

The Netherlands Mental Health Survey and Incidence Study-2 (NEMESIS-2): design and methods

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Abstract

The psychiatric epidemiological population study NEMESIS-2 (Netherlands Mental Health Survey and Incidence Study-2) replicates and expands the first Netherlands Mental Health Survey and Incidence Study (NEMESIS-1) conducted from 1996 to 1999. The main objectives of the new study are to provide up-to-date figures on the prevalence, incidence, course and consequences of mental disorders, and to study trends in mental disorders and service use, with the use of a new sample. New topics not included in NEMESIS-1 were added, e.g. impulse-control disorders, and genetic correlates of mental disorders through gathering DNA from saliva samples. This paper gives an overview of the design of NEMESIS-2, especially of its recently completed first wave. NEMESIS-2 is a prospective study among Dutch-speaking subjects aged 18–64 years from the general Dutch population. Its baseline wave included 6646 subjects. Three waves are planned with three year-intervals between the waves. A multistage, stratified random sampling procedure was applied. The baseline wave of NEMESIS-2 was performed between November 2007 and July 2009. Face-to-face interviews were administered with the Composite International Diagnostic Interview (CIDI) 3.0. The response rate was 65.1%, and 76.4% of the respondents donated saliva. The sample was reasonably nationally representative, but younger subjects were somewhat underrepresented. In conclusion, we were able to build a comprehensive dataset of good quality, permitting several topics to be studied in the future.
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Introduction

NEMESIS-1, which baseline wave was conducted in 1996, was the first Dutch nationally representative survey that estimated the prevalence of mental disorders (Bijl *et al.*, 1998a, 1998b). It also studied psychiatric comorbidity (de Graaf *et al.*, 2002a, 2003, 2004a; Krabbendam *et al.*, 2004; Vollebergh *et al.*, 2001), somatic comorbidity (Buist-Bouwman *et al.*, 2005; Neeleman *et al.*, 2004; Thewissen

et al., 2005), and consequences of mental disorders in terms of functional impairments (Bijl and Ravelli, 2000a, Buist-Bouwman *et al.*, 2004; Ormel *et al.*, 2004; Spijker *et al.*, 2004a), service use and unmet need (Bijl and Ravelli, 2000b; ten Have *et al.*, 2002, 2003, 2004, 2006; Sareen *et al.*, 2007), and costs (Cuijpers *et al.*, 2007a; Hakkaart-van Roijen *et al.*, 2004; Smit *et al.*, 2006).

Because of the study's longitudinal design, with three waves during a three-year period, it was also possible to

study incidence (Bijl *et al.*, 2002; Cuijpers *et al.*, 2004, 2007b; de Graaf *et al.*, 2002b; Hanssen *et al.*, 2005; Krabbendam *et al.*, 2005; van Laar *et al.*, 2007; Plaisier *et al.*, 2007; Smit *et al.*, 2004) and course of mental disorders (de Bruijn *et al.*, 2005, 2006; Spijker *et al.*, 2000, 2001, 2002, 2004b).

NEMESIS-1 showed that the lifetime prevalence of any axis-I Diagnostic and Statistical Manual of Mental Disorders, Third Edition, Revised (DSM-III-R) among the Dutch population was 41.2%; the 12-month prevalence was 23.2% (Bijl *et al.*, 1998b). Psychiatric comorbidity was more often the rule than the exception; for example, of subjects with a 12-month mood disorder, 60.5% had an additional disorder (de Graaf *et al.*, 2002b). Mental disorders were found to have a high impact on functioning in various domains (Bijl *et al.*, 2000a), and also after recovery, functioning was worse than among subjects without a disorder (Ormel *et al.*, 2004). Direct and indirect costs of axis-I disorders have been estimated at €669 million per million people per year (reference year: 2003) (Smit *et al.*, 2006). Indirect costs were much higher than direct costs (85% versus 15%), because of the large number of work loss days associated with mental disorders. Of those with any 12-month disorder, 33.9% used professional care, especially general medical care; and unmet need for care was reported by 16.8% of those with a disorder (Bijl *et al.*, 2000b). From an international perspective, a relatively high proportion of Dutch people with mental disorders sought treatment (Bijl *et al.*, 2003; de Graaf *et al.*, 2008).

It is the question whether these figures, which are a decade old, still hold. Therefore, a new survey – NEMESIS-2 – has started, which repeats and expands NEMESIS-1, and includes the CIDI 3.0 based on the DSM-IV system. This paper describes the objectives, methods and design of NEMESIS-2.

Aims of the study

About a decade after the start of NEMESIS-1, the Dutch field of mental health and the Ministry of Health, Welfare and Sport felt that new figures on the mental health state of the population were needed. Although some new Dutch data became available through the European Study on the Epidemiology of Mental Disorders (ESEMeD), this study and its Dutch part had some major disadvantages: the cross-sectional design, a low number of Dutch respondents (2372), a low number of respondents that were surveyed on impulse-control disorders, and a relatively low response rate (56.4%) in the Netherlands. Therefore, in 2007 the ministry made it financially possible to commence the fieldwork of NEMESIS-2.

The first main objective of NEMESIS-2 is to provide up-to-date figures on the prevalence, incidence, course and consequences of DSM-IV mental disorders, as well as their correlates. In NEMESIS-1 only internalizing (mood and anxiety disorders) and substance use disorders were included. NEMESIS-2 has been expanded to include externalizing disorders [like attention deficit hyperactivity disorder (ADHD) and conduct disorders]. An advantage of assessing a broader spectrum of disorders is that this gives more insight into gender-related differences than studying internalizing and substance use disorders alone. With regard to correlates of mental disorders, an important addition is that DNA from saliva is gathered and stored to study genetic correlates in the future.

The second main objective is to show time trends for the 12-year period between both studies in prevalence of disorders, service use and need for care. Worldwide, trend studies based on general population surveys are rare. For the United States, trend figures are known from two comparable general population studies. The prevalence of any 12-month mental disorder in the National Comorbidity Survey-Replication (NCS-R) conducted between 2001 and 2003 did not change compared to the National Comorbidity Survey (NCS) from 1990 to 1992 (30.5% versus 29.4%) (Kessler *et al.*, 2005a, 2005b). However, treatment increased from 12.2% to 20.1% for the whole population (Kessler *et al.*, 2005a; Wang *et al.*, 2005a). A marked increase was found in the general medical services sector (Wang *et al.*, 2006). For Great Britain, the same pattern was found: no significant change in the prevalence of mental disorders occurred between 1993 and 2000, but psychotropic medication use doubled in those designated as psychiatric cases, and among non-cases an even higher increase was seen (Brugha *et al.*, 2004). In contrast to these studies, another study from the United States showed an increase in major depression from 3.3% in 1991–1992 to 7.1% in 2001–2002 (Compton *et al.*, 2006). There is no clear explanation why these few studies do not show the same picture.

Methods

Sample

A multistage, stratified random sampling procedure was applied. First, a random sample of 184 of the 443 existing municipalities was drawn, stratified by four regions (north, east, south, west) and population density (five levels). The four largest cities (Amsterdam, Rotterdam, The Hague, Utrecht) were included in advance. Twenty-four Strata (4 × 5 + 4) were used to stratify the sample. By means of the distribution of number of inhabitants aged 18–64 over these strata, the number of addresses was determined per

municipality. Secondly, from post registers a random sample of addresses of private households in the selected municipalities was drawn, each with the same selection probability. Third, a random individual aged 18–64 years was selected from the household, based on the most recent birthday at first contact. Insufficient fluency in Dutch was set as an exclusion criterion. Substitution was not allowed when the potential respondent could not be interviewed. Addresses of institutions were excluded; thus institutionalized individuals (i.e. those living in hostels, hospices, prisons) were excluded. However, individuals selected who were temporarily living in institutions could be interviewed later during the fieldwork when they returned home.

Fieldwork

The baseline wave was performed from November 2007 to July 2009. To optimize response, fieldwork was spread over a relatively long period so that there was sufficient time to re-contact potential respondents. The fieldwork consisted of three phases. In phase 1 initial contact efforts were made. Selected households were sent an introduction letter signed by the Minister of Health, Welfare and Sport, endorsing the study and seeking participation. This letter was accompanied by a brochure explaining the study goals in more detail; it also referred to a website for potential respondents. Brochure and website contained answers to frequently asked questions, and included a free phone number for additional information. Within one week, trained telephonists phoned the household if a phone number was available (30% of the households had no landline or only an unlisted number). They ascertained whether the household had residents younger than 65 (82% of the households), and if this was the case, they sought permission for an interview. Subsequently, an interviewer made contact to make an appointment for the interview. If no phone number was available, the interviewer contacted the household in person. In this phase, in return for respondent's time and cooperation, a €10-gift certificate was handed over at the end of the interview. In order to minimize a tendency to focus on easy-to-recruit cases, interviewers were given addresses in small amounts in the first two phases.

In phase 2, those who were not 'hard refusers' or could not be reached in phase 1, were re-contacted face-to-face. In the case of a face-to-face refusal in phase 1, re-contact was made by another interviewer. Before contact was made, a glossy leaflet was sent to the selected person or household, to attract those who were not responsive to the letter from the minister. The leaflet gave reasons why the

study was performed, some preliminary general results based on the first 3000 interviews, and some comments made by respondents about how they had experienced the interview. The incentive was now a €15-gift certificate or a gift shown in the leaflet. Interviewers had an extra average budget of €3.50 per interview, which could be used discretionally while negotiating at the door. During phases 1 and 2 together, at least 10 phone calls or visits at different times of the day and on different days of the week had to be performed to make contact.

In phase 3, a random selection of 33% of the unresolved cases was chosen for special recruitment effort. The remaining 67% were terminated. In NCS-R and ESEMeD this 'endgame' strategy was likewise applied to use the finances in this phase as efficiently as possible (Alonso *et al.*, 2004; Kessler *et al.*, 2004). The incentive was at least €15, which could be raised to €40 during the negotiation. Interviewers were paid extra for their efforts, both per interview and for an earlier ascertained number of interviews. In the case that a potential respondent considered the interview duration too long, a shortened version was offered, in which only the CIDI with the core mental disorders and socio-demographic variables were administered. This phase was performed only by interviewers who had achieved sufficiently high response rates in the previous phases. Re-contact was performed by an interviewer who had not been seen before by a potential respondent.

Almost all interviews were held at the respondent's home. It was stated at the recruitment that the interview should be held privately. Nonetheless, during 18.2% of cases a third person at least was present in the room; and in 69.3% of cases for at least half of the time. However, this did not result in underreporting of mental disorders, since no significant difference in prevalence was found among those interviewed with another person present for at least half of the time compared to the other respondents [any lifetime disorder: odds ratio (OR) = 0.88 (95% confidence interval (CI) = 0.75–1.02); any 12-month disorder: OR = 0.90 (95% CI = 0.73–1.11); controlled for sex, age and living situation].

The average duration of the assessment was 95 minutes, on average 41 minutes for the CIDI and 54 for the additional questionnaire. The duration of the assessment varied widely, depending on the number of diagnoses.

At the end of the interview, respondents were asked to evaluate the interview: 67.9% rated it positively, 30.8% neutrally and 1.4% negatively. Compared to those with a positive evaluation, those who were negative or neutral were more often aged 55–64 years, unemployed, in the lowest income category, and more often had any lifetime or

any 12-month mental disorder. No differences were found for other socio-demographic variables and interview duration. Most of these findings are similar to those found in NEMESIS-1 (de Graaf *et al.*, 2004b).

In principal 96.4% of respondents were willing to participate in a second interview after three years. Those disinclined to participate again were more often in the lowest educational level, in the lowest income category, unemployed, of non-Western origin, lived alone, lived in a big city, had a shorter interview duration, a negative interview evaluation, and were less often aged 45–54 years. No differences were found for sex, being religious, or any lifetime and 12-month mental disorder.

The study proposal, field procedures and information for respondents were approved by the Medical Ethics Review Committee for Institutions on Mental Health Care (METIGG). Respondents provided written informed consent to participate in the interview, after full written and verbal information about the study was given before and at the start of the baseline assessment.

Interviewers

Ninety-eight professional interviewers of the fieldwork agency GfK (Growth from Knowledge) Panel Services Benelux, with their team of five supervisors, conducted the fieldwork. Interviewers were selected on their experience with systematic face-to-face data collection, experience with sensitive topics and ability to achieve a good response in other studies. Because young interviewers might be less successful in getting respondents to admit their mental problems, interviewers had to be at least 25 years old. They were trained in the CIDI, the additional questionnaire and collection of saliva during a three-day course by the Dutch CIDI training centre of the Interdisciplinary Center for Psychiatric Epidemiology (University of Groningen) and the NEMESIS-team, ending with an official CIDI-certification. Before commencing fieldwork, interviewers had to perform a series of practice interviews with semi-scripted responses. After the fieldwork started, the fieldwork agency had contact with the interviewers on at least two occasions per month. To keep interviewers motivated, they were kept informed about the progress of the study via a number of newsletters. Six months after fieldwork started, a meeting was organized for the interviewers to discuss fieldwork problems and to exchange tips on improving response.

Fieldwork was monitored over the entire data collection period by the NEMESIS-team and the fieldwork agency. Interviews were checked for any comments added to answers. In cases of (important) missing data, interviewers

re-contacted respondents. Per interviewer, several items were monitored: interview duration, number of affirmative answers to the screener questions [a 'learning' effect may take place causing an interviewer to get into the habit of avoiding parts of the interview by skipping screening questions, resulting in a decrease in disorder prevalences over the fieldwork period, as happened in a German study (Matschinger *et al.*, 2005), although we found no evidence for this], respondent's interview evaluation, follow-up permission, response and response on saliva donation. Whenever doubts about the interview quality arose, some interviews were tape-recorded. One member of the NEMESIS-team listened to the tapes and gave feedback. Furthermore, to monitor fieldwork quality, within two weeks after the interview 10% of respondents were sent a short questionnaire regarding demographics, evaluation and length of the interview. Interviewers were informed that these quality control procedures were performed.

Interviewers were paid both per interview, interview duration and recruitment time. Paying by interview alone could cause the earlier-mentioned tendency of negative answers to screening questions, and a low response rate because interviewers would tend to focus on easy-to-recruit respondents.

Diagnostic instrument

Presence of lifetime and recent DSM-IV disorders was evaluated with the CIDI 3.0, which was developed and adapted for use in the World Health Organization (WHO)-World Mental Health (WMH) Survey Initiative. In the Netherlands, the CIDI 3.0 was used in ESEMeD, which is part of this initiative. The WMH-CIDI 3.0 was first produced in English and underwent a rigorous process of adaptation in order to obtain a conceptually and cross-culturally comparable version in Dutch (Alonso *et al.*, 2004; de Graaf *et al.*, 2008). This process included forward and backward translations, review by an expert panel, and pretesting. The first author of this paper was in charge of this for the Dutch ESEMeD-CIDI (de Graaf *et al.*, 2008). The CIDI 3.0 version used in NEMESIS-2 was an improvement on this one. The ESEMeD countries were the first WMH-countries to commence fieldwork (2001–2003) with the CIDI 3.0, using an early version (version 18). Later versions were improved when other WMH-countries came into the field. NEMESIS-2 made use of the CIDI 3.0 version 21, which was internationally the most recent version when the survey was being prepared. For this version some additional translations from English into Dutch had to be made. Furthermore, we translated from scratch the expanded drug section which the WHO-CIDI

Advisory Committee created in 2007 as an option, in order to assess drug abuse and dependence on various drugs (see for a discussion on 'overall' versus individual drug diagnoses: Cottler, 2007; Kessler and Merikangas, 2007).

In NEMESIS-2 not all CIDI sections were used. Most disorder sections and the suicidality section were included, but for various reasons (lasting too long; comparison with NEMESIS-1) many non-disorder sections were not included. Questions not about disorders were included in an additional questionnaire (see next paragraph). The CIDI and the additional questionnaire were laptop computer-assisted during a face-to-face interview.

CIDI 3.0 generates both DSM-IV and International Classification of Diseases, 10th revision (ICD-10) diagnoses. Organic exclusion rules were used to construct diagnoses, in order to ascertain that symptoms were not exclusively due to a somatic cause, an injury, or use of drugs, alcohol or medication. Hierarchy rules were used to calculate diagnoses; these diagnoses are used if psychiatric comorbidity is not the subject being studied. Substance abuse was defined as abuse without dependence. Clinical calibration studies in various countries (Haro *et al.*, 2006) found that the CIDI 3.0 assesses anxiety, mood and substance use disorders with generally good validity in comparison to blinded clinical reappraisal interviews with the SCID (Structured Clinical Interview for DSM-IV). Studies on earlier CIDI versions also concluded that the CIDI assesses disorders with generally acceptable reliability and validity, with the exception of psychosis (Andrew and Peters, 1998; Wittchen, 1994). CIDI 3.0 diagnoses of impulse-control disorders have not been validated in the study of Haro *et al.* (2006).

The retrospective assessment of childhood ADHD in the CIDI 3.0 was based on the Diagnostic Interview Schedule (DIS) for DSM-IV (Robins *et al.*, 1995). A clinical reappraisal interview carried out in a subsample of the NCS-R using the ADHD Rating Scale (DuPaul *et al.*, 1998) found a strong association between these DIS questions and the clinical diagnoses, based on a four-category classification scheme that categorized respondents according to whether they reported no childhood ADHD symptoms, subthreshold symptoms, or threshold symptoms with and without adult persistence (Fayyad *et al.*, 2007).

Compared to the CIDI 1.1 used in NEMESIS-1, CIDI 3.0 has important improvements and extensions (for an overview, see Kessler and Üstün, 2004, 2008). In our view, three are the most important. First, disorder severity was included for all disorders, with the Sheehan Disability Scale (Leon *et al.*, 1997). By means of this, it can be studied whether those who have the most severe disorders are treated or whether a large proportion of those obtaining

treatment only have a mild DSM-IV disorder or none at all (Druss *et al.*, 2007; Kessler *et al.*, 2005a; The WHO WMH Survey Consortium, 2004). Second, treatment was not only measured in general, but also per disorder. This makes it possible to study delays in initial treatment contact after first disorder onset (Wang *et al.*, 2005b, 2007). Third, CIDI 3.0 also includes child-adolescent impulse-control disorders and their residual symptoms in adulthood (Kessler *et al.*, 2005b). Therefore, in NEMESIS-2 ADHD, conduct disorder, and oppositional defiant disorder could also be assessed. This was limited to respondents aged 18–44 because of concerns about recall bias in older subjects (Kessler *et al.*, 2007).

CIDI 3.0 starts with a screening section with key questions for most disorders. There are two reasons for this. The first is to reduce interview duration because of the expanded number of measured disorders and number of questions per section. The second is to minimize the possibility that respondents learn how to shorten the interview by answering negatively to key questions if these are asked each time at the beginning of a disorder-section. Participants responding affirmatively to a key question were administered the CIDI section of the disorder involved. A screener was not implemented in CIDI 1.1 used in NEMESIS-1. We used the so-called long path of the questionnaire, in which the sections were administered to all respondents (except for impulse-control disorders where the age range was limited).

The following disorders were included (Table 1): mood disorders (major depression, dysthymia, bipolar disorder); anxiety disorders [panic disorder, agoraphobia, social phobia, specific phobia, generalized anxiety disorder (GAD)]; substance use disorders (alcohol/drug abuse and dependence); impulse-control disorders (ADHD, conduct disorder, oppositional defiant disorder); schizophrenia; and antisocial personality disorder.

Questions on schizophrenia constituted an extension and improvement to those of the CIDI 1.1. Where at least one lifetime psychotic symptom from a list of 20 was answered affirmatively ($N = 1084$), a clinical re-interview was administered by phone using questions from the SCID (response 73.3%). Questions were asked about the content and disturbing effect of the symptoms and whether there was a plausible explanation for the symptom(s). All respondents who still remained positive on psychotic symptoms after the re-interview were discussed in a team with the interviewer and a psychiatrist specialized in schizophrenia. The diagnoses of schizophrenia are based on the data from the clinical re-interviews.

Antisocial personality disorder was measured with questions from the International Personality Disorder

Table 1 Topics covered and instruments used in NEMESIS-2

Topic	Instrument/measure	NEMESIS-2		
		Baseline T_0	Follow-up T_1	Follow-up T_2
<i>I. Demographics</i> Sex, age, highest educational attainment, ethnicity, religion, urbanicity of place of residence (present and during youth), living situation (including number and age of children), employment situation (also of partner) and income (also of partner)	Self-constructed questions	X	X	X
<i>II. Mental health</i> Internalizing and substance use disorders: major depression, dysthymia, bipolar disorder, panic disorder, agoraphobia, social phobia, specific phobia, GAD, alcohol abuse and dependence, drug abuse and dependence Externalizing disorders: ADHD, conduct disorder, oppositional defiant disorder Schizophrenia	Mental disorder sections of the CIDI 3.0	X	X	X
	Mental disorder sections of the CIDI 3.0	X	X ¹	X ¹
	An adaptation of the CIDI 1.1 schizophrenia section used in NEMESIS-1	X	X	X
Antisocial personality disorder	IPDE	X	X	X
Tobacco use	Self-constructed questions	X	X	X
Changes in psychiatric symptoms	Life chart interview among subgroups (e.g. those with a recent depression or panic disorder)		X ¹	X ¹
<i>III. Somatic health</i> Somatic disorders	Self-constructed questions based on the NEMESIS-1 questionnaire	X	X	X
Physical activity	One question of the IPAQ at T_0 and the IPAQ at T_1 and T_2	X	X	X
<i>IV. Vulnerability indicators</i> Neuroticism	EPQ	X	X	X
Extraversion	EPQ	X		
Childhood trauma	Self-constructed questions based on the NEMESIS-1 questionnaire	X		
Psychiatric problems in the family	Self-constructed questions based on the NEMESIS-1 questionnaire		X	
Suicidality	Suicidality section of the CIDI 3.0	X	X	X
Discrimination	Self-constructed questions		X	
<i>V. Precipitating and sustaining factors</i> Recent life events	Based on the Brugha Life events section	X	X	X

Table 1 *Continued*

Topic	Instrument/measure	NEMESIS-2		
		Baseline T_0	Follow-up T_1	Follow-up T_2
Social support	To be decided		X	X
Loneliness	To be decided		X	
Delinquency	To be developed		X	X
<i>VI. Functioning</i>				
Functional impairment: general	SF-36	X	X	X
Functional impairment: disorder specific	Sheehan Disability Scale within the mental disorder sections of the CIDI 3.0	X	X	X
Work loss	Three questions from the WHODAS	X	X	X
<i>VII. Treatment seeking</i>				
Service use: general	Adaptation of the self-constructed NEMESIS-1 questionnaire	X	X	X
Service use: disorder specific	Within the mental disorder sections of the CIDI 3.0	X	X	X
Medication	Adaptation of the self-constructed NEMESIS-1 questionnaire	X	X	X
Informal care	Self-constructed questions		X	X
Unmet need	Self-constructed question	X	X	X
Attitudes towards psychiatric patients	Based on Kwekkeboom, 2000	X		
Attitudes towards professional treatment	Five questions from the ESEMeD-CIDI	X		
<i>VIII. Sexuality</i>				
Sexual behaviour and sexual orientation	Self-constructed questions	X	X	X
Sexual problems and sexual abuse	Self-constructed questions	X	X	X
Service use for sexual problems	Self-constructed questions	X	X	X
<i>IX. Violence</i>				
Violence in partner relations	Self-constructed questions	X	X	X
Violence against one's children	Self-constructed questions	X	X	X
Violence in other situations	Self-constructed questions		X	X

¹ To be decided.

Examination (IPDE; Loranger *et al.*, 1994), which are part of CIDI 3.0 (Huang *et al.*, 2009; Lenzenweger *et al.*, 2007).

The Dutch CIDI used in NEMESIS-2 was programmed at Harvard University in Boston with the Blaise software system. The programming was thoroughly controlled and tested by the NEMESIS-team tracking out all logically possible interview branches for each section. This is extremely important because the CIDI has many and often complex

skips. A wrongly programmed skip can have large consequences, even the inability to calculate a disorder prevalence, which occurred for drug disorders in ESEMeD (de Graaf *et al.*, 2008).

On the basis of a pretest, only minor adjustments were made to the computerized version of the CIDI and additional questionnaire. After the pretest, because of the relatively long interview, it was decided not to include the obsessive compulsive disorder (OCD) section.

Additional questionnaire

The additional questionnaire was administered after the CIDI. Table 1 lists topics included in the additional questionnaire and intended topics of follow-up waves. The additional questionnaire was constructed in such a way that comparison of important variables would be possible with NEMESIS-1.

- *Socio-demographics.* Sex, age, educational attainment, ethnicity, religion, urbanicity of place of residence (present and during youth), living situation, number and age of children, employment situation and income of respondent and his/her partner.
- *Mental health problems.* Psychotic symptoms (see earlier) and tobacco use (frequency in previous four weeks).
- *Somatic health problems and physical activity.* With regard to 17 chronic somatic disorders, questions were asked on presence and treatment in the previous 12 months, and age of onset. Physical activity was measured by number of physically active days, that is performing at least moderate intensive activities for at least 30 minutes a day, in an average week, based on the International Physical Activity Questionnaire (IPAQ) (Craig *et al.*, 2003).
- *Vulnerability factors.* Neuroticism and extraversion were measured with the Dutch shortened 24-item version of the Eysenck Personality Questionnaire (the EPQ-Revised Short Scale) (Eysenck *et al.*, 1976, 1985). Childhood trauma was measured with seven negative life events before the age of 16 (like death of parent and divorce of parents), and by items on abuse and neglect during one's youth (frequency of emotional neglect, psychological, physical and sexual abuse).
- *Negative life events.* The presence of 10 negative life events in the previous 12 months was measured, based on the Brugha Life events section (Brugha *et al.*, 1985). Examples are: death of a relative or friend, divorce, and financial difficulties.
- *Functioning.* General functional impairment was assessed by the MOS Short-form Health Survey (SF-36) (Stewart *et al.*, 1988; Ware and Sherbourne, 1992). 'Days out of role' was measured as number of days lost from work or other normal activities (three questions based on the WHO Disability Assessment Schedule (WHODAS) (Von Korff *et al.*, 2008).
- *Service use.* Service use was measured by means of the service use section of NEMESIS-1 (Bijl and Ravelli, 2000b). Service use was assessed with the question: 'In the previous 12 months, have you visited . . . for emotional problems or alcohol or drugs problems of your own?' This question was asked in respect of 16 care providers/services: general health care (general practitioners; company doctors; social

work; home care and district nursing; physiotherapists or haptonomists; medical specialists or other general health care professionals), specialized mental health care (psychiatrists, psychologists and psychotherapists; addiction care; part-time psychiatric treatment; and admission into mental hospitals), or other types of care (alternative care providers; pastoral care; persons in one's close social network; self-help groups; telephone help lines; and information or care by means of the Internet). If the respondent had visited a care provider/service, information on the type of care, number of visits, and age of onset of treatment were inquired. Furthermore, medication use for emotional or substance use problems in the previous 12 months and its onset, and unmet need of care in the previous 12 months, were measured.

- *Attitudes towards psychiatric patients and towards seeking professional help.* Attitude towards psychiatric patients was measured with a five-item questionnaire used in other Dutch studies (Kwekkeboom, 2000; Mootz, 1990; van't Veer, *et al.*, 2005). Examples of questions are: 'Would you object to having someone who has been admitted into a mental hospital as a neighbour', ' . . . close friend', ' . . . babysitter'. Attitude towards seeking professional help for mental problems was measured with five questions which were included in ESEMeD. Examples are: 'If you had a serious emotional problem, would you definitely go for professional help?' and 'How comfortable would you feel talking about emotional problems with a professional?'
- *Sexuality.* Questions on sexuality included sexual behaviour in the previous 12 months (heterosexual, homosexual, bisexual contacts), sexual orientation (attracted to women or/and men), sexual problems (miscarriage, fertility problems, abortion, sex addiction), sexual abuse (frequency of sexual abuse before and after age 16), and service use in the previous 12 months because of sexual problems.
- *Violence.* Violence experienced as victim or perpetrator in interpersonal relationships: during one's youth (see earlier), in previous or current steady relationships (frequency and recency of emotional neglect, psychological and physical abuse by and against the partner), violence against one's children during their upbringing (frequency of emotional neglect, psychological and physical abuse).

DNA

Because mental disorders are highly heritable (Sullivan *et al.*, 2000), genetic factors and their interaction with environmental factors are important determinants of incidence and course. To be able to study genetic factors, respondents were asked at the end of the interview to donate some saliva. In the brochure sent beforehand to respondents,

information was given on its goal. It was assured that it was possible to engage in the interview without donating saliva. Respondents were asked to provide a second written informed consent for permission to use genetic information. From 76.4% of the respondents DNA was stored. Compared to respondents willing to donate, those not willing were more often in the lowest educational level and the lowest income category, unemployed, of non-Western origin, living alone, living in a big city, less often had any lifetime disorder, and more often had a shorter interview duration. There were no differences in sex, age, being religious, any lifetime impulse-control disorder, antisocial personality disorder and any 12-month disorder.

Saliva was collected in Oragene-DNA Self Collection Kits (DNA Genotek, Ottawa, Canada). Samples were posted by the interviewer to Maastricht University, where DNA was extracted using the AutoGenFlex DNA isolation system (Autgen, Hilliston, MA, USA) according to manufacturer's instructions. DNA samples were stored at -20°C for future genomic analysis.

Response

Table 2 shows the results of the sample procedure and the response. In calculating the response, an adjustment for the denominator was made among the households that could never be contacted (741), to correct for the small percentage that would not contain an eligible respondent, for example because the respondent was not aged 18–64 years or was not sufficiently fluent in Dutch. Conform NCS-R and ESEMeD (Alonso *et al.*, 2004; Kessler *et al.*, 2004), the response rate calculation was based on weighted data because the endgame phase undersampled hard-to-recruit households as a random 67% of the unresolved cases of phase 1 and 2 were terminated and 33% were chosen for special recruitment efforts in the endgame phase. The response rate was 65.1%, which was equal to that in NEMESIS-1 (64.2%; Bijl *et al.*, 1998a). The response in phases 1, 2 and 3 was 43%, 28% and 20%, respectively. Of the 6646 respondents, 5035 were interviewed in phase 1, 1294 in phase 2 and 317 in phase 3. Analyses of participant differences between the phases showed no differences between phases 1 and 2, but those who participated in phase 3 more often lived alone, lived in a smaller town, were non-religious and were less often in the highest educational level. No differences were found for other socio-demographic variables. When controlled for socio-demographics, there were no differences between respondents in the various phases for the disorder categories, except for any lifetime impulse-control disorder which was more often found among phase 3 respondents (Table 3).

Table 2 Response and non-response in NEMESIS-2

	N	Percentage
Initial sample of addresses ¹	15 239	
Gross sample of addresses of private households	14 541	100
Households without a person aged 18–64	2 792	19.2
Problems with Dutch language	336	2.3
Cognitive problems	8	0.1
During the whole fieldwork period not in the Netherlands	56	0.4
Net sample of eligible respondents	11 349	78.0
Net sample of eligible respondents	11 349	100
Refusal ^{2,3}	3 307	29.1
Not able ^{2,4}	158	1.4
No contact ^{2,5}	1 211	10.7
Unsuccessful matching of CIDI and additional questionnaire	27	0.3
Unweighted uncorrected response	6 646	58.6
Unweighted corrected response ⁶	6 646	59.4
Weighted corrected response ⁷	6 646	65.1

¹ Of the 15,239 drawn addresses, 698 were not part of the sample because of the following reasons: neglected/destroyed house (33), house not built yet/uninhabitable (43), commercial building/institute (286), house unoccupied (267), address not found (69).

² The non-response categories are the reasons of the last contact effort.

³ Refusal: refusal through the helpdesk of the fieldwork agency (227), refusal before respondent selection could take place (405), soft refusal (358), hard refusal (2102), refusal by someone else within the household (194), break off of the interview by the respondent without continuation (21).

⁴ Not able: temporarily not able (87), physically not able (40), mentally not able (31).

⁵ No contact: no contact with the household (1094), no contact with the respondent (117).

⁶ In calculating the response, an adjustment for the denominator was made among the households that could never be contacted (741), to correct for the small percentage that would not contain an eligible respondent, for example because the respondent was not aged 18–64 years or was not sufficiently fluent in Dutch.

⁷ The response rate calculation was based on weighted data because the endgame phase undersampled hard-to-recruit households, as a random 67% of the unresolved cases in phase 1 and 2 were terminated and 33% were chosen for special recruitment efforts in the endgame phase.

Table 3 Comparison of the prevalence of mental disorders among respondents according to the phase in which they were interviewed, in adjusted relative risk ratios (adj. RRR) and 95% confidence intervals (CI)

	Phase 2 Adj. RRR ¹ (95% CI) ²	Phase 3 Adj. RRR ¹ (95% CI) ²	<i>p</i> ³
Any lifetime disorder	0.97 (0.85–1.10)	1.13 (0.89–1.42)	NS
Mood disorder	0.97 (0.83–1.13)	0.94 (0.71–1.25)	NS
Anxiety disorder	0.94 (0.81–1.10)	0.98 (0.74–1.30)	NS
Substance use disorder	0.99 (0.84–1.17)	1.12 (0.83–1.51)	NS
Impulse-control disorder	1.35 (0.97–1.87)	2.15 (1.34–3.46) ⁴	NS
Antisocial personality disorder	0.76 (0.49–1.17)	0.90 (0.43–1.88)	NS
Any 12-month disorder	0.97 (0.82–1.15)	1.06 (0.79–1.42)	NS
Mood disorder	1.14 (0.89–1.46)	0.91 (0.56–1.47)	NS
Anxiety disorder	0.91 (0.74–1.12)	1.01 (0.70–1.46)	NS
Substance use disorder	0.89 (0.65–1.21)	1.12 (0.67–1.86)	NS
Impulse-control disorder	1.15 (0.59–2.25)	2.02 (0.82–4.99)	NS

¹ The results are adjusted for differences in sex, age, education, living situation, employment situation and urbanicity.

² The reference category is phase 1.

³ The significance of the adjusted RRRs for the comparison of the prevalence between phase 2 and 3.

NS, not significant.

Table 2 also shows the reasons of non-response of the last contact effort. If we define refusal not on the basis of the last contact effort but on the basis of ever having refused during the different contact efforts in the different phases, refusal was more often seen (32.8%) than non-contact (6.5%). The more intensive recruitment methods of NEMESIS-2 are demonstrated by the somewhat lower percentage of non-contacts compared to NEMESIS-1 (7.9%).

Partial non-response was negligible due to the computer-assisted interview. Among 140 respondents a shortened interview (CIDI and core socio-demographic characteristics) was administered in phase 3.

A non-response survey was conducted, in which we surveyed reasons for non-participation, demographics, feelings of depression and nervousness during the past four weeks, using the Mental Health Inventory (MHI-5; five items; $\alpha = 0.82$ for the non-response survey and $\alpha = 0.81$ for the survey), and four items from the CIDI screener (three childhood impulse-control disorder symptoms; one on general physical health). This survey was not conducted directly after a first refusal by a potential respondent, because of the possibility of re-contacting this person at a later date. The non-response study achieved a response rate of 26.1% (1229 of 4703) of all non-responders. Compared to responders, non-responders were more often male, less often 18–24 years, less often living alone, less often of non-

Dutch origin. Non-responders significantly more often had mood and anxiety problems according to the MHI-5 [OR = 1.75 (1.45–2.11)], and at least one childhood impulse-control symptom [OR = 2.04 (1.76–2.35)], when controlled for demographics. No differences were found for physical health.

Sample characteristics and weighting

Table 4 shows the distribution of demographic variables of the study sample (first column) and the population (last column) according to Statistics Netherlands (for the year 2008; www.cbs.nl). The sample has a mean age of 44.3 years [standard deviation (SD) = 12.5] and 55.2% consists of women. The most common level of education was higher professional/university; 67.8% were married or cohabiting; 20.8% lived alone; 74.6% were in paid employment; 5.7% were of non-western origin, which was defined as respondent or at least one parent not born in Western Europe or North America (mainly of Surinamese, Antillean, Turkish and Moroccan origin).

Respondents reflected the Dutch population reasonably well. Males, younger people (especially 18–24 years), lower secondary educated people, and those not in paid employment were underrepresented. Those living alone were somewhat overrepresented, probably due to the applied household sample procedure. Subjects of Turkish and

Table 4 Demographic characteristics of the NEMESIS-2-sample ($N=6646$) and of the Dutch population according to Statistics Netherlands

	NEMESIS-2		Dutch population (%)
	Unweighted (%)	Weighted (%)	
<i>Sex</i>			
Male	44.8	50.3	50.4
Female	55.2	49.7	49.7
<i>Age</i>			
18–24	7.3	12.3	13.1
25–34	16.9	19.6	19.3
35–44	25.6	24.9	24.7
45–54	23.9	23.1	22.9
55–64	26.3	20.1	20.0
<i>Education</i>			
Primary, basic vocational	5.0	7.7	8.3
Lower secondary	27.5	22.6	22.8
Higher secondary	32.3	41.7	41.3
Higher professional, university	35.3	28.0	27.7
<i>Living situation</i>			
With partner and children	38.3	39.8	38.8
With partner without children	29.5	27.3	27.8
Single parent	5.5	5.1	4.1
Alone	20.8	15.6	17.1
With parents	5.0	10.4	10.4
With other(s)	0.9	1.7	1.8
<i>Employment situation</i>			
Paid job	74.6	76.3	68.5
No paid job	25.4	23.7	31.5
<i>Ethnicity</i>			
Dutch	86.2	84.1	79.7
Other Western	8.2	8.7	9.5
Turkish	0.7	1.0	2.3
Moroccan	0.8	1.3	1.9
Surinamese	1.6	1.7	2.2
Antillean	0.7	0.7	0.8
Other non-Western	1.9	2.4	3.7
<i>Urbanicity</i>			
Very high	16.1	18.7	18.9
High	26.5	29.6	29.3
Medium	22.6	18.9	19.1
Low	21.6	21.1	21.1
Very low	13.2	11.7	11.7

Moroccan origin were clearly underrepresented, but this was not true for those of Surinamese and Antillean origin. People living in (bigger) towns were somewhat underrepresented.

By means of post-stratification, a weighting factor was constructed to correct for different response rates in differ-

ent population groups, for differences in the probability of selection of respondents within households, and for differences in the probability of selection in phase 3, so that it was possible to generalize the results to the general population. The following population characteristics from 2008 obtained from Statistics Netherlands were used to

construct the weighting factor: sex, age, partner status (living with or without partner), educational level and urbanicity (six categories). After weighting, the distribution of the demographic variables of the study sample came close to that of the general population.

Future waves

As stated earlier, 96.4% of respondents declared their willingness at the end of the baseline interview to engage in follow-up assessment. Two more waves are planned after baseline, each three years after the previous wave. NEMESIS-1 had a period of one year between the baseline and second wave and two years between the second and third waves. For NEMESIS-2, a longer follow-up period between the waves was chosen, to enlarge the number of incident disorder cases and to follow a longer course of disorders. Enlarging this period has the disadvantage that it is more difficult to hold on to the cohort. Various techniques were and will be applied, such as sending Christmas and birthday cards (including a change of address card), sending first study results, and updating the website for respondents, to show results.

Table 1 shows which topics we plan to include in the second and third waves. A part of the topics from the baseline wave will be reassessed. Changes in psychiatric symptoms will be assessed in both follow-up waves among specific subgroups (e.g. those with recent depression or panic disorder) with life charts (Lyketsos *et al.*, 1994; Terluin *et al.*, 2006). CIDI 3.0 assesses psychiatric problems in the family, but only among respondents with a 12-month mental disorder. Therefore, psychiatric problems in the family will be assessed in the first follow-up wave. Furthermore, social support, experienced discrimination, delinquency, violence outside the partner relationship, and informal care will be assessed.

Conclusion

We were able to build a comprehensive, high-quality dataset, on the basis of which several topics can be studied in the future. The addition of externalizing disorders and of greater detail within the CIDI sections resulted in a much more extensive dataset than in NEMESIS-1. Also the collection of DNA makes the NEMESIS-2 dataset of value.

The response rate was 65.1%, which is about the same as in NEMESIS-1 (64.2%). The response rate in the Dutch ESEMeD survey, which was performed between both NEMESIS-studies, was relatively low (56.4%). We felt that to perform NEMESIS-2 in a qualitatively good way, the

fieldwork had to be organized so that the response would be higher. This implied high fieldwork costs. In the phase of funding and during fieldwork, this was one of the main focal points. Due to the intensive recruitment methods with repeated efforts, it was possible to reach a relatively high response for the Dutch situation. Not only in the Netherlands (Stoop, 2005), but also worldwide (Galea and Tracey, 2007), at least in Western countries, willingness to participate in scientific studies has decreased dramatically in the last decade. This is probably because people are frequently requested to participate in marketing surveys. As a result, in the United States the response of the NCS-R (71%) was lower than in NCS (80%) about a decade earlier, and in Australia it dropped from 78% in 1997 to 60% in 2007 in two comparable general population studies (Slade *et al.*, 2009).

Systematic survey non-response could lead to bias in the estimates of disorder prevalence and service need. People with mental disorders tend to have a higher refusal rate than those without mental disorders (Allgulander, 1989; de Graaf *et al.*, 2000; Eaton *et al.*, 1992; Turner *et al.*, 1998). In our non-response survey among 26.1% of the non-responders it was found that they significantly more often had mood and anxiety problems and childhood impulse-control problems than respondents. Furthermore, studying differences between respondents from the various phases showed that hard-to-reach respondents from phase 3 more often had a childhood impulse-control disorder, but not other disorders. We conclude that it is not unlikely that in our study too, the prevalence of disorders, especially of impulse-control disorders, will be underestimated. In the NCS-R however, there was no evidence that the prevalence of diagnostic stem questions for any DSM-IV disorder differed significantly between respondents and non-respondents included in the non-respondent survey (Kessler *et al.*, 2005b).

The youngest age group was underrepresented. This was also the case in the first wave of NEMESIS-1 (Bijl *et al.*, 1998a) and its follow-ups (de Graaf *et al.*, 2000), and in other studies (Ribisl *et al.*, 1996). Non-response among young adults can be a particular source of bias for problems like substance use disorder, which are much more common in this age group (Bijl *et al.*, 1998b).

This study excluded people who had not mastered the Dutch language and people who are homeless or who remain institutionalized for long periods. As such people account for only a very small proportion of the Dutch population, prevalence results would hardly differ if they were included.

With regard to our future waves, 96.4% of the respondents were willing to cooperate. This bodes well for a low attrition rate of these waves.

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Declaration of interest statement

The authors have no competing interests.

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