116	39	20	M10	105	36	20
M10	107	38	22	M10	111	36	22	T01	99	46	21
U02	90	23	9	O09	89	36	19	X02	85	40	22
O09	78	38	16	E12	83	41	28	H01	82	36	15
E12	66	25	14	Å04	63	35	21	U02	78	16	6
N05	49	26	11	H01	59	43	18	E12	72	38	23
R01	48	33	13	N02	58	30	7	N07	66	16	3
H01	44	44	12	O07	56	35	4	S02	63	1	0
D03	40	38	7	O03	44	44	6	O09	57	27	15
K08	36	24	12	M12	42	41	10	N02	55	32	15
O03	36	33	8	N05	39	26	3	C04	52	0	0
Å04	33	21	7	N07	39	21	1	O03	52	30	5
O07	31	31	5	C03	38	30	13	W11	49	11	0
W01	30	28	20	P04	33	32	9	O07	43	16	2
N02	29	28	1	W01	28	28	9	N05	40	16	8
N07	29	22	2	D03		12	3	C03	39	17	5
P04	26	26	0	K08		13	9	M52	39	20	11
C03	21	21	8	U02		12	5	P04	37	15	0
Other	378	165	67	Z02		13	8	Å02	33	27	14
				Å02		11	10	D03	31	11	0
Sum	2267	1084	477	Other	806	218	69	M03	30	7	0
								Å04	30	19	14
				Sum	2758	1243	566	R01	29	4	0
								Y06	29	0	0
								M12	26	15	7
								W04	26	8	0
								K08	25	13	9
								W01	24	9	0
								B03	20	4	0
								B05	19	1	0
								Z02	19	10	10
								Å12	19	4	0
								D08	18	10	8
								F01	17	10	0
								Y05	16	3	0
								O66	15	6	0

E08	13	6	0
F02	13	12	3
M28	13	7	0
Å06	11	2	0
E09	9	2	0
I05	9	0	0
Y08	9	1	0
D14	8	0	0
Z05	8	0	0
G03	7	5	0
E06	6	0	0
E17	6	4	0
D06	5	0	0
I01	5	0	0
Å11	5	3	0
F04	4	2	0
F10	4	0	0
E11	3	0	0
E25	3	2	0
O46	3	3	0
E22	2	1	0
O01	2	0	0
B10	1	0	0
F07	1	0	0
F08	1	0	0
K09	1	0	0
O67	1	0	0
W13	1	0	0
Y07	1	0	0
Y10	1	0	0
Y11	1	0	0
I01	0	0	0
M37	0	0	0
M57	0	0	0
O27	0	0	0
O31	0	0	0
O35	0	0	0
O36	0	0	0
O37	0	0	0
O50	0	0	0
O72	0	0	0
Other		128	41
Sum	2699	1098	548

2015

Clinic	Treat	F-up	Rem
A01	734	505	182
A04	175	113	33
O09	109	13	0
T01	106	36	0
B01	95	79	32
M10	95	42	15
H01	93	51	4
X02	83	7	0
S02	73	37	0
U02	73	14	0
N07	71	20	0
E12	59	49	20
N02	47	41	6
N05	45	5	0
M52	40	7	3
C04	36	0	0
O07	35	31	3
M03	34	5	0
Å04	34	14	7
D03	31	18	0
M12	31	9	0
O03	29	21	10
C03	26	13	11
Z02	26	13	9
M57	25	0	0
K08	23	16	0
B03	22	14	0
Å02	22	11	0
E08	18	10	0
O27	17	17	7
P04	17	0	0
W01	17	17	5
Y06	15	7	0
D08	14	2	0
G03	14	6	0
I05	13	0	0
O66	13	13	0
R01	13	6	0
Y05	13	2	0

2016

Clinic	Treat	F-up	Rem
A01	715	298	117
A04	178	95	24
T01	98	20	0
O09	85	40	0
X02	82	49	0
B01	81	43	28
O27	80	52	7
H01	77	23	6
M10	75	17	6
E12	67	35	7
C03	64	30	20
N07	64	1	0
U02	63	0	0
C04	49	0	0
O07	49	28	5
W11	44	2	0
N02	40	13	0
M52	36	34	0
N05	35	26	0
O03	35	24	8
S02	32	7	0
W01	31	29	11
Y06	31	5	0
Å04	30	12	10
M03	26	1	0
B03	23	1	0
D03	23	15	0
K08	23	13	0
L01	21	0	0
M37	21	1	0
Z02	21	6	0
E17	20	12	0
Å12	20	1	0
M28	19	7	0
R01	19	5	0
Å02	19	5	0
W04	17	6	0
O66	15	15	5
Y05	15	2	0

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2	D14	12	0	0	F01	13	0	0
3	W11	12	0	0	E09	11	0	0
4	E17	10	6	0	M12	10	3	0
5	W04	10	4	0	O72	9	1	0
6	Å06	10	8	0	B05	7	3	0
7	Å12	10	2	0	E08	7	3	0
8	E09	9	1	0	I05	7	0	0
9	B05	7	2	0	G03	6	2	0
10	L01	7	0	0	Z05	6	0	0
11	M28	7	1	0	Å06	6	4	0
12	Y08	6	1	0	D08	5	4	0
13	E06	5	0	0	E06	5	0	0
14	F02	5	0	0	I02	5	2	0
15	Å11	5	0	0	M57	5	0	0
16	I02	4	1	0	Y08	3	1	0
17	M37	4	4	0	F04	2	2	0
18	O72	4	1	0	O71	2	0	0
19	D06	2	0	0	E22	1	0	0
20	F01	2	2	0	Y11	1	0	0
21	F10	2	0	0	Å11	1	0	0
22	Y11	2	0	0	B10	0	0	0
23	B10	1	0	0	D06	0	0	0
24	E25	1	0	0	D14	0	0	0
25	F04	1	0	0	E25	0	0	0
26	Z05	1	0	0	F02	0	0	0
27	E11	0	0	0	F10	0	0	0
28	E22	0	0	0	P04	0	0	0
29	F07	0	0	0	E11	0	0	0
30	F08	0	0	0	F07	0	0	0
31	K09	0	0	0	F08	0	0	0
32	O01	0	0	0	K09	0	0	0
33	O46	0	0	0	O01	0	0	0
34	O67	0	0	0	O46	0	0	0
35	O71	0	0	0	O67	0	0	0
36	W13	0	0	0	W13	0	0	0
37	Y07	0	0	0	Y07	0	0	0
38	Y10	0	0	0	Y10	0	0	0
39	Other		147	76	Other			104
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41	Sum	2575	1444	423	Sum	2555	998	358
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STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of cohort studies

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(a) Indicate the study’s design with a commonly used term in the title or the abstract	1
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	2-3
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	5
Objectives	3	State specific objectives, including any prespecified hypotheses	5-6
Methods			
Study design	4	Present key elements of study design early in the paper	8-10
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5, 6, 8, 9
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up	6, 7, 8
		(b) For matched studies, give matching criteria and number of exposed and unexposed	
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	7
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	5, 6,7
Bias	9	Describe any efforts to address potential sources of bias	
Study size	10	Explain how the study size was arrived at	6
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	8, 9
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	8, 9
		(b) Describe any methods used to examine subgroups and interactions	
		(c) Explain how missing data were addressed	8, 9
		(d) If applicable, explain how loss to follow-up was addressed	
		(e) Describe any sensitivity analyses	
Results			

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed (b) Give reasons for non-participation at each stage (c) Consider use of a flow diagram	10
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders (b) Indicate number of participants with missing data for each variable of interest (c) Summarise follow-up time (eg, average and total amount)	10, 11 11, 13, 14
Outcome data	15*	Report numbers of outcome events or summary measures over time	11-14
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included (b) Report category boundaries when continuous variables were categorized (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	
Discussion			
Key results	18	Summarise key results with reference to study objectives	16
Limitations			
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	16, 18
Generalisability	21	Discuss the generalisability (external validity) of the study results	19, 20
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	23, 24

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.

BMJ Open

Treatment Outcomes for Eating Disorders in Sweden, 2012-2016 "Data from the National Quality Registry"

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2018-024179.R3
Article Type:	Research
Date Submitted by the Author:	23-Nov-2018
Complete List of Authors:	Södersten, Per; Karolinska Institutet Brodin, Ulf; Karolinska Institutet, Sjöberg, Jennie; Mandometer Clinic Zandian, Modjtaba; Karolinska Institutet Bergh, Cecilia; Mandometer Clinic,
Primary Subject Heading:	Public health
Secondary Subject Heading:	Health policy
Keywords:	Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, PUBLIC HEALTH, STATISTICS & RESEARCH METHODS

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Treatment Outcomes for Eating Disorders in Sweden, 2012-2016

“Data from the National Quality Registry”

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4367 words excluding abstract, strengths and limitations, references, acknowledgements, and

figure legends

52 references

5 figures

2 tables

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Abstract

Objective To report the outcomes of eating disorders treatment in Sweden in 2012-2016.

Design The number of patients treated and the number of patients not fulfilling an eating disorders diagnosis (remission) at one year of follow-up at the clinics listed in the National Quality Registry for Eating Disorders Treatment were analyzed. The published outcomes at three clinics, that used survival analysis to estimate outcomes, were compared with their outcomes in the registry. Outcomes at the three biggest clinics were compared.

Setting All eating disorders clinics.

Participants All patients treated at eating disorders clinics.

Intervention Cognitive behavioural therapy at most clinics and normalization of eating behaviour at the three clinics with published outcomes.

Outcome measure Proportion of patients in remission.

Results About 2600 patients were treated annually, fewer than half were followed-up, and remission rates decreased from 21% in 2014 to 14% in 2016. Outcomes, which differed amongst clinics and within clinics over time, have been publically overestimated by excluding patients lost to follow-up. The published estimated rate of remission at three clinics that treated 1200 patients in 1993-2011 was 27, 28, and 40% at one year of follow-up. The average rate of remission over the three last years at the biggest of these clinics was 36%, but decreased from 29 and 30% to 16 and 14% at the two other of the biggest clinics.

Conclusions With more than half the patients lost to follow-up and no data on relapse in the National Quality Registry, it is difficult to estimate the effects of eating disorders treatment in

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3 Sweden. Analysis of time to clinically significant events, including an extended period of
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5 follow-up, has improved the quality of the estimates at three clinics. Overestimation of
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7 remission rates has misled health care policies. The effect of eating disorders treatment has
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9 also been overestimated internationally.
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For peer review only

Strengths and limitations of this study

- This study has the strength of analyzing all patients treated, followed-up, and treated to remission at all eating disorders clinics over five years in Sweden.
- These outcomes are available in the National Quality Registry for Eating Disorders Treatment but have not been published in the scientific literature.
- Three clinics have published outcomes at three-month intervals making it possible to compare these outcomes with their outcomes in the registry.
- The study has the strength of showing that a time-to-event analysis improves compliance, facilitating estimation of outcomes.
- It is a limitation that whereas outcomes in the registry covered the years 2012-2016, the published outcomes at the three clinics covered the years 1993-2011.

INTRODUCTION

The National Quality Registries in Sweden have been developed starting in the 1970s and today there are about 100 registries, covering virtually all kinds of disease (1). The Swedish Association of Local Authorities and Regions (SALAR) and the Swedish Government recently agreed to strengthen the registries financially, pointing to their key role in the development of all aspects of health care, improving the quality of care, facilitating research, including international comparisons of outcomes, guiding health care policies, and making it possible for anyone to compare the outcomes of treatment at individual clinics (1,2). Indeed, the SALAR has a website for such comparisons (3).

The Swedish National Quality Registry for Eating Disorders Treatment, Riksät, was established in 1999 and has published 11 reports, written in Swedish, in 2001-2016 (4). Following the aims of the registries, the objective of Riksät is to “document the outcome of treatment” (quote from the first report in 2001). Thus, the important measures are the number of patients treated and the number of patients in remission at follow-up. These numbers are listed in Riksät but have not been analyzed and reported in the scientific literature. The first aim of the present study is to examine the rate of remission at all eating disorders clinics in Sweden.

The results in Riksät have been publicized nationally as demonstrating increasing rates of remission over the years to 56% in 2015 and that “70% of the patients are ‘cured’ within one year” (4,5). Because these outcomes are better than the outcomes reported in the scientific literature (6,7), the second aim of this study is to examine their evidence basis.

There are three clinics in Sweden, that have published outcomes (8). Because these clinics (Mandometer Clinics) also report to Riksät it is possible to compare their published

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3 outcomes with their outcomes in Riksät. The biggest of the three Mandometer clinics is the
4 clinic in the County Council of Stockholm (Mando). The third aim of this study is to compare
5 the outcomes at Mando with the outcomes at the two other of the biggest clinics in Sweden,
6 the Stockholm Centre for Eating Disorders (SCED) and the Capio Centre for Eating Disorders
7 (Capio).
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16 The fourth aim of this study is to call the attention of policy makers to the fact that
17 outcomes of eating disorders treatment have been overestimated not only in Sweden but in
18 other countries as well.
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23 **METHODS**

24 **Patients and diagnostic procedures**

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27 Riksät lists the number of patients entering treatment each year and the number of patients
28 followed-up one year later, although the exact time of follow-up is not mentioned. More than
29 90% of the patients entering treatment at the specialist clinics are listed in the registry, but
30 patients that are treated at general psychiatric units may not be listed. Whilst there is no
31 information on how many these patients might be, most patients treated are listed in the
32 registry. There is no information on long term outcome, including relapse.
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46 At the beginning of treatment and at follow-up the patients completed the Eating
47 Disorders Examination Questionnaire (EDE-Q), which measures eating disorders symptoms
48 (9), and the Clinical Impairment Assessment (CIA), which measures psychosocial functioning
49 as a consequence of the eating disorder (10). The EDE-Q was used for patients older than 10
50 years and the CIA was used for patients older than 18 years. A semistructured interview was
51 used for children and adults to determine overall psychiatric symptoms and social functioning
52 (see e.g., (11)). Using these procedures, the patients were diagnosed with Anorexia Nervosa,
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3 Bulimia Nervosa, Eating Disorder Not Otherwise Specified, or Binge Eating Disorder relying
4 on the criteria in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (12).
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7 Patients who no longer fulfilled the diagnostic criteria for an eating disorder were listed as in
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10 remission. About 4-5% of the patients in the yearly reports had been treated before when
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12 entering treatment.
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16 Riksät reports changes in the patients' social functioning and their experiences of the
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18 treatment, and these secondary measures improve in parallel as patients go into remission but
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20 will not be considered in this analysis.
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24 Whilst Riksät thus includes two time points for assessment, the Mandometer clinics
25
26 have developed a treatment in which the patients are assessed at three-month intervals and
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28 followed-up 1, 2, 3, 6, 9, 12, 18, 24, 36, 48, and 60 months after remission. The procedures,
29
30 including the criteria for inclusion, exclusion, and remission were published in 2002 (13), and
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32 have been re-published many times (e.g., (8)); another description may be redundant. The
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34 Mandometer clinics also report their outcomes to Riksät.
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39 **Treatments**

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42 The 2012-2014 Riksät reports did not specify the treatments used beyond mentioning that
43
44 these were guided by "the principles of cognitive behavioural therapy" (CBT) and that they
45
46 could be used with individual patients or with groups of patients. Medical intervention was
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48 used for monitoring and restoring physical health and psychopharmacology was also used,
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50 absence of evidence of their efficiency was pointed out. The 2015-2016 reports provide
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52 details on treatments. Thus, CBT was used with on average 52% of the children and with 72%
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54 of the adults, psychodynamic therapy was used with on average 21% of the children and with
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56 24% of the adults, and family-based therapies were used with on average 38% of the children.
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3 The treatment developed at the Mandometer clinics was described in 1996 (14), re-published
4 some years on (8,13), and because it has since been described in several other papers, another
5 description may be redundant. Suffice it to say that an important intervention is teaching
6 patients how to eat normally using real time visual feedback on how much food to eat and
7 how quickly to eat it. A video of how this method works was published recently (15). In
8 addition, the patients are provided with warmth, that exerts an anxiolytic effect in 30 minutes
9 (16), their physical activity is reduced, and they are assisted in restarting their social
10 interactions (13). Interestingly, re-establishing normal eating behaviour is also the most
11 important intervention in CBT, although it is not clear how this is achieved (7).

25 **Description of outcomes**

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28 Initially, Riksät reported the combined outcomes at the clinics across regions in Sweden, the
29 reports published in 2009 and 2010 were incomplete, and no report was published in 2011.
30 However, the outcomes at individual clinics were reported in 2012-2016. The number of
31 patients treated at each clinic and the proportion of patients who were followed-up are listed
32 in one set of tables in these reports. The number and the proportion of patients in remission at
33 follow-up are listed in another set of tables. These numbers have been combined into one
34 table (supplementary table) and used in the analysis.

45 **Combined outcomes at all clinics**

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48 The numbers of patients treated, followed-up, and treated to remission have been summarized
49 for all clinics. The number of patients in remission has been related to the number of patients
50 treated as well as to the number of patients followed-up in an attempt to explain the high
51 remission rates publicized in Sweden.

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3 If the treatment and the follow-up assessments are about the same at all clinics, the
4 probability for remission should be the same in all clinics. This hypothesis, which can be
5 formalized as: $H_0: P_i(\text{Remission}) = P_0(\text{Remission})$ for all clinics, $i=1, 2, 3, \dots, n$, was tested
6 using a test for homogeneity of the data (17).
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13 In 2012-2013 Riksät listed the number of clinics that treated and followed-up at least 20
14 patients. The number of patients treated to remission at these clinics was listed in 2012, but in
15 2013 the number of patients treated to remission included clinics that had followed-up at least
16 10 children or 10 adult patients. In 2014-2016 the number of patients treated, followed-up,
17 and treated to remission was listed for all clinics. Using these data (supplementary table), the
18 number of clinics following-up at least 20 patients have been analyzed. Outcomes at clinics
19 following-up fewer than 10 patients have also been analyzed.
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30 **Published outcomes at Mandometer clinics**

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34 Mandometer clinics have published the outcomes of 1428 patients treated at six clinics in four
35 countries over various periods of time in 1993-2011, and these data are available in the
36 supplementary files of (8). The three Swedish clinics, in Alingsås, Danderyd, and Huddinge,
37 treated 1200 of these patients. The clinic in Huddinge, within the Stockholm County Council,
38 is the oldest clinic and is referred to as Mando in this analysis. The probability of going into
39 remission over consecutive three-month intervals up to 12 months at these clinics was
40 estimated using a life-table approach to survival analysis (18). The rate of failure amongst
41 censored patients was estimated to be 20%, yielding a conservative estimate of treatment
42 outcomes. This analysis allows comparison between these published outcomes and the
43 outcomes for the same clinics listed in Riksät.
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57 **Outcomes at individual clinics**

Outcomes were compared amongst SCED, Capio, and Mando.

Patient and public involvement

This study is an analysis of patient data in a registry and those patients did not participate in the analysis. The results will be openly available at mandometer.com.

RESULTS

Patient characteristics

The characteristics of the patients at the start of treatment were stable over all years and measures of variability are therefore not included. The average proportion of males was 4.6%, the average proportion of children and adolescents, who were <18 years old, was 29%. The age, obviously, was variable and the average mean (SD) age of all patients was 23.1 (8.9) years. The proportion of the various eating disorders diagnoses was also stable over the years and average values are presented in Table 1.

Table 1. Diagnoses amongst patients entering treatment for eating disorders in Sweden in 2012-2016. There were about 2600 patient each year and the proportions are averaged over these years. Children were <18 years old.

Diagnosis	Proportion (%)	
	Children	Adults
Anorexia Nervosa	39	20
Bulimia Nervosa	8	32
Eating Disorder Not Otherwise Specified	45	37

Binge Eating Disorder	1	6
Other*	7	5

*Not specified.

Combined outcomes at all clinics

Figure 1 shows that the total number of patients treated at all clinics increased to about 2600 in 2013, and remained relatively stable over the following years. The figure also shows that fewer than half the patients were typically followed-up a year later and that the rate of remission was about 21% in 2012-2014, and decreased to 14% in 2016. The number of patients treated to remission increased from 477 in 2012 to 589 in 2014 and decreased to 358 in 2016. There is no information on possible differences in the number of patients in remission related to the diagnosis at the start of treatment.

--- Please insert Figure 1 about here ---

Figure 2 shows firstly, that the rate of remission at all clinics that followed-up their patients was less than 50% in 2012-2014, 29% in 2015, and 36% in 2016. Secondly, the figure shows that the rate of remission at clinics that had treated at least one patient to remission increased to 56% in 2015 and decreased to 54% in 2016. The second analysis thus excluded patients followed-up at clinics that did not treat a single patient to remission. The significance of these two calculations of remission rates is clarified in the Discussion.

--- Please insert Figure 2 about here ---

Variability in outcomes

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3 The probability of going into remission in 2012 was significantly different amongst the 17
4 clinics that had treated patients in all recorded years ($P < 0.001$; $\text{Chi}^2 = 80.2$, $\text{df} = 16$). The
5 probability of going into remission was also significantly different amongst the five clinics
6 that had treated at least 100 patients in 2012 ($P < 0.001$; $\text{Chi}^2 = 23.7$, $\text{df} = 4$). Analysis of the other
7 years gives similar results.
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16 Analysis of the results at SCED showed that the probability of going into remission was
17 significantly different over the years ($P < 0.001$; $\text{Chi}^2 = 46.3$, $\text{df} = 4$). Analysis of the other
18 clinics gives similar results.
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23 24 **Combined outcomes at clinics that followed-up at least 20 patients**

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26 Because Riksät reported on clinics that had followed-up at least 20 patients in 2012-2013 and
27 for all clinics in 2014-2016, the number of clinics reporting their outcomes was lower in
28 2012-2013 (21 and 23) than in 2014-2016 (70, 64, and 59). However, it is possible to compare
29 how many clinics had treated, followed-up, and treated at least 20 patients to remission in
30 2012-2016.
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40 Figure 3 shows that more clinics had treated at least 20 patients in 2016 than in 2012.
41 Whereas the clinics that had treated at least 20 patients in 2012 were selected for having
42 followed them up, only 45% of these clinics followed-up at least 20 patients in 2016. About
43 one in three of these clinics had treated at least 20 patients to remission in 2012 compared to
44 about one in eight in 2016. The results in the other years fall in between the results in 2012
45 and 2016.
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3 Out of the 33 clinics that had treated at least 20 patients in 2016 (Figure 3, green bar at
4 the very left), three (9%) had not followed-up any patient, and 21 (64%) had not treated a
5 single patient to remission. These 21 clinics had treated a total of 857 patients, with a median
6 (range) of 32 (20-98) patients/clinic.
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13 **Combined outcomes at clinics that followed-up fewer than 10 patients**

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17 Figure 4 shows that amongst the about 2600 patients who were treated annually in 2013-2016,
18 the number of patients treated at clinics that followed-up fewer than 10 patients increased to
19 more than 1000 in the last two years. In parallel, the proportion of patients who were
20 followed-up and treated to remission at these clinics decreased. Fewer than one in ten of the
21 patients were treated to remission in the final three years. Please note that the values for 2012
22 include clinics that followed up fewer than 20 patients. Clinics following-up fewer than 10
23 patients were not reported separately this year.
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38 **Published outcomes at Mandometer clinics**

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41 Table 2 shows that the proportion of patients in remission at 12 months assessments was at
42 least 27% and significantly different at the three Mandometer clinics, whose outcomes are
43 published. Treatment continues after the 12 months at these clinics and the proportion of
44 patients in remission increases after various, prolonged periods of time. Please note that these
45 clinics had been operating over various periods of time.
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Table 2. Proportion of patients in remission at Mandometer clinics.

Outcome	Clinic		
	Alingsås	Danderyd	Mando
Operation (years)	2	7	18
<u>12 months assessment</u>			
Patients in remission	13	72	219
Patients not in remission	36	107	552
Proportion in remission	27	40*	28
<u>Continued treatment (months)</u>			
Patients in remission	19	141	490
Patients not in remission	27	27	170
Proportion in remission	39	82	68

*P=0.0017 compared to Alingsås and Mando after P=0.0069 (overall difference).

It may be mentioned that the time to remission depends on the diagnosis at admission, with the longest time to remission for patients with anorexia nervosa (8).

Outcomes at the three biggest clinics

SCED had treated about four times more patients annually (median: 715; range: 696-724) than Capio (175; 157-178) and Mando (123; 81-168), and followed-up about the same proportion of patients (43; 32-69%) as Capio (50; 48-65%) and Mando (43; 32-83%). These proportions are similar to the average proportions of follow-up at all clinics over these years (Figure 1).

Figure 5 shows that Mando had treated a bigger proportion of patients to remission than SCED and Capio in 2014-2016. Whilst the rate of remission was relatively stable at on average 36% at Mando over these three years, it decreased from 29% to 16% at SCED and from 30% to 14% at Capio. In 2016, the proportion of patients treated to remission at Mando (35%) was about twice as big as the corresponding proportion at SCED (16%) and Capio (14%).

--- Please insert Figure 5 about here ---

DISCUSSION

Patient characteristics, diagnostic procedures, and treatments

The characteristics of the patients, who have been treated for eating disorders in Sweden, including the proportion of males and children, age and diagnosis, have been relatively stable in recent years and are similar to the characteristics of eating disorders patients in other countries (19). It is worth noting that whilst a minority of the patients were diagnosed with Binge Eating Disorder, that disorder is now the most common eating disorder (20). Although the diagnostic procedures may differ amongst clinics (19), most of the procedures used in Sweden have been developed in other countries. In addition, the treatments used in Sweden,

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3 including CBT, psychodynamic therapy, and family therapy, as well as medical and
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5 psychopharmacological interventions aiming at restoring physical and mental health are the
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7 same as those recommended in the guidelines and used in most countries (19,21–26). The
8
9 treatment at the Mandometer clinics differs in that an important intervention is the
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11 normalization of eating behaviour using real time visual feedback on how to eat as described
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13 many times and most recently by video (15). The differences and similarities amongst the
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15 Mandometer treatment and CBT have been described in detail recently, including the
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17 differences in outcomes (7).
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22 **Outcomes in Sweden**

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26 About 2600 patients were treated annually at the eating disorders clinics in Sweden in 2012-
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28 2016, fewer than half were followed-up, and the proportion of patients treated to remission
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30 decreased from one in five in 2012 to less than one in seven in 2016. However, remission
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32 rates which are more than three times higher have been publicized nationally. These estimates
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34 were derived by excluding patients lost to follow-up and patients followed-up at clinics that
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36 did not treat patients to remission. In 2016, only four clinics treated 20 patients to remission;
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38 most clinics treated a small number of patients, followed-up a few, and treated only one
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40 patient in ten to remission. Outcomes varied significantly between clinics each year and
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42 within clinics over years. In addition, in 2016 more than half the 33 clinics that had treated on
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44 average 32 patients had failed to treat a single patient to remission; one of these clinics had
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46 treated 98 patients unsuccessfully.
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52 **Interpretation and comparison with published outcomes**

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56 Whilst these findings indicate that the procedures of treatment and follow-up differ amongst
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58 clinics in Sweden, a word of caution seems appropriate. For example, although outcomes
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3 were significantly different over years at the biggest clinic (SCED), patients were treated to
4 remission all years, suggesting that a statistically significant within-clinic variation may be
5
6 less significant clinically. However, it seems unlikely that the decrease from a rate of
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8 remission of about 30% in 2014 at this clinic to about half that rate two years later is a matter
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10 of random variation. And the similar decrease in the rate of remission at another clinic in
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12 these years (Capio) suggests that the procedures at these clinics had deteriorated, at least
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14 temporarily.

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21 Possible reasons for the variation in outcomes include changes in staffing, training of
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23 staff, patient compliance to treatment, and the physical conditions in the clinics, factors that
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25 affect outcomes in multicenter clinical trials (27). Whilst the “study protocol” of the
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27 multicenter trial aims at reducing the influence of these factors, there is no standard protocol
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29 for the treatment of eating disorders. And although there is agreement that the treatment
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31 guidelines for eating disorders should be followed, this consensus view has not yet improved
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33 outcomes (21–23,25,28–30). For example, an attempt at implementing CBT, which is
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35 recommended in all guidelines, in combination with antidepressant medication for the
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37 treatment of bulimia nervosa in primary care in the U.S. resulted in a 70% dropout rate (31).
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39 A similar effort in general practice in the U.K. found that out of 683 patients with a diagnosis
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41 of bulimia, about half of the 272 patients who entered CBT completed the treatment, and
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43 although those patients improved, they were not free of eating disorders symptoms after
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45 treatment (32). A recent study aiming to implement CBT for anorexia nervosa in general
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47 practice produced similar results. Thus, out of 257 patient referrals, 44 patients started in
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49 treatment and 22 completed the treatment (33), findings that were replicated in another recent
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51 study (34). Compliance is thus a general problem in the treatment of eating disorders, not a
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53 “Swedish” problem, but it can be improved as discussed below.
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3 Whether these factors are causally related to the decrease in remission rates in 2015-
4 2016 remains to be determined. But it may be of some significance that as the number of
5 patients treated at clinics that treated fewer than ten patients to remission increased, the
6 proportion of patients followed-up and treated to remission decreased (Figure 4). And when
7 the number of patients followed-up at all clinics increased in 2015, there was a marked
8 decrease in the proportion of patient treated to remission (Figures 1 and 2).
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18 The Mandometer treatment was developed starting in 1993, a theoretical framework and
19 preliminary findings were reported in 1996 (14,35). A randomized controlled trial
20 demonstrated its effectiveness and outcomes for 1428 patients treated at six clinics in four
21 countries were subsequently reported (8,13). The combined rate of remission at these clinics
22 was estimated to be about 75% in on average one year of treatment and the rate of relapse was
23 estimated to be about 10% over five years of follow-up (8). Similar to Riksät, estimates were
24 done amongst all patients entering treatment. However, far more patients were lost to follow-
25 up at Riksät's one year time point of follow-up than to Mandometer's procedure of
26 monitoring patients at three-month intervals throughout treatment and at 1, 2, 3, 6, 9, 12, 18,
27 24, 36, 48, and 60 months of follow-up (8). Despite the difference, the rate of remission at the
28 Mando clinic in the Stockholm County Council was on average 33% in 2012-2016 according
29 to the Riksät calculation, which is about half the estimated published 75% rate of remission
30 after on average one year of treatment (8). A comprehensive description of all patients,
31 including those who take a long time to go into remission, is available in the supplementary
32 files of (8), which report outcomes at three month intervals at all Mando clinics.
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54 Average remission rates should be viewed cautiously as outcomes varied between
55 clinics. Thus, the published rate of remission at 12 months differed significantly at the three
56 Mandometer clinics, yet it was higher than the average values reported for all clinics in each
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3 of the five years in Riksät. Differences in treatment methods between the Mandometer clinics
4 and the other clinics may explain the differences in outcomes (7) and it is possible that
5
6 outcomes will be more consistent at the Mandometer clinics once they have been operating
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8 for a longer period of time. For example, the Alingsås clinic had been treating patients for
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10 only two years and reached a rate of remission of only 39%. The variation in the rate of
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12 remission at 12 months at the Mandometer clinics in Amsterdam (16%), San Diego (52%),
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14 and Melbourne (25%) (8), support previous findings that international cultural and medical
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16 system differences also affect treatment outcomes (36). Thus, patients treated in San Diego
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18 improved rapidly, but they were often prevented from continuing in treatment because of the
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20 financial constraints of their insurance policies (8), a problem that would not affect patients in
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22 Sweden. It should be noted that relatively few patients had been treated at these clinics.
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30 Dropout and relapse are significant events in the treatment of eating disorders (7,37,38),
31 and neither these events, nor remission, should be expected to occur after a predetermined
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33 period of time such as at one year of follow-up as used in Riksät. Also, the precise time for
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35 follow-up is not mentioned. It seems likely that this procedure explains why more than half
36
37 the patients were lost to follow-up in Riksät. Practical approaches to survival analysis,
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39 including time-to-event analysis, are long available (18,39) and should be used in studies of
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41 outcomes of eating disorders treatment. The higher level of compliance at the Mandometer
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43 clinics (8) offers support for their value.
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49 Considering the difference between outcomes at Mando and the other Swedish clinics,
50 including the fact that several hundred patients have been treated to remission, and that the
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52 rate of relapse has been reduced to an estimated 10% at the Mando clinics, a randomized
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54 controlled trial comparing outcomes at these clinics may be redundant; an attempt at a
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56 comparison (40), was fraught with problems (8). The major treatment in Swedish clinics is
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3 CBT and a detailed analysis showed that the remission rates after CBT are lower than those
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5 after Mandometer treatment (7). Psychodynamic therapy is also used in Swedish clinics,
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7 although outcomes of this therapy are inferior to those of CBT (41). Similarly, the use of
8
9 family-based therapies with children in Sweden as in other countries, probably does not
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11 explain the differences in outcomes. Differences in patient characteristics at admission may
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13 contribute to differences in treatment outcomes and the possibility that such differences exist
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15 should be examined, although the published literature indicates that they do not (42). Also,
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17 there are no differences in the Swedish referral system such that more severely ill patients at
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19 one of the clinics might explain differences in outcomes.
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25 **Implications for policy makers**

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28 Overestimations of the outcomes of the treatment for eating disorders in Sweden have been
29
30 publicized over several years (4), including the claim that “70% of the patients are ‘cured’
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32 within one year”, which is maintained on Sweden’s National Educational Radio Channel (5).
33
34 This is similar to the international claim that CBT is “efficacious for a range of eating
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36 disorder presentations in the short and long-term” (30), publicized as: “Based on a solid
37
38 empirical foundation, the transdiagnostic enhanced CBT approach will immediately become
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40 the gold standard for the treatment of eating disorders” (43), and “[the effect of CBT] is the
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42 most dramatic that we have seen in the literature ... [including] the potency ... and the
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44 impressive maintenance of change over the 19-months follow-up” (44). The published
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46 evidence does not support these claims (7,45–47) and evidence that the outcomes of CBT
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48 have been overestimated for the treatment of other disorders is gradually emerging (48,49).
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50 These overstatements have misinformed health policy makers and can now be corrected.
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57 The importance of the National Quality Registries in guiding health care policies in
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59 Sweden was recently re-emphasized (50). In order to guide decisions on matters of health
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3 care, national and international registries must offer reliable information. Widely publicized
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5 “facts” need to be critically examined. Policy makers should be aware that once ill advised
6
7 policies have been established, retrospectively controlling their evidence basis can be
8
9 ineffective, and even strengthen the misguided policy (51,52).
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13 **Acknowledgements**

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16
17 We thank Sara Norring, Riksät, Anna Sandelin, the Centre of Registries Västra Götaland, and
18
19 Fredrik Westander and Lale Björne-Fergéus, SALAR, for information on Riksät.
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23 **Transparency declaration**

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25
26 Södersten affirms that the manuscript is an honest, accurate, and transparent account of the
27
28 study being reported; that no important aspects of the study have been omitted; and that any
29
30 discrepancies from the study as planned (and, if relevant, registered) have been explained.
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34 **Ethics approval**

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37
38 The project was approved by the Regional Ethical Review Board of Stockholm (Dnr
39
40 2015/456-31).
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43 **Authors**

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47 Södersten examined the registry data in detail over the last two years. He reviewed his
48
49 examinations for all authors at regular intervals during the examination period. He is
50
51 responsible for the overall content as guarantor and assumes responsibility for all aspects of
52
53 the work. All data used for the analysis are included as a supplementary table to this
54
55 submission, which all authors are happy to share with other researchers.
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3 Brodin is medical statistician and has performed all statistical analyses and reviewed these for
4
5 all authors at regular intervals during the examination period.
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9 Sjöberg is clinical director of the Mandometer Clinic in Alingsås and responsible for
10
11 treatment and data collection and reporting to the registry in 2012-2016.
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15 Zandian is clinical quality controller and has been responsible for data collection and
16
17 reporting to the registry in 2012-2016.
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21 Bergh is clinical director for the Mandometer Clinic in Huddinge and responsible for
22
23 treatment at all Mandometer clinics.
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27 All authors have seen and reviewed several versions of the manuscript and agreed to its final
28
29 version.
30
31

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33 Södersten is: “the corresponding author and attests that all listed authors meet authorship
34
35 criteria and that no others meeting the criteria have been omitted”.
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37

38 **Contributorship**

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40
41 Åsa Lundqvist BA of the Mandometer Clinic in Stockholm has been contact person with the
42
43 Rikät registry staff over the years 2012-2016. Ms Lundqvist supervised the reporting of data
44
45 to the registry and is in charge of the follow-up programme of the Mandometer Clinic.
46
47
48

49 **Competing interests**

50
51
52 Complete openness concerning financial arrangements is intended here. Brodin, Sjöberg and
53
54 Zandian declare that they have no financial interests related to this study. Our research is
55
56 carried out at the Karolinska Institute, where Södersten is a professor em. The research is
57
58 translated clinically by Mando Group AB, a company started by Södersten and Bergh, who
59
60

1
2
3 have 47.5% of the stock each. Professor Michael Leon of the University of California at
4
5 Irvine has 5%. Mando Group AB contracts with the County Council of Stockholm every fifth
6
7 year to treat patients with eating disorders. Mando Groups AB signed its first contract in 1997
8
9 with the County Council of Stockholm and, since then, its treatment is one of the standards of
10
11 care offered to the citizens of Stockholm. This arrangement is the same as when the County
12
13 Council of Stockholm contracts with its own clinics to treat patients with all kinds of disease,
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15 including eating disorders. That is to say, the County Council of Stockholm provides eating-
16
17 disorder services to the citizens of Stockholm both through a clinic of its own and through
18
19 Mando Group AB. There is a third provider of care for patients with eating disorders in
20
21 Stockholm, which is a private clinic. All health care in Sweden is funded through the tax
22
23 system; private pay is extremely uncommon. It should be added firstly, that Mando Group AB
24
25 is in compliance with the recommendation of the International Committee of Medical Journal
26
27 Editors on “Author Responsibilities-Conflicts of Interest”
28
29 [http://www.icmje.org/recommendations/browse/roles-and-responsibilities/author-](http://www.icmje.org/recommendations/browse/roles-and-responsibilities/author-responsibilities--conflicts-of-interest.html)
30
31 [responsibilities--conflicts-of-interest.html](http://www.icmje.org/recommendations/browse/roles-and-responsibilities/author-responsibilities--conflicts-of-interest.html). Secondly, it should also be added that all profit
32
33 that Mando Group AB has made has been re-invested in research and development and that
34
35 there have been no dividends to stock owners. All of the above is declared in all manuscript
36
37 submissions and thus far, journals have judged it necessary to publish only some of the
38
39 details. It seems, however, that the potential ethical problem when scientists translate their
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41 research findings into the clinic in a company is not unlike that which arises when any
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43 scientist, in an academic setting is developing a theory and needs further economic funding
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45 for her/his work and may receive recognition and financial benefits for the work. The
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47 incentive is, in part, economic in this case as well and the ethical “problem” is similar in both
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49 cases. However, the more important incentive is the improvement of the treatment of patients
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51 with eating disorders. We are researchers working in an academic setting and like many other
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3 medical research institutes today, the Karolinska Institute encourages scientists to translate
4 their research into the clinic in companies that aim to generate financial profits to be used for
5 research and development (see:
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10 http://ki.se.proxy.kib.ki.se/sites/default/files/summary_strategy2018.pdf).
11
12

13 **Funding**

14
15
16
17 This work was supported by The County Council of Stockholm grant number HNSV 15896,
18 HSN 1502-0291, project 3252.
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20
21

22 **Role of the sponsor**

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25
26 The sponsor had no influence on the work.
27
28

29 **Data sharing statement**

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33 The data used for this analysis are available in a supplementary table.
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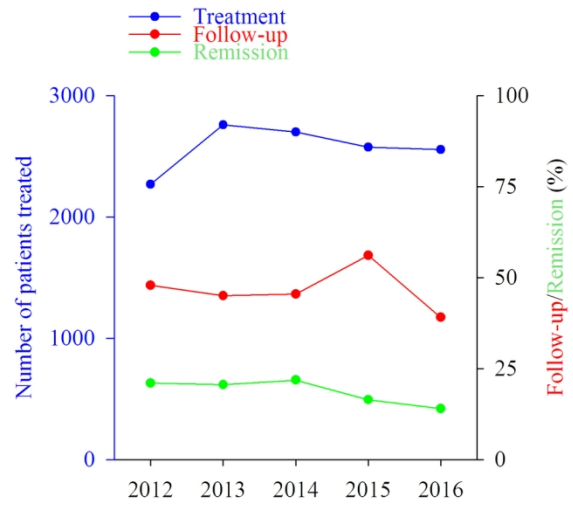


Figure 1. Number of patients treated at all clinics in Sweden and proportion of patients followed-up and in remission one year later. The year on the x-axis indicates the year of follow-up, the corresponding number of patients starting their treatment the year before.

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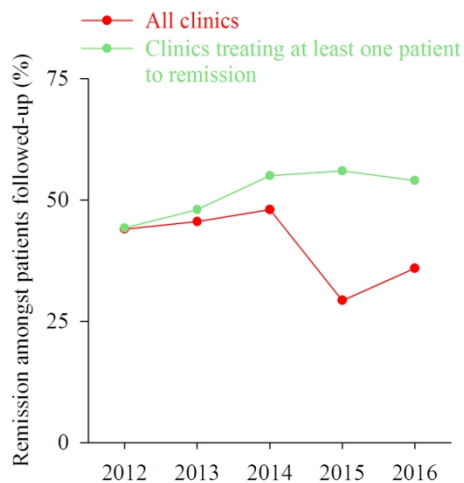


Figure 2. Proportion of patients in remission at all clinics that followed-up their patients and at clinics that treated at least one patient to remission.

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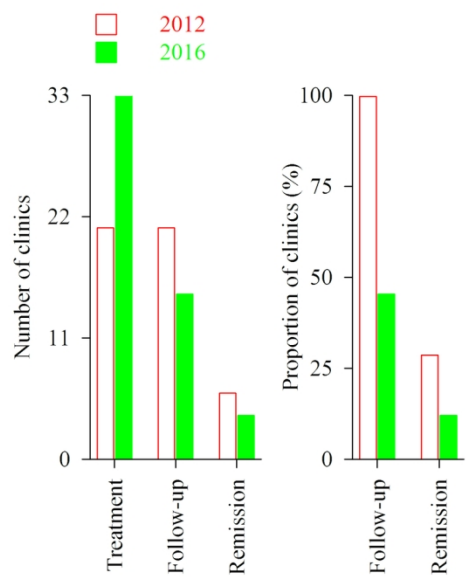


Figure 3. Number of clinics that treated, followed-up, and treated at least 20 patients to remission and proportion of clinics that followed-up and treated at least 20 patients to remission in 2012 and 2016.

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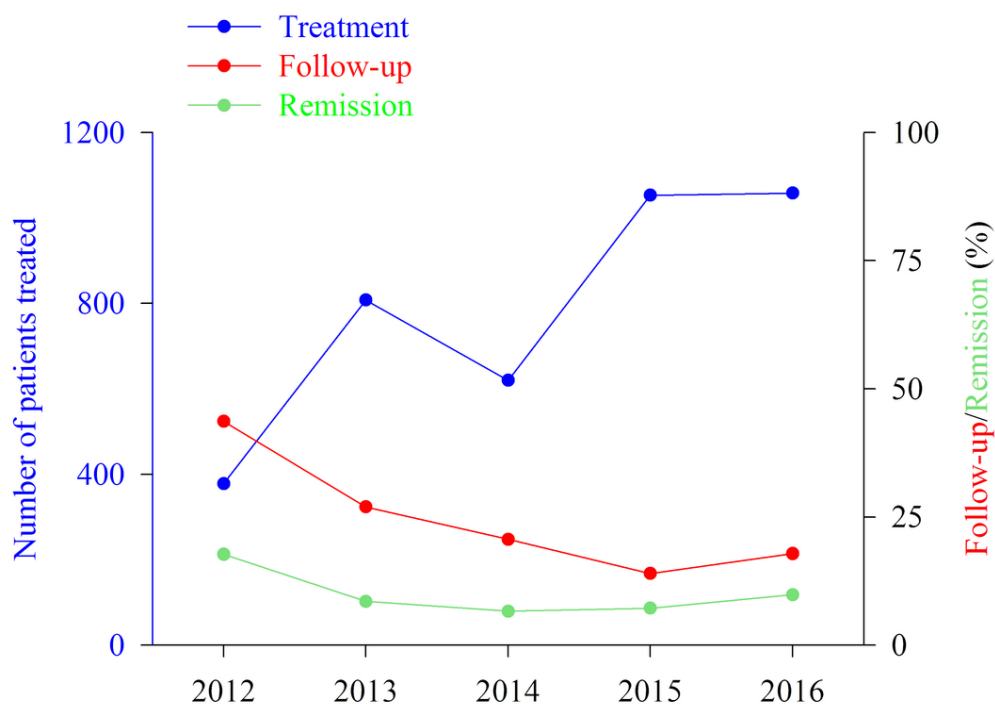


Figure 4. Number of patients treated at clinics that followed-up fewer than 10 patients (2013-2016) or 20 patients (2012) and proportion of patients followed-up and in remission one year later. The year on the x-axis indicates the year of follow-up, the corresponding number of patients starting their treatment the year before.

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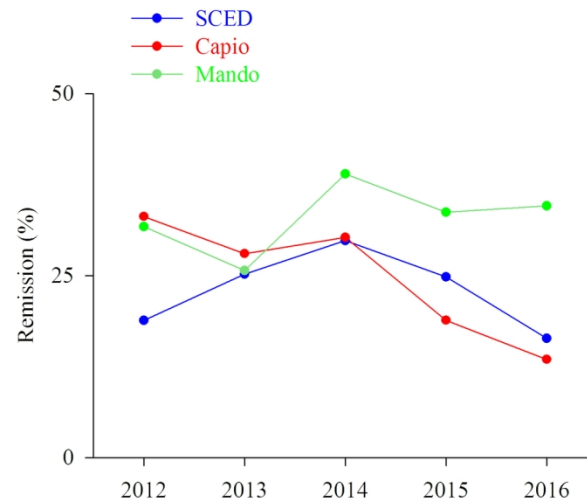


Figure 5. Proportion of patients treated to remission at the three clinics that treated more patients to remission than any other clinic, the Stockholm Centre for Eating Disorders (SCED), the Capiro Centre for Eating Disorders (Capiro), and the Mandometer Clinic in Stockholm (Mando).

127x180mm (300 x 300 DPI)

Supplementary table.

Number of patients treated (Treat), followed-up (F-up), and in remission at follow-up (Rem) at eating disorders clinics in Sweden in 2012-2016. The three clinics in the Stockholm County Council are the Stockholm Centre for Eating Disorders (SCED, A01), Caphio Centre for Eating Disorders (Caphio, A04), and the Mandometer Clinic (Mando (B01). Other is the combination of all clinics that followed-up fewer than 20 patients in 2012-2013 and fewer than 10 patients in 2014-2016.

Whilst most of the cells can be filled in, it is not possible to fill in all cells, because of the procedures of follow-up. The clinics are arranged from the maximal-minimal number of patients treated.

2012				2013				2014			
Clinic	Treat	F-up	Rem	Clinic	Treat	F-up	Rem	Clinic	Treat	F-up	Rem
A01	696	224	131	A01	710	305	179	A01	705	339	210
A04	157	93	52	A04	176	88	49	A04	162	77	49
B01	123	53	39	B01	168	54	43	B01	136	59	53
T01	120	50	21	T01	116	39	20	M10	105	36	20
M10	107	38	22	M10	111	36	22	T01	99	46	21
U02	90	23	9	O09	89	36	19	X02	85	40	22
O09	78	38	16	E12	83	41	28	H01	82	36	15
E12	66	25	14	Å04	63	35	21	U02	78	16	6
N05	49	26	11	H01	59	43	18	E12	72	38	23
R01	48	33	13	N02	58	30	7	N07	66	16	3
H01	44	44	12	O07	56	35	4	S02	63	1	0
D03	40	38	7	O03	44	44	6	O09	57	27	15
K08	36	24	12	M12	42	41	10	N02	55	32	15
O03	36	33	8	N05	39	26	3	C04	52	0	0
Å04	33	21	7	N07	39	21	1	O03	52	30	5
O07	31	31	5	C03	38	30	13	W11	49	11	0
W01	30	28	20	P04	33	32	9	O07	43	16	2
N02	29	28	1	W01	28	28	9	N05	40	16	8
N07	29	22	2	D03		12	3	C03	39	17	5
P04	26	26	0	K08		13	9	M52	39	20	11
C03	21	21	8	U02		12	5	P04	37	15	0
Other	378	165	67	Z02		13	8	Å02	33	27	14
				Å02		11	10	D03	31	11	0
Sum	2267	1084	477	Other	806	218	69	M03	30	7	0
								Å04	30	19	14
				Sum	2758	1243	566	R01	29	4	0
								Y06	29	0	0
								M12	26	15	7
								W04	26	8	0
								K08	25	13	9
								W01	24	9	0
								B03	20	4	0
								B05	19	1	0
								Z02	19	10	10
								Å12	19	4	0
								D08	18	10	8
								F01	17	10	0
								Y05	16	3	0
								O66	15	6	0

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E08	13	6	0
F02	13	12	3
M28	13	7	0
Å06	11	2	0
E09	9	2	0
I05	9	0	0
Y08	9	1	0
D14	8	0	0
Z05	8	0	0
G03	7	5	0
E06	6	0	0
E17	6	4	0
D06	5	0	0
I01	5	0	0
Å11	5	3	0
F04	4	2	0
F10	4	0	0
E11	3	0	0
E25	3	2	0
O46	3	3	0
E22	2	1	0
O01	2	0	0
B10	1	0	0
F07	1	0	0
F08	1	0	0
K09	1	0	0
O67	1	0	0
W13	1	0	0
Y07	1	0	0
Y10	1	0	0
Y11	1	0	0
I01	0	0	0
M37	0	0	0
M57	0	0	0
O27	0	0	0
O31	0	0	0
O35	0	0	0
O36	0	0	0
O37	0	0	0
O50	0	0	0
O72	0	0	0
Other		128	41
Sum	2699	1098	548

2015

Clinic	Treat	F-up	Rem
A01	734	505	182
A04	175	113	33
O09	109	13	0
T01	106	36	0
B01	95	79	32
M10	95	42	15
H01	93	51	4
X02	83	7	0
S02	73	37	0
U02	73	14	0
N07	71	20	0
E12	59	49	20
N02	47	41	6
N05	45	5	0
M52	40	7	3
C04	36	0	0
O07	35	31	3
M03	34	5	0
Å04	34	14	7
D03	31	18	0
M12	31	9	0
O03	29	21	10
C03	26	13	11
Z02	26	13	9
M57	25	0	0
K08	23	16	0
B03	22	14	0
Å02	22	11	0
E08	18	10	0
O27	17	17	7
P04	17	0	0
W01	17	17	5
Y06	15	7	0
D08	14	2	0
G03	14	6	0
I05	13	0	0
O66	13	13	0
R01	13	6	0
Y05	13	2	0

2016

Clinic	Treat	F-up	Rem
A01	715	298	117
A04	178	95	24
T01	98	20	0
O09	85	40	0
X02	82	49	0
B01	81	43	28
O27	80	52	7
H01	77	23	6
M10	75	17	6
E12	67	35	7
C03	64	30	20
N07	64	1	0
U02	63	0	0
C04	49	0	0
O07	49	28	5
W11	44	2	0
N02	40	13	0
M52	36	34	0
N05	35	26	0
O03	35	24	8
S02	32	7	0
W01	31	29	11
Y06	31	5	0
Å04	30	12	10
M03	26	1	0
B03	23	1	0
D03	23	15	0
K08	23	13	0
L01	21	0	0
M37	21	1	0
Z02	21	6	0
E17	20	12	0
Å12	20	1	0
M28	19	7	0
R01	19	5	0
Å02	19	5	0
W04	17	6	0
O66	15	15	5
Y05	15	2	0

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2	D14	12	0	0	F01	13	0	0
3	W11	12	0	0	E09	11	0	0
4	E17	10	6	0	M12	10	3	0
5	W04	10	4	0	O72	9	1	0
6	Å06	10	8	0	B05	7	3	0
7	Å12	10	2	0	E08	7	3	0
8	E09	9	1	0	I05	7	0	0
9	B05	7	2	0	G03	6	2	0
10	L01	7	0	0	Z05	6	0	0
11	M28	7	1	0	Å06	6	4	0
12	Y08	6	1	0	D08	5	4	0
13	E06	5	0	0	E06	5	0	0
14	F02	5	0	0	I02	5	2	0
15	Å11	5	0	0	M57	5	0	0
16	I02	4	1	0	Y08	3	1	0
17	M37	4	4	0	F04	2	2	0
18	O72	4	1	0	O71	2	0	0
19	D06	2	0	0	E22	1	0	0
20	F01	2	2	0	Y11	1	0	0
21	F10	2	0	0	Å11	1	0	0
22	Y11	2	0	0	B10	0	0	0
23	B10	1	0	0	D06	0	0	0
24	E25	1	0	0	D14	0	0	0
25	F04	1	0	0	E25	0	0	0
26	Z05	1	0	0	F02	0	0	0
27	E11	0	0	0	F10	0	0	0
28	E22	0	0	0	P04	0	0	0
29	F07	0	0	0	E11	0	0	0
30	F08	0	0	0	F07	0	0	0
31	K09	0	0	0	F08	0	0	0
32	O01	0	0	0	K09	0	0	0
33	O46	0	0	0	O01	0	0	0
34	O67	0	0	0	O46	0	0	0
35	O71	0	0	0	O67	0	0	0
36	W13	0	0	0	W13	0	0	0
37	Y07	0	0	0	Y07	0	0	0
38	Y10	0	0	0	Y10	0	0	0
39	Other		147	76	Other			104
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STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cohort studies*

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	1
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	2-3
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	5
Objectives	3	State specific objectives, including any prespecified hypotheses	5-6
Methods			
Study design	4	Present key elements of study design early in the paper	8-10
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5, 6, 8, 9
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up	6, 7, 8
		(b) For matched studies, give matching criteria and number of exposed and unexposed	
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	7
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	5, 6,7
Bias	9	Describe any efforts to address potential sources of bias	
Study size	10	Explain how the study size was arrived at	6
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	8, 9
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	8, 9
		(b) Describe any methods used to examine subgroups and interactions	
		(c) Explain how missing data were addressed	8, 9
		(d) If applicable, explain how loss to follow-up was addressed	
		(e) Describe any sensitivity analyses	
Results			

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed (b) Give reasons for non-participation at each stage (c) Consider use of a flow diagram	10
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders (b) Indicate number of participants with missing data for each variable of interest (c) Summarise follow-up time (eg, average and total amount)	10, 11 11, 13, 14
Outcome data	15*	Report numbers of outcome events or summary measures over time	11-14
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included (b) Report category boundaries when continuous variables were categorized (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	
Discussion			
Key results	18	Summarise key results with reference to study objectives	16
Limitations			
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	16, 18
Generalisability	21	Discuss the generalisability (external validity) of the study results	19, 20
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	23, 24

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.

BMJ Open

Treatment Outcomes for Eating Disorders in Sweden: data from the National Quality Registry

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2018-024179.R4
Article Type:	Research
Date Submitted by the Author:	28-Nov-2018
Complete List of Authors:	Södersten, Per; Karolinska Institutet Brodin, Ulf; Karolinska Institutet, Sjöberg, Jennie; Mandometer Clinic Zandian, Modjtaba; Karolinska Institutet Bergh, Cecilia; Mandometer Clinic,
Primary Subject Heading:	Public health
Secondary Subject Heading:	Health policy
Keywords:	Health policy < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, PUBLIC HEALTH, STATISTICS & RESEARCH METHODS

SCHOLARONE™
Manuscripts

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3 **Treatment Outcomes for Eating Disorders in Sweden. Data from the National Quality**
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5 **Registry**
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9 Per Södersten, Ulf Brodin, Jennie Sjöberg, Modjtaba Zandian, Cecilia Bergh
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39 4367 words excluding abstract, strengths and limitations, references, acknowledgements, and
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41 figure legends
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43 52 references
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45 5 figures
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Abstract

Objective To report the outcomes of eating disorders treatment in Sweden in 2012-2016.

Design The number of patients treated and the number of patients not fulfilling an eating disorders diagnosis (remission) at one year of follow-up at the clinics listed in the National Quality Registry for Eating Disorders Treatment were analyzed. The published outcomes at three clinics, that used survival analysis to estimate outcomes, were compared with their outcomes in the registry. Outcomes at the three biggest clinics were compared.

Setting All eating disorders clinics.

Participants All patients treated at eating disorders clinics.

Intervention Cognitive behavioural therapy at most clinics and normalization of eating behaviour at the three clinics with published outcomes.

Outcome measure Proportion of patients in remission.

Results About 2600 patients were treated annually, fewer than half were followed-up, and remission rates decreased from 21% in 2014 to 14% in 2016. Outcomes, which differed amongst clinics and within clinics over time, have been publically overestimated by excluding patients lost to follow-up. The published estimated rate of remission at three clinics that treated 1200 patients in 1993-2011 was 27, 28, and 40% at one year of follow-up. The average rate of remission over the three last years at the biggest of these clinics was 36%, but decreased from 29 and 30% to 16 and 14% at the two other of the biggest clinics.

Conclusions With more than half the patients lost to follow-up and no data on relapse in the National Quality Registry, it is difficult to estimate the effects of eating disorders treatment in

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3 Sweden. Analysis of time to clinically significant events, including an extended period of
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5 follow-up, has improved the quality of the estimates at three clinics. Overestimation of
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7 remission rates has misled health care policies. The effect of eating disorders treatment has
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9 also been overestimated internationally.
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For peer review only

Strengths and limitations of this study

- This study has the strength of analyzing all patients treated, followed-up, and treated to remission at all eating disorders clinics over five years in Sweden.
- These outcomes are available in the National Quality Registry for Eating Disorders Treatment but have not been published in the scientific literature.
- Three clinics have published outcomes at three-month intervals making it possible to compare these outcomes with their outcomes in the registry.
- The study has the strength of showing that a time-to-event analysis improves compliance, facilitating estimation of outcomes.
- It is a limitation that whereas outcomes in the registry covered the years 2012-2016, the published outcomes at the three clinics covered the years 1993-2011.

INTRODUCTION

The National Quality Registries in Sweden have been developed starting in the 1970s and today there are about 100 registries, covering virtually all kinds of disease (1). The Swedish Association of Local Authorities and Regions (SALAR) and the Swedish Government recently agreed to strengthen the registries financially, pointing to their key role in the development of all aspects of health care, improving the quality of care, facilitating research, including international comparisons of outcomes, guiding health care policies, and making it possible for anyone to compare the outcomes of treatment at individual clinics (1,2). Indeed, the SALAR has a website for such comparisons (3).

The Swedish National Quality Registry for Eating Disorders Treatment, Riksät, was established in 1999 and has published 11 reports, written in Swedish, in 2001-2016 (4). Following the aims of the registries, the objective of Riksät is to “document the outcome of treatment” (quote from the first report in 2001). Thus, the important measures are the number of patients treated and the number of patients in remission at follow-up. These numbers are listed in Riksät but have not been analyzed and reported in the scientific literature. The first aim of the present study is to examine the rate of remission at all eating disorders clinics in Sweden.

The results in Riksät have been publicized nationally as demonstrating increasing rates of remission over the years to 56% in 2015 and that “70% of the patients are ‘cured’ within one year” (4,5). Because these outcomes are better than the outcomes reported in the scientific literature (6,7), the second aim of this study is to examine their evidence basis.

There are three clinics in Sweden, that have published outcomes (8). Because these clinics (Mandometer Clinics) also report to Riksät it is possible to compare their published

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3 outcomes with their outcomes in Riksät. The biggest of the three Mandometer clinics is the
4 clinic in the County Council of Stockholm (Mando). The third aim of this study is to compare
5 the outcomes at Mando with the outcomes at the two other of the biggest clinics in Sweden,
6 the Stockholm Centre for Eating Disorders (SCED) and the Capio Centre for Eating Disorders
7 (Capio).
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16 The fourth aim of this study is to call the attention of policy makers to the fact that
17 outcomes of eating disorders treatment have been overestimated not only in Sweden but in
18 other countries as well.
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23 **METHODS**

24 **Patients and diagnostic procedures**

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27 Riksät lists the number of patients entering treatment each year and the number of patients
28 followed-up one year later, although the exact time of follow-up is not mentioned. More than
29 90% of the patients entering treatment at the specialist clinics are listed in the registry, but
30 patients that are treated at general psychiatric units may not be listed. Whilst there is no
31 information on how many these patients might be, most patients treated are listed in the
32 registry. There is no information on long term outcome, including relapse.
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46 At the beginning of treatment and at follow-up the patients completed the Eating
47 Disorders Examination Questionnaire (EDE-Q), which measures eating disorders symptoms
48 (9), and the Clinical Impairment Assessment (CIA), which measures psychosocial functioning
49 as a consequence of the eating disorder (10). The EDE-Q was used for patients older than 10
50 years and the CIA was used for patients older than 18 years. A semistructured interview was
51 used for children and adults to determine overall psychiatric symptoms and social functioning
52 (see e.g., (11)). Using these procedures, the patients were diagnosed with Anorexia Nervosa,
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3 Bulimia Nervosa, Eating Disorder Not Otherwise Specified, or Binge Eating Disorder relying
4 on the criteria in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (12).
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6 Patients who no longer fulfilled the diagnostic criteria for an eating disorder were listed as in
7
8 remission. About 4-5% of the patients in the yearly reports had been treated before when
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10 entering treatment.
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16 Riksät reports changes in the patients' social functioning and their experiences of the
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18 treatment, and these secondary measures improve in parallel as patients go into remission but
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20 will not be considered in this analysis.
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24 Whilst Riksät thus includes two time points for assessment, the Mandometer clinics
25
26 have developed a treatment in which the patients are assessed at three-month intervals and
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28 followed-up 1, 2, 3, 6, 9, 12, 18, 24, 36, 48, and 60 months after remission. The procedures,
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30 including the criteria for inclusion, exclusion, and remission were published in 2002 (13), and
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32 have been re-published many times (e.g., (8)); another description may be redundant. The
33
34 Mandometer clinics also report their outcomes to Riksät.
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38 39 **Treatments**

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42 The 2012-2014 Riksät reports did not specify the treatments used beyond mentioning that
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44 these were guided by "the principles of cognitive behavioural therapy" (CBT) and that they
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46 could be used with individual patients or with groups of patients. Medical intervention was
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48 used for monitoring and restoring physical health and psychopharmacology was also used,
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50 absence of evidence of their efficiency was pointed out. The 2015-2016 reports provide
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52 details on treatments. Thus, CBT was used with on average 52% of the children and with 72%
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54 of the adults, psychodynamic therapy was used with on average 21% of the children and with
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56 24% of the adults, and family-based therapies were used with on average 38% of the children.
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3 The treatment developed at the Mandometer clinics was described in 1996 (14), re-published
4 some years on (8,13), and because it has since been described in several other papers, another
5 description may be redundant. Suffice it to say that an important intervention is teaching
6 patients how to eat normally using real time visual feedback on how much food to eat and
7 how quickly to eat it. A video of how this method works was published recently (15). In
8 addition, the patients are provided with warmth, that exerts an anxiolytic effect in 30 minutes
9 (16), their physical activity is reduced, and they are assisted in restarting their social
10 interactions (13). Interestingly, re-establishing normal eating behaviour is also the most
11 important intervention in CBT, although it is not clear how this is achieved (7).

25 **Description of outcomes**

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27
28 Initially, Riksät reported the combined outcomes at the clinics across regions in Sweden, the
29 reports published in 2009 and 2010 were incomplete, and no report was published in 2011.
30 However, the outcomes at individual clinics were reported in 2012-2016. The number of
31 patients treated at each clinic and the proportion of patients who were followed-up are listed
32 in one set of tables in these reports. The number and the proportion of patients in remission at
33 follow-up are listed in another set of tables. These numbers have been combined into one
34 table (supplementary table) and used in the analysis.

45 **Combined outcomes at all clinics**

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48 The numbers of patients treated, followed-up, and treated to remission have been summarized
49 for all clinics. The number of patients in remission has been related to the number of patients
50 treated as well as to the number of patients followed-up in an attempt to explain the high
51 remission rates publicized in Sweden.

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3 If the treatment and the follow-up assessments are about the same at all clinics, the
4 probability for remission should be the same in all clinics. This hypothesis, which can be
5 formalized as: $H_0: P_i(\text{Remission}) = P_0(\text{Remission})$ for all clinics, $i=1, 2, 3, \dots n$, was tested
6 using a test for homogeneity of the data (17).
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13 In 2012-2013 Riksät listed the number of clinics that treated and followed-up at least 20
14 patients. The number of patients treated to remission at these clinics was listed in 2012, but in
15 2013 the number of patients treated to remission included clinics that had followed-up at least
16 10 children or 10 adult patients. In 2014-2016 the number of patients treated, followed-up,
17 and treated to remission was listed for all clinics. Using these data (supplementary table), the
18 number of clinics following-up at least 20 patients have been analyzed. Outcomes at clinics
19 following-up fewer than 10 patients have also been analyzed.
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30 **Published outcomes at Mandometer clinics**

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34 Mandometer clinics have published the outcomes of 1428 patients treated at six clinics in four
35 countries over various periods of time in 1993-2011, and these data are available in the
36 supplementary files of (8). The three Swedish clinics, in Alingsås, Danderyd, and Huddinge,
37 treated 1200 of these patients. The clinic in Huddinge, within the Stockholm County Council,
38 is the oldest clinic and is referred to as Mando in this analysis. The probability of going into
39 remission over consecutive three-month intervals up to 12 months at these clinics was
40 estimated using a life-table approach to survival analysis (18). The rate of failure amongst
41 censored patients was estimated to be 20%, yielding a conservative estimate of treatment
42 outcomes. This analysis allows comparison between these published outcomes and the
43 outcomes for the same clinics listed in Riksät.
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58 **Outcomes at individual clinics**

Outcomes were compared amongst SCED, Capio, and Mando.

Patient and public involvement

This study is an analysis of patient data in a registry and those patients did not participate in the analysis. The results will be openly available at mandometer.com.

RESULTS

Patient characteristics

The characteristics of the patients at the start of treatment were stable over all years and measures of variability are therefore not included. The average proportion of males was 4.6%, the average proportion of children and adolescents, who were <18 years old, was 29%. The age, obviously, was variable and the average mean (SD) age of all patients was 23.1 (8.9) years. The proportion of the various eating disorders diagnoses was also stable over the years and average values are presented in Table 1.

Table 1. Diagnoses amongst patients entering treatment for eating disorders in Sweden in 2012-2016. There were about 2600 patient each year and the proportions are averaged over these years. Children were <18 years old.

Diagnosis	Proportion (%)	
	Children	Adults
Anorexia Nervosa	39	20
Bulimia Nervosa	8	32
Eating Disorder Not Otherwise Specified	45	37

Binge Eating Disorder	1	6
Other*	7	5

*Not specified.

Combined outcomes at all clinics

Figure 1 shows that the total number of patients treated at all clinics increased to about 2600 in 2013, and remained relatively stable over the following years. The figure also shows that fewer than half the patients were typically followed-up a year later and that the rate of remission was about 21% in 2012-2014, and decreased to 14% in 2016. The number of patients treated to remission increased from 477 in 2012 to 589 in 2014 and decreased to 358 in 2016. There is no information on possible differences in the number of patients in remission related to the diagnosis at the start of treatment.

--- Please insert Figure 1 about here ---

Figure 2 shows firstly, that the rate of remission at all clinics that followed-up their patients was less than 50% in 2012-2014, 29% in 2015, and 36% in 2016. Secondly, the figure shows that the rate of remission at clinics that had treated at least one patient to remission increased to 56% in 2015 and decreased to 54% in 2016. The second analysis thus excluded patients followed-up at clinics that did not treat a single patient to remission. The significance of these two calculations of remission rates is clarified in the Discussion.

--- Please insert Figure 2 about here ---

Variability in outcomes

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3 The probability of going into remission in 2012 was significantly different amongst the 17
4 clinics that had treated patients in all recorded years ($P < 0.001$; $\text{Chi}^2 = 80.2$, $\text{df} = 16$). The
5 probability of going into remission was also significantly different amongst the five clinics
6 that had treated at least 100 patients in 2012 ($P < 0.001$; $\text{Chi}^2 = 23.7$, $\text{df} = 4$). Analysis of the other
7 years gives similar results.
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16 Analysis of the results at SCED showed that the probability of going into remission was
17 significantly different over the years ($P < 0.001$; $\text{Chi}^2 = 46.3$, $\text{df} = 4$). Analysis of the other
18 clinics gives similar results.
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23 24 **Combined outcomes at clinics that followed-up at least 20 patients**

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27 Because Riksät reported on clinics that had followed-up at least 20 patients in 2012-2013 and
28 for all clinics in 2014-2016, the number of clinics reporting their outcomes was lower in
29 2012-2013 (21 and 23) than in 2014-2016 (70, 64, and 59). However, it is possible to compare
30 how many clinics had treated, followed-up, and treated at least 20 patients to remission in
31 2012-2016.
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40 Figure 3 shows that more clinics had treated at least 20 patients in 2016 than in 2012.
41 Whereas the clinics that had treated at least 20 patients in 2012 were selected for having
42 followed them up, only 45% of these clinics followed-up at least 20 patients in 2016. About
43 one in three of these clinics had treated at least 20 patients to remission in 2012 compared to
44 about one in eight in 2016. The results in the other years fall in between the results in 2012
45 and 2016.
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3 Out of the 33 clinics that had treated at least 20 patients in 2016 (Figure 3, green bar at
4 the very left), three (9%) had not followed-up any patient, and 21 (64%) had not treated a
5 single patient to remission. These 21 clinics had treated a total of 857 patients, with a median
6 (range) of 32 (20-98) patients/clinic.
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13 **Combined outcomes at clinics that followed-up fewer than 10 patients**

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17 Figure 4 shows that amongst the about 2600 patients who were treated annually in 2013-2016,
18 the number of patients treated at clinics that followed-up fewer than 10 patients increased to
19 more than 1000 in the last two years. In parallel, the proportion of patients who were
20 followed-up and treated to remission at these clinics decreased. Fewer than one in ten of the
21 patients were treated to remission in the final three years. Please note that the values for 2012
22 include clinics that followed up fewer than 20 patients. Clinics following-up fewer than 10
23 patients were not reported separately this year.
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38 **Published outcomes at Mandometer clinics**

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41 Table 2 shows that the proportion of patients in remission at 12 months assessments was at
42 least 27% and significantly different at the three Mandometer clinics, whose outcomes are
43 published. Treatment continues after the 12 months at these clinics and the proportion of
44 patients in remission increases after various, prolonged periods of time. Please note that these
45 clinics had been operating over various periods of time.
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Table 2. Proportion of patients in remission at Mandometer clinics.

Outcome	Clinic		
	Alingsås	Danderyd	Mando
Operation (years)	2	7	18
<u>12 months assessment</u>			
Patients in remission	13	72	219
Patients not in remission	36	107	552
Proportion in remission	27	40*	28
<u>Continued treatment (months)</u>			
Patients in remission	19	141	490
Patients not in remission	27	27	170
Proportion in remission	39	82	68

*P=0.0017 compared to Alingsås and Mando after P=0.0069 (overall difference).

It may be mentioned that the time to remission depends on the diagnosis at admission, with the longest time to remission for patients with anorexia nervosa (8).

Outcomes at the three biggest clinics

SCED had treated about four times more patients annually (median: 715; range: 696-724) than Capio (175; 157-178) and Mando (123; 81-168), and followed-up about the same proportion of patients (43; 32-69%) as Capio (50; 48-65%) and Mando (43; 32-83%). These proportions are similar to the average proportions of follow-up at all clinics over these years (Figure 1).

Figure 5 shows that Mando had treated a bigger proportion of patients to remission than SCED and Capio in 2014-2016. Whilst the rate of remission was relatively stable at on average 36% at Mando over these three years, it decreased from 29% to 16% at SCED and from 30% to 14% at Capio. In 2016, the proportion of patients treated to remission at Mando (35%) was about twice as big as the corresponding proportion at SCED (16%) and Capio (14%).

--- Please insert Figure 5 about here ---

DISCUSSION

Patient characteristics, diagnostic procedures, and treatments

The characteristics of the patients, who have been treated for eating disorders in Sweden, including the proportion of males and children, age and diagnosis, have been relatively stable in recent years and are similar to the characteristics of eating disorders patients in other countries (19). It is worth noting that whilst a minority of the patients were diagnosed with Binge Eating Disorder, that disorder is now the most common eating disorder (20). Although the diagnostic procedures may differ amongst clinics (19), most of the procedures used in Sweden have been developed in other countries. In addition, the treatments used in Sweden,

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3 including CBT, psychodynamic therapy, and family therapy, as well as medical and
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5 psychopharmacological interventions aiming at restoring physical and mental health are the
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7 same as those recommended in the guidelines and used in most countries (19,21–26). The
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9 treatment at the Mandometer clinics differs in that an important intervention is the
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11 normalization of eating behaviour using real time visual feedback on how to eat as described
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13 many times and most recently by video (15). The differences and similarities amongst the
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15 Mandometer treatment and CBT have been described in detail recently, including the
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17 differences in outcomes (7).
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22 **Outcomes in Sweden**

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26 About 2600 patients were treated annually at the eating disorders clinics in Sweden in 2012-
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28 2016, fewer than half were followed-up, and the proportion of patients treated to remission
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30 decreased from one in five in 2012 to less than one in seven in 2016. However, remission
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32 rates which are more than three times higher have been publicized nationally. These estimates
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34 were derived by excluding patients lost to follow-up and patients followed-up at clinics that
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36 did not treat patients to remission. In 2016, only four clinics treated 20 patients to remission;
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38 most clinics treated a small number of patients, followed-up a few, and treated only one
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40 patient in ten to remission. Outcomes varied significantly between clinics each year and
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42 within clinics over years. In addition, in 2016 more than half the 33 clinics that had treated on
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44 average 32 patients had failed to treat a single patient to remission; one of these clinics had
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46 treated 98 patients unsuccessfully.
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52 **Interpretation and comparison with published outcomes**

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56 Whilst these findings indicate that the procedures of treatment and follow-up differ amongst
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58 clinics in Sweden, a word of caution seems appropriate. For example, although outcomes
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3 were significantly different over years at the biggest clinic (SCED), patients were treated to
4 remission all years, suggesting that a statistically significant within-clinic variation may be
5 less significant clinically. However, it seems unlikely that the decrease from a rate of
6 remission of about 30% in 2014 at this clinic to about half that rate two years later is a matter
7 of random variation. And the similar decrease in the rate of remission at another clinic in
8 these years (Capio) suggests that the procedures at these clinics had deteriorated, at least
9 temporarily.

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21 Possible reasons for the variation in outcomes include changes in staffing, training of
22 staff, patient compliance to treatment, and the physical conditions in the clinics, factors that
23 affect outcomes in multicenter clinical trials (27). Whilst the “study protocol” of the
24 multicenter trial aims at reducing the influence of these factors, there is no standard protocol
25 for the treatment of eating disorders. And although there is agreement that the treatment
26 guidelines for eating disorders should be followed, this consensus view has not yet improved
27 outcomes (21–23,25,28–30). For example, an attempt at implementing CBT, which is
28 recommended in all guidelines, in combination with antidepressant medication for the
29 treatment of bulimia nervosa in primary care in the U.S. resulted in a 70% dropout rate (31).
30 A similar effort in general practice in the U.K. found that out of 683 patients with a diagnosis
31 of bulimia, about half of the 272 patients who entered CBT completed the treatment, and
32 although those patients improved, they were not free of eating disorders symptoms after
33 treatment (32). A recent study aiming to implement CBT for anorexia nervosa in general
34 practice produced similar results. Thus, out of 257 patient referrals, 44 patients started in
35 treatment and 22 completed the treatment (33), findings that were replicated in another recent
36 study (34). Compliance is thus a general problem in the treatment of eating disorders, not a
37 “Swedish” problem, but it can be improved as discussed below.

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3 Whether these factors are causally related to the decrease in remission rates in 2015-
4 2016 remains to be determined. But it may be of some significance that as the number of
5 patients treated at clinics that treated fewer than ten patients to remission increased, the
6 proportion of patients followed-up and treated to remission decreased (Figure 4). And when
7 the number of patients followed-up at all clinics increased in 2015, there was a marked
8 decrease in the proportion of patient treated to remission (Figures 1 and 2).
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18 The Mandometer treatment was developed starting in 1993, a theoretical framework and
19 preliminary findings were reported in 1996 (14,35). A randomized controlled trial
20 demonstrated its effectiveness and outcomes for 1428 patients treated at six clinics in four
21 countries were subsequently reported (8,13). The combined rate of remission at these clinics
22 was estimated to be about 75% in on average one year of treatment and the rate of relapse was
23 estimated to be about 10% over five years of follow-up (8). Similar to Riksät, estimates were
24 done amongst all patients entering treatment. However, far more patients were lost to follow-
25 up at Riksät's one year time point of follow-up than to Mandometer's procedure of
26 monitoring patients at three-month intervals throughout treatment and at 1, 2, 3, 6, 9, 12, 18,
27 24, 36, 48, and 60 months of follow-up (8). Despite the difference, the rate of remission at the
28 Mando clinic in the Stockholm County Council was on average 33% in 2012-2016 according
29 to the Riksät calculation, which is about half the estimated published 75% rate of remission
30 after on average one year of treatment (8). A comprehensive description of all patients,
31 including those who take a long time to go into remission, is available in the supplementary
32 files of (8), which report outcomes at three month intervals at all Mando clinics.
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54 Average remission rates should be viewed cautiously as outcomes varied between
55 clinics. Thus, the published rate of remission at 12 months differed significantly at the three
56 Mandometer clinics, yet it was higher than the average values reported for all clinics in each
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3 of the five years in Riksät. Differences in treatment methods between the Mandometer clinics
4 and the other clinics may explain the differences in outcomes (7) and it is possible that
5
6 outcomes will be more consistent at the Mandometer clinics once they have been operating
7
8 for a longer period of time. For example, the Alingsås clinic had been treating patients for
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10 only two years and reached a rate of remission of only 39%. The variation in the rate of
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12 remission at 12 months at the Mandometer clinics in Amsterdam (16%), San Diego (52%),
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14 and Melbourne (25%) (8), support previous findings that international cultural and medical
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16 system differences also affect treatment outcomes (36). Thus, patients treated in San Diego
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18 improved rapidly, but they were often prevented from continuing in treatment because of the
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20 financial constraints of their insurance policies (8), a problem that would not affect patients in
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22 Sweden. It should be noted that relatively few patients had been treated at these clinics.
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30 Dropout and relapse are significant events in the treatment of eating disorders (7,37,38),
31 and neither these events, nor remission, should be expected to occur after a predetermined
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33 period of time such as at one year of follow-up as used in Riksät. Also, the precise time for
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35 follow-up is not mentioned. It seems likely that this procedure explains why more than half
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37 the patients were lost to follow-up in Riksät. Practical approaches to survival analysis,
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39 including time-to-event analysis, are long available (18,39) and should be used in studies of
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41 outcomes of eating disorders treatment. The higher level of compliance at the Mandometer
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43 clinics (8) offers support for their value.
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49 Considering the difference between outcomes at Mando and the other Swedish clinics,
50 including the fact that several hundred patients have been treated to remission, and that the
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52 rate of relapse has been reduced to an estimated 10% at the Mando clinics, a randomized
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54 controlled trial comparing outcomes at these clinics may be redundant; an attempt at a
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56 comparison (40), was fraught with problems (8). The major treatment in Swedish clinics is
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3 CBT and a detailed analysis showed that the remission rates after CBT are lower than those
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5 after Mandometer treatment (7). Psychodynamic therapy is also used in Swedish clinics,
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7 although outcomes of this therapy are inferior to those of CBT (41). Similarly, the use of
8
9 family-based therapies with children in Sweden as in other countries, probably does not
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11 explain the differences in outcomes. Differences in patient characteristics at admission may
12
13 contribute to differences in treatment outcomes and the possibility that such differences exist
14
15 should be examined, although the published literature indicates that they do not (42). Also,
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17 there are no differences in the Swedish referral system such that more severely ill patients at
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19 one of the clinics might explain differences in outcomes.
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25 **Implications for policy makers**

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28 Overestimations of the outcomes of the treatment for eating disorders in Sweden have been
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30 publicized over several years (4), including the claim that “70% of the patients are ‘cured’
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32 within one year”, which is maintained on Sweden’s National Educational Radio Channel (5).
33
34 This is similar to the international claim that CBT is “efficacious for a range of eating
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36 disorder presentations in the short and long-term” (30), publicized as: “Based on a solid
37
38 empirical foundation, the transdiagnostic enhanced CBT approach will immediately become
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40 the gold standard for the treatment of eating disorders” (43), and “[the effect of CBT] is the
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42 most dramatic that we have seen in the literature ... [including] the potency ... and the
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44 impressive maintenance of change over the 19-months follow-up” (44). The published
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46 evidence does not support these claims (7,45–47) and evidence that the outcomes of CBT
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48 have been overestimated for the treatment of other disorders is gradually emerging (48,49).
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50 These overstatements have misinformed health policy makers and can now be corrected.
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57 The importance of the National Quality Registries in guiding health care policies in
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59 Sweden was recently re-emphasized (50). In order to guide decisions on matters of health
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3 care, national and international registries must offer reliable information. Widely publicized
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5 “facts” need to be critically examined. Policy makers should be aware that once ill advised
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7 policies have been established, retrospectively controlling their evidence basis can be
8
9 ineffective, and even strengthen the misguided policy (51,52).
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13 **Acknowledgements**

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16
17 We thank Sara Norring, Riksät, Anna Sandelin, the Centre of Registries Västra Götaland, and
18
19 Fredrik Westander and Lale Björne-Fergéus, SALAR, for information on Riksät.
20
21
22

23 **Transparency declaration**

24
25
26 Södersten affirms that the manuscript is an honest, accurate, and transparent account of the
27
28 study being reported; that no important aspects of the study have been omitted; and that any
29
30 discrepancies from the study as planned (and, if relevant, registered) have been explained.
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34 **Ethics approval**

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38 The project was approved by the Regional Ethical Review Board of Stockholm (Dnr
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40 2015/456-31).
41
42

43 **Contributorship**

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45
46
47 Södersten examined the registry data in detail over the last two years. He reviewed his
48
49 examinations for all authors at regular intervals during the examination period. He is
50
51 responsible for the overall content as guarantor and assumes responsibility for all aspects of
52
53 the work. All data used for the analysis are included as a supplementary table to this
54
55 submission, which all authors are happy to share with other researchers.
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3 Brodin is medical statistician and has performed all statistical analyses and reviewed these for
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5 all authors at regular intervals during the examination period.
6
7

8
9 Sjöberg is clinical director of the Mandometer Clinic in Alingsås and responsible for
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11 treatment and data collection and reporting to the registry in 2012-2016.
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15 Zandian is clinical quality controller and has been responsible for data collection and
16
17 reporting to the registry in 2012-2016.
18
19

20
21 Bergh is clinical director for the Mandometer Clinic in Huddinge and responsible for
22
23 treatment at all Mandometer clinics.
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26
27 All authors have seen and reviewed several versions of the manuscript and agreed to its final
28
29 version.
30
31

32
33 Södersten is: “the corresponding author and attests that all listed authors meet authorship
34
35 criteria and that no others meeting the criteria have been omitted”.
36
37

38 **Acknowledgement**

39
40
41 Åsa Lundqvist BA of the Mandometer Clinic in Stockholm has been contact person with the
42
43 Rikät registry staff over the years 2012-2016. Ms Lundqvist supervised the reporting of data
44
45 to the registry and is in charge of the follow-up programme of the Mandometer Clinic.
46
47
48

49 **Competing interests**

50
51
52 Complete openness concerning financial arrangements is intended here. Brodin, Sjöberg and
53
54 Zandian declare that they have no financial interests related to this study. Our research is
55
56 carried out at the Karolinska Institute, where Södersten is a professor em. The research is
57
58 translated clinically by Mando Group AB, a company started by Södersten and Bergh, who
59
60

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2
3 have 47.5% of the stock each. Professor Michael Leon of the University of California at
4
5 Irvine has 5%. Mando Group AB contracts with the County Council of Stockholm every fifth
6
7 year to treat patients with eating disorders. Mando Groups AB signed its first contract in 1997
8
9 with the County Council of Stockholm and, since then, its treatment is one of the standards of
10
11 care offered to the citizens of Stockholm. This arrangement is the same as when the County
12
13 Council of Stockholm contracts with its own clinics to treat patients with all kinds of disease,
14
15 including eating disorders. That is to say, the County Council of Stockholm provides eating-
16
17 disorder services to the citizens of Stockholm both through a clinic of its own and through
18
19 Mando Group AB. There is a third provider of care for patients with eating disorders in
20
21 Stockholm, which is a private clinic. All health care in Sweden is funded through the tax
22
23 system; private pay is extremely uncommon. It should be added firstly, that Mando Group AB
24
25 is in compliance with the recommendation of the International Committee of Medical Journal
26
27 Editors on “Author Responsibilities-Conflicts of Interest”
28
29 [http://www.icmje.org/recommendations/browse/roles-and-responsibilities/author-](http://www.icmje.org/recommendations/browse/roles-and-responsibilities/author-responsibilities--conflicts-of-interest.html)
30
31 [responsibilities--conflicts-of-interest.html](http://www.icmje.org/recommendations/browse/roles-and-responsibilities/author-responsibilities--conflicts-of-interest.html). Secondly, it should also be added that all profit
32
33 that Mando Group AB has made has been re-invested in research and development and that
34
35 there have been no dividends to stock owners. All of the above is declared in all manuscript
36
37 submissions and thus far, journals have judged it necessary to publish only some of the
38
39 details. It seems, however, that the potential ethical problem when scientists translate their
40
41 research findings into the clinic in a company is not unlike that which arises when any
42
43 scientist, in an academic setting is developing a theory and needs further economic funding
44
45 for her/his work and may receive recognition and financial benefits for the work. The
46
47 incentive is, in part, economic in this case as well and the ethical “problem” is similar in both
48
49 cases. However, the more important incentive is the improvement of the treatment of patients
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51 with eating disorders. We are researchers working in an academic setting and like many other
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3 medical research institutes today, the Karolinska Institute encourages scientists to translate
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5 their research into the clinic in companies that aim to generate financial profits to be used for
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7 research and development (see:

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10 http://ki.se.proxy.kib.ki.se/sites/default/files/summary_strategy2018.pdf).
11
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13 **Funding**

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17 This work was supported by The County Council of Stockholm grant number HNSV 15896,
18
19 HSN 1502-0291, project 3252.
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21

22 **Role of the sponsor**

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25
26 The sponsor had no influence on the work.
27
28

29 **Data sharing statement**

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33 The data used for this analysis are available in a supplementary table.
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Figure legends

Figure 1. Number of patients treated at all clinics in Sweden and proportion of patients followed-up and in remission one year later. The year on the x-axis indicates the year of follow-up, the corresponding number of patients starting their treatment the year before.

Figure 2. Proportion of patients in remission at all clinics that followed-up their patients and at clinics that treated at least one patient to remission.

Figure 3. Number of clinics that treated, followed-up, and treated at least 20 patients to remission and proportion of clinics that followed-up and treated at least 20 patients to remission in 2012 and 2016.

Figure 4. Number of patients treated at clinics that followed-up fewer than 10 patients (2013-2016) or 20 patients (2012) and proportion of patients followed-up and in remission one year later. The year on the x-axis indicates the year of follow-up, the corresponding number of patients starting their treatment the year before.

Figure 5. Proportion of patients treated to remission at the three clinics that treated more patients to remission than any other clinic, the Stockholm Centre for Eating Disorders (SCED), the Capio Centre for Eating Disorders (Capio), and the Mandometer Clinic in Stockholm (Mando).

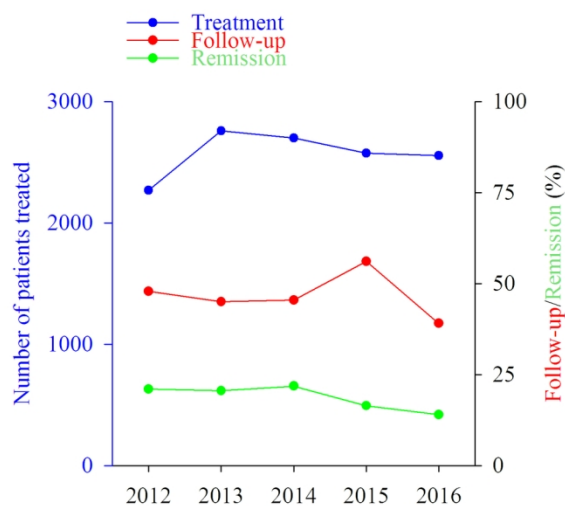


Figure 1. Number of patients treated at all clinics in Sweden and proportion of patients followed-up and in remission one year later. The year on the x-axis indicates the year of follow-up, the corresponding number of patients starting their treatment the year before.

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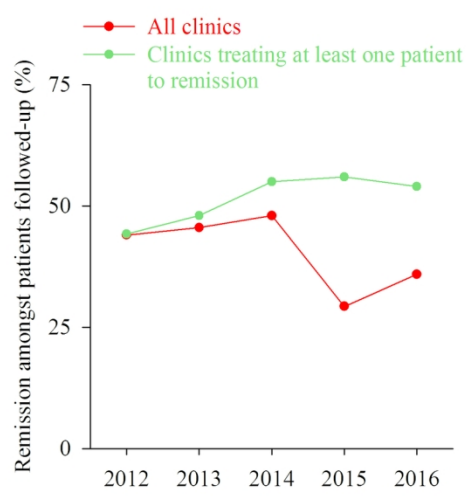


Figure 2. Proportion of patients in remission at all clinics that followed-up their patients and at clinics that treated at least one patient to remission.

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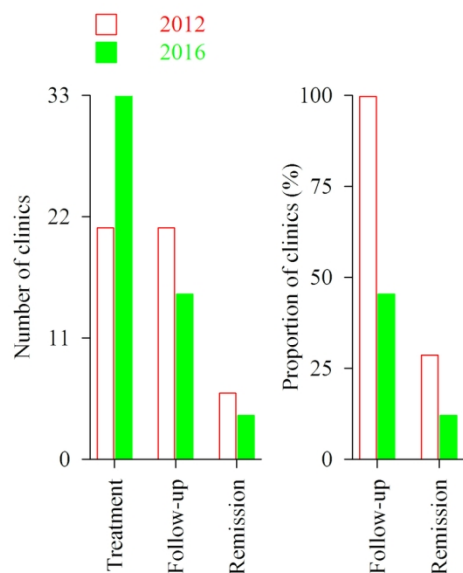


Figure 3. Number of clinics that treated, followed-up, and treated at least 20 patients to remission and proportion of clinics that followed-up and treated at least 20 patients to remission in 2012 and 2016.

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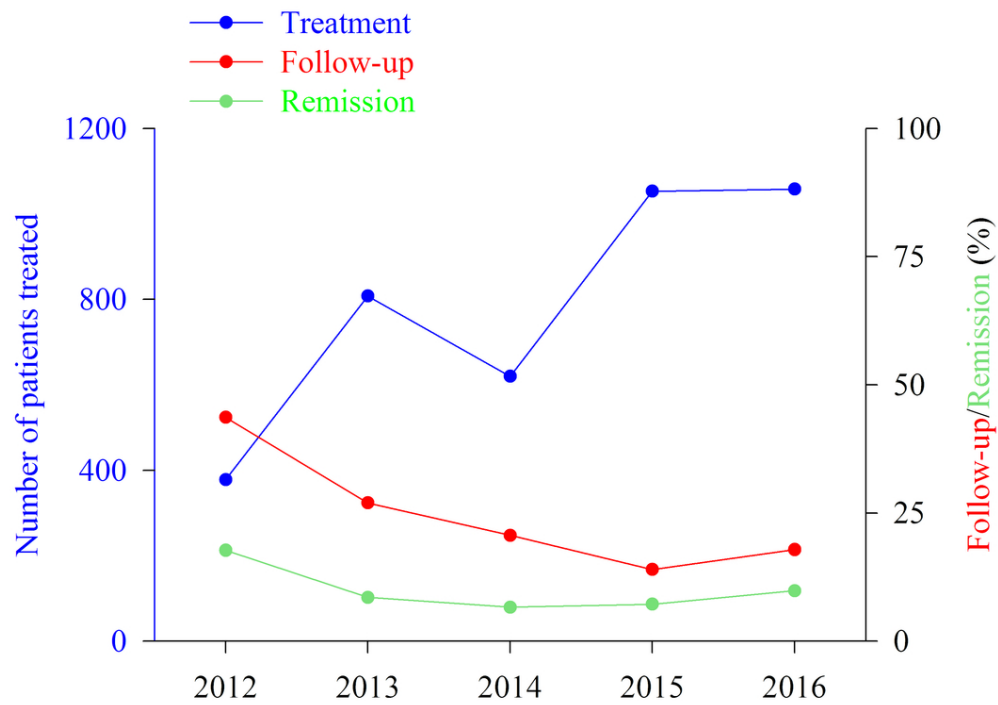


Figure 4. Number of patients treated at clinics that followed-up fewer than 10 patients (2013-2016) or 20 patients (2012) and proportion of patients followed-up and in remission one year later. The year on the x-axis indicates the year of follow-up, the corresponding number of patients starting their treatment the year before.

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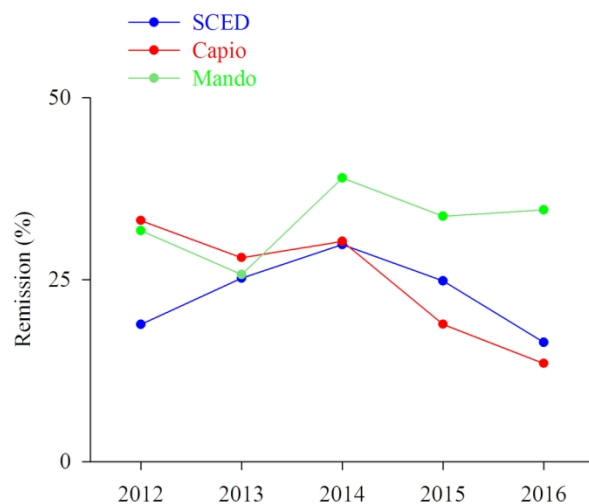


Figure 5. Proportion of patients treated to remission at the three clinics that treated more patients to remission than any other clinic, the Stockholm Centre for Eating Disorders (SCED), the Capiro Centre for Eating Disorders (Capiro), and the Mandometer Clinic in Stockholm (Mando).

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Supplementary table.

Number of patients treated (Treat), followed-up (F-up), and in remission at follow-up (Rem) at eating disorders clinics in Sweden in 2012-2016. The three clinics in the Stockholm County Council are the Stockholm Centre for Eating Disorders (SCED, A01), Caphio Centre for Eating Disorders (Caphio, A04), and the Mandometer Clinic (Mando (B01). Other is the combination of all clinics that followed-up fewer than 20 patients in 2012-2013 and fewer than 10 patients in 2014-2016.

Whilst most of the cells can filled in, it is not possible to fill in all cells, because of the procedures of follow-up. The clinics are arranged from the maximal-minimal number of patients treated.

2012				2013				2014			
Clinic	Treat	F-up	Rem	Clinic	Treat	F-up	Rem	Clinic	Treat	F-up	Rem
A01	696	224	131	A01	710	305	179	A01	705	339	210
A04	157	93	52	A04	176	88	49	A04	162	77	49
B01	123	53	39	B01	168	54	43	B01	136	59	53
T01	120	50	21	T01	116	39	20	M10	105	36	20
M10	107	38	22	M10	111	36	22	T01	99	46	21
U02	90	23	9	O09	89	36	19	X02	85	40	22
O09	78	38	16	E12	83	41	28	H01	82	36	15
E12	66	25	14	Å04	63	35	21	U02	78	16	6
N05	49	26	11	H01	59	43	18	E12	72	38	23
R01	48	33	13	N02	58	30	7	N07	66	16	3
H01	44	44	12	O07	56	35	4	S02	63	1	0
D03	40	38	7	O03	44	44	6	O09	57	27	15
K08	36	24	12	M12	42	41	10	N02	55	32	15
O03	36	33	8	N05	39	26	3	C04	52	0	0
Å04	33	21	7	N07	39	21	1	O03	52	30	5
O07	31	31	5	C03	38	30	13	W11	49	11	0
W01	30	28	20	P04	33	32	9	O07	43	16	2
N02	29	28	1	W01	28	28	9	N05	40	16	8
N07	29	22	2	D03		12	3	C03	39	17	5
P04	26	26	0	K08		13	9	M52	39	20	11
C03	21	21	8	U02		12	5	P04	37	15	0
Other	378	165	67	Z02		13	8	Å02	33	27	14
				Å02		11	10	D03	31	11	0
Sum	2267	1084	477	Other	806	218	69	M03	30	7	0
								Å04	30	19	14
				Sum	2758	1243	566	R01	29	4	0
								Y06	29	0	0
								M12	26	15	7
								W04	26	8	0
								K08	25	13	9
								W01	24	9	0
								B03	20	4	0
								B05	19	1	0
								Z02	19	10	10
								Å12	19	4	0
								D08	18	10	8
								F01	17	10	0
								Y05	16	3	0
								O66	15	6	0

E08	13	6	0
F02	13	12	3
M28	13	7	0
Å06	11	2	0
E09	9	2	0
I05	9	0	0
Y08	9	1	0
D14	8	0	0
Z05	8	0	0
G03	7	5	0
E06	6	0	0
E17	6	4	0
D06	5	0	0
I01	5	0	0
Å11	5	3	0
F04	4	2	0
F10	4	0	0
E11	3	0	0
E25	3	2	0
O46	3	3	0
E22	2	1	0
O01	2	0	0
B10	1	0	0
F07	1	0	0
F08	1	0	0
K09	1	0	0
O67	1	0	0
W13	1	0	0
Y07	1	0	0
Y10	1	0	0
Y11	1	0	0
I01	0	0	0
M37	0	0	0
M57	0	0	0
O27	0	0	0
O31	0	0	0
O35	0	0	0
O36	0	0	0
O37	0	0	0
O50	0	0	0
O72	0	0	0
Other		128	41
Sum	2699	1098	548

2015

Clinic	Treat	F-up	Rem
A01	734	505	182
A04	175	113	33
O09	109	13	0
T01	106	36	0
B01	95	79	32
M10	95	42	15
H01	93	51	4
X02	83	7	0
S02	73	37	0
U02	73	14	0
N07	71	20	0
E12	59	49	20
N02	47	41	6
N05	45	5	0
M52	40	7	3
C04	36	0	0
O07	35	31	3
M03	34	5	0
Å04	34	14	7
D03	31	18	0
M12	31	9	0
O03	29	21	10
C03	26	13	11
Z02	26	13	9
M57	25	0	0
K08	23	16	0
B03	22	14	0
Å02	22	11	0
E08	18	10	0
O27	17	17	7
P04	17	0	0
W01	17	17	5
Y06	15	7	0
D08	14	2	0
G03	14	6	0
I05	13	0	0
O66	13	13	0
R01	13	6	0
Y05	13	2	0

2016

Clinic	Treat	F-up	Rem
A01	715	298	117
A04	178	95	24
T01	98	20	0
O09	85	40	0
X02	82	49	0
B01	81	43	28
O27	80	52	7
H01	77	23	6
M10	75	17	6
E12	67	35	7
C03	64	30	20
N07	64	1	0
U02	63	0	0
C04	49	0	0
O07	49	28	5
W11	44	2	0
N02	40	13	0
M52	36	34	0
N05	35	26	0
O03	35	24	8
S02	32	7	0
W01	31	29	11
Y06	31	5	0
Å04	30	12	10
M03	26	1	0
B03	23	1	0
D03	23	15	0
K08	23	13	0
L01	21	0	0
M37	21	1	0
Z02	21	6	0
E17	20	12	0
Å12	20	1	0
M28	19	7	0
R01	19	5	0
Å02	19	5	0
W04	17	6	0
O66	15	15	5
Y05	15	2	0

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2	D14	12	0	0	F01	13	0	0
3	W11	12	0	0	E09	11	0	0
4	E17	10	6	0	M12	10	3	0
5	W04	10	4	0	O72	9	1	0
6	Å06	10	8	0	B05	7	3	0
7	Å12	10	2	0	E08	7	3	0
8	E09	9	1	0	I05	7	0	0
9	B05	7	2	0	G03	6	2	0
10	L01	7	0	0	Z05	6	0	0
11	M28	7	1	0	Å06	6	4	0
12	Y08	6	1	0	D08	5	4	0
13	E06	5	0	0	E06	5	0	0
14	F02	5	0	0	I02	5	2	0
15	Å11	5	0	0	M57	5	0	0
16	I02	4	1	0	Y08	3	1	0
17	M37	4	4	0	F04	2	2	0
18	O72	4	1	0	O71	2	0	0
19	D06	2	0	0	E22	1	0	0
20	F01	2	2	0	Y11	1	0	0
21	F10	2	0	0	Å11	1	0	0
22	Y11	2	0	0	B10	0	0	0
23	B10	1	0	0	D06	0	0	0
24	E25	1	0	0	D14	0	0	0
25	F04	1	0	0	E25	0	0	0
26	Z05	1	0	0	F02	0	0	0
27	E11	0	0	0	F10	0	0	0
28	E22	0	0	0	P04	0	0	0
29	F07	0	0	0	E11	0	0	0
30	F08	0	0	0	F07	0	0	0
31	K09	0	0	0	F08	0	0	0
32	O01	0	0	0	K09	0	0	0
33	O46	0	0	0	O01	0	0	0
34	O67	0	0	0	O46	0	0	0
35	O71	0	0	0	O67	0	0	0
36	W13	0	0	0	W13	0	0	0
37	Y07	0	0	0	Y07	0	0	0
38	Y10	0	0	0	Y10	0	0	0
39	Other		147	76	Other			104
40								
41	Sum	2575	1444	423	Sum	2555	998	358
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STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of cohort studies

Section/Topic	Item #	Recommendation	Reported on page #
Title and abstract	1	(a) Indicate the study’s design with a commonly used term in the title or the abstract	1
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	2-3
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	5
Objectives	3	State specific objectives, including any prespecified hypotheses	5-6
Methods			
Study design	4	Present key elements of study design early in the paper	8-10
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	5, 6, 8, 9
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up	6, 7, 8
		(b) For matched studies, give matching criteria and number of exposed and unexposed	
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	7
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	5, 6,7
Bias	9	Describe any efforts to address potential sources of bias	
Study size	10	Explain how the study size was arrived at	6
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	8, 9
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	8, 9
		(b) Describe any methods used to examine subgroups and interactions	
		(c) Explain how missing data were addressed	8, 9
		(d) If applicable, explain how loss to follow-up was addressed	
		(e) Describe any sensitivity analyses	
Results			

Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed (b) Give reasons for non-participation at each stage (c) Consider use of a flow diagram	10
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders (b) Indicate number of participants with missing data for each variable of interest (c) Summarise follow-up time (eg, average and total amount)	10, 11 11, 13, 14
Outcome data	15*	Report numbers of outcome events or summary measures over time	11-14
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included (b) Report category boundaries when continuous variables were categorized (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	
Discussion			
Key results	18	Summarise key results with reference to study objectives	16
Limitations			
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	16, 18
Generalisability	21	Discuss the generalisability (external validity) of the study results	19, 20
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	23, 24

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at www.strobe-statement.org.