National and cross-national surveys of patient experiences: a structured review

Report from Kunnskapssenteret (Norwegian Knowledge Centre for the Health Services)

No 7–2008

Structured Review

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Norwegian Knowledge Centre for the Health Services

Background: The measurement of patient experiences is an important component of health services evaluation. Several countries now have programs of work that include national surveys of patients undertaken at regular intervals. The identification and review of large scale surveys of patient experiences including programs of work, will inform the organisation and design of future surveys aimed at comparing patient views of health care quality across countries. **Objective:** To identify and review national and cross-national surveys, including programs of work relating to patient experiences and satisfaction. **Methods:** Structured review of national and cross-national surveys of patient experiences or satisfaction for OECD and non-OECD European Union member countries undertaken from 1997 onwards. All patient groups and general population surveys were included. Searches of electronic databases and the web were undertaken and a link to an electronic questionnaire was sent to contact persons identified by the OECD. Published articles relating to national and cross-national surveys of patient experiences or satisfaction with health care were retrieved

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from the following databases: CINAHL, EMBASE, MED-LINE(R) and PsycINFO. On-line searches were used to identify websites relating to organizations involved in the measurement of patient experiences. **Results:** The searches of the electronic databases produced 2506 references from which 166 were obtained on the basis of the contents of the title or abstract. 55 surveys met the inclusion criteria, 42 of which were national and 13 were cross-national. **Conclusion:** There have been a large number of national and cross-national surveys of patient experiences, the majority of which were part of nine programs of work and ongoing initiatives. The review is an important information resource for understanding the current status of large scale survey work relating to the measurement of patient experiences. The organisation including expertise and infrastructure, together with the design of the surveys included in the review, will inform future work relating to national and cross-national comparisons of patient views of health care quality.

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Norwegian Knowledge Centre for the Health Services
Oslo, February 2008

National and Cross-National Surveys of Patient Experiences: A Structured Review

A review of national and cross-national programs and surveys of work relating to the measurement of patient experiences with health care

Prepared for the OECD Health Care Quality Indicators Project

A Final Report

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CONFLICTS OF INTEREST

AMG, ES and KD are employed by the Norwegian Knowledge Centre for the Health Services, the work of which was included within the review.

Key messages

There have been a large number of national and cross-national surveys of patient experiences, the majority of which are part of ongoing programs of work. It is recommended that those undertaking measurement of patient experiences draw upon this large volume of work as a means of informing future surveys and give consideration to:

1. Organisation and infrastructure including the potential for collaboration
2. Survey methodology
3. Questionnaires with evidence for data quality, reliability and validity including evidence for cross-cultural equivalence
4. Methods of reporting and dissemination of results to interested groups

The review's main implications for the Organisation for Economic Co-operation and Development and its Health Care Quality Indicators Project relating to the cross-national measurement of patient experiences are to give consideration to:

1. Collaboration with individuals and groups that have been active in national and cross-national surveys and particularly infrastructure and programs of work
2. Survey methodology that can be implemented in a consistent way cross-nationally
3. Questionnaires that have evidence for data quality, reliability, and cross-cultural equivalence
4. Reporting of results including case-mix adjustment and presentation that recognises the needs of interested groups

Executive summary

BACKGROUND

The measurement of patient experiences is an important component of health services evaluation. Several countries now have programs of work that include national surveys of patients undertaken at regular intervals. The identification and review of large scale surveys of patient experiences including programs of work, will inform the organisation and design of future surveys aimed at comparing patient views of health care quality across countries.

OBJECTIVE

To identify and review national and cross-national surveys, including programs of work relating to patient experiences and satisfaction.

METHODS

Structured review of national and cross-national surveys of patient experiences or satisfaction for OECD and non-OECD European Union member countries undertaken from 1997 onwards for which results were available at the end of April 2007. All patient groups and general population surveys were included. Searches of electronic databases and the web were undertaken and a link to an electronic questionnaire was sent to contact persons identified by the OECD. Published articles relating to national and cross-national surveys of patient experiences or satisfaction with health care were retrieved from the following databases: CINAHL, EMBASE, MEDLINE(R) and PsycINFO using search terms derived from previous systematic reviews relating to patient experiences. On-line searches were used to identify websites relating to organizations involved in the measurement of patient experiences. These websites were searched for relevant information including survey reports. Data were extracted relating to the background to the survey, survey design, reporting of results, important references and website links. Members of the OECD Health Care Quality Indicators Project group were asked to name contact persons with knowledge of survey work within countries that were not covered in the main review. The contact persons were sent an email with a link to an electronic questionnaire that asked for information relating to survey work.

RESULTS

The searches of the electronic databases produced 2506 references from which 166 were obtained on the basis of the contents of the title or abstract. 55 surveys met the inclusion criteria, 42 of which were national and 13 were cross-national. Nine ongoing programs of work had undertaken 39 of these surveys: the Canadian Community Health Survey (CCHS), The Commonwealth Fund (USA), Consumer Assessment of Healthcare Providers and Systems (USA), Department of Quality Measurement (Denmark), Dutch Centre for Consumer Experience in Health Care, Norwegian Knowledge Centre for the Health Services, Picker Institute Europe, Unit of Patient Evaluation (Denmark), and the World Health Organisation (WHO) program The Health Systems Responsiveness. The Commonwealth Fund, Picker Institute Europe and WHO have undertaken cross-national comparisons of patient experiences. The CCHS, The Commonwealth Fund and WHO programs are all surveys of the general population. The remainder relate to patients who have received care and for the CAHPS and one of the surveys undertaken by the Dutch Centre, health plan members and health insurance enrolees respectively.

Six cross-national surveys were not part of ongoing programs of work: the Diabetes Attitudes Wishes and Needs (DAWN) study, the European Research into the Treatment of Cancer (EORTC) study, the European Psychiatric Services Inputs Linked to Outcome Domains and Needs (EPSILON) study, the European Task Force on Patient Evaluations of General Practice (EUROPEP), primary care in 12 countries, and spinal cord injury in three countries. Ten national surveys were not ongoing national programs and included acute care hospitals (Ireland), antenatal care (Sweden), breast health practices (Canada), Centers' for Womens's Health (USA), HIV infection (USA), cystic fibrosis (UK), depression among African-American women (USA), maternity care (England, Scotland), and osteopathy (USA).

The link to the electronic questionnaire was emailed to nine contact persons and eight responded. In addition to the work above, respondents provided information relating to ongoing surveys or programs of work for Iceland, Japan, New Zealand and Turkey. Japan and New Zealand have also been part of cross-national surveys.

CONCLUSION

There have been a large number of national and cross-national surveys of patient experiences, the majority of which were part of nine programs of work and ongoing initiatives. Four further ongoing surveys or national programs of work were also identified through responses to a questionnaire. The review is an important information resource for understanding the current status of large scale survey work relating to the measurement of patient experiences. The organisation including expertise and infrastructure, together with the design of the surveys included in the review, will inform future work relating to national and cross-national comparisons of patient views of health care quality.

Background

The number of published articles reporting the application, development and evaluation of questionnaires that are designed to assess patient experiences or satisfaction with health care delivery is considerable (24, 78, 79). Whilst the majority of this work has taken place at the local level in relation to individual providers, national governments in several countries now require comparisons of providers (22, 25, 34, 53, 81). International organisations such as the Organization for Economic Cooperation and Development (OECD) and World Health Organization (WHO) have emphasised the importance of the patient's perspective in the evaluation of health care delivery (54, 65).

International comparisons of patient experiences are important for identifying areas for improvement across health services. Differences between countries as well as recurring patterns of patient experiences across countries can help identify opportunities to learn from national and international efforts to improve health care quality (75). In the European Union patients who are not happy with the access to care or the quality of care in their own countries can seek health care in other EU countries (23). Comparable information can help inform decision making on the part of patients, clinicians, insurers and health policy makers.

Organisations responsible for national programs relating to the measurement of patient experiences have undertaken comparisons across a number of countries. The Picker Patient Experience Questionnaire was used as a basis for comparing patients' perceptions of the quality of acute hospital care across Germany, Sweden, Switzerland, the UK and USA (22, 53). Organisations responsible for national programs within the Nordic countries have collaborated in the development of a survey and questionnaire that will be used to compare the experiences of patients receiving inpatient care across these countries (66). There have also been surveys of the general population undertaken by The Commonwealth Fund (20, 21, 38, 73, 76) and the WHO (60, 82). Other comparisons have been made in relation to specific groups of patients as a component of larger research projects, including patients from oncology settings across four European countries (16) and patients with diabetes in 13 countries (67). Finally, there are widely used questionnaires such as those developed by the Consumer Assessment of Healthcare Providers and Systems (CAHPS) and used within a national program of surveys within the USA (1, 2), that have been translated for use in other countries including the Netherlands (7, 27).

The difficulties in making such international comparisons are well documented and consideration must be given to methods of questionnaire translation, consistency in survey design and sampling processes, and differences in patient characteristics (22). For valid comparisons to be made across countries questionnaires must demonstrate cross-cultural equivalence, that is similar levels of data quality, reliability and validity. In the absence of such equivalence it is difficult to ascertain whether any differences found between countries is related to real differences in health care quality or differences in questionnaire performance. The forward-backwards translation methodology is designed to promote cross-cultural equivalence (14, 59). However, there is variation in the reporting of the results of such translation procedures, the focus often being on the results of cross-national comparisons rather than underpinning methodology. The sampling and recruitment of patients and survey administration including use of reminders and incentives, must also be consistent across countries so as to ensure representative samples. Comparisons must also control for potential confounders (22). The results of a systematic review found that a number of patient characteristics were consistently associated with patient satisfaction including age, education and health status (24). Hence it is important that these variables are controlled for when reporting the results of cross-national comparisons.

The work that follows presents the findings of a structured review of national and cross-national surveys relating to the measurement of patient experiences. The review is designed to inform the OECD’s work relating to cross-national comparisons of health care quality from the perspective of the patient. The objectives are to identify and describe existing approaches to patient experiences measurement that have involved national and cross-national comparisons. The review was undertaken in a structured way that involved defined searches of the literature and criteria relating to inclusion and data extraction.

Method

SCOPE OF THE REVIEW

The review describes national and cross-national surveys of patient experiences or satisfaction for the OECD and non-OECD EU member countries that were undertaken from 1997 onwards. This includes different patient groups and the general population. Searches of electronic databases and the web were undertaken and a link to an electronic questionnaire was sent to contact persons identified by the OECD.

SEARCH STRATEGY

The search strategy was designed to retrieve work relating to national and cross-national surveys of patient experiences and satisfaction irrespective of the patient population or health care setting, including the objectives, design and conduct and reporting of results. Published articles relating to national and cross-national surveys of patient experiences and satisfaction with health care for the years 1997 to 2007 were retrieved from the following databases: CINAHL, EMBASE, MEDLINE(R) and PsycINFO using terms derived from previous reviews undertaken within the field of patient experiences (24, 33, 78, 79) together with terms relevant to national and cross-national surveys of patients.

Journal articles relating to such surveys rarely include all information relevant to the infrastructure and methodology underpinning the work. Therefore internet searches were undertaken to identify websites relating to organisations involved in the measurement of patient experiences, nationally and cross-nationally. These websites were searched for relevant information. Important examples include The Commonwealth Fund (19-21, 72-77), Consumer Assessment of Healthcare Providers and Systems (CAHPS) program (18, 26), Picker Institute Europe (53) and World Health Organisation websites.

The review includes relevant articles and information written in English or the Scandinavian languages accessible at the end of the first quarter of 2007. Non-English articles that have an English language abstract were used as a basis to contact authors for any further information written in English. The citation lists of articles were examined for other relevant work. Downloaded articles and other sources of information were included within a Reference Manager database for application of the inclusion criteria.

Surveys that included questions relating solely to health care use or views of health services as opposed to experiences of health care were not included in the review. Similarly, surveys that include only one global question relating to perceived quality or satisfaction with health care were not included in the review. Such questions are sometimes used as supplementary questions in health-related surveys but do not assess patient experiences in sufficient detail. Finally, data collection for the survey must have been completed as described in a published article, report, or on a website. Surveys in progress or planned were referred to when sufficient information was available.

DATA EXTRACTION

The headings under which the data were extracted from articles and other information sources are shown in Table 1 and include background to the survey, design of the survey, reporting of results and references.

The background to the survey includes the organisation undertaking the work including any collaborators. Information relating to funding sources was also sought. The objectives include the rationale for the measurement and reporting of patient experiences. Information relating to the recipients of survey results can include patients, health care personnel, health care managers and policy makers. The final component of the background to the survey relates to the history of the work including the survey frequency and previous years in which it took place.

Information relating to the design of the survey includes the health care setting, population, questionnaire description and evaluation and data collection methods. The setting includes health care setting, specialties and types of treatment. The population includes inclusion and exclusion criteria, for example, age and type of admission or treatment. Relevant information relating to the questionnaire can be divided into questionnaire content and development and testing. The former includes questionnaire length (number of items), scales of patient experiences and item scaling. The latter includes the methodology of development (for example, literature review and patient interviews) and evaluation of data quality, reliability and validity; criteria that are widely recognised in the evaluation of questionnaires designed to measure patient experiences and satisfaction (78). Questionnaires that have been used cross-nationally must have evidence for cross-cultural equivalence for valid comparisons across countries to be made (22). Information relating to the translation process and testing was extracted.

Table 1 Data extraction

1 Background to survey	
Organisation(s)	Organisation responsible for undertaking the work including collaborators
Funding	Organisations funding the work
Objectives	Function of survey including intended audience
Countries	Taking part in cross-national surveys
Recipients of results	Patients, health care personnel, health care managers/providers, health care policy makes and government
History	Previous years in which the survey has been undertaken
2 Design	
Setting	Health care setting
Population	Inclusion and exclusion criteria
Questionnaire	Description, development, evaluation, translation and testing for cross-cultural equivalence
Data collection	Sampling, administration mode, reminders, response rate
3 Reporting of results	
Media	Peer-reviewed article, report, website
Adjustments	Co-morbidity, age, sex, etc
4 References	

The methods of data collection include sampling, sampling period, survey administration, use of reminders and response rates. Sampling includes how patients were identified, whether the process was random together with gross and net samples. The sampling period includes the start and finish dates of the sampling period. Information relating to the interval between recruitment and survey administration was also sought. Survey administration includes face to face interviews, postal questionnaires, telephone-interview questionnaires and electronic questionnaires. Reminders include the use and type of reminders together with the time interval after the first contact was made. Finally, the response rate is reported.

Information relevant to reporting the results of surveys includes the type of media used and adjusting for confounders. The former can include articles within peer-reviewed journals, reports and websites. Information relating to the methods of adjusting the data to take account of confounders across health care providers or countries was also extracted. This includes variables such as age, sex, education and health status.

QUESTIONNAIRE FOR CONTACT PERSONS

Members of the OECD's Health Care Quality Indicator Project (HCQIP) group were asked for details of contact persons that may have information relating to national or cross-national work. The contact persons were emailed a link to an electronic questionnaire that includes questions relating to the design and conduct of national surveys within their country. They were also asked to attach relevant articles and reports. This was designed to help ensure that all OECD and non-OECD EU member countries are included in the review irrespective of language. They were emailed a reminder and preliminary results from the review were presented at a HCQIP meeting and members from countries not included in the review were asked to provide information relating to possible contact persons.

The content of the questionnaire was designed to obtain the information shown in Table 1. The project leader constructed 23 questions relating to background to the survey, design and reporting of results. The draft questionnaire was then completed by four researchers with experience of undertaking national surveys of patients within the Norwegian Knowledge Centre for the Health Services. The researchers made comments on the questionnaire which were then discussed with the project leader. Changes were made to the wording of questions and nine questions were added. The questionnaire was then discussed at meeting between the project leader and two members of the OECD, Niek Klazinga and Sandra Garcia Armesto. Further changes were made to the wording and some questions were removed. The final questionnaire had 28 questions and comprised the themes shown in Table 2: background (2 questions), national surveys (6 questions), patients' taking part in the national survey (3 questions), data collection for the national survey (9 questions), the questionnaire (3 questions), reporting of results (3 questions), and other patient surveys (2 questions). Several of the questions include an option where respondents can give further information in the form of a text box if the response options were insufficient or if they wished to give further information. Respondents were also asked to upload up to five files relating to the survey work.

Table 2 Content of the electronic questionnaire

A Background	Number of response options
1. Survey work that has taken place or is ongoing	7
2. Respondent’s role in the work	10
B National surveys	
3. Year of most recent national survey	1
4. Year of first survey	1
5. Frequency of survey	7
6. Organisation(s) involved – development, organisation, running	5
7. Organisation(s) funding the survey	5
8. Survey aims	11
C Patients	
9. Patient groups taking part in the survey	7
10. Min and max age of patients	2
11. Information used to contact patients	4
D Data collection	
12. Random sampling	3
13. Organisation(s) undertaking survey	5
14. Method of determining number of patients for each provider	4
15. Questionnaire administration	9
16. Time lag between care and receipt of questionnaire	8
17. Use/type of reminders	5
18. Sample size	2
19. Number of respondents	2
20. Testing for response bias	3
E The questionnaire	
21. Methods of development	9
22. Number of items	1
23. Methods of testing	9
F Reporting of results	
24. Who received the results	8
25. Level(s) at which results were reported	10
26. Case-mix adjustment	3
G Other patient surveys	
27. Developmental work and national surveys relating to other groups	20
28. Ongoing national program	2

Results

SEARCH STRATEGY

The searches of the electronic databases produced 2506 references from which 166 were obtained on the basis of the contents of the title or abstract. There were 55 surveys that met the inclusion criteria, of which 42 were national and 13 were cross-national. There were nine ongoing programs of work that were responsible for 39 of these surveys.

Nine surveys did not meet the inclusion criteria, two of which were cross-national and four were national. The first cross-national survey related to the European Union Eurobarometer. The standard Eurobarometer includes three questions relating to health system views rather than experiences of care. The Eurobarometer has included some questions relating to the public views of health systems in one of its special surveys undertaken in 1996 (64). However, these questions related to the public views on health system performance rather than patient experiences or satisfaction. There was one global satisfaction question relating to the way health care runs in the country (64). The second cross-national survey assessed patient experiences in relation to wards and day surgery departments run by a private health care company in four European countries and hence was unrepresentative (58). There were three national surveys of patients in the countries that were not OECD or EU members; Israel (37), Slovenia (55) and Taiwan (17) relating to the general population, general practice and six diagnoses/procedures relating to hospital care respectively. The four remaining national surveys that did not meet the inclusion criteria related to satisfaction with dental services in the UK (10), a cancer information helpline in the Netherlands (70), the Health Care in Canada Survey of the general populations views of the health service rather than experiences with care (62), and a general population survey in Lithuania relating to the quality of primary care services that was not published in an English language journal (63).

SURVEYS MEETING THE INCLUSION CRITERIA

Table 3 shows the national and cross-national surveys meeting the inclusion criteria that were found for the OECD and non-OECD EU member countries. They are presented according to whether they related to a program of work, a national survey or a cross-national survey. The nine programs of work include the Canadian Community Health Survey (CCHS) (40), The Commonwealth Fund in the USA (73), Consumer Assessment of Healthcare Providers and Systems (HP-CAHPS) in the USA (1-4), Department of Quality Measurement in Denmark (57), Dutch Centre for Consumer Experience in Health Care (7,27), Norwegian Knowledge Centre for the Health Services (32-35), Picker Institute Europe in the UK (23), Unit of Patient Evaluation in Denmark (87), and the World Health Organisation (WHO) program The Health Systems Responsiveness (86). The Commonwealth Fund, Picker Institute Europe and the WHO have undertaken cross-national comparisons of patient experiences. The CCHS, The Commonwealth Fund and WHO programs are based on surveys of the general population. The remainder of the programs relate to patients who have received care and in the case of the CAHPS and one survey undertaken by the Dutch centre, members of health plans and health insurance enrolees respectively.

Table 4 shows the cross-national work that has taken place across OECD and non-OECD EU member countries in relation to the three broad categories of hospital inpatients, general practice/ primary care, general population and other groups that have been surveyed. Hospital inpatients are one of the most surveyed groups at the national level and particularly when national programs are considered, but there has been just one cross-national comparison by the Picker Institute Europe (22). There have been three cross-national comparisons of general practice or primary care patients involving 4 (74), 12 (56) and 17 (85) countries within Table 3. The majority of cross-national surveys have involved the general population, most of which were undertaken by The Commonwealth Fund in terms of number of surveys, but the general population survey undertaken by the WHO included the largest number of countries.

Table 5 shows the 13 cross-national surveys in greater detail. The seven that were part of ongoing programs include the work of The Commonwealth Fund, Picker Institute Europe and the WHO. The Commonwealth Fund has undertaken three types of surveys involving telephone interviews with members of the general population within five or six countries in relation to non-institutionalised elderly, health system views, primary and ambulatory care, and sicker adults (72-75, 77). The Picker Institute Europe has undertaken two surveys, one of adult inpatients receiving acute care in five countries (22, 53) and the other assessing the experiences of the general population in eight countries (23). Finally, the WHO has undertaken what is by far the largest survey, involving members of the general population in 60 countries (60, 82).

Table 5 shows the six cross-national surveys that were not part of programs of work including: the Diabetes Attitudes Wishes and Needs study (67), the European Research into the Treatment of Cancer (EORTC) study (15,16), the European Psychiatric Services Inputs Linked to Outcome Domains and Needs (EPSILON) study (9), the European Task Force on Patient Evaluations of General Practice (EUROPEP) (85), primary care in 12 countries (56), and spinal cord injury in three countries (28).

Table 6 shows the ten national surveys that were not part of national programs including: acute care hospitals in Ireland (81), antenatal care in Sweden (51), breast health practices in Canada (80), Centers' for Womens's Health in the USA (6), cystic fibrosis in the UK (83), depression among African-American women in the USA (71), HIV infection in the USA (84), maternity care in the UK (52, 69), and osteopathy in the USA (61).

The remainder of the results gives more detailed information in the form of tables describing each survey. The programs of work including ongoing national and cross-national surveys are presented first. The tables relating to the programs are preceded by a description of the program which includes details of related work and surveys that are planned. The information extracted for the programs of work came from various sources including articles published in peer-review scientific journals, reports and websites. The addresses of websites relating to the programs of work are given in the text that precedes the tables. Many of the websites give further information relating to individual surveys and reports in the form of pdf files.

The programs of work are followed by two sets of tables that relate to the surveys that were not part of programs of work. These are shown in chronological order. The national surveys are presented first followed by the cross-national surveys. Such work was largely undertaken as part of research projects and hence information relating to these surveys largely came from articles published in peer-review scientific journals.

Each table relates to one survey or survey population and if the same survey has been repeated over time, the table gives information for the most recent and refers to the earlier surveys in the row relating to history. For the programs of surveys including those undertaken by The Commonwealth Fund and Picker Institute Europe, available survey names were used within the table titles together with the organisation or program name. In the absence of a survey name and particularly in relation to the surveys that were not part of a national program, the majority of which came from journal articles, an appropriate title was given that related to the population and/or setting together with a reference. The country or number of countries included was also given alongside the table title. The results of the electronic questionnaire are shown at the end of the Results.

Table 3 National and cross-national surveys of patient experiences within OECD and EU countries

OECD / non-OECD EU members	National programs[a]	Other national	Cross-national
Australia			Elderly- Schoen (2000), responsiveness- Ustun (2001), health system- Schoen (2002), GP- Schoen (2004), sick people- Schoen (2005), diabetes- Peyrot (2006)
Austria			Responsiveness- Ustun (2001), GP- Wensing (2004)
Belgium			Responsiveness- Ustun (2001), GP- Wensing (2004), cancer- Bredart (2007)
Canada	Canadian Community Health Survey	Breast health – Stamler (2002)	Elderly- Schoen, (2000), responsiveness- Ustun (2001), health system- Schoen (2002), GP- Schoen (2004), sick people- Schoen (2005), spinal cord injury in primary care- Donelly (2007)
Czech Republic			Responsiveness- Ustun (2001)
Denmark	Unit for Patient Evaluation, Department of Quality Measurement		Schizophrenia- Becker (2000), responsiveness- Ustun (2001), GP- Kerssens (2004), GP- Wensing (2004), diabetes- Peyrot (2006)
Finland			Responsiveness- Ustun (2001), GP- Kerssens (2004), GP- Wensing (2004)
France			Responsiveness- Ustun (2001), GP- Wensing (2004), diabetes- Peyrot (2006), cancer - Bredart (2007)
Germany			Responsiveness- Ustun (2001), GP- Wensing (2004), Sick people- Schoen (2005), health system- Coulter (2005), diabetes- Peyrot (2006), cancer - Bredart (2007)
Greece			Responsiveness- Ustun (2001), GP- Kerssens (2004)
Hungary			Responsiveness- Ustun (2001)
Iceland			Responsiveness- Ustun (2001), GP- Kerssens (2004), GP- Wensing (2004)
Ireland		Acute care inpatients - Sweeney (2003)	Responsiveness- Ustun (2001), GP- Kerssens (2004)
Italy			Schizophrenia- Becker (2000), GP- Kerssens (2004), health system- Coulter (2005), cancer- Bredart (2007)
Japan			Diabetes- Peyrot (2006)
Korea			Responsiveness- Ustun (2001)
Luxembourg			Responsiveness- Ustun (2001)
Mexico			Responsiveness- Ustun (2001)
Netherlands	Dutch Centre for Consumer Experience in Health Care		Schizophrenia- Becker (2000),responsiveness- Ustun (2001), GP- Kerssens (2004), GP- Wensing (2004), diabetes- Peyrot (2006)
New Zealand			Health system- Schoen (2002), elderly- Schoen (2000), GP- Schoen (2004), sick people- Schoen (2005) , responsiveness- Ustun (2001)
Norway	Norwegian Knowledge Centre for the Health Services		GP- Wensing (2004), GP- Kerssens (2004), diabetes- Peyrot (2006)
Poland			Health system- Coulter (2005) , responsiveness- Ustun (2001), diabetes- Peyrot (2006), cancer- Bredart (2007)
Portugal			Responsiveness- Ustun (2001), GP- Kerssens (2004), GP- Wensing (2004)
Slovak Republic			Responsiveness- Ustun (2001)
Spain			Schizophrenia - Becker (2000), Responsiveness- Ustun (2001), GP- Wensing (2004), Health system- Coulter (2005), diabetes- Peyrot (2006), cancer- Bredart (2007)
Sweden		Antenatal care - Hildingsson (2005)	Responsiveness- Ustun (2001), GP- Wensing (2004), diabetes- Peyrot (2006)
Switzerland			Responsiveness- Ustun (2001), GP- Wensing (2004), Health system- Coulter (2005)
Turkey			GP- Wensing (2004)
United Kingdom	Picker Institute Europe	Maternity care – Hundley (2000), cystic fibrosis – Wlaters (2002), Maternity care - Redshaw 2006	Elderly- Schoen (2000), ,responsiveness- Ustun (2001), Health system- Schoen (2002), GP- Kerssens (2004), GP- Schoen (2004), GP- Wensing (2004), sick people- Schoen (2005), health system- Coulter (2005), diabetes- Peyrot (2006), cancer- Bredart (2007), spinal cord injury in primary care- Donelly (2007)
United States	The Commonwealth Fund, Consumer Assessment of Healthcare Providers and Systems (CAHPS)	Osteopathy – Licciardone (2001), National Centers of Women's Health –Anderson (2002), HIV – Wilson (2002), depression among African-American women - Scarcini (2004)	Schizophrenia- Becker (2000), Elderly- Schoen (2000), responsiveness- Ustun (2001), Health system- Schoen (2002), GP- Schoen (2004), sick people- Schoen (2005), diabetes- Peyrot (2006), spinal cord injury in primary care- Donelly (2007),
Non OECD EU members:			
Bulgaria			Responsiveness- Ustun (2001)
Estonia			Responsiveness- Ustun (2001)
Cyprus			Responsiveness- Ustun (2001)
Latvia			Responsiveness- Ustun (2001)
Lithuania			Responsiveness- Ustun (2001)
Malta			Responsiveness- Ustun (2001)
Romania			Responsiveness- Ustun (2001)
Slovenia			GP- Wensing (2004)

[a] National programs includes organisations or survey work funded as part of an ongoing program of surveys within a country. This includes multiple surveys of different patient groups (Norway, Picker Institute Europe), hospital inpatients (Denmark), psychiatry patients (Denmark) and the general population (Canada, The Commonwealth Fund) and consumers of health plans (CAHPS).

Table 4 Cross-national surveys of patient experiences by population

OECD / non-OECD EU members	Hospital inpatients	General practice / primary care	General population survey [a]	Other patient groups
Australia		Schoen (2004)[b]	Elderly- Schoen (2000), health system- Schoen (2002), sick people- Schoen (2005), responsiveness- Ustun (2001)	Diabetes- Peyrot (2006)
Austria		Wensing (2004)	Responsiveness- Ustun (2001)	
Belgium		Wensing (2004)	Responsiveness- Ustun (2001)	Cancer- Bredart (2007)
Canada		Schoen (2004)	Elderly- Schoen, (2000), health system- Schoen (2002), sick people- Schoen (2005), responsiveness- Ustun (2001)	Spinal cord injury in primary care- Donelly (2007)
Czech Republic			Responsiveness- Ustun (2001)	
Denmark		Wensing (2004), Kerssens (2004)	Responsiveness- Ustun (2001)	Schizophrenia- Becker (2000), diabetes- Peyrot (2006)
Finland		Wensing (2004), Kerssens (2004)	Responsiveness- Ustun (2001)	
France		Wensing (2004)	Responsiveness- Ustun (2001)	Diabetes- Peyrot (2006), cancer: Bredart (2007)
Germany	Coulter (2001)	Wensing (2004)	Sick people- Schoen (2005), health system- Coulter (2005) , responsiveness- Ustun (2001)	Diabetes- Peyrot (2006), cancer: Bredart (2007)
Greece		Kerssens (2004)	Responsiveness- Ustun (2001)	
Hungary			Responsiveness- Ustun (2001)	
Iceland		Wensing (2004)	Responsiveness- Ustun (2001)	
Ireland		Kerssens (2004)	Responsiveness- Ustun (2001)	
Italy		Kerssens (2004)	Health system- Coulter (2005)	Schizophrenia- Becker (2000), cancer- Bredart (2007)
Japan				Diabetes- Peyrot (2006)
Korea			Responsiveness- Ustun (2001)	
Luxembourg			Responsiveness- Ustun (2001)	
Mexico			Responsiveness- Ustun (2001)	
Netherlands		Wensing (2004), Kerssens (2004)	Responsiveness- Ustun (2001)	Schizophrenia- Becker (2000), diabetes- Peyrot (2006)
New Zealand		Schoen (2004)	Health system- Schoen (2002), elderly- Schoen (2000), sick people- Schoen (2005) , responsiveness- Ustun (2001)	
Norway		Wensing (2004), Kerssens (2004)		Diabetes- Peyrot (2006)
Poland			Health system- Coulter (2005) , responsiveness- Ustun (2001)	Diabetes- Peyrot (2006), cancer- Bredart (2007)
Portugal		Wensing (2004), Kerssens (2004)	Responsiveness- Ustun (2001)	
Slovak Republic			Responsiveness- Ustun (2001)	
Spain		Wensing (2004)	Health system- Coulter (2005), responsiveness- Ustun (2001)	Schizophrenia: Becker (2000), diabetes- Peyrot (2006), cancer- Bredart (2007)
Sweden	Coulter (2001)	Wensing (2004)	Responsiveness- Ustun (2001)	Diabetes- Peyrot (2006)
Switzerland	Coulter (2001)	Wensing (2004)	Health system- Coulter (2005) , responsiveness- Ustun (2001)	
Turkey		Wensing (2004)		
United Kingdom	Coulter (2001)	Wensing (2004) Schoen (2004), Kerssens (2004)	Health system- Schoen (2002), elderly- Schoen (2000), sick people- Schoen (2005), health system- Coulter (2005) , responsiveness- Ustun (2001)	Spinal cord injury in primary care- Donelly (2007) [b], diabetes- Peyrot (2006), cancer- Bredart (2007)
United States	Coulter (2001)	Schoen (2004)	Health system- Schoen (2002), elderly- Schoen (2000), sick people- Schoen (2005) , responsiveness- Ustun (2001)	Schizophrenia- Becker (2000), diabetes- Peyrot (2006), spinal cord injury in primary care- Donelly (2007)
Non OECD EU members:				
Bulgaria			Responsiveness- Ustun (2001)	
Estonia			Responsiveness- Ustun (2001)	
Cyprus			Responsiveness- Ustun (2001)	
Latvia			Responsiveness- Ustun (2001)	
Lithuania			Responsiveness- Ustun (2001)	
Malta			Responsiveness- Ustun (2001)	
Romania			Responsiveness- Ustun (2001)	
Slovenia		Wensing (2004)		

[a] The work relating to general populations surveys was undertaken by The Commonwealth Fund, Picker Institute Europe or the WHO.

[b] This survey involved a general population survey but related to primary care experiences.

Table 5 Cross-national surveys of patient experiences

Author and organisations	Objectives	Countries	Setting and population	Sample size (response rate %)	Questionnaire
Becker et al (2000), The EPSILON study	To produce standardised European versions of five instruments in key areas of mental health service in five languages, and to compare data from five centres	Denmark, England, Italy, Netherlands, Spain	Adults aged 18-65 with schizophrenia, ICD-10 diagnosis F20	404 (63.42, excluding Denmark)	Verona Service Satisfaction Scale – European version
Schoen et al (2000), The Commonwealth Fund	To assess and contrast the health care experiences of the US elderly with their counterparts in other industrialised countries	Australia, Canada, New Zealand, United Kingdom and United States	Men and women aged 65 and over who were non-institutionalised	3515	57 items
Üstün et al (2001), Letkovicova et al (2005), The World Health Organisation	To develop various methods of comparable data collection on health and health system responsiveness.	60 countries	Adults aged 18 and over from private households having been in contact with the health care system last 12 months prior to interview. Institutionalised individuals were excluded.	Long-form face to face (93), brief face to face (59), postal (48), telephone (25-55)	WHO responsiveness modules
Coulter and Cleary (2001), Jenkinson et al (2002), Picker Institute Europe	To describe the nature and frequency of problems reported by hospital patients in the United Kingdom, Germany, Sweden, Switzerland and the USA, and to develop and test a core set of questions to measure patients' experiences of in-patient care	Germany, Sweden, Switzerland, UK, USA	Adult inpatient acute health care	46-74%	Picker Institute Adult In-patient Survey and the 15-item Picker Patient Experience Questionnaire (PPE-15)
Schoen et al (2002), The Commonwealth Fund	Cross-sectional cross-national survey to compare health care system views and experiences.	Australia, Canada, New Zealand, UK, USA	Non-institutionalised adults.	7213	64 items.
Schoen et al (2004), The Commonwealth Fund	Comparison of primary and ambulatory care experiences to inform policy	Australia, Canada, New Zealand, UK	Adults aged 18 and over	8672	
Kerssens et al (2004)	Comparison of patient satisfaction across countries and make comparisons with WHO performance measures	12 countries: Belarus, Denmark, Finland, Greece, Ireland, Israel, Italy, Netherlands, Norway, Portugal, UK, Ukraine	Adult general practice patients including: elderly, chronic obstructive pulmonary disease, diabetes, disabled, inflammatory bowel disease, migrants, rheumatism	5133	Quality of Care Through the Patients' Eyes (QUOTE)
Wensing et al (2004), European Task Force on Patient Evaluations of General Practice Care (EUROPEP)	To examine associations between patient satisfaction and characteristics of health systems	17 countries: Austria Belgium, Denmark, Finland, France, Germany, Iceland, Israel, Netherlands, Norway, Portugal, Slovenia, Spain, Sweden, Switzerland, Turkey, UK	Adult general practice patients from 36 practices per country	25 052 (67-89)	EUROPEP instrument
Schoen et al (2005), The Commonwealth Fund	Comparative study of sicker patients examining issues of access to care, care co-ordination, chronic disease care and safety risks.	Australia, Canada, Germany, New Zealand, United Kingdom, United States.	Adults aged 18 and over.	6958	93 items
Coulter and Jenkinson (2005), Picker Institute Europe	To learn more about European people's views on the responsiveness of their country's health system and healthcare providers	8 countries: Germany, Italy, Poland, Slovenia, Spain, Sweden, Switzerland, UK	Public aged 16 and over. Those who did not have any care, treatment or tests within previous 12 months were excluded.	8119 (13-60)	
Peyrot et al (2006), Diabetes Attitudes Wishes and Needs (DAWN) study	To assess country- and individual level patterns in patient and provider perceptions of diabetes care	13 countries: Australia, Denmark, France, Germany, India, Japan, Netherlands, Norway, Poland, Spain, Sweden, United Kingdom, USA	500 adult patients with diabetes mellitus from each region (Scandinavian countries grouped together)	5104 (92.8)	Ease of access, financial barriers, quality of team collaboration, patient-provider collaboration
Donelly et al (2007)	To describe the utilization, accessibility and satisfaction of primary and preventive health care services to individuals with long-term spinal cord injuries	Canada, UK, USA	Adult spinal cord patients aged 15-55	373	The Health Care Questionnaire
Bredart et al (2007), European Organisation for Research and Treatment of Cancer (EORTC)	To identify variables associated with patient satisfaction	France, Germany, Italy, Spain, Sweden, Taiwan	Adult cancer patients hospitalised for > 3 days for medical oncology or surgery	762 (84.91)	EORTC IN-PATSAT32

Table 6 National surveys of patient experiences that are not part of national programs

Author and organisations	Objectives	Country	Setting and population	Sample size (response rate %)	Questionnaire
Hundley et al (2000)	A cross-sectional survey of women's view of their care in association with maternity services, to determine the extent to which recommendations from recent policy documents had been adopted in practice	Scotland	Maternity care and women giving birth	1137 (69)	Specific to study but based on validated questionnaires
Licciardone and Herron (2001)	To describe patients attending osteopathic physicians, their satisfaction with care, asses their perceptions of osteopathic medicine and to compare them with patients who visit allopathic physicians and non-physician clinicians	USA	General population aged 18 and over and having a home telephone	127 (9.3)	Patient Satisfaction Questionnaire
Leeseberg Stamler et al (2002)	To study the satisfaction, knowledge and usage of organized breast screening clinics among Canadian women	Canada	All Canadian women aged 25 and over	1224 (49.5)	10 items - knowledge, use, satisfaction
Anderson et al (2002)	To evaluate the quality of primary care services provided in 15 National Centers of Excellence in Women's Health (CoE) in comparison with quality of care benchmarks from national and local surveys	USA	Clinical care centers and women aged 18 and over who had at least one primary care visit at the CoE within the year prior to the survey.	3111 (70.7)	10-item Primary Care Satisfaction Survey for Women and a single global satisfaction item
Wilson et al (2002)	To assess care experiences and related characteristics among HIV patients	USA	Inpatient and outpatient care among HIV patients aged 18 and over	2864 (71) and 2267 (65) at follow-up	Picker survey on quality and Picker Ambulatory Care Questionnaire
Walters (2002)	Review of three surveys of adults with cystic fibrosis and two surveys of children with cystic fibrosis collected by the Cystic Fibrosis Trust to study aspects of health care services	UK	Health care for cystic fibrosis patients aged 16 and over and member of the Cystic Fibrosis Trust for participation in the adult survey in either 1990, 1994 or 2000. Parents known to Cystic Fibrosis Trust to participate in children survey in 1992 or 1995	866 (82.7) 1069 (57.2) 1245 (54.5) 542 (54.2) 488 (54.2)	26 items - hotel/ professional aspects of satisfaction, clinic facilities, general practice
Sweeney et al (2003)	To compare hospitals to stimulate quality improvement and enhance quality of care	Ireland	Medical and surgical inpatients	1950 (59.5)	95 items
Scarinci et al (2004)	To use a cross-sectional national representative survey to examine the relationship between physician-patient interaction and depression among African-American women	USA	General practice and African-American women on the NBWHP mailing list	1821 (38)	12 items – physician-patient interaction
Hildingsson and Rådestad (2005)	To report how satisfied Swedish women are with their antenatal care	Sweden	Antenatal care in Sweden among pregnant patients	3293 (72)	Satisfaction with medical/emotional aspects of care, midwife, content of care
Redshaw et al (2007)	To assess current clinical practice from the patient's perspective, key areas of concern and changes in maternity care over the last ten years. This will form a benchmark of current practice, a baseline for assessing change, will inform policy and support implementation of change and serve as a point of comparison for local audit works	England	Maternity health for mothers aged 16 and over	(63)	Several aspects of care were assessed

Canadian Community Health Survey

The Canadian Community Health Survey (CCHS) is the result of a joint initiative between the Canadian Institute for Health- Information (CIHI), Statistics Canada and Health Canada (40). The central objective of the CCHS is to gather health-related data at the sub-provincial levels of health region or combined health regions. The primary objectives are: firstly, to provide timely, reliable estimates of health determinants, health status and health care utilisation; and secondly, to develop a flexible survey questionnaire that fills information gaps at the regional level, has focused survey content for important data and deals with emerging health and health care issues as they arise.

Data collection takes place over two years. The first year is a large general population survey designed to give reliable estimates at the health region level. The second year is a smaller survey designed to give provincial level data relating to specific health topics.

The primary use of the data is health surveillance including the prevalence of disease and other forms of health research. The data are used by the research community and other health professionals. The data is used by government to plan, implement and evaluate programs to improve the health of the nation and efficiency of health services. The data is also used by non-profit health organisations and academic researchers for research designed to contribute to public health. The media use the survey results to raise awareness about health.

The CCHS includes members of the general population aged 12 years and over living in private dwellings in the ten Canadian provinces and the three territories. Persons living on Indian Reserves or Crown lands, residents of institutions, full-time members of the armed forces and residents of certain remote regions are excluded. Questionnaires were developed in collaboration with Statistics Canada, other government departments and/or academic fields and are designed for computer-assisted interviewing.

The 2005 survey questionnaire comprised 292 pages that cover a number of themes and priority areas including timely access, quality and health status and wellness. 14 items related to patient satisfaction.

Healthy Canadians – A Federal Report on Comparable Health Indicators 2006 (40) was the third in a series of reports prepared by the government. The results were age standardised. Further information relating to the CCHS can be found on the websites http://www.hc-sc.gc.ca/hcs-sss and http://www.statcan.ca.

Table 7 Health Canada and Statistics Canada Canadian Community Health Survey (CCHS)	Canada
1 Background to survey	
Organisation(s)	Health Canada and Statistics Canada.
Funding	Canadian Government.
Objectives	To provide timely, reliable, cross-sectional estimates of health determinants, health status and health utilization in Canada, obtain data at the sub-provincial level, create a flexible survey instrument that meets specific health region data gaps, develops focused survey content for key data and deals with merging health and health care issues as they arise.
Recipients of results	Government, health professionals and researchers.
History	The survey has been collected biannually by Statistics Canada since 1991. The Health Service Access Survey (HSAS) was collected in November to December 2001. Its objective was to provide information on the experiences in using some selected health care services, because such questions were not included among the 14 health indicators used to generate federal, provincial and territorial reports as agreed in the 2000 First Minister's Health Accord. The survey included persons aged 15 years and over with questions on patient experiences, acceptance and perceptions of waiting for care. It became part of the Canadian Community Health Survey in 2003. Health Canada has published federal reports in 2002, 2004 and 2006 on comparable health indicators that included information on healthcare services experiences collected in 2001, 2003 and 2005. The 2006 report included three themes: health status and wellness, timely access and quality; and seven priority areas: catastrophic drug coverage and pharmaceutical management, diagnostic and medical equipment, healthy Canadians, health human resources, home care, other programs and services, and primary health care. The theme quality included questions on patient satisfaction. While the CCHS includes the general population aged 12 and over, the reports include only those aged 15 and over.
2 Design	
Setting	
Population	General population.
Inclusion/exclusion criteria	General population aged 12 and over who have experienced health care services in the last 12 months. Persons living on First Nation reserves and on Crown lands, residents of institutions, full-time members of the Canadian Armed Forces and residents of certain remote regions were excluded. Approximately 98% of the Canadian population aged 12 and over is covered by the survey.
Questionnaire	
Length	292 pages that cover a number of themes and priority areas including timely access, quality and health status and wellness. 14 items relate to patient satisfaction.
Scales (items)	Health care system satisfaction in province or community (4), satisfaction with community-based care (2), satisfaction with hospital care (3), satisfaction with overall healthcare services (2), satisfaction with physician care (2), telephone help-

	line (1).
Item scaling	Four- (excellent, good, fair, poor) and five-point scales (very satisfied, somewhat satisfied, neither satisfied nor dissatisfied, somewhat dissatisfied, very dissatisfied), dichotomised for purposes of analysis (excellent or good and very or somewhat satisfied combined).
Development	Each CCHS survey cycle questionnaire has been developed in collaboration with specialists from Statistics Canada, other departments and/or academic fields. All CCHS questions are designed administration by computer-assisted interviewing. One field test which involved Statistics Canada's Regional Offices was carried out prior to the 2005 survey. Its aim was to test the respondents' reaction to the survey and feedback questions, field operations and procedures and data collector computer application, interview training, to obtain estimates of the various sections and to study response rates.
Data quality	
Reliability	
Validity	
Data collection	
Sampling	A sample of 130 000 respondents was needed to provide reliable estimates for all 122 Health Regions. The data file available for analysis includes 119 regions, excluding three thinly populated territories, and includes approximately 68 000 respondents. Three sampling frames were used: 50% of households came from an area frame (similar to the Labour Force Survey, a multistage stratified cluster sampling frame with dwelling as final sampling unit), 49% from a frame of telephone numbers, and 1% from random digital calling frame. The two first types of frames (50/50) were used in most regions while the random digital calling only was used in the two regions of Northern Quebec and Northern Saskatchewan. Only an area frame was used in Nunavjut. An area frame and a small random digital call frame were used in Yukon and Northwest Territories. Responding to the survey was voluntary.
Sampling period	From 4 January 2005 to 30 June 2005.
Survey administration	Computer-assisted personal (area frame) and computer-assisted telephone interviewing (telephone list frame and random digital call).
Reminders	
Response rate	78.9% overall and 83% and 75.4% for the area and phone frames respectively.
3 Reporting of results	
Media	Report.
Adjustments	Age standardised.
4 References	
Health Canada. Healthy Canadians. A Federal Report on Comparable Health Indicators 2006. Health Canada, 2006.	

The Commonwealth Fund

The Commonwealth Fund is a private foundation that provides funding for research on health care issues. The Fund aims to promote a high performing health care system including improved access, quality and efficiency with a focus on people with low incomes, the uninsured, minorities, the young and the old. Support is given to independent research and grants are designed to improve health care practice and policy. There is also an international program in health policy that is designed to improve health care policy and practice in the US and other industrialised countries.

The Funds national and cross-national program of surveys are designed to trends in health coverage, access and quality, and general policy/practice issues. The surveys have included questionnaire items relating to patient experiences and satisfaction (19-21, 72-77). The surveys relate to different research questions but all are based on telephone surveys of the general population that include screening questions so that specific groups or recipients of health care can be identified.

The surveys are funded by The Commonwealth Fund and the survey work is undertaken by organisations with expertise in field work including Harris Interactive Incorporated and Princeton Survey Research Associates International. The cross-national surveys have involved collaboration with the research partners of these survey organisations located in the other countries. The Fund has also collaborated with academic institutions including the Harvard School of Public Health in the development of questionnaires, data analysis and report writing.

The Commonwealth Fund website lists 39 documents relating to surveys of the general population, health care personnel and health care opinion leaders. By topics (and number of surveys) that are not mutually exclusive they are grouped into care of the elderly (2), child health/development (1), health care quality (2), health insurance (14), health system performance (4) international health policy (10), Medicare (4), opinion leaders (9), patient-centred care (1), state health policy (2), and underserved populations (1). One survey relating to a special group of individuals with high-deductible and consumer driven health plans (31) was not reviewed because it was very specific to the USA. There are a number of reports and scientific publications relating to the different surveys which address different research questions.

The national surveys are summarised in Tables 7 below and the cross-national surveys in Table 6 above. More detailed information is given in the Tables that follow which relate to the individual surveys. The national surveys relate to health care quality as perceived by different ethnic and racial groups, health insurance, men's and women's health, older adults, parent views of young children's care and public views of the health system. The survey relating to health insurance was first undertaken in 1996 and is now biennial. The surveys relating to older adults and parents have been undertaken twice in 1999/2004 and 1996/2000 respectively. Cross-national surveys have related to the elderly, health care system views, primary and ambulatory care and sicker adults. The surveys relating to health care system views and sicker adults have been undertaken twice in 1998/2001 and in 2002/2005 respectively. These surveys have all included the English speaking countries Australia, Canada, New Zealand, United Kingdom and United States with the inclusion of Germany in the 2005 survey relating to sicker adults. The results of the cross-national surveys are targeted at health ministers and decision-makers in each of the countries.

Table 8 The Commonwealth Fund national surveys

Author	Survey year(s)	Objective	Population	Sample size (response rate %)	Questionnaire / no. of items
Schoen et al (2003)	1998	To assess adults' experiences with preventative care, relationships with physicians, and caregiving, comparing men and women	Men and women aged 18 and over living in households with telephones in the US	1500 men, 2850 women	212
Collins et al (2002)	2001	To assess health care quality as perceived by different racial/ethnic groups	Adults from four racial/ethnic groups ages 18 and over, living in households with telephones in continental US	6722 (54.3)	143
Halfon et al (2005)	1996, 2000	To assess the quality of developmental services through parent-reports	Parents of children ages 4 to 35 months living in households with telephones	2068 (65.6)	Promoting Health Development Survey (PHDS), together with satisfaction items (original survey had 125 items)
Collins et al (2006)	1996, 1997, 2001, 2003, 2005	To assess the stability of adults' health insurance coverage, cost-related difficulties in accessing care, and the extent and impact of medical bill problems.	General population adults aged 19 and over, living in households with telephones in continental US	4350	169
Collins et al (2006)	1999, 2004	To describe the health and financial security of adults aged 50 to 70 years	Adults ages 50 to 70 in households with telephones in continental US	2007 (71.6)	145
Schoen et al (2006)	2006	To assess public views and experience of the health care system	Adults ages 18 and over, living in households with telephones in continental US	1023	41

The surveys have common elements including the telephone mode of administration with members of the general population following random sampling. For the surveys which have specific groups as a focus, for example parents of young children, the telephone-administered interviews include filter questions.

Many of the items relating to health and service use are found within all of the survey questionnaires. There was little information available relating to questionnaire development. The development of the questionnaires used in the cross-national surveys of the elderly, health service views and sicker adults involved collaboration with the Harvard School of Public Health. Generally the items do not contribute to scales and there is little or no reporting of data quality, reliability and validity. An exception is the parent-reported Promoting Healthy Development Survey (11, 12) which was included within the questionnaire used in the national survey of parents.

The survey samples are based on random samples of members of the general population that are nationally representative with oversampling where necessary. The survey results are weighted so that they are representative of the general population. The Commonwealth Fund has produced reports for all of the surveys and several have a large number of related reports that include the results of subgroup analysis. Further information relating to each of the surveys is available on The Commonwealth Fund website together with links to questionnaires, reports, result summaries and journal articles www.commonwealthfund.org/index.htm.

The Commonwealth Fund – national surveys

Table 9 The Commonwealth Fund Women's and men's health survey	USA
1 Background to survey	
Organisation(s)	The Commonwealth Fund and Louis Harris and Associates, Inc.
Funding	The Commonwealth Fund.
Objectives	To assess adults' experiences with preventative care, relationships with physicians, and caregiving, assessing differences between men and women.
Recipients of results	
History	The survey was undertaken in 1998. Much of the subsequent reporting has related to women's health, including a comparison with women in Israel.
2 Design	
Setting	General population survey.
Population	
Inclusion/exclusion criteria	Men and women aged 18 and over in the USA.
Questionnaire	See (Falik and Collins, 1996).
Length	212 items with many relating just to women. Each telephone interview lasted on average 20-25 minutes.
Scales (items)	Items are grouped in sections that do not comprise scales: access to care and use (29 items), crime/battering/rape/abuse (40 items), factuals (19 items), health habits (4 items), health insurance (20 items), health status (14 items), knowledge and health risks and protection measures for osteoporosis (3 items), menopause and hormone replacement therapy (7 items), mental health (18 items), relationships between patients and physicians (29 items), work and caregiving activities (18 items).
Item scaling	Variable item scaling and descriptors.
Development	
Data quality	
Reliability	
Validity	

Data collection	
Sampling	2850 women with over-samples of African-Americans, Hispanic and Asian women and 1500 men with oversamples of African-Americans and Hispanic men.
Sampling period	7 May to 10 November 1998.
Survey administration	Telephone interview conducted in either Cantonese, English, Korean, Mandarin, Spanish, or Vietnamese.
Reminders	
Response rate	
3 Reporting of results	
Media	Journal article, report, website.
Adjustments	Results were weighted by age, sex, education, race/ethnicity, geographic region, and, insurance status using the 1997 Current Population Survey from the US Census Bureau to produce representative results for the 104 million women and 97 million men 18 years of age and older in the USA.
4 References	
Collins KS, Schoen C, Joseph S et al. Health concerns across a woman's lifespan: The Commonwealth Fund 1998 Survey of Women's Health. The Commonwealth Fund, 1999. Donelan K, Falik M, DesRoches S. Caregiving: challenges and implications for women's health. Women's Health Issues 2001;11:185–200. Falik MM, Collins KS. Baltimore: The John Hopkins University Press, 1996. Women's Health: The Commonwealth Fund Survey. Sandman D, Simantov E, An C. Out of touch: American men and the health care system. The Commonwealth Fund, 2000. Schoen C, Simantov E, Gross R et al. Disparities in women's health and health care experiences in the United States and Israel: Findings from 1998 national women's health surveys. Women and Health 2003;37:49-70.	

Table 10 The Commonwealth Fund USA
The Commonwealth Fund Survey of parents of young children

1 Background to survey	
Organisation(s)	The Commonwealth Fund, National Center for Health Statistics.
Funding	American Academy of Pediatrics, The Commonwealth Fund, Friends of Children Fund, The Gerber Foundation, Health Resources and Services Administration, Maternal and Child Health Bureau.
Objectives	To assess the quality of developmental services through parent-reports.
Recipients of results	
History	The content of the National Survey of Early Childhood Health (NSECH) built upon The Commonwealth Fund survey of parents of young children and the Child and Adolescent Health Measurement Initiative Promoting Development Survey. There are a number of articles and reports relating to specific research questions and aspects of the survey.
2 Design	
Setting	General population of parents and preventative health.
Population	Parents.

Inclusion/exclusion criteria	Parents of children aged 4 to 35 months.
Questionnaire	Promoting Health Development Survey (PHDS), together with satisfaction items (Bethel et al, 2001; Bethel et al, 2002).
Length	The original questionnaire comprised 125 items. Telephone interviews lasted 30 minutes.
Scales (items)	The items within the original questionnaire can be grouped into: background and sociodemographic (16), child activities, discipline and routines (16), child care and guidance (36), health insurance (14), introductory/screening (8), parental health (9), pregnancy related (24), social network and support (2). Within these there are four satisfaction items relating to global satisfaction with well-child care, information satisfaction, time satisfaction and overall satisfaction based on a possible recommendation to others. Four composite quality measures of all or nothing, preference sensitive, unmet need and mean coverage based on responses to items relating to anticipatory guidance and parental education (20), family assessment (5), smoking, drug and alcohol assessment (2) and family-centred care (4).
Item scaling	Global satisfaction (0-10 where 0 is the worst and 10 the best health care), information satisfaction (yes/no), time satisfaction (not enough time, about the right amount of time, too much time), overall satisfaction based on a recommendation to others (very unlikely, somewhat unlikely, somewhat likely, very likely). Scale length and descriptors for the remainder of the items varies according to the content of the items.
Development	The Child and Adolescent Health Initiative expert panel guided the selection of topics for inclusion in the parent-reported Promoting Healthy Development Survey (PHDS). PHDS topics were selected that were: firstly, appropriate for all children in the specified age group; secondly, supported by scientific evidence or expert consensus; thirdly, important to parents following cognitive interviews and focus groups; fourthly, were reliable and valid; fifthly, were not measured with greater reliability or validity elsewhere; and sixthly, not already represented in the survey.
Data quality	Proportion of completed interviews was 79.2%.
Reliability	Cronbach's alpha for the four composite measures ranged from 0.51-0.82 (Bethell et al, 2004).
Validity	
Data collection	
Sampling	The NSECH was conducted as a module of the State and Local Area Integrated Telephone Survey. Stratified random-digit-dial sampling was used to achieve a nationally representative sample of 2068 parents. Households with a black or Hispanic child meeting the inclusion criteria were oversampled to improve the precision of subgroup estimates.
Sampling period	February to July 2000.
Survey administration	Telephone interview in English with a Spanish option.
Reminders	
Response rate	65.6%.
3 Reporting of results	
Media	Journal article, report and website.
Adjustments	Sampling weights were used to adjust for multiple-telephone households, unit non-response, non-coverage of non-telephone households and for the oversampling of

	minority children. All data were weighted to the US population of children aged 4 to 35 months.
4 References	
Bethell C, Peck C, Schor E. Assessing health system provision of well-child care: the promoting Health Development Survey. Pediatrics 2001;107:1084-1094. Bethell C, Peck C, Abrams M et al. Partnering with parents to promote the health development of young children enrolled in Medicaid. The Commonwealth Fund, 2002. Bethell C, Reuland CHP, Halfon N et al. Measuring the quality of preventative and developmental services for young children: national estimates and patterns of clinicians' performance. Pediatrics 2004;113:1973-1983. Halfon N, Inkelas M, Mistry R et al. Satisfaction with health care for young children. Pediatrics 2004;113:1965-1972. Halfon N, Inkelas M, Abrams M et al. Quality of preventative health care for young children: strategies for improvement. The Commonwealth Fund, 2005. Young KT, Davis K, Schoen C. The Commonwealth Fund survey of parents with young children. The Commonwealth Fund, 1996.	

Table 11 The Commonwealth Fund 2001 health care quality survey	USA
1 Background to survey	
Organisation(s)	The Commonwealth Fund and Princeton Survey Research Associates International.
Funding	The Commonwealth Fund.
Objectives	To assess health care quality as perceived by different racial/ethnic groups in the USA.
Recipients of results	
History	The survey was first undertaken in 2001 and has not been undertaken since.
2 Design	
Setting	General population survey.
Population	General population adults in continental USA.
Inclusion/exclusion criteria	
Questionnaire	
Length	143 items. The interviews lasted 25 minutes.
Scales (items)	The questionnaire comprises single items, the grouping of which was informed by areas defined in the report (Collins et al, 2002) and includes: access to health care (13 items), background questions (19 items), chronic disease management (6 items), cultural competence and health care (13 items), health and health care information (9 items), health care quality (13 items), health status (9 items), insurance coverage (4 items), interactions with the health care system (12 items), introductory questions (3 items), language and interpretation facilities (10 items), medical errors (6 items), preventative care (14 items), use of alternative health care (12 items).
Item scaling	Variable scale length and descriptors.
Development	
Data quality	

Reliability	
Validity	
Data collection	
Sampling	Random-digit-dial telephone survey with up to 20 attempts at contact for each household. Communities with high proportions of Asian, Black and Hispanic households were oversampled. The final sample was 6722 adults.
Sampling period	30 April to 5 November 2001.
Survey administration	Telephone with interviews conducted in English, Spanish, Mandarin, Cantonese, Vietnamese or Korean.
Reminders	
Response rate	72% of those contacted for interviews agreed to participate. Counting adults who were not reached by telephone, the overall response rate was 54.3%.
3 Reporting of results	
Media	Report, website.
Adjustments	Data were weighted post hoc to correct for disproportionate sampling and non-response and to make the results representative of all US adults aged 18 years and over by age, sex, education, marital status, race/ethnicity, household size, and geographic region using the US Census Bureau's March 2001 Current Population Survey. The final weighted sample is representative of the 185 million adults aged 18 and over who live in the continental US in telephone households.
4 References	
Collins KS, Hughes DL, Doty MM et al. Diverse communities, common concerns: assessing health care quality for minority Americans. The Commonwealth Fund, 2002. Saha S, Arbeleaz JJ, Cooper LA. Patient-physician relationship and racial disparities in the quality of health care. American Journal of Public Health 2003;93:1713-1719.	

Table 12 The Commonwealth Fund The Commonwealth Fund Survey of older adults	USA
1 Background to survey	
Organisation(s)	Commonwealth Fund, International Communications Research.
Funding	The Commonwealth Fund.
Objectives	To describe the health and financial security of adults aged 50 to 70 years.
Recipients of results	
History	This is the second Commonwealth Fund survey undertaken with this group. The first was undertaken in 1999 in collaboration with Princeton Survey Research Associates.
2 Design	
Setting	General population survey.
Population	
Inclusion/exclusion criteria	Adults aged 50 to 70 years. Individuals or couples were excluded who said they were not working because they were retired, disabled, unemployed or in receipt of Medicaid because of a disability.

Questionnaire	
Length	145 items. The telephone interviews lasted an average of 25 minutes.
Scales (items)	Individual items are grouped in sections of the questionnaire rather than scales: access to care and medical bills (10), background and demographics (31), caregiving and home health care (2), choice (3), current health insurance coverage (15), experiences with provider networks (2), health experiences (3), insurance costs (13), Medicare experiences (6), policy options (12), prescription drugs (5 items), quality of care (17), retirement security (13), switching doctors (2), worries and concerns (3), work and marital status (8).
Item scaling	Variable scale length and descriptors.
Development	
Data quality	
Reliability	
Validity	
Data collection	
Sampling	Nationally representative general population sample of 2007 adults aged 50 to 70 years living in the continental USA.
Sampling period	14 August to 21 November 2004.
Survey administration	Telephone interview in English or Spanish.
Reminders	
Response rate	71.6%.
3 Reporting of results	
Media	Report, website.
Adjustments	The results were weighted to make the results representative of all adults in the relevant age range within the continental US.
4 References	
Collins SR, Davis K, Schoen C et al. Health coverage for aging baby boomers: findings from the Commonwealth Fund Survey for older adults. The Commonwealth Fund, 2006.	

Table 13 The Commonwealth Fund 2005 biennial health insurance survey	USA
1 Background to survey	
Organisation(s)	The Commonwealth Fund and Princeton Survey Research Associates International.
Funding	The Commonwealth Fund.
Objectives	To assess the stability of adults' health insurance coverage, cost-related difficulties in accessing care, and the extent and impact of medical bill problems.
Recipients of results	The Commonwealth Fund.
History	The Commonwealth Fund surveys relating to health insurance began in 1996 and are now biennial.
2 Design	
Setting	General population survey.
Population	
Inclusion/exclusion criteria	General population adults aged 19 and over, living in households with telephones in continental USA.
Questionnaire	
Length	169 items.
Scales (items)	Items are grouped in sections of the questionnaire rather than scales: background screening (5), factuals and demographics (19), family insurance coverage (9), general views about quality of care, access and cost experiences (23), health status and chronic conditions (17), individual market (5), insurance costs (32), insurance difficulties (11), introduction (3), medical debt (9), personal current insurance coverage and recent time uninsured (12), policy options (10), views of employer coverage (11), work and health care (3).
Item scaling	Variable scale length and descriptors.
Development	
Data quality	
Reliability	
Validity	
Data collection	
Sampling	Random, nationally representative sample of 4350 adults. The report by Collins et al (2006) was limited to 3352 respondents aged 19 to 64 years.
Sampling period	Telephone interviews were conducted between 18 August and 5 January 2005.
Survey administration	Telephone interviews conducted in English.
Reminders	
Response rate	
3 Reporting of results	
Media	Journal article, report, website.

Adjustments	The data were weighted to the US adult population by age, sex, education, race/ethnicity, geographic region, household size, and telephone service interruption using the US Census Bureau's 2005 Annual Social and Economic Supplement. The weighted sample is representative of the approximately 212 million US adults aged 19 and over, including 172.5 million adults aged 19 to 64.

4 References

Collins SR, Davis K, Doty MM et al. Gaps in health insurance: an all-American problem. The Commonwealth Fund, 2006.
Collins SR, Ho A. From coast to coast: the affordability crisis in US health care. The Commonwealth Fund, 2004.
Edwards N, Doty MM, Schoen C. The erosion of employer-based health coverage and the threat to workers' health care. The Commonwealth Fund, 2002.
Hoffman C, Schoen C, Rowland D et al. Gaps in health coverage among working-age Americans and the consequences. Journal of Health Care for the Poor and Underserved 2001;12:272-289.

Table 14 The Commonwealth Fund — USA

The Commonwealth Fund Survey of public views of the US health care system

1 Background to survey	
Organisation(s)	The Commonwealth Fund and Harris Interactive, Inc.
Funding	The Commonwealth Fund.
Objectives	To assess how the public views and experiences the US health care system.
Recipients of results	The Commonwealth Fund.
History	This was the first survey of this type undertaken by The Commonwealth Fund.
2 Design	
Setting	General population survey.
Population	
Inclusion/exclusion criteria	General population adults aged 18 and over, living in households with telephones in continental USA.
Questionnaire	
Length	41 items.
Scales (items)	Individual items are grouped in sections of the questionnaire rather than scales: actions to improve care quality (4), care coordination (4), experiences and concerns about access, costs and administration (5), health care coverage (6), health status (1), important health care issues for presidential and congressional action (9), inefficient, poorly coordinated , unsafe care (4), need for quality/cost information and payments that reward performance (3), overall views on the health care system (1), political affiliation (1), worries about affordability and access to high quality care (3).
Item scaling	
Development	
Data quality	
Reliability	
Validity	
Data collection	

Sampling	Random-digit-dial telephone survey. The final sample was 1023.
Sampling period	1 June to 5 June 2006.
Survey administration	Telephone interview conducted in English.
Reminders	
Response rate	
3 Reporting of results	
Media	Report, website.
Adjustments	
4 References	
Schoen C, How SKH, Weinbaum I et al. Public views on shaping the future of the US health system. The Commonwealth Fund, 2006.	

The Commonwealth Fund – international surveys

Table 15 The Commonwealth Fund 1999 international health policy survey of the elderly	Five countries
1 Background to survey	
Organisation(s)	The Commonwealth Fund. Harris Interactive, Inc and international affiliates.
Funding	The Commonwealth Fund.
Objectives	To assess and contrast the health care experiences of the US elderly with their counterparts in other industrialised countries.
Countries	Australia, Canada, New Zealand, United Kingdom and United States.
Recipients of results	Health ministers, decision makers in each country.
History	
2 Design	
Setting	General population survey.
Population	
Inclusion/exclusion criteria	Men and women aged 65 and over who were noninstitutionalised.
Questionnaire	
Length	57 items. Each telephone interview lasted on average 12 minutes.
Scales (items)	Individual items are grouped in sections of the questionnaire rather than scales: access to care (3), anxieties (5), experiences with care (17), factuals (6), financial burdens (2), health and insurance status (4), introduction and screening (3), prescription drugs (4), worklife and caregiving (13). The number of items varied very slightly by country.
Item scaling	Variable scale length and descriptors.
Development	Researchers from the Harvard University School of Public Health, Harris Interative Inc., and the Commonwealth Fund collaborated in the design of the questionnaire.

	Several items were adapted or taken from previous international surveys and the questionnaire was reviewed by health care experts in all nations.
Translation	
Data quality	
Reliability	
Validity	
Data collection	
Sampling	Random sampling of nationally representative households in each country: Australia (701), Canada (700), New Zealand (700), UK (714), USA (700).
Sampling period	April to June 1999.
Survey administration	Telephone interview.
Reminders	
Response rate	
3 Reporting of results	
Media	Journal article, report, website.
Adjustments	The survey results were weighted by age, sex, education, race/ethnicity, insurance status, and geographic region using the 1997 Current Population Survey from the US Census Bureau to produce representative results for the 104 million women and 97 million men aged 18 and over in the USA.
4 References	
Donelan K, Blendon RJ, Schoen C et al. The elderly in five nations: the importance of universal coverage. Health Affairs 2000;19:226-235. Schoen C, Strumpf E, Davis K et al. The elderly's experiences with health care in five nations: Findings from The Commonwealth Fund 1999 International Health Policy Survey. The Commonwealth Fund, 2000.	

Table 16 The Commonwealth Fund 2001 international health policy survey	Five countries
1 Background to survey	
Organisation(s)	The Commonwealth Fund, Harvard School of Public Health and Harris Interactive.
Funding	
Objectives	Cross-sectional cross-national survey to compare health care system views and experiences.
Countries	Australia, Canada, New Zealand, United Kingdom and the United States.
Recipients of results	Health ministers, decision makers in each country.
History	The survey was first undertaken in 1998.
2 Design	
Setting	General population survey.
Population	
Inclusion/exclusion criteria	Noninstitutionalized adult population.

Questionnaire	
Length	64 items.
Scales (items)	Items are grouped in sections of the questionnaire rather than scales: access to care (9), access to health care for different population groups (5), country of birth, language and minority status (4), demographics (12), experience with health care (18), financial burden and fears (7), health care coverage (3), health status (4), introduction and screening (1), overview of health system (3). The number of items varied very slightly by country.
Item scaling	Variable scale length and descriptors.
Development	Designed by researchers at the Commonwealth Fund and the Harvard School of Public Health and reviewed by experts in each country and pretested.
Translation	
Data quality	
Reliability	
Validity	
Data collection	
Sampling	Total sample was 7213: Australia (1412), Canada (1400), New Zealand (1400), United Kingdom (1400), United States (1401). The cross-sectional survey data were collected by Harris Interactive.
Sampling period	April to May 2001.
Survey administration	Telephone interview.
Reminders	
Response rate	Differences in survey design across nations precluded the calculation of response rates.

3 Reporting of results

Media	Journal article, report, website.
Adjustments	Poststratification weights were applied to adjust for minor variation in demographic characteristics between samples and known population figures.

4 References

Blendon RJ, Schoen C, DesRoches CM et al. Inequalities in health care: a five-country survey. Health Affairs 2002;21:182-191.
Schoen C, Blendon RJ, DesRoches CM et al. Comparison of health care system views and experiences in five nations, 2001. The Commonwealth Fund, 2002.

Table 17 The Commonwealth Fund 2004 Commonwealth Fund international health policy survey of adults' experiences	Five countries
1 Background to survey	
Organisation(s)	The Commonwealth Fund International and Harris Interactive and country affiliates.
Funding	The Commonwealth Fund and The Health Foundation.
Objectives	To examine associations between patient satisfaction and characteristics of health systems.
Countries	Australia, Canada, New Zealand, United Kingdom, United States.
Recipients of results	Health ministers, decision makers in each country.
History	This was the seventh in a series of annual international surveys.
2 Design	
Setting	General population survey.
Population	Primary care and ambulatory care experiences.
Inclusion/exclusion criteria	Adults aged 18 and over.
Questionnaire	
Length	The telephone interviews lasted an average of 17 minutes.
Scales (items)	Items are grouped in sections of the questionnaire rather than scales: access to care (3), coordination of care (10), demographics (10), health care coverage (3), health status, chronic conditions and self-care (8), hospitalisations/emergency room (9) introduction and screening (2), out of pocket costs (1), overall views of the health system (5), patient/physician relationship (22), prescription drug use and medication errors (9), preventative care and health promotion (5), use of information technology (4). The number of items varied very slightly by country.
Item scaling	Variable scale length and descriptors.
Development	Designed by researchers at the Commonwealth Fund and Harris Interactive with the advice of and review by experts in each country. It drew upon existing questionnaires.
Translation	
Data quality	
Reliability	
Validity	
Data collection	
Sampling	Total sample was 8672: Australia (1400), Canada (1410), New Zealand (1400), UK (3061), USA (1401).
Sampling period	Telephone interviews were undertaken from 29 March to 17 May 2004.
Survey administration	Telephone interviews were conducted by Harris Interactive and affiliates. Interviews were conducted in English with French and Spanish options in Canada and the USA.
Reminders	
Response rate	

3 Reporting of results	
Media	Journal article, report, website.
Adjustments	
4 References	
Schoen C, Osborn R, Huynh PT et al. Pimary care and health system performance: adults’ experiences in five countries. Health Affairs 2004;W4:487-503.	

Table 18 The Commonwealth Fund International health policy survey of sicker adults	Six countries
1 Background to survey	
Organisation(s)	The Commonwealth Fund, Harvard School of Public Health and Harris International.
Funding	The Commonwealth Fund and The Health Foundation.
Objectives	Comparative study of sicker patients examining issues of access to care, care co-ordination, chronic disease care and safety risks.
Countries	Australia, Canada, Germany, New Zealand, United Kingdom, United States.
Recipients of results	Health ministers and decision-makers in each country.
History	The survey of sicker adults was also undertaken in 2002 but this was the first time it included Germany.
2 Design	
Setting	General population survey.
Population	Sicker adults within the general population.
Inclusion/exclusion criteria	The survey screened initial random samples of adults aged 18 and over who met at least one of four criteria: reported their health as fair or poor; reported that they had had serious illness, injury, or disability that required intensive medical care in the past two years; or reported that in the past two years they had undergone major surgery or had been hospitalized for something other than a normal, uncomplicated delivery.
Questionnaire	
Length	93 items dependent on the country and individual characteristics. The telephone interviews lasted 17 minutes on average.
Scales (items)	Items are grouped in sections of the questionnaire rather than scales: access to health care (7), coordination of care (5), demographics (8), emergency room use (4), experience with specialists (6), experiences with care in hospital (16), health care coverage (4), introduction and screening (4), overview of health care system (1), patient safety measures (8), prescription medication use (5), preventative health care (17), rating of overall care (2), relationship with doctor (6). Items within several sections are dependent on the care received, underlying medical conditions, insurance coverage and demographic factors.
Item scaling	Variable scale length and descriptors.
Development	Designed by researchers at the Harvard School of Public Health, The Commonwealth Fund and Harris Interactive with the advice of and review by experts in each country.

Translation	
Data quality	
Reliability	
Validity	
Data collection	
Sampling	Random samples of the general population were telephoned and screened for health status. The total sample was 6958: Australia (702), Canada (751), Germany (1503), New Zealand (704), UK (1770), USA (1527).
Sampling period	Telephone interviews were undertaken from 17 March to 9 May 2005 in Australia, Canada, New Zealand, UK, USA and from 9 May to 12 June 2005 in Germany.
Survey administration	Harris Interactive and country affiliates conducted the interviews. Interviews were conducted in German in Germany and English in the other countries with French and Spanish options in Canada and the USA.
Reminders	
Response rate	
3 Reporting of results	
Media	Journal article, report, website.
Adjustments	Final samples were weighted to reflect the distribution of the adult population based on initial screening demographics.

4 References

Blendon R, Schoen C, DesRoches C et al. Common concerns amid diverse systems: health care experiences in five countries. Health Affairs 2003;3:106-121.

Davis K, Choen C, Schoenbaum SC et al. Mirror, mirror on the wall: an update on the quality of American health care through the patient's lens. The Commonwealth Fund, 2006.

Schoen C, Osborn R, Huynh PT et al. Taking the pulse of health care systems: experiences of patients with health problems in six countries. Health Affairs 2005;5:W509-W525.

Consumer Assessment of Health Care Providers and Systems (CAHPS)

The Consumer Assessment of Health Care Providers and Systems (CAHPS) Consortium was initiated by the US Agency for Health Care Research and Quality (AHRQ) in 1995. It originally focused on health plans but now covers all health services. Consortium participants include the US Department of Health and Human Services agencies of Centers for Medicare and Medicaid Services (CMS) and Centers of Disease Control and Prevention. Organisations that have been funded by the AHRQ to develop and test surveys include Harvard Medical School, RAND, the Research Triangle Institute and American Institutes of Research. Westat is funded by the AHRQ to provide support to the CAHPS Consortium and manage the CAHPS User Network and CAHPS Benchmarking database.

CAHPS undertook the development and promotion of a standardised survey comprising questions that individuals consider important in the selection of health plans (39). Methods were developed for analysing the survey data that would produce reliable data for the comparison of health plans. Dissemination methods including presentation formats were developed that would enable the CAHPS survey to reach the intended audiences of consumers, plans, providers and purchasers in a way that was understandable.

There have been two phases of the CAHPS, CAHPS I (1995-2001) and CAHPS II (2002-2007). CAHPS I was concerned with the development, testing and evaluation of the HP-CAHPS questionnaire and survey methodology for health plans. Three other questionnaires were also developed: the Experience of Care and Health Outcomes Survey (ECHO) relating to behavioural health (30), the GP-CAHPS for general practice, and the Persons with Mobility Impairment (PWMI-CAHPS). CMS implemented a number of Medicaid beneficiary surveys using the CAHPS questionnaires. The HP-CAHPS questionnaire was merged with the National Committee for Quality Assurance (NCQA) consumer satisfaction questionnaire in 1998. Implementation of CAHPS surveys became part of the NCQA accreditation and the Healthcare Effectiveness Data and Information Set (HEDIS) reporting for health plans. The CAHPS was also adopted by the Department of Defence, US Office of Personnel Management, state Medicaid programs, and private purchasers.

CAHPS II has continued to develop HP-CAHPS as well as new questionnaires and surveys including the A-CAHPS for ambulatory care, AI-CAHPS for American Indians, ESRC-CAHPS for end stage renal disease, H-CAHPS for hospital care (36), and NH-CAHPS for nursing home care. The A-CAHPS was developed to bring together the GP-CAHPS and HP-CAHPS for the comprehensive assessment of ambulatory care. There have also been applications and evaluations of the CAHPS questionnaires in other countries including the Netherlands (7, 27).

The CAHPS survey methodology comprises several elements designed to ensure standardisation: questionnaires for different populations, optional supplementary questions, protocols relating to data collection, data analysis including programs, and, guidelines and formats for reporting. For example, the CAHPS Health Plan Survey and Reporting Kit 2007, includes the information necessary for undertaking a survey relating to an individual health plan (Agency for Healthcare Research and Quality, 2006). The table below summarises the HP-CAHPS survey.

The National CAHPS Benchmarking Database (the CAHPS Database) is the national repository for the CAHPS survey data. The main purpose of the database is to facilitate comparisons of CAHPS survey results by and among survey sponsors. Sponsors and others can compare their own survey results with benchmarks including regional and national averages, in order to assess plan performance and help focus quality improvement initiatives. It also offers an important source of primary data for research related to patient experiences. The database currently comprises nine years of data from the CAHPS Health Plan survey. For 2006 the database includes survey results for 327 000 adults and children enrolled in commercial, Medicaid, SCHIP, and Medicare plans.

The CAHPS Database also includes an annual chartbook, sponsor reports, custom analyses and reports, research briefs, and research files. The chartbook has cross-sector comparisons of survey results for commercial (adult and child), Medicaid (adult and child), SCHIP (child), and Medicare (adult) populations (1-3). Sponsor reports are given to participants annually and include a customised report comparing their results to appropriate benchmarks including regional and national distributions. The Annual Chartbook provides cross-sector comparisons of CAHPS healthplan survey results for commercial (adults and child), Medicaid (adult and child), SCHIP (child) and Medicare (adult) populations. The research files include aggregated respondent level data across sponsors and health plans for commercial, Medicaid, and SCHIP populations.

In addition to the CAHPS health plan survey, the CAHPS database has developed a component for the CAHPS hospital survey (H-CAHPS) and is currently developing plans for a national database to support the CAHPS Clinician/Group Survey. The CAHPS Database will continue to expand as the number and variety of CAHPS surveys grows. The CAHPS database is one of the resources that informs the AHRQ National Health Care Quality Report and National Healthcare Disparities Reports (1, 2).

For 2007, the CAHPS Database and the National Committee for Quality Assurance (NCQA) have entered into an agreement stipulating the data collection responsibilities for each organisation. The CAHPS Database is accepting submissions from Medicaid and SCHIP sponsors only, while NCQA is accepting submissions from commercial sponsors, which it will share with the CAHPS Database. The two organisations have guidelines relating to the different versions of the HP-CAHPS that they will accept. Further information is available on the website www.cahps.ahrq.gov.

Table 19 Consumer Assessment of Health Care Providers and Systems The CAHPS Health Plan Survey	USA
1 Background to survey	
Organisation(s)	The Consumer Assessment of Health Care Providers and Systems (CAHPS) Consortium is an initiative of the Agency for Health Care Research and Quality (AHRQ). Consortium participants include the U.S. Department of Health and Human Services agencies of Centers for Medicare and Medicaid Services (CMS) and Centers of Disease Control and Prevention. Private organisations that have been funded by the AHRQ to develop and test surveys include: Harvard Medical School, Massachusetts; RAND, California; Research Triangle Insitute, North California; and, American Institutes of Research, Washington, DC. Westat is funded by the AHRQ to provide support to the CAHPS Consortium and manage the CAHPS User Network and CAHPS Benchmarking database.
Funding	AHRQ.
Objectives	The goals of the first CAHPS Consortium (CAHPS I) were: • Develop questionnaires, data collection protocols, analysis methods, reporting methods that could be used across organisations and health plans • Develop and test patient experiences questionnaires relating to health plans and services • Develop and test different reporting methods for users • Design and implement an evaluation of CAHPS protocol and products • Assess whether CAHPS results and reports aid users in their health plan selection The goals of the current CAHPS II are: • Maintain and refine the CAHPS Health Plan Survey • Develop and test CAHPS surveys at the medical and individual provider levels • Further develop and test survey products – ECHO Survey for behavioural health services, CAHPS Hospital Survey, CAHPS In-Center Hemodialysis Survey, CAHPS Nursing Home Surveys, CAHPS People with Mobility Impairments Survey • Assess usefulness of CAHPS data for quality improvement purposes • Evaluate the effectiveness of CAHPS survey products in applied settings • Evaluate alternative data collection methods • Refine and expand reporting guidelines • Translate questionnaires and reports into Spanish and provide guidelines for translation into other languages • Conduct research on cultural comparability
Recipients of results	Health care organisations, government, patients, researchers.
History	AHRQ launched CAHPS in 1995 and was designed to make it possible to compare health care organisations over time and provide resources that organisations can use to produce comparative information for users.
2 Design	
Setting	Health plans and medical care.
Population	Recipients of commercial (adult and child) and Medicaid (adult and child) health plans.
Inclusion/exclusion criteria	Individuals must have been enrolled in a plan for six months or longer without a break in enrollment during the first six months (Medicaid) and twelve months or longer with no more than a 45 day break during the 12 months (commercial).

Questionnaire	The CAHPS Health Plan Survey and Reporting Kit for 2007 includes versions 3.0 and 4.0 of the questionnaires which are designed for use with adults and children enrolled in commercial and Medicaid health plans. The primary difference between the adult and child questionnaires is that the former asks respondents aged 18 and over about their own experiences, while the latter ask parents or guardians about the experiences of their children aged 17 and under. The information below relates to the latest version, 4.0, of the questionnaires. Questionnaires are available in English and Spanish.
Length	The adult and child questionnaires have 39 and 41 core items respectively. The core items are applicable across populations, payers and health care delivery systems. Topics covered by the core items include access, demographics, enrolment/coverage, global ratings, how well doctors communicate, health status, plan administration, screener items for patients with chronic conditions, use of proxy respondent, and utilisation. Version 3.0 of the child questionnaire also includes 31 supplemental items for children with chronic conditions. Version 4.0 is being revised to include such items. There are other supplemental items for adults (8 items) and children (10 items) that individual organisations, including providers, undertaking surveys can include.
Scales (items)	Core items form four composite scales of getting needed care, getting care quickly, how well doctors communicate and customer service.
Item scaling	Three scales of “0-10” (for ratings), “how often: never, sometimes, usually, always” and “yes, no”.
Development	Literature review, invitation to individuals or organisations to submit measures, input from individuals and organisations, cognitive interviews with patients. The resulting questionnaire was piloted in a sample of 55 000 patients across three states. The questionnaire has been translated into Spanish using the forward-backwards procedure (Morales et al, 2003). The HP-CAHPS is now in its fourth version and has undergone revisions in relation to the number of core items, item ordering, item wording and response scales.
Data quality	CAHPS 1.0 Adult: 5% of missing data were considered inappropriately missing (Marshall et al, 2001).
Reliability	CAHPS 1.0 Adult and Child: responses from 300 individuals per health plan were found to give sufficient reliability estimates for health plan comparisons (Hays et al, 1999). CAHPS 2.0 Adult: responses from 170 individuals per health plan were found to give sufficient reliability estimates for health plan comparisons (Hargreaves et al, 2003).
Validity	CAHPS 1.0 Adult: confirmatory factor analysis showed that the questionnaire measures five aspects of health plan performance (Marshall et al, 2001). CAHPS 2.0 Adult: confirmatory factory analysis showed that a five factor model fitted the data better than alternative models (Hargreaves et al, 2003). CAHPS 1.0 Adult and Child: the global rating of the health plan item correlated significantly with willingness to recommend the plan (r=0.75) and consumer interest in signing up for a plan (r=0.75) (Hays et al, 1999).
Data collection	
Sampling	The CAHPS Health Plan Survey and Reporting Kit includes survey guidelines and protocols. Any vendor who administers the appropriate version of a survey and follows CAHPS data collection and submission protocols may submit data to the CAHPS Database. However, NCQA, which has a vendor certification process, requires that vendors be certified in order to submit CAHPS Health Plan Survey results for HEDIS and accreditation purposes. Sample drawn must not include more than one individual from each household. Individuals must have primary health coverage through the plan. Individuals

	switching products within the same plan are counted as enrolled within the product that they were enrolled in the longest. 600 is the minimum sample size needed to obtain the recommended 300 completed questionnaires per plan/product with an assumed 50% response rate. Vendors are recommended to increase samples sizes if poor contact information is anticipated. The CAHPS database contains 327 621 respondents for 2006 across 795 plans from commercial, Medicaid, SCHIP and Medicare sectors.
Sampling period	
Survey administration	Postal questionnaire, telephone or mixed administration is recommended. Internet enhancement is also accepted.
Reminders	Post card reminder at ten days, second questionnaire at 30 days and telephone call three weeks after the second questionnaire.
Response rate	Assumed to be 50%.
3 Reporting of results	
Media	Journal articles, report, website.
Adjustments	Data are adjusted for age, education and self-reported health status. Sponsors have the option of adjusting the case mix for other factors as well.
4 References	
CAHPS® Health Plan Survey and Reporting Kit 2007. Agency for Healthcare Research and Quality, 2006. Homer CJ, Fowler FJ, Gallagher PM et al. The Consumer Assessment of Health Plan Study (CAHPS) Survey of Children' Health Care. Journal of Quality Improvement 199;25:369-377. Marshall GN, Morales LS, Elliot M. Confirmatory factor analysis of the Consumer Assessment of Health Plans Study (CAHPS) 1.0 Core Survey. Psychological Assessment 2001;13:216-229. Morales LS, Weech-Maldonado R, Elliot MN et al. Psychometric properties of the Spanish Consumer Assessment of Health Plans Survey (CAHPS). Hispanic Journal of Behavioural Sciences 2003;25:386-409. Hargreaves JL, Hays RD, Cleary PD. Psychometric properties of the Consumer Assessment of Health Plans Survey (CAHPS®) 2.0 Adult Core Survey. Health Services Research 2003;38:1509-1527. Hays RD, Shaul JA, Williams VAL et al. Psychometric properties of the CAHPS™ 1.9 survey measure: Consumer Asssessment of Health Plans Study (Cahps™). Medical Care 1999;37:MS22-MS31. U.S. Department for Health and Human Services. 2006 CAHPS® Health Plan Survey Chartbook: What Consumers Say About Their Experiences with Their Health Plans and Medical Care. Agency for Healthcare Research and Quality, 2006.	

Department of Quality Measurement for Aarhus, Denmark

The Department of Quality Measurement for Aarhus in Denmark had responsibility for national surveys of psychiatry patients or their next of kin in 2005 and 2006. The department had previously undertaken surveys at the district level. The responsibility for the national surveys now resides with the government, regions and districts in Denmark.

The results of the surveys of patients and their carers are designed to inform health professionals, patient and carer organisations and politicians. There have been five national surveys in 2005 and 2006 that include district psychiatric care, forensic psychiatry, inpatient care, residential care and residential day care (Table 8). The carers of the different groups have also been surveyed. However, the sample size for the forensic psychiatry group was very small and hence not reported.

The five surveys have used a similar survey methodology and questionnaire. Surveys include all patients receiving care over a specific period at centres throughout Denmark. Staff hand questionnaires to patients who then return the questionnaire in the post. Patients are also asked if they would be willing to name a carer who is also sent a questionnaire. The five surveys have used very similar questionnaires in terms of themes and items. The questionnaires were developed with psychiatric patients receiving care in different settings and hence are generic in scope including items that are relevant to psychiatric patient experiences in general as opposed to specific forms of care. The questionnaires do not comprise scales and results are reported at the item level. There is no published evidence relating to the data quality, reliability and validity of the questionnaire.

The tables that follow describe each of the five surveys. Further information relating to the national surveys including the national reports summarised in the tables that follow, can be found on the website for Psychiatry, Region North in Denmark www.psykiatri.rn.dk.

Table 20 Department of Quality Measurement, Aarhus

Author	Year of survey	Objectives	Population	Sample size (response rate %)	Questionnaire / no. of items
Ane Feldskov[a]	2005-2006	To report patient experiences of forensic psychiatry in Denmark	Patients aged 18 and over	117 (50)	28
Ane Feldskov[a]	2005	To report patient and carer experiences of psychiatric inpatient care in Denmark	Psychiatric inpatients aged 18 and over and their carers	Patients - 4601 (65), carers - 1101 (48)	Patients - 28, carer - 28
Ane Feldskov[a]	2005	To report on patient and carer experiences of district psychiatric care in Denmark	Patients aged 18 and over and their carers	Patients- 10 395 (67), carers - 4615 (53)	Patients - 25, carer - 28
Ane Feldskov[a]	2006	To report patient and carer experiences of psychiatric day care in Denmark	Residents aged 18 and over and their carers	Patients - 2279 (83)	27
Ane Feldskov[a]	2006	To report patient and carer experiences of residential psychiatric care in Denmark	Patients aged 18 and over and their carers	Patients - 2294 (72), carers -791 (60)	Patients - 28, carers - 27

[a] Project leader.

Table 21 Department of Quality Measurement, Aarhus — Denmark
Patient experiences of forensic psychiatry

1 Background to survey	
Organisation(s)	Department for Quality Measurement, Arhus.
Funding	Danish Ministry of the Interior and Health.
Objectives	To assess and report on patient experiences with forensic psychiatric inpatient care in Denmark.
Recipients of results	Patients and their carers, hospitals, Danish Regions, Danish Ministry of the Interior and Health.
History	This was the first national survey.
2 Design	
Setting	17 forensic psychiatric wards in Denmark.
Population	
Inclusion/exclusion criteria	Patients aged 18 and over who were inpatients in one of 17 wards across Denmark. Excluded patients included those who were not inpatients, those being transferred to a high security ward, those permitted to leave the ward and return, dementia sufferers and the mentally retarded. When the questionnaire was give to them patients were asked whether one of their carers could be surveyed including spouses, family, friends and neighbours. Carers working at the residents residential facility were excluded. However, very few carers were asked to participate and so the results were not reported.
Questionnaire	
Length	28 items.
Scales (items)	The questionnaire does not comprise scales, results being reported at the item level. Themes include: communication, continuity and coordination, information,

	patient and involvement, physical environment, professional contribution.
Item scaling	Items are scaled with between two- and five-point descriptive scales.
Development	The first pilot included 56 patients who received inpatient care or district psychiatric care within Arhus. The questionnaire was then revised following interviews with 27 patients from across Denmark. The carer questionnaires were tested with self-completion and follow-up interviews. This included 42 spouses, family members, friends or neighbours of patients receiving day and residential care, district psychiatric care and inpatient care across Denmark.
Data quality	
Reliability	
Validity	
Data collection	
Sampling	All 235 patients receiving care from 17 forensic psychiatric wards in Denmark during the sampling period. 117 (50%) responded. Non-respondents were more likely to have a length of stay of under two months and there were some differences in the diagnoses but these differences were not statistically tested
Sampling period	15 February 2005 to 14 February 2006.
Survey administration	Patients received the questionnaire from staff and returned it by post. If a questionnaire could not be handed to the patient then it was posted as soon as possible.
Reminders	
Response rate	50%.
3 Reporting of results	
Media	Report.
Adjustments	
4 References	

Kvalitsafdelingen i Arhus Amt. Patienterne har ordet: undersøgelse på de psykiatriske sengeafsnit i Nordyjyllands Amt, 2005.
Kvalitsafdelingen i Arhus Amt. Pårørende har ordet: undersøgelse på de psykiatriske sengeafsnit i Nordyjyllands Amt, 2005.
Kvalitsafdelingen i Arhus Amt. Patienterne og de pårørende har ordet: undersøgelse på de psykiatriske sengeafsnit i Danmark. Landsdaekkende Psykiatriundersøgelser, 2005.
Kvalitsafdelingen i Arhus Amt. Patienterne har ordet: undersøgelse på de retspsykiatriske sengeafsnit i Danmark. Landsdaekkende Psykiatriundersøgelser, 2005.

Table 22 Department of Quality Measurement, Aarhus Patient and carer experiences of psychiatric inpatient care	Denmark
1 Background to survey	
Organisation(s)	Department for Quality Measurement, Arhus.
Funding	Danish Ministry of the Interior and Health.
Objectives	To assess and report on patient experiences with forensic psychiatric inpatient care in Denmark.
Recipients of results	Patients and their carers, hospitals, Danish Regions, Danish Ministry of the Interior and Health.
History	This was the first national survey.
2 Design	
Setting	175 psychiatric inpatient wards.
Population	
Inclusion/exclusion criteria	Patients aged 18 and over who were inpatients at one of the wards between 15 February and 14 June 2005. Patients were excluded if they were: being transferred to a high security ward, not inpatients, permitted to leave the ward and return, being transferred to a somatic hospital, dementia sufferers, mentally retarded or dying. When the questionnaire was given to them, patients were asked whether one of their carers could be surveyed including spouses, family, friends and neighbours.
Questionnaire	
Length	28 items.
Scales (items)	The questionnaire does not comprise scales, results being reported at the item level. Themes within the patient questionnaire include: communication, continuity and coordination, information, patient and involvement, physical environment, professional contribution. Themes within the carer questionnaire include communication, information, carer involvement, psychiatric care.
Item scaling	Items are scaled with between two- and five-point descriptive scales.
Development	Discussion with experts/health professionals and consideration of the content of earlier survey questionnaires. The first pilot included 56 patients who received inpatient care or district psychiatric care within Arhus. The questionnaire was then revised following interviews with 27 patients from across Denmark. The carer questionnaires were tested with self-completion and follow-up interviews. This included 42 spouses, family members, friends or neighbours of patients receiving day and residential care, district psychiatric care and inpatient care across Denmark.
Data quality	
Reliability	
Validity	
Data collection	
Sampling	All 7047 patients receiving care from 175 psychiatric wards in Denmark during the sampling period. 4601 (65%) responded. 1101 (48%) from 2273 carers responded to the questionnaire. For both groups, non-respondents were more likely to be male but this was not statistically tested.

Sampling period	15 February to 14 June 2005.
Survey administration	Patients received the questionnaire from staff and returned it by post. If a questionnaire could not be handed to the patient then it was posted as soon as possible. Carers were posted questionnaires.
Reminders	
Response rate	Patients 65%, carer 48%.

3 Reporting of results

Media	Report.
Adjustments	

4 References

Kvalitsafdelingen i Arhus Amt. Patienterne har ordet: undersøgelse på de psykiatriske sengeafsnit i Nordyjyllands Amt, 2005.
Kvalitsafdelingen i Arhus Amt. De pårørende har ordet: undersøgelse på de psykiatriske sengeafsnit i Nordyjyllands Amt, 2005.
Kvalitsafdelingen i Arhus Amt. Patienterne og de pårørende har ordet: undersøgelse på de psykiatriske sengeafsnit i Danmark. Landsdaekkende Psykiatriundersøgelser, 2005.

Table 23 Department of Quality Measurement, Aarhus — Denmark

Patient and carer experiences of district psychiatry

1 Background to survey

Organisation(s)	Department for Quality Measurement, Arhus.
Funding	Danish Ministry of the Interior and Health.
Objectives	To assess and report on patient experiences with district psychiatry care in Denmark.
Recipients of results	Patients and their carers, hospitals, Danish Regions, Danish Ministry of the Interior and Health.
History	This was the first national survey.

2 Design

Setting	131 district psychiatric centres.
Population	
Inclusion/exclusion criteria	Patients aged 18 and over who had direct contact with a clinician three or more times within district psychiatry. Patients were excluded if they were: suffering from acute psychotic illness, dementia sufferers, mentally retarded or dying. When the questionnaire was given to them, patients were asked whether one of their carers could be surveyed including spouses, family, friends and neighbours.
Questionnaire	
Length	Patients (25 items), carer (28 items).
Scales (items)	The questionnaire does not comprise scales, results being reported at the item level. Themes within the patient questionnaire include: communication, continuity and coordination, information, patient and involvement, physical environment, professional contribution. Themes within the carer questionnaire include communication, information, carer involvement, psychiatric care.

Item scaling	Items are scaled with between two- and five-point descriptive scales.
Development	Discussion with experts/health professionals and consideration of the content of earlier survey questionnaires. The first pilot included 56 patients who received inpatient care or district psychiatric care within Arhus. The questionnaire was then revised following interviews with 27 patients from across Denmark. The carer questionnaires were tested with self-completion and follow-up interviews. This included 42 spouses, family members, friends or neighbours of patients receiving day and residential care, district psychiatric care and inpatient care across Denmark.
Data quality	
Reliability	
Validity	
Data collection	
Sampling	All 15 537 patients attending district psychiatry centres in Denmark during the sampling period. 10 395 (67%) responded. 8774 of the patients carers were posted a questionnaire and 4615 (53%) responded. Non-respondents for the carers were more likely to be male but this was not statistically tested.
Sampling period	1 January to 28 February 2005.
Survey administration	Patients received the questionnaire from staff and returned it by post. If a questionnaire could not be handed to the patient then it was posted as soon as possible. Carers were posted questionnaires.
Reminders	
Response rate	Patients 67%, carer 53%.

3 Reporting of results

Media	
Adjustments	Report.

4 References

Kvalitsafdelingen i Arhus Amt. Patienterne har ordet: undersøgelse i distriktspykiatrien i Nordyjyllands Amt, 2005.
Kvalitsafdelingen i Arhus Amt. De pårørende har ordet: undersøgelse i distriktspykiatrien i Nordyjyllands Amt, 2005.
Kvalitsafdelingen i Arhus Amt. Patienterne og de pårørende har ordet. Undersøgelse i distriktpsykiatrisken i Danmark. Landsdaekkende Psykiatriundersøgelser, 2005.

Table 24 Department of Quality Measurement, Aarhus Patient experiences of psychiatric day care	Denmark
1 Background to survey	
Organisation(s)	Department for Quality Measurement, Arhus.
Funding	Danish Ministry of the Interior and Health.
Objectives	To assess and report on patient experiences with psychiatric day care in Denmark.
Recipients of results	Patients, carers, institutions, Danish Regions, Danish Ministry of the Interior and Health.
History	This was the first national survey.
2 Design	
Setting	Patients attending 83 psychiatric day care facilities.
Population	
Inclusion/exclusion criteria	Patients aged 18 and over receiving one or more days of care at a psychiatric day care facility. Patients received a questionnaire for each day care facility they attended in the month of May. Patients that did not have any contact with staff were excluded. Patients who were psychiatric or somatic inpatients that were too ill to complete a questionnaire, dementia sufferers and the mentally retarded were excluded from the survey.
Questionnaire	
Length	27 items.
Scales (items)	The questionnaire does not comprise scales, results being reported at the item level. Themes include: communication, continuity and coordination, information, patient involvement, physical environment, professional contribution
Item scaling	Items are scaled with between two- and five-point descriptive scales.
Development	Discussion with experts/health professionals and consideration of the content of earlier survey questionnaires. The questionnaire was tested in a pilot survey with 117 patients from district psychiatric services, hospital wards and social psychiatry settings. The first pilot included 56 patients who received inpatient care or district psychiatric care within Arhus. The questionnaire was then revised following interviews with 27 patients from across Denmark. Finally, before the national survey the questionnaire was tested through interviews with 34 patients receiving either residential psychiatric care or psychiatric day care.
Data quality	
Reliability	
Validity	
Data collection	
Sampling	All 2760 patients attending 83 social psychiatric day care facilities within the May 2006 were posted a questionnaire and 2279 responded. Non-respondents were more likely to be male but this was not not tested for statistical significance.
Sampling period	May 2006.
Survey administration	Patients received the questionnaire from staff and returned it by post. If a questionnaire could not be handed to the patient then it was posted as soon as possible.

Reminders	
Response rate	83%.
3 Reporting of results	
Media	Report.
Adjustments	
4 References	
Kvalitsafdelingen i Arhus Amt. Brugerne har ordet: undersøgelse i de socialpsykiatriske beskaeftigelses-, aktivitets- og samvaerstilbud i Danmark. Landsdaekkende Psykiatriundersøgelser, 2006.	

Table 25 Department of Quality Measurement, Aarhus — Denmark
Patient and carer experiences of residential psychiatric care

1 Background to survey	
Organisation(s)	Department for Quality Measurement, Arhus.
Funding	Danish Ministry of the Interior and Health.
Objectives	To assess and report on patient and carer experiences of residential psychiatric care in Denmark.
Recipients of results	Patients and their carers, institutions, Danish Regions, Danish Ministry of the Interior and Health.
History	This was the first national survey but followed local surveys undertaken in 2001-2002.
2 Design	
Setting	Patients and their carers from 123 psychiatric dwellings/residential care facilities.
Population	
Inclusion/exclusion criteria	Patients aged 18 and over who were a resident for one or more days. Patients received a questionnaire for each residential facility that they stayed in. Patients who were psychiatric or somatic inpatients that were too ill to complete a questionnaire, dementia sufferers and the mentally retarded were excluded from the survey. When the questionnaire was give to them, patients were asked whether one of their carers could be surveyed. Carers working at the patients residential facility were excluded.
Questionnaire	
Length	Residents (28 items), carer (27 items).
Scales (items)	The questionnaire does not comprise scales, results being reported at the item level. Themes include: communication, continuity and coordination, information, patient and carer involvement, physical environment, professional contribution.
Item scaling	Items are scaled with between two- and five-point descriptive scales.
Development	Discussion with experts/health professionals and consideration of the content of earlier survey questionnaires. The questionnaire was tested in a pilot survey with 117 patients from district psychiatric services, hospital wards and social psychiatry settings. The first pilot included 56 patients who received inpatient care or district psychiatric care within Arhus. The questionnaire was then revised following interviews with 27 patients from across Denmark. Finally, before the national survey the questionnaire was tested through interviews with 34 patients receiving either

	residential psychiatric care or psychiatric day care. The carer questionnaires were tested with self-completion and follow-up interviews. This included 42 spouses, family members, friends or neighbours of patients receiving day and residential care, district psychiatric care and inpatient care across Denmark.
Data quality	
Reliability	
Validity	
Data collection	
Sampling	All patients for the month of May 2006 that met the inclusion critieria were included. 3197 patients were given a questionnaire and 2294 (72%) responded. 1326 carers were given a questionnaire and 791 (60%) responded. Non-respondents were more likely to be male but statistical significance was not tested.
Sampling period	May 2006 for patients and questionnaires were sent to the carers from June to July 2006.
Survey administration	Patients received the questionnaire from staff and returned it by post. Carers received the questionnaire in the post and returned it by post.
Reminders	
Response rate	Patients 72%, carer 60%.

3 Reporting of results

Media	Report.
Adjustments	

4 References

Kvalitsafdelingen i Arhus Amt. Beboerne og de pårørende har ordet: undersøgelse i de socialpsykiatriske borformer. Landsdaekkende Psykiatriundersøgelser, 2006.

Dutch Centre for Consumer Experience in Health Care

The Dutch Centre for Consumer Experience in Health Care (Centrum Klantervaring Zorg) was founded in December 2006. The Centre is an independent foundation governed by a board of six members, two representing patient/consumer organisations, two representing health insurers, and two representing health care providers' with an independent chairman. The Centre is funded by the Foundation for patient organisations, organisations for people with disabilities and the elderly ('Fonds PGO'). This foundation in turn, is funded by the Ministry of Health. The statutory aim of the Centre is to develop, implement and lead a national standard for reliable and valid measurements and comparisons of consumer experiences in health care. This standard is called the Consumer Quality Index, or CQ-index (CQI). The CQI is based on American CAHPS questionnaires and Dutch QUOTE instruments, which both measure consumers' experiences of care (7, 27).

The Centre for Consumer Experience in Health Care does not develop questionnaire or undertake surveys. It coordinates and oversees questionnaire development by research institutes and universities, according to the Centre's guidelines. The majority of the CQI questionnaires were developed by the Netherlands Institute for Health Services Research, www.nivel.nl. NIVEL also cooperates with the Centre in developing and maintaining the aforementioned guidelines for developing and implementing surveys.

Questionnaires developed according to the guidelines are based on literature reviews and existing survey instruments; the formal involvement of all stakeholders, including patient/consumer organisations, health insurers and health care providers, qualitative research and particularly patient focus groups; and, psychometric testing. Questionnaires developed according to the guidelines are formally approved by the board of the Centre and are freely available for use on the website of the Centre, www.centrumklantervaringzorg.nl. The development and evaluation of questionnaires has been described in reports in Dutch and articles in peer-reviewed journals. To prevent surveys taking place at the same time within the same populations, the Centre requests that potential users inform the Centre of their work.

The Centre accredits certified survey vendors. These comprise both for-profit market research firms and non-profit research institutes affiliated with or founded by patient organisations. These survey vendors are allowed too undertake CQI surveys that serve 'official' purposes, that is, surveys that are used for external accountability of providers to the Inspectorate for Health Care or for consumer information published on the government website www.kiesbeter.nl.

As of January 2008 there are five CQI questionnaires available on the website of the Centre for Consumer Experience in Health Care:

- The CQI Health care and Health Insurance, a self-administered mail survey;
- The CQI Cataract surgery, a self-administered mail survey;
- The CQI Total Hip/Total Knee Arthroplasty, a self-administered mail survey;
- The CQI Care for people with disabilities, comprising a self-administered mail surveys for client's representatives and interview protocols for clients, including clients with intellectual disabilities;
- The CQI Long-term care (nursing homes, homes for the elderly, home care), comprising interview protocols for nursing home clients and clients in homes for the elderly, and self-administered mail surveys for home care clients and for representatives of psychogeriatric clients.

These questionnaires were all used in 2007 national surveys. Data collection has finished, but the survey results of CQI Cataract surgery, the CQI Total Hip/Total Knee Arthroplasty, the CQI Care for people with disabilities, and the CQI Longterm care are currently being processed to serve as consumer information. This consumer information consists of case-mix adjusted report cards per hospital, per provider of care for the handicapped, or longterm care provider. The aim of this consumer information is to assist patients in choosing a health care provider.

The surveys of health insurance enrolees and people with disabilities have been published (Table 26). The results of the surveys of cataract surgery, hip and knee arthroplasty and longterm care will be published along with the presentation of consumer information on www.kiesbeter.nl in 2008. The reports will be published on www.centrumklantervaringzorg.nl. Two tables below give further information relating to the published surveys summarised in Table 9.

Finally, several new questionnaires are being developed with the following expected in 2008: CQI General practice, CQI Physiotherapy, CQI Diabetes, CQI Inpatient hospital care, CQI Rheumatoid arthritis, CQI Breast cancer care, CQI Outpatient mental health care.

Table 26 Dutch Centre for Consumer Experience in Health Care

Author	Year of survey	Objective	Population	Sample size (response rate %)	Questionnaire / no. of items
De Boer et al (2007)	2007	To assess and report on patient experiences with outpatient health care and health insurance	Enrolees of all Dutch health insurers (n=32)	23 970 (37)	CQI Health care and health insurance 115
PriceWaterhouse-Coopers (2007)	2007	To assess and report on people with disabilities, their next of kin and carers experiences of care	Clients of providers of care for people with disabilities (n=101)	Interview 11 598 (65), next-of-kin postal 5535 (34), postal carers 16 259 (42)	CQI Care for people with disabilities: Interviews 48, postal next-of-kin 70, postal carer78

Table 27 Dutch Centre for Consumer Experience in Health Care Netherlands
Enrolees of all Dutch health insurers

1 Background to survey	
Organisation(s)	Centre for Consumer Experience in Health Care, NIVEL.
Funding	Centre for Consumer Experience in Health Care, health insurers.
Objectives	To assess and report on patient experiences with outpatient care and health insurance in the Netherlands.
Recipients of results	Patients, health insurers, government.
History	This was the third national survey of the Dutch insured.
2 Design	
Setting	Enrolees of all Dutch health insurers.
Population	
Inclusion/exclusion criteria	Enrolees aged 18 and over.
Questionnaire	CQI Health care and health insurance.
Length	115 items.
Scales (items)	Access to care (8), conduct of health care providers (5), conduct of health insurance employees (5), information about health insurance (3), reimbursement of bills (2) timeliness of care (6).
Item scaling	Four point scale of never, sometimes, usually, always.
Development	The CQI was developed using a translated version of the American CAHPS 3.0 combined with Dutch survey instruments developed by the Dutch consumer organisation (Delnoij et al, 2005; Hendriks et al, 2005).
Data quality	Levels of missing data ranged from 1.7-5.9%.
Reliability	The level of Cronbach's alpha met the criterion of 0.7 for all scales: access to care (.77), conduct of health care providers (.83), conduct of health insurance employees (.91), information about health insurance (.76), reimbursement of bills (.70) timeliness of care (.85) (De Boer et al, 2007).
Validity	Construct validity was assessed by correlating scales and with other variables expected to be related to patient experiences including age, health status, and education.

Data collection	
Sampling	23 970 enrolees from all 32 health insurers in the Netherlands. Non-respondents were slightly younger and more likely to be male (p<0.001). 8 644 patients responded.
Sampling period	Summer 2007.
Survey administration	Postal questionnaire.
Reminders	One reminder letter after 1 week, 1 reminder plus questionnaire after 3 weeks, 1 reminder letter after 5 weeks.
Response rate	37%.
3 Reporting of results	
Media	Report and website.
Adjustments	Scores were adjusted for age, education and health.
4 References	
Delnoij DMJ et al. Made in the USA: the import of American Consumer Assessment of Health Plan Surveys (CAHPS) into the Dutch social insurance system. European Journal of Public Health 2004; 14:43. Hendriks M, et al. Ervaringen van verzekerden met de zorg en de zorgverzekeraars. Consumenteninformatie voor www.kiesBeter.nl. Utrecht: NIVEL, 2005. De Boer et al. Ervaringen van verzekerden met de zorg en de zorgverzekeraars. CQ-index Zorg en Zorgverzekering, meting 2007. Utrecht: NIVEL/CKZ, 2007.	

Table 28 Dutch Centre for Consumer Experience in Health Care — Netherlands
Care for people with disabilities

1 Background to survey	
Organisation(s)	NIVEL, Vilans, Price Waterhouse Coopers.
Funding	Vereniging Gehandicaptenzorg Nederland (VGN).
Objectives	To assess and report clients' with disabilities, their next-of-kin and carers experiences with care for people with disabilities.
Recipients of results	Patients, providers, government.
History	This was the first year of this survey among clients, next of kin and carers relating to people with disabilities.
2 Design	
Setting	Clients aged 18 and over, next-of kin of children, carers of adults with intellectual disabilities.
Population	
Inclusion/exclusion criteria	Clients and their representatives.
Questionnaire	CQI Care for people with disabilities (4 versions).
Length	CQI Care for people with disabilities: interviews (48), mail survey of next-of-kin for children (70), mail survey of carers of adults with intellectual disabilities (78).
Scales (items)	Interviews: autonomy (8), courtesy and professonal competence (6), daytime activities (5), housing situation (6). Mail surveys: accessibility (3), contnuity of care (2), courtesy (4), daytime activities (3), housing situation (4), information (8),

	personal care (2), professional competence (6), safety (3), short stay support (5), support at home (2).
Item scaling	Four point scales.
Development	The development of the instruments followed a literature review, focus group discussion with clients and consultation with an expert group of professionals involved in care for people with disabilities (Brandt et al, 2007).
Data quality	Missing data varied from 0.0 to over 75.0% for the three groups.
Reliability	Cronbach's alpha met the criterion of 0.6 for almost all scales. For the interviews alpha varied from 0.57-0.81. For the mail surveys, alpha varied from 0.60-0.85. Reliability was also assessed for subgroups.
Validity	Construct validity was assessed through comparisons with background variables and other variables expected to be related to patient experiences including age, education and health status.
Data collection	
Sampling	11 598 interviews, 5535 mail surveys, 16 259 mail surveys of carers (PriceWaterhouseCoopers 2007).
Sampling period	October 2006 – April 2007
Survey administration	Postal questionnaire and structured interviews.
Reminders	Postal questionnaire: letter after 2 weeks, questionnaire after 3 weeks (occasionally).
Response rate	Interviews (65%) mail surveys of next-of-kin (34%), mail surveys of carers (42%).
3 Reporting of results	
Media	Report and website.
Adjustments	Scores were adjusted for age, health status and level of intellectual disabilities (interviews) and for age, health status and educational (mail survey).
4 References	
Brandt H, Zuidgeest M, Sixma H. Pilot ontwikkeling CQ-index Gehandicaptenzorg:Meten van de kwaliteit van de gehandicaptenzorg vanuit het cliëntenperspectief. Utrecht: NIVEL, 2007. PriceWaterhouseCoopers. Weten voor beter. Brancherapport benchmark gehandicaptenzorg. PWC in cooperation with Vilans, NIVEL, Research voor Beleid, Desan, 2007.	

Norwegian Knowledge Centre for the Health Services

The Norwegian Knowledge Centre for the Health Services was founded in 2004. The Centre is organised under The Directorate for Health and Social Affairs but is scientifically and professionally independent. The Centre gathers and disseminates evidence about the effect and quality of methods and interventions within all parts of the health services. The uptake of this evidence by the health services is also an important goal for the Centre's activities.

The section with responsibility for the measurement of patients' and employees' experiences with health services has undertaken several national surveys of patient experiences of health care within Norway. Repeated surveys have been undertaken for general medical and surgical adult inpatients (25) with a national survey of outpatients taking place more recently (32). National surveys have been undertaken for adult psychiatric inpatients (35) and outpatients (34) and parents of children receiving inpatient paediatric care (33). The surveys are summarised in Table 10.

In 2007 the section has undertaken surveys of parents of children receiving psychiatric care, adult cancer patients and a further survey of adult inpatients from medical and surgical departments. A second survey of psychiatric outpatients starts in the final quarter of 2007. Developmental work is underway for surveys planned in 2008 relating to out-of-hours emergency care, rehabilitation and substance misuse centres. There was also a survey of general practitioners in 2006 which assessed their experiences with district psychiatric services (13). Finally, the Centre has been involved in developing a survey methodology and questionnaire for use in cross-national comparisons of somatic inpatient care for the Nordic countries. The questionnaire has been tested in Norway (66).

The surveys have all used self-administered postal questionnaires with reminders. Sampling procedures have been used that take account of the size of the hospitals and the number of patients. The survey methodology is published as a separate report which describes the survey design and reporting including questionnaire development and evaluation, sampling procedures and methods of adjusting for variables known to be associated with patient experiences.

Questionnaires have been developed when structured reviews of the literature have not revealed a suitable Norwegian questionnaire or one available for translation (32-35). Questionnaire development is informed by the findings of the literature review, interviews with patients and focus groups of experts including clinicians (32). This process is designed to ensure that the questionnaires have content validity or that they measure the important aspects of patient experiences in sufficient depth. The questionnaires comprise summated rating scales that are based on tests of data quality, exploratory factor analysis, internal consistency analysis, test-retest reliability and construct validity.

The results of the surveys are published in the form of reports for government and individual health care units including hospitals. The results are also available online in the form of a statistical bank which can be used to produce tables and a website intended to inform patients. National comparisons of hospitals and clinics have been adjusted to take account of variables found to be associated with patient experiences. Reports are produced for individual hospitals, health regions and at the national level. The tables that follow describe the five published surveys. Further information and links to published articles and reports and other documents are available at the website www.kunnskapssenteret.no.

Table 29 Norwegian Knowledge Centre for the Health Services

Author	Year of survey	Objective	Population	Sample size (response rate %)	Questionnaire / no. of items
Garratt et al (2005)	2003/2004	To assess and report on patient experiences with outpatient care in Norway	Patients aged 16 and over attending outpatient clinics and day units in Norway	19 266 (53.9)	OutPatient Experiences Questionnaire 24
Garratt et al (2006)	2004	To assess and report psychiatric patients experiences with outpatient care	Psychiatric outpatients aged 18 and over	6677 (43.3)	Psychiatric OutPatient Experiences Questionnaire 11
Garratt et al (2006)	2005	To assess and report psychiatric patients experiences with inpatient care	Psychiatric inpatients aged 18 and over	2676 (35)	Psychiatric InPatient Experiences Questionnaire 11
Danielsen et al (2007)	1996, 1998, 2002/2003, 2006	To assess and report on patient experiences with inpatient hospital care in Norway	Patients aged 16 years and over discharged from inpatient departments in Norway	13 700 (50.9)	Patient Experiences Questionnaire 24
Garratt et al (2007)	2005	To assess and report on parent experiences with paediatric inpatient care in Norway	Next-of-kin of children aged under 16 .	3308 (53.8)	Parent Experiences of Paediatric Care Questionnaire 25

Table 30 Norwegian Knowledge Centre for the Health Services Hospital outpatients	Norway
1 Background to survey	
Organisation(s)	Norwegian Knowledge Centre for the Health Services.
Funding	Regional Health Enterprises.
Objectives	To assess and report on patient experiences with outpatient care in Norway.
Recipients of results	Patients, hospitals, health regions, government.
History	This was the first national survey of Norwegian outpatients.
2 Design	
Setting	Adult outpatients.
Population	
Inclusion/exclusion criteria	Somatic outpatients aged 16 and over.
Questionnaire	OutPatient Experiences Questionnaire (OPEQ).
Length	24 items.
Scales (items)	Clinic access (2), communication (6), hospital standards (3), information (6), organisation (4), pre-visit communication (3).
Item scaling	Ten point end-anchored scales.
Development	The OPEQ was developed folllowing a literature review, interviews with patients and a focus groups with outpatient staff. This process was designed to ensure content validity (Garratt et al, 2005).
Data quality	Levels of missing data ranged from 1.7-5.9% (Garratt et al, 2005).
Reliability	Levels of item-total correlation were above 0.5 for all but items within the scale of pre-visit communication (Garratt et al, 2005). The level of Cronbach's alpha met the criterion of 0.7 for all but one scale: clinic access (0.76), communication (0.85) organisation (0.80) hospital standards (0.75) information (0.88), pre-visit communication (0.59). Test-retest questionnaires were sent to 270 patients 6 days after they returned the first questionnaire. Retest respondents who had been re-hospitalized were excluded. Test-retest intraclass correlations exceeded 0.7 with one exception: clinic access (0.81), communication (0.81), organisation (0.80), hospital standards (0.65), information (0.87), pre-visit communication (0.84).
Validity	Factor analysis explained 69% of the variation between patients, identifying three factors described as clinic access, communication and organisation which comprised items relevant to all outpatients. The other three scales were based on theoretical considerations. Construct validity was assessed by correlating scales and with other variables expected to be related to patient experiences including age, health status and outcome, appointment flexibility, continuity of care and waiting time (Garratt et al, 2005).
Data collection	
Sampling	12 367 patients from 23 hospitals in northern and western regions of Norway in 2003 and 23 352 patients from 29 hospitals in the eastern, middle and southern regions in 2004. Non-respondents were slightly younger and more likely to be male (p<0.05). 19 266 patients responded.

Sampling period	Autumn of 2003 and 2004.
Survey administration	Postal questionnaire.
Reminders	One reminder questionnaire after 3 weeks.
Response rate	53.9%.
3 Reporting of results	
Media	Journal article, report and website.
Adjustments	Scores were adjusted for age, gender, education and health.
4 References	
Garratt AM, Bjærtnes ØA, Krogstad U et al. The Outpatient Experience Questionnaire (OPEQ): data quality, reliability, and validity in patients attending 52 Norwegian hospitals. Quality and Safety in Health Care 2005;14:433-437. Garratt AM, Andresen Ø, Krogstad U et al. Development and evaluation of the patient experiences questionnaire for somatic outpatients.Tidskrift Nor Laegeforen 2005;125:421-424.	

Table 31 Norwegian Knowledge Centre for the Health Services Psychiatric inpatients	Norway
1 Background to survey	
Organisation(s)	Norwegian Knowledge Centre for the Health Services.
Funding	Ministry of Health and Social Affairs.
Objectives	To assess and report psychiatric patients' experiences with inpatient care.
Recipients of results	Patients, hospitals, health regions and government.
History	This was the first year of this survey of psychiatric inpatients.
2 Design	
Setting	Adult psychiatric inpatients.
Population	
Inclusion/exclusion criteria	Patients aged 18 and over. Geriatric psychiatry patients and patients being treated for addiction were excluded.
Questionnaire	Psychiatric In-Patient Experiences Questionnaire (PIPEQ).
Length	11 items.
Scales (items)	Items form a unidimensional scale.
Item scaling	Five-point scale of not at all, to a little extent, to a moderate extent, to a large extent, to a very large extent.
Development	The development of the PIPEQ followed a literature review, interviews with 12 patients about which aspects of care were important with psychiatric services and consultation with an expert group of clinicians and health care professionals involved in the care of psychiatric patients (Garratt et al, 2006). This was designed to ensure content validity and hence that items adequately address important aspects of patient experiences. The questionnaire was designed to be brief while covering the important aspects of patient experiences of psychiatric care. The PIPEQ was piloted by means of a self-completed questionnaire with 244 patients aged 18 years and over attending clinics in Stavanger Norway during the first quarter of 2005; 68 (28%) responded (Garratt et al, 2006). Three different methods

	of administering the questionnaire were tested in consecutive samples of patients: first, giving the questionnaire for the patient to complete on the day of discharge before they left the clinic; secondly, mailing the questionnaire to the patient's home; or, thirdly giving the patient the option of either of these methods (Bjertnæs et al, 2006). Following piloting the wording of some of the items was simplified. The resulting questionnaire included eleven items with broad applicability to respondents that include aspects of the clinician interaction and information provision.
Data quality	Missing data ranged from 1.5- 4.4% for each item (Garratt et al, 2006).
Reliability	Item-total correlations were acceptable and ranged from 0.55 to 0.82 and Cronbach's alpha was 0.91 for the unidimensional scale suggesting that the questionnaire might be suitable for assessing individual patients (Garratt et al, 2006).
Validity	Factor analysis produced a single factor explaining 52% of the variation with factor loadings ranging from 0.58-0.87. Correlations or t-tests were conducted in relation to variables measuring health service quality, health, outcomes and a number of variables relating to health care process. There were significant correlations ($p<0.05$) in the range of 0.31-0.65 with variables relating to appropriateness of discharge time, cooperation with family, influence in decision making, overall satisfaction, need for use of force for admittance and quality of activities. Patients who were admitted against their will had poorer scores ($P<0.05$) than those who were not (Garratt et al, 2006).
Data collection	
Sampling	7656 inpatients discharged from psychiatric centres in Norway received a questionnaire. 2676 responded (35%). The median age of respondents was 43 and 60% were female.
Sampling period	September to December 2005.
Survey administration	Postal questionnaire.
Reminders	One reminder questionnaire after 4 weeks.
Response rate	35%.
3 Reporting of results	
Media	Journal article, report and website.
Adjustments	Scores were adjusted for variables found to be associated with patient experiences: age, marital status, diagnosis group, whether admission was voluntary or not.
4 References	
Bjertnæs ØA, Garratt AM, Johannessen JO. Relationship between data collection methods and results in user surveys in mental health care. Tidskrift Nor Laegeforen 2006;126:1481-1483. Garratt AM, Danielsen K, Bjertnæs ØA et al. The Psychiatric In-Patient Experiences Questionnaire (PIPEQ): data quality, reliability and validity. Tidskrift Nor Laegeforen 2006;126:1478-1480.	

Table 32 Norwegian Knowledge Centre for the Health Services Psychiatric outpatients	Norway
1 Background to survey	
Organisation(s)	Norwegian Knowledge Centre for the Health Services.
Funding	Ministry of Health and Social Affairs.
Objectives	To assess psychiatric patients' experiences with outpatient care.
Recipients of results	Patients, hospitals, health regions and government.
History	This was the first year of this survey of psychiatric outpatients.
2 Design	
Setting	Adult psychiatric outpatients.
Population	
Inclusion/exclusion criteria	Patients aged 18 and over. Geriatric psychiatry patients and patients being treated for addiction were excluded.
Questionnaire	Psychiatric OutPatient Experiences Questionnaire (POPEQ).
Length	11 items.
Scales (items)	Clinician interaction (6), information (2) and outcomes (3).
Item scaling	Five-point scale of not at all, to a little extent, to a moderate extent, to a large extent, to a very large extent.
Development	Literature review of questionnaires within psychiatry was used to identify domains and items of potential relevance to psychiatric outpatients (Garratt et al, 2006). Twelve patients were interviewed about which aspects of outpatient care were important to them. An initial questionnaire was discussed with clinical staff and piloted in a survey of 1238 patients in one Norwegian health region. This process was designed to ensure content validity.
Data quality	Missing data ranged from 1.5% to 12.1% for each item.
Reliability	Item-total correlations were acceptable and ranged from 0.51 to 0.79. Cronbach's alpha was above 0.90 for all items combined, suggesting the instrument might be suitable for assessing individual patients. Cronbach's alpha for three theory based scales ranged from 0.81-0.87. Test-retest reliability intraclass correlations ranged from 0.75-0.90 (Garratt et al, 2006).
Validity	Factor analysis produced a single factor explaining 53.7% of the variation with factor loadings ranging from 0.54 to 0.84. Eighty correlations or t-tests in relation to variables measuring health service quality, health, outcomes and a number of variables relating to health care process were highly significant (P<0.01) and all but two mean differences were highly significant (P<0.001) (Garratt et al, 2006).
Data collection	
Sampling	15 422 patients from 90 Norwegian clinics were mailed a questionnaire and 6677 responded. Non-respondents were more likely to be male and somewhat younger.
Sampling period	September 2004 with questionnaires mailed by mid October.
Survey administration	Postal questionnaire.
Reminders	Reminders were mailed at three weeks.
Response rate	43.3%.

3 Reporting of results	
Media	Journal article, report and website.
Adjustments	Scores were adjusted for age and gender.
4 References	
Bjørngaard JH, Ruud T, Garratt A et al.The contribution of psychiatric care units to the quality of mental health care: patient experiences and clinician ratings of outpatient teams. Psychiatric Services 2007;58:1102-1107. Garratt A, Bjørngaard JH, Dahle KAa et al. The Psychiatric Out-Patient Experiences Questionnaire (POPEQ): data quality, reliability and validity in patients attending 90 Norwegian clinics. Nordic Journal of Psychiatry 2006;60:89-96.	

Table 33 Norwegian Knowledge Centre for the Health Services Hospital inpatients	Norway
1 Background to survey	
Organisation(s)	Norwegian Knowledge Centre for the Health Services.
Funding	Ministry of Health and Social Affairs.
Objectives	To assess and report on patient experiences with inpatient hospital care in Norway.
Recipients of results	Patients, hospitals, health regions and government.
History	The first national survey took place in 1996 and thereafter in 1998, 2003, 2006. The 2006 survey included a new version of the questionnaire.
2 Design	
Setting	Inpatients discharged from Norwegian hospitals.
Population	
Inclusion/exclusion criteria	Patients aged 16 and over discharged from 62 Norwegian hospitals.
Questionnaire	Patient Experiences Questionnaire (PEQ).
Length	24 items.
Scales (items)	Communication (3), contact with next-of-kin (2), doctor Services (2), general satisfaction (2), hospital and equipment (2), information examinations (2), information future complaints (2), information medication (2), nursing services (3), organization (4).
Item scaling	Ten-point end anchored scales revised in 2007 to a five-point scale of not at all, to a little extent, to a moderate extent, to a large extent, to a very large extent.
Development	Existing questionnaires were reviewed following literature searches designed to retrieve questionnaires in Scandinavian or Anglo-American languages (Pettersen et al, 2004). Items were selected that: were relevant to at least 25% of patients admitted to general surgical or medical departments, focused on specific aspects of hospital care rather than satisfaction with care, and included medical and nursing aspects of hospital services. Pilot studies, patient interviews, a review of patients' written comments and discussion with hospital clinicians and administrators were undertaken before a draft version of the questionnaire was produced. Two surveys with patients from 14 hospitals were conducted in 1996 and 1998.
Data quality	Missing data for scales ranged from 0.07-1.27% (Pettersen et al, 2004).
Reliability	Item-total correlations were above 0.57. Cronbach's alpha was above 0.70 for 8 of

	10 scales. Hospital organization and information medication were below 0.70. Test-retest of 150 respondents contacted two weeks after receiving the first questionnaire, but excluding those who had been re-hospitalized between the two mailings (response rate 67%), gave intra-class correlations from 0.62 to 0.85 (Pettersen et al, 2004).
Validity	Scale construction was based on the results of factor analysis and theoretical considerations. Mean differences by sex and age were small but were evidence for construct validity. Patients with unfulfilled expectations scored substantially lower on all scales compared to those with fulfilled expectations (Pettersen et al, 2004).
Data collection	
Sampling	62 hospitals during 2002 and 2003 including 26 983 patients of whom 13 700 responded.
Sampling period	Six week period during 2002 and 2003.
Survey administration	Postal questionnaire. Questionnaires were mailed three weeks after patients were discharged from hospital.
Reminders	One reminder questionnaire at 4 weeks.
Response rate	50.9%.
3 Reporting of results	
Media	Journal article, report and website.
Adjustments	Scores were adjusted for age, gender, education and health.
4 References	
Danielsen K, Garratt AM, Bjertnæs ØA et al. Patient experiences in relation to health care process and provider characteristics. Scandanavian Journal of Public Health 2007;35:70-77. Pettersen KI, Veenstra M, Guldvog B et al. The Patient Experiences Questionnaire: development, validity and reliability. International Journal of Quality in Health Care 2004;16:453-463.	

Table 34 Norwegian Knowledge Centre for the Health Services Next-of-kin of paediatric inpatients	Norway
1 Background to survey	
Organisation(s)	Norwegian Knowledge Centre for the Health Services.
Funding	Ministry of Health and Social Affairs.
Objectives	To assess and report parent experiences with Norwegian paediatric health care services.
Recipients of results	Patients, hospitals, health regions and government.
History	This was the first year of this survey relating to parent experiences.
2 Design	
Setting	Paediatric department inpatient care.
Population	
Inclusion/exclusion criteria	Next-of-kin of children aged under 16. Rehabilitation, neonatal, outpatients and psychiatric units were excluded.
Questionnaire	Parent Experiences of Paediatric Care (PEPC) Questionnaire.

Length	25 items.
Scales (items)	Doctor services (5), hospital facilities (4), information – discharge (3), information – tests and examinations (2), nursing services (7), organisation (4).
Item scaling	Five-point scale of not at all, to a little extent, to a moderate extent, to a large extent, to a very large extent.
Development	A literature review was followed by 15 unstructured interviews with parents, consultation with an expert group of health professionals and a pilot study on 11 parents at a University hospital. This process was designed to ensure the content validity of the PEPC (Garratt et al, 2007). After some minor changes to the questionnaire a pilot survey was done with 592 parents whose children had attended the same hospital as inpatients, of which 326 responded.
Data quality	From 1.1% to 2% missing data for most items with only 'quality of activities' having higher levels of missing data above 4.5% at 6.5% (Garratt et al, 2007).
Reliability	Item-total correlations for the final scales were acceptable and ranged from 0.49 to 0.80. Levels of Cronbach's alpha were above 0.70 and three were above 0.80. 148 of 270 parents (54.8%) were mailed a test-retest questionnaire and responded. Four scales gave reliability estimates above 0.8 and the final two met the criterion of 0.70 (Garratt et al, 2007).
Validity	Factor analysis produced five factors accounting for 60.9% of the total variation. 21 of 28 items had factor loadings above 0.5, the remaining 7 were above 0.3. The factors could be identified as nursing services, doctor services, organisation/ information relating to examinations and tests, information relating to discharge and hospital facilities. Item-total correlation analyses also supported item-discriminant validity. Correlations between the final 6 scales (based on 25 items) and other variables followed a priori hypotheses (Garratt et al, 2007).
Data collection	
Sampling	6414 parents of children aged up to 16 years of age randomly selected from all 20 hospitals with a paediatric department in Norway. 3308 responded (1943 (60.2%) medical, 622 (19.3%) surgical, 664 (20.6%) other type of treatment), of which 1186 followed one reminder. The mean age of the children was 5.3 years and 43.4% were female. The age and gender of children of the non-respondents were not significantly different, but length of stay (2.60 versus 2.95 days) was significantly shorter among children of non-respondents (p<0.05).
Sampling period	Within 12 weeks from the start of September 2006.
Survey administration	Postal questionnaire.
Reminders	A reminder was sent to non-respondents after 4 weeks.
Response rate	53.8%.
3 Reporting of results	
Media	Journal article, report and website.
Adjustments	Scores were adjusted for variables found to be associated with parent experiences: the child's age, parent's age and parent's education.
4 References	
Garratt A, Bjertnæs ØA, Barlinn J. Parent experiences of paediatric care (PEPC) questionnaire: reliability and validity following a national survey. Acta Paediatrica 2007;96:246-252.	

Picker Institute Europe

The Picker Institute originates from the Patient-Centred Care Program established by the James Picker Foundation and The Commonwealth Fund of New York in 1986. The Picker Institute Inc. funds education and research in the fields of patient-centred care and cooperates with and supports educational institutions and other interested entities and persons. It is an independent, not for profit research and development institute with charitable status, and its mission is to encourage a more comprehensive understanding of the theoretical and practical aspects of patient-centred care through emphasising the patient's concerns or experiences with healthcare. The Picker Institute Europe was established as a UK registered Charity in 2000 which followed a history of cooperation with European organisations.

National surveys have been undertaken in England and Europe since 1998. The Picker Surveys in the US and Canada are now conducted by the National Research Corporation (NRC). In Europe the Picker Institute Europe has responsibility for further development of the Picker questionnaires and conducting national surveys, the exceptions being Germany and Switzerland, where local offices have translated and adapted the Picker questionnaires to each country's health care system before undertaking the surveys. Since 1998 Picker Institute Europe has completed 21 national surveys in England involving more than 1.1 million patients, and it is responsible for the National Co-ordination Centre for Acute Care Patient Surveys on behalf of the Healthcare Commission. The survey program was initiated by the Government following the publication of the White Paper "The new NHS – modern dependable" in 1997, which proposed the introduction of regular surveys of patients to allow comparisons of experiences over time and between different parts of the country. Picker also conducts other surveys that are not nationally representative. In 2005 Picker undertook over 200 surveys on behalf of NHS Trusts.

Table 11 shows the national surveys that are described on the Picker Institute website and include ambulance services (29), cancer (5), coronary heart disease (41), diabetes (50), emergency care (42), general practice (46), hospital inpatients (49), hospital outpatients (45), mental health (44), stroke (48) and young people (68). The surveys of coronary heart disease, emergency care, general practice, inpatients, mental health, and outpatients have been undertaken twice or more. The two cross-national surveys undertaken by the Picker Institute Europe relate to adult inpatient acute care (22) and members of the general public that received care in the previous twelve months (23) in five and eight countries respectively. The Tables on the pages that follow present each of the national and cross-national surveys in greater detail.

Table 35 Picker Institute Europe national surveys for England

Author	Year of survey	Objective	Population	Sample size (response rate %)	Questionnaire / no. of items
Airey C et al (2002)	1999/ 2000	To assess quality of NHS care as seen by cancer patients	Patients with one of six types of cancer	65 337 (74)	97
Ramm et al (2004)	2004	To assess quality of NHS care as seen by young patients	Patients aged 0 to 17 years treated as inpatients or day cases	62 277	89
Graham C et al (2004)	2003	To assess the quality of NHS ambulance services	Adults aged 16 and over who were attended to or taken to hospital by an ambulance following emergency 999 or urgent calls	12 282 (51)	27
Healthcare Commission (2005)	1999, 2004	To assess NHS care quality as seen by patients diagnosed with coronary artery disease	Patients with a primary diagnosis of coronary heart disease	3784 (75)	Coronary Heart Disease In-Patient Experience Questionnaire 83
Healthcare Commission (2005)	2002/3, 2004/5	To assess NHS care quality as seen by patients who had been acute outpatients	Patients aged 16 and over who attended an outpatient department	84 280	Picker Adults Outpatient Questionnaire 56
Healthcare Commission (2005)	1998, 2002, 2003, 2004, 2005	To assess the quality of NHS primary care	Patients aged 16 and over registered with a GP	116 939 (47)	Local Health Services Questionnaire 55
Healthcare Commission (2005)	2003, 2004	To assess the quality of NHS patient care as seen by patients at emergency departments	Patients aged 16 and over attending an emergency department	55 339 (44)	Picker Adult Emergency Questionnaire 49
Healthcare Commission (2005)	2004, 2005	To assess the quality of NHS patient care as seen by stroke patients	Patients whose primary diagnosis was intracerebral haemorrhage, cerebral infarction or stroke	1713 (65)	54
Healthcare Commission (2006)	2004, 2005, 2006	To assess quality of NHS mental health care	Patients aged 16 and over on the Care Program Approach	(37.7)	58
Healthcare Commission (2006)	2006	To assess the quality of NHS care for patients with diabetes	Patients aged 16 and over diagnosed with diabetes	68 500 (55)	75
Healthcare Commission (2006)	2002, 2004, 2005	To assess the quality of NHS care for acute hospital inpatients	Patients aged 16 and over who had an overnight stay in a hospital	81 000 (59)	Picker Patient Experience Questionnaire 75

The Picker Institute Europe is expanding its range of surveys. The first national maternity survey and the outpatient feedback survey are currently being collected, the latter being a follow up to the 2004 survey. Picker is also planning to adjust and present the national results by applying logistic regression analysis.

The Picker Institute Germany has surveyed more than 170 000 patients, with patients from more than 250 hospitals. Further information is available in German at www.pickerinstitut.de. The Picker Institute Switzerland has surveyed more than 250 000 patients. Their first surveys were regional and included Zürich, Bern and Lausanne. In 2001 the questionnaires for adult inpatients and rehabilitation patients were certified by the Koordinations- und Informationsstelle für Qualitätsförderung, and since then they have also developed questionnaires for more specific patient groups, taking the Swiss health system into account. Further information is available in German at www.picker.ch.

The Picker surveys use questionnaires that have been developed in collaboration with health care personnel and other experts. Questionnaire development includes literature reviews, in-depth qualitative interviews with patients and their families, cognitive interviews, pilot tests and evaluation of reliability and validity. This process is designed to ensure that the questionnaire measures what is intended and that the reports based on the surveys can be used for policy implementation. The Picker questionnaire was originally developed in the US and has been adapted to the health care systems of other countries, other languages and/or specific diagnostic groups, such as coronary heart disease patients. The original Picker Instrument comprises 40 items, where ordinal measurement items are dichotomized and transformed into scales measuring different aspects of patient experiences. The questionnaire also exists in a shorter 15-item format (53) and includes other patient experience or health outcome variables, some of which can be used to describe variation in patient experiences among survey participants.

The Picker Institute Europe national survey’s results are published in a report. In addition one report is published for each participating trust, which can, if it wishes, include further questions in addition to those in the core questionnaire collected by all trusts. In the national reports the data are usually unweighted and responses to individual items have been reported as percentages. In the trust reports scores for individual items are compared with those for other trusts and national benchmarks. Further information relating to each survey is given on the pages that follow. Further information is available on the websites www.nhssurveys.org and www.healthcarecommission.org.uk/nation nalfindings/surveys/patientsurveys.

Table 36 Picker Institute Europe Cancer survey 1999/2000	England
1 Background to survey	
Organisation(s)	Picker Institute Europe, Department of Health, Imperial College School of Medicine at St Mary's London, National Centre for Social Research.
Funding	Commission for Health Improvement.
Objectives	The purpose was to assess the quality of NHS patient care, as seen by hospital patients who had been treated for cancer.
Recipients of results	Department of Health and NHS trusts.
History	This was the first survey of cancer patients.
2 Design	
Setting	Cancer health care.
Population	
Inclusion/exclusion criteria	Patients diagnosed with one of six types of cancer discharged between July 1999 and June 2000: colorectal (C18-21), lung (C34), breast (C50), prostate (C56), ovarian (C61) or non-Hodgkin's lymphoma (C82-85).
Questionnaire	
Length	97 items.
Scales (items)	Items are grouped in sections that do not comprise scales: about you (15), finding out what was wrong with you (19), first hospital treatment (28), hospital visit (9), leaving hospital (11), out-patient appointments (14).
Item scaling	Three-point scales, dichotomised into 'problem scores' for purpose of analysis.
Development	
Data quality	
Reliability	
Validity	
Data collection	
Sampling	The sample of patients was drawn from the hospital administrative records of 172 NHS trusts estimated to have 150 or more qualifying patients. 123 984 patients were selected and 92 683 were mailed a questionnaire of which 65 337 responded.
Sampling period	
Survey administration	Postal questionnaire.
Reminders	Two reminders.
Response rate	74%.
3 Reporting of results	
Media	Report.
Adjustments	Data were unweighted. Response rates differed between Trusts and consequently there were differences by age, gender and diagnosis. However, the differences

	between the unweighted and weighted results were small enough not to merit weighting.

4 References

Airey C, Becher H, Erens B et al. National surveys of NHS patients: Cancer: National Overview 1999/2000. Department of Health, 2002.

Table 37 Picker Institute Europe — England

Ambulance trusts survey 2004

1 Background to survey	
Organisation(s)	Picker Institute Europe, Department of Health and the Healthcare Commission.
Funding	Healthcare Commission.
Objectives	The purpose was to assess the quality of NHS ambulance health services.
Recipients of results	Department of Health and NHS trusts.
History	This was the first survey relating to ambulance health services.
2 Design	
Setting	Adult emergency or urgent case health service.
Population	
Inclusion/exclusion criteria	Patients aged 16 and over either attended to or taken to hospital by ambulance following emergency 999 or urgent calls.
Questionnaire	
Length	27 items.
Scales (items)	Items are grouped in sections that do not comprise scales: about you (3), ambulance crew (8), calling an ambulance (6), journey to hospital (5), not conveyed to hospital (3), overall (2).
Item scaling	Three-point scales, dichotomised into 'problem scores' for purposes of analysis.
Development	Questionnaire development was based on a literature review including existing questionnaires, patient focus groups, expert group, patient interviews and a postal survey. Literature searches and review of seven questionnaires used by ambulance trusts suggested that all stages of patient experiences from the initial 999 call to handover at hospital should be included in the questionnaire. Focus groups with patients from three trusts that had used ambulance emergency or urgent services in the last 12 months identified eight topics: the initial 999 call, arrival of ambulance, treatment at incident, conveyance or non-conveyance, journey to hospital, handover at hospital, ambulance crew and complaints. There followed an importance study with 22 patients who were presented with a list of 26 statements based on the review and focus group interviews. Following this a draft questionnaire was circulated among the 13 members of the Ambulance Survey Advisory Group. Cognitive interviews with patients who had recent experience of ambulance emergency or urgent services were then used to assess face validity. Finally, a postal survey was conducted with 1200 patients from 3 Ambulance NHS trusts.
Data quality	
Reliability	
Validity	

Data collection	
Sampling	Hospital staff from the participating 31 ambulance trusts selected a random sample of 850 patients from each hospital's administrative records. 26 336 patients were contacted and 12 282 responded.
Sampling period	One to two weeks in October 2003.
Survey administration	Postal questionnaire.
Reminders	Two reminders.
Response rate	51%.
3 Reporting of results	
Media	Report.
Adjustments	
4 References	
Dunckley M, Osborn C, Magee H et al. Development and pilot testing of the questionnaire for use in NHS Trust-based Ambulance Emergency Services patient survey. Picker Institute Europe, 2004. Graham C, Dunckley M, Reeves R et al. Patient survey report 2004 – ambulance services. Healthcare Commission, 2004.	

Table 38 Picker Institute Europe — England
Young patient survey 2004

1 Background to survey	
Organisation(s)	Picker Institute Europe and the Healthcare Commission.
Funding	Commission for Health Improvement.
Objectives	The purpose was to assess the quality of NHS patient care, as seen by young hospital patients.
Recipients of results	Department of Health and NHS trusts.
History	This was the first survey relating to young patients.
2 Design	
Setting	Health care among young patients.
Population	
Inclusion/exclusion criteria	Patients aged 17 and under who were treated as either inpatients or day cases in any part of the trust including adult wards. Psychiatric and maternity patients were excluded.
Questionnaire	Picker Paediatric Survey 2000 that was modified into two questionnaires identical in content; the parent or guardian version for children aged 12 and under and the young patients version for those aged 13 and over.
Length	89 items.
Scales (items)	Items are grouped in sections that do not comprise scales: admission to hospital (1), care and treatment (9), doctor (6), emergency or immediately referred (3), hospital and ward (17), leaving hospital (11), nurses (8), operations and procedures (8), pain (3), waiting list or planned admission (6).
Item scaling	Three-point scales, dichotomised into 'problem scores' for purposes of analysis.

Development	The development of items was based on focus group discussions with patients and discussion with Commission for Health Improvement (CHI). Cognitive interviews assessed patient understanding of items. An ‘Importance Study’ involved 100 patients and parents were asked which topics they rated as most important. After this process items were refined and a pilot survey undertaken with 800 young patients from two NHS trusts with two follow-up reminders to non-respondents.
Data quality	
Reliability	
Validity	
Data collection	
Sampling	150 trusts participated. Across 146 trusts staff selected a random sample of 850 patients from the hospital’s administrative records. In the remaining four trusts only 500 eligible patients were selected. 125 827 patients were contacted and 62 277 responded. Patients of all ages, but particularly those aged 12 and over, were encouraged to answer the questionnaire themselves. 66% of respondents were parents, 17% the parent and the patient and 16% the young patient alone.
Sampling period	Patients had been discharged from the trusts counting back from the last date of either November 2003 or January 2004.
Survey administration	Postal questionnaire.
Reminders	Two reminders.
Response rate	
3 Reporting of results	
Media	Report.
Adjustments	

4 References

Ramm J, Reeves R, Graham C. Patient survey report 2004 – young patients. Healthcare Commission, 2004.
Ramm J, Hopwood B, Reeves R. Development and Pilot testing of the NHS Acute & Specialist Trust Young Patient Survey 2004. Picker Institute Europe, 2004.

Table 39 Picker Institute Europe Coronary heart disease survey 2004	England
1 Background to survey	
Organisation(s)	Picker Institute Europe, Department of Health and the Healthcare Commission.
Funding	Healthcare Commission.
Objectives	To assess the quality of NHS patient care, as seen by hospital patients who had been diagnosed with coronary heart disease.
Recipients of results	Department of Health and NHS trusts.
History	The survey of patients' with coronary heart disease was first undertaken in 1999.
2 Design	
Setting	Coronary heart disease patients' health care.
Population	
Inclusion/exclusion criteria	Patients whose primary diagnosis was coronary heart disease. Specialist cardiac trusts and trusts not being specialist acute trusts were not eligible to participate in the survey.
Questionnaire	Coronary Heart Disease In-Patient Experience Questionnaire (I-PEQ CHD).
Length	83 items.
Scales (items)	Items are grouped in sections that do not comprise scales which for 1999 survey were: co-ordination (7), discharge (6), hospital environment (8), information and communication (6), pain (2), patient involvement (6). Scales from the 1999 survey included co-ordination, discharge, hospital environment, information and communication, pain, patient involvement.
Item scaling	Three-point scales, dichotomised into 'problem scores' for purposes of analysis.
Development	Parts of the questionnaire are similar to the 1999 coronary heart disease survey which was partly based on the Picker Adult in-Patient Survey.
Data quality	Following the 1999 survey it was recommended that the pain items be removed in future applications because a large number of respondents did not report pain (Jenkinson et al, 2002). Missing data ranged from 2.7-13.6% for items.
Reliability	Kuder-Richardson 20-test statistics for scales used in 1999 survey: co-ordination 0.60, discharge (0.71), hospital environment (0.66), information and communication (0.74), pain (0.65), patient involvement (0.64).
Validity	For the 1999 data, construct validity as assessed through comparisons of sociodemographic groups, appeared to be good.
Data collection	
Sampling	About one third of England's acute and specialist NHS trusts participated. Questionnaires were sent to 5185 patients and 3784 responded. Specialist cardiac trusts and trusts non-specialist acute trusts were not eligible.
Sampling period	January to February 2004.
Survey administration	Postal questionnaire.
Reminders	Two reminders.
Response rate	75%.

3 Reporting of results	
Media	Journal article and report.
Adjustments	

4 References

Airey C, Bruster S, Calderwood L et al. National surveys of NHS patients – Coronary Heart Disease 1999: National Report Summary of Key Findings. Department of Health, 2001.
Healthcare Commission. Coronary heart disease survey of patients 2004. Healthcare Commission, 2005.
Jenkinson C, Coulter A, Bruster S et al. The coronary heart disease in-patient experience questionnaire (I-PEQ (CHD): Results from the survey of National Health Service patients. Quality of Life Research 2002;11:721-727.
Jenkinson C, Coulter A, Bruster S et al. Factors relating to patients' reports about hospital care for coronary heart disease in England. Journal of health services research and policy 2003;8:83-86.

Table 40 Picker Institute Europe — England
Emergency department survey 2004/2005

1 Background to survey	
Organisation(s)	Picker Institute Europe, Department of Health and the Healthcare Commission.
Funding	Healthcare Commission.
Objectives	The purpose was to assess the quality of NHS patient care, as seen by hospital patients who were patients at emergency departments.
Recipients of results	Department of Health and NHS trusts.
History	The survey was previously undertaken in 2003.
2 Design	
Setting	Acute emergency department care.
Population	
Inclusion/exclusion criteria	Adults aged 16 and over attending a main emergency department. Those who attended minor injuries units, medical or surgical admission units were excluded.
Questionnaire	Picker Adult Emergency Questionnaire.
Length	49 items.
Scales (items)	Items are grouped in sections that do not comprise scales: about you (7), arrival at the emergency department (7), doctors and nurses (7), hospital environment and facilities (3), information (3), leaving the emergency department (5), overall (3), your care and treatment (14).
Item scaling	Three-point scales, dichotomised into 'problem scores' for purposes of analysis.
Development	Data from 2003 informed questionnaire development. Most trusts chose to use the extended 12-page rather than the 8-page core questionnaire and so it was possible to study which items in the extended 12-page questionnaire could be included in the 2004/2005 survey's core questionnaire. Item selection also took account of items from the 2003 performance indicators, the Department of Health's Public Service Agreement targets and the 2002 Emergency department importance study with 49 issues rated by patients. All lead contacts in NHS trusts participating in the 2003 survey were asked to give comments by email. There were a few changes to the earlier 2003 survey. Five items were removed from the core questionnaire but remained in the item bank and one item was removed from both. There were a few minor changes to some items within either the core questionnaire or the item bank.

	39 items were directly comparable between the 2003 and 2004/2005 surveys.
Data quality	
Reliability	
Validity	
Data collection	
Sampling	All 153 NHS trusts with an emergency department participated. At each trust staff selected a random sample of 850 patients from the hospital's administrative records who had attended its emergency department over a three month period. 129 948 patients were contacted and 55 339 responded.
Sampling period	June, July or August 2004.
Survey administration	Postal questionnaire.
Reminders	Two reminders.
Response rate	44%.
3 Reporting of results	
Media	Report.
Adjustments	
4 References	

Bullen N, Magee H, Reeves R. Development and pilot testing of the NHS Acute Trust Emergency Department Survey 2003. Picker Institute Europe, 2003.
Commission for Health Improvement. Accident and emergency patient survey. Commission for Health Improvement, 2003.
Healthcare Commission. Patient Survey Programme 2004/5. Emergency Department: key findings. Healthcare Commission, 2005.
Reeves R. Preparation of core questionnaire for Emergency Department survey 2004/5. Picker Institute Europe, 2004.

Table 41 Picker Institute Europe National survey of stroke patients 2004 and 2005	England
1 Background to survey	
Organisation(s)	Picker Institute Europe, Department of Health and the Healthcare Commission.
Funding	Healthcare Commission.
Objectives	The purpose was to assess the quality of NHS patient care, as seen by hospital patients who had been stroke patients.
Recipients of results	Department of Health and NHS trusts.
History	This was the first survey of stroke patients.
2 Design	
Setting	Stroke patients' health care.
Population	
Inclusion/exclusion criteria	Patients whose primary diagnosis was intracerebral haemorrhage, cerebral infarction or stroke.
Questionnaire	
Length	54 and 49 items for the years 2004 and 2005 respectively.
Scales (items)	Items are grouped in sections that do not comprise scales which for 2004 were: about you (5), admission to hospital (3), after your stay in hospital (9), diagnosis (3), hospital doctors (4), leaving hospital (10), nursing staff (5), your care and treatment in hospital (14).
Item scaling	Three-point scales, dichotomised into 'problem scores' for purposes of analysis.
Development	Questionnaire development was based on a literature review, expert group, pilot survey and cognitive interviews with patients. The literature search of peer-reviewed and grey literature was designed to identify aspects of stroke patient experience. The expert advisory group was drawn from the Intercollegiate Working Party for Stroke at the Royal College for Physicians. Following the construction of the questionnaire items, cognitive interviews with patients were then used to test face validity. The pilot survey by mail included 187 patients from three NHS trusts who had been admitted to hospital between September and November 2003 following a stroke (response rate 63.6%). The questionnaire was revised following the pilot and there was further consultation with the advisory group and cognitive interviews with patients.
Data quality	
Reliability	
Validity	
Data collection	
Sampling	One in three of 51 NHS acute non-specialist hospital trusts in England participated in autumn 2004 and drew a random sample of 2786 stroke patients who had been discharged over a three month period. Each trust had their sample validated by a clinician to confirm diagnosis. 1713 patients responded. In the summer of 2005, there were 875 respondents who took part in a follow up survey. There were significant differences between respondents and non-respondents to the follow up survey with lower response rates from those under 51 or above 81 years of age, living in more socio-economic deprived areas, poorer health status, poorer

	experiences with hospitals reported in 2004 survey.
Sampling period	Drawn in the autumn 2004 from patients discharged 1 April to 30 June 2004.
Survey administration	Postal questionnaire.
Reminders	Two reminders.
Response rate	65%.
3 Reporting of results	
Media	Report.
Adjustments	
4 References	
Healthcare Commission. Survey of patients 2005 Stroke. Healthcare Commission, 2005. Healthcare Commission. Survey of patients 2006. Caring for people after they have had a stroke. Healthcare Commission, 2006. Howell E, Dunckley M, Reeves R. Development and pilot testing of the questionnaire for use in NHS trust-based stroke survey. Picker Institute Europe, 2004.	

Table 42 Picker Institute Europe Outpatient department survey 2004/2005	England
1 Background to survey	
Organisation(s)	Picker Institute Europe, Department of Health and the Healthcare Commission.
Funding	Healthcare Commission.
Objectives	The purpose was to assess the quality of NHS patient care, as seen by hospital patients who had been acute outpatients.
Recipients of results	Department of Health and NHS trusts.
History	The survey was previously undertaken in 2002/2003.
2 Design	
Setting	Acute outpatient health care.
Population	
Inclusion/exclusion criteria	Adults aged 16 and over who attended an outpatient department during June, July or August 2004. Patients from maternity and psychiatric clinics were excluded.
Questionnaire	The Picker Adult Outpatient Questionnaire.
Length	56 items.
Scales (items)	Items are grouped in sections that do not comprise scales: about the appointment (9), before the appointment (4), hospital environment and facilities (3), leaving the outpatients department (7), overall impression (4), seeing a doctor (8), seeing another professional (4), tests and treatment (7), waiting (3), your background (7).
Item scaling	Three-point scales, dichotomised into ‘problem scores’ for purposes of analysis.
Development	The questionnaire was based on the 2002/2003 outpatient survey questionnaire which was developed following focus groups with patients and discussion with the Commission for Health Improvement. The development also drew upon the Picker Emergency Department survey. The resulting items were then tested in cognitive interviews with patients’ to assess their understanding of items. A subsequent

	‘importance study’ involved members of public who had recent outpatient experience. The questionnaire was then refined and piloted by means of a postal questionnaire with 850 patients; 2 reminders were sent to non-respondents. 43 items were directly comparable between the 2002/2003 and 2004/2005 surveys. Omitted questions were made available in a item bank. Questionnaire modifications took account of the Department of Health’s Public Service Agreement targets and items included in the 2003 performance indicator. Recent patients of outpatient departments took part in an importance study, rating 46 issues. Feedback was asked from all lead contacts at NHS trust who took part in the 2002/2003 survey. Five items were omitted, and some minor changes were made to some items both in the core questionnaire and to items in the item bank.
Data quality	
Reliability	
Validity	
Data collection	
Sampling	At 169 trusts staff selected a random sample of 850 patients from the hospital’s administrative records. 143 596 patients were contacted and 84 280 responded.
Sampling period	Patients attending hospital in June, July or August 2004.
Survey administration	Postal questionnaire.
Reminders	Two reminders.
Response rate	
3 Reporting of results	
Media	Report.
Adjustments	
4 References	
Bullen N, Reeves R, Richards N. Development and Pilot testing of the NHS Acute Trust Outpatient Survey 2003. Picker Institute Europe, 2003. Commission for Healthcare Improvement and National Health Service Survey Advice Centre. Outpatients patient survey 2003. Commission for Health Improvement and National Health Service Survey Advice Centre, 2003. Healthcare Commission. Patient Survey Programme 2004/2005 Outpatient department: key findings. Healthcare Commission, 2005. Reeves R, Chisholm C. Preparations of core questionnaire for Outpatients survey 2004/2005. Picker Institute Europe, 2005.	

Table 43 Picker Institute Europe Primary care survey 2005	England
1 Background to survey	
Organisation(s)	Picker Institute Europe, Department of Health and the Healthcare Commission.
Funding	Healthcare Commission.
Objectives	The purpose was to assess the quality of NHS primary care.
Recipients of results	Department of Health and NHS trusts.
History	The survey was previously undertaken in 2003 and 2004 and most of the survey development was done prior to those two data collections. Both surveys had a response rate of 49%, slightly higher than the 2005 survey's 47%. The General Practice survey was undertaken in 1998 and 2002 whch had very similar aims to the primary care survey starting in 2003. However, the sampling methodology was different, as the sample was drawn from the Electoral Register. The data from 1998 and 2002 were weighted by age, sex and health authority prior to analysis and the response rates were 64.5% and 58.2%. The 2005 survey's report includes only longitudinal comparisons, whenever possible, with the 2003 and 2004 surveys.
2 Design	
Setting	Adult primary health care.
Population	
Inclusion/exclusion criteria	Adults aged 16 and over registered with a General Practitioner.
Questionnaire	Local Health Services Questionnaire 2004 (modified).
Length	55 items.
Scales (items)	Items are grouped in sections that do not comprise scales: about you (7), dental care (7), health promotion (4), making an appointment (5), medicines (7), overall about your GP surgery/health centre (4), referrals (4), seeing another professional (5), seeing a doctor (8), visiting the GP surgery (4).
Item scaling	Three-point scales, dichotomised into 'problem scores' for purposes of analysis.
Development	Development started prior to the survey that was carried out in 2003. A literature review of 14 questionnaires, including the two general practice surveys from 1998 and 2002, identified eleven topics used in a first version of the questionnaire. Cognitive interviews with 41 patients were used to test the questionnaire structure and item comprehensibility. Some changes were made to the wording and content of items. Further changes were made after consulting representatives of the Commission for Healthcare Improvement, Department of Health and the British Dental Association. There was not time for a pilot survey. Improvements were made to the 2003 primary care survey following consultation with 22 primary care trusts, consideration of the 2003 survey dataset and cognitive interviews with 30 patients. Minor changes were made to the questionnaire, in consultation with the CHI. 32 items were directly comparable between the 2003 and 2004 surveys. Some items were removed from the 2003 core questionnaire, but trusts could still choose to include these. An eight-page core questionnaire with 55 items was developed, with additional validated items added to an item bank from which individual trusts could choose to add items to the survey. The topics covered in the 2003 survey were restructured in the 2004 survey. No pilot survey was carried out prior to the 2004 survey. In preparation for the 2005 survey few changes were made to the local health

	services questionnaire from the 2004 survey. Further development of the questionnaire was based on comments from trusts, consideration of the 2004 dataset, the inclusion of items in the 2004 PSA targets and the inclusion of items in the 2004 performance indicators. Six items were removed from the 2004 core questionnaire. Some minor changes were made to item ordering and wording. Six items were added.
Data quality	
Reliability	
Validity	
Data collection	
Sampling	All NHS primary care trusts participated and hospital staff selected a random sample of 850 patients from each hospital’s administrative records. 257 505 patients were contacted and 116 939 responded.
Sampling period	January to March 2005.
Survey administration	Postal questionnaire.
Reminders	Two reminders.
Response rate	47%.
3 Reporting of results	
Media	Report.
Adjustments	

4 References

Airey C, Bruster S, Erens B et al. National surveys of NHS patients: general practice 1998. NHS Executive, 1999.
Boreham R, Airey C, Erens B et al. The national surveys of NHS patients: general practice 2002. Department of Health, 2003.
Chisholm A, Osborn C, Magee H et al. Development of the questionnaire for use in the Primary Care Trust survey programme. Picker Institute Europe, 2004.
Chisholm A, Reeves R, Graham C et al. Patient survey report 2004 – primary care. Healthcare Commission, 2004.
Chisholm A, Osborn C, Magee H et al. Preparation of core questionnaire for local health services survey 2005. Picker Institute Europe, 2005.
Commission for Health Improvement. Local health services patient survey 2003. Commission for Health Improvement, 2003.
Healthcare Commission. Survey of patients 2005. Primary care trust. Healthcare Commission, 2005.

Table 44 Picker Institute Europe England
National survey of adult inpatients 2006

1 Background to survey	
Organisation(s)	Picker Institute Europe, Department of Health and the Healthcare Commission.
Funding	Healthcare Commission.
Objectives	The purpose was to assess the quality of NHS patient care, as seen by acute hospital inpatients.
Recipients of results	Department of Health and NHS trusts.

History	The survey was previously undertaken in 2002, 2004 and 2005.
2 Design	
Setting	Acute adult inpatient health care.
Population	
Inclusion/exclusion criteria	Adults aged 16 and over who had an overnight stay. Psychiatric and maternity patients were excluded.
Questionnaire	Picker Patient Experience Questionnaire (PPE-15).
Length	75 items.
Scales (items)	Items are grouped in sections that do not comprise scales: about you (7), admission to hospital (1), doctors (4), emergency care (4), emergency department (4), hospital and ward (11), leaving hospital (10), nurses (5), operators & procedures (8), overall (5), pain (2), waiting list or planned admission (5), your care and treatment (9).
Item scaling	Three-point scales, dichotomised into ‘problem scores’ for purposes of analysis.
Development	Four versions of the Picker Adult Inpatient Questionnaire were pilot tested in 2001. First, the four-page (31 items) core and twelve-page (108 items) enhanced questionnaires were pioted in two English inner city NHS trusts. Following focus groups and cognitive interviews with patients, changes were made to the content and wording to create two more comprehensive surveys; the eight-page extended core questionnaire and the 16-page extended enhanced questionnaire. Additional items on ethnicity and health status were included. These two longer questionnaires were then pilot tested in a rural NHS trust. Alongside all four questionnaires a one-page questionnaire was included which asked patients what they thought of the inpatient questionnaire. Following the evaluation of internal consistency and the additional one-page questionnaire, it was found that the 16-page questionnaire performed less well. The conclusion was that the 15 core items (PPE-15), performed equally well across all four surveys. The four-page questionnaire was too short to include all relevant ethnic and health status variables so the eight-page version was preferred. Most trusts chose to use the extended twelve-page version in the Adult Inpatient Survey 2002. There was a minor revision prior to the 2004 survey. The development of the questionnaire used in the 2005 adult inpatient survey built upon the 2002 and 2004 adult inpatient surveys. This process started in January 2005 with the 2004 questionnaire and had five phases: first, consultation with the Healthcare Commission and experts in the field of acute inpatient care; second, modification of the questionnaire and guidance; third, ten cognitive interviews with patients to assess face validity, including 28 new items; four, postal survey in three acute hospitals in the summer of 2005; and five, further consultation with the Healthcare Commission and the Department of Health Prior to the pilot survey. Three items were removed and several were added. For the 2006 survey three new items relating to health status were added to the section ‘about you’.
Data quality	
Reliability	
Validity	
Data collection	
Sampling	Staff at 167 acute or specialist trusts in England selected a random sample of 850 patients from the hospital’s administrative records. The eligible patients had been discharged from hospital after at least one overnight stay. 141 447 patients were contacted and almost 81 000 responded. All trusts were required to submit their

	final sample of 850 randomly selected patients prior to data collection. These gross samples were checked by researchers at the Acute Co-ordination Centre (ACC) for sampling and data errors based on problems known from the earlier patient surveys; 38 major errors and 141 minor errors were found. 28 trusts were advised to redraw their sample. The minor errors could be handled by the ACC and trusts were not advised to draw new random samples.
Sampling period	Between June and August 2006.
Survey administration	Postal questionnaire.
Reminders	Two reminders.
Response rate	59%.
3 Reporting of results	
Media	Report.
Adjustments	
4 References	
Boyd J, Wood D, Reeves R. Development and pilot testing of the questionnaire for use in the acute adult inpatient survey. Picker Institute Europe, 2005. Boyd J. Inpatient survey 2006: Sampling problems. Picker Institute Europe, 2007. Bullen N , Reeves R. Acute Inpatient Survey National Overview 2001/02. Department of Health, 2003. Healthcare Commission. Survey of patients 2005. Healthcare Commission, 2006. Healthcare Commission. Inpatients. The views of hospital inpatients in England. Key findings from the 2006 survey. Healthcare Commission, 2007. Reeves R et al. Development and pilot testing of questionnaires for use in the acute NHS trust inpatient survey programme. Picker Institute Europe, 2002. Reeves R. Preparations of core questionnaire for inpatient survey 2004. Picker Institute Europe, 2004. Reeves R, Ramm J, Cornelius V et al. Patient survey report 2004 – adult inpatients. Healthcare Commission, 2004.	

Table 45 Picker Institute Europe National survey of people with diabetes 2006	England
1 Background to survey	
Organisation(s)	Picker Institute Europe, Department of Health and the Healthcare Commission.
Funding	The National Clinical Director for Diabetes, Royal College of General Practitioners and Diabetes UK.
Objectives	The purpose was to assess the quality of NHS health care for patients diagnosed with diabetes.
Recipients of results	Department of Health and NHS trusts.
History	This was the first survey relating to diabetes.
2 Design	
Setting	Adult health care for patients diagnosed with diabetes.
Population	
Inclusion/exclusion criteria	Adults aged 16 years and over diagnosed with diabetes.
Questionnaire	

Length	75 items.
Scales (items)	Items are grouped in sections that do not comprise scales: access to GP services (6), background (8), check-ups (7), diagnosis (6), education and training (7), management of your diabetes (13), psychological and emotional support (3), stays in hospital (10), tests (15).
Item scaling	Three-point scales, dichotomised into ‘problem scores’ for purposes of analysis.
Development	
Data quality	
Reliability	
Validity	
Data collection	
Sampling	All 152 NHS primary care trusts participated and hospital staff selected a random sample of 850 patients from each hospital’s administrative records. Almost 125 000 patients were contacted and about 68 500 responded.
Sampling period	Autumn 2006.
Survey administration	Postal questionnaire.
Reminders	Two reminders.
Response rate	55%.
3 Reporting of results	
Media	Report.
Adjustments	
4 References	
Healthcare Commission. Diabetes. The views of people with diabetes. Key findings from the 2006 survey. Healthcare Commission, 2007.	

Table 46 Picker Institute Europe Survey of users of mental health services 2006	England
1 Background to survey	
Organisation(s)	Picker Institute Europe, Department of Health and the Healthcare Commission.
Funding	Healthcare Commission.
Objectives	The purpose was to assess the quality of NHS mental health care.
Recipients of results	Department of Health and NHS trusts.
History	Surveys of mental health patients from 81 trusts were undertaken in 2004 and 2005.
2 Design	
Setting	Adult mental health care.
Population	
Inclusion/exclusion criteria	Adults aged 16 years and over who were on the Care Program Approach (CPA) and had used mental health services between 1 September 2005 and 30 November 2005.

Questionnaire	
Length	58 items.
Scales (items)	Items are grouped in sections that do not comprise scales: about you (4), counselling (3), crisis care (4), health professionals (15), medications (5), overall (4), standards (3), support in the community (6), your care and treatment (2), your care co-ordinator (2), your care plan (3), your care review (5), your family or carer (2).
Item scaling	Three-point scales, dichotomised into 'problem scores' for purposes of analysis.
Development	Prior to the 2004 survey a literature review was undertaken which included a review of eight questionnaires. Telephone and face-to-face interviews took place with mental health professionals and individuals working in the mental health voluntary sectors. Focus groups and cognitive interviews were held with people with mental health problems. There followed a postal survey of three NHS mental health trusts in the spring of 2003 which was followed by consultation with an advisory group including members of the Department of Health Mental Health Task Force. There was a voluntary survey in 34 mental health trusts in the summer of 2003 (mean response rate 40%). The questionnaire was then revised and piloted in the autumn of 2003. There was a survey of 200 non-respondents and a randomised trial to test methods of enhancing response rates. Before the 2005 survey further changes were made to the 2004 mental health survey informed by the analysis of the 2004 survey dataset, feedback from trusts, service user forums, mental health advisory group, six cognitive interviews, and a collaboration between the Healthcare Commission and The Cambridgeshire & Peterborough Mental Health Partnership NHS trust in June 2004. Minor changes were made to seven items, four items were removed and four were added.
Data quality	
Reliability	
Validity	
Data collection	
Sampling	Participants included 79 mental health trusts providing secondary mental health services including combined mental health and social care trusts and primary care trusts responsible for adult mental health. Hospital staff selected a random sample of 850 patients aged 16-65 who received mental health services within a two month period. 65 797 patients were contacted and 24 796 responded. 19 494 of those who responded were aged 16-65 (39%).
Sampling period	Patients that used mental health services from 1 September 2005 to 1 November 2005.
Survey administration	Postal questionnaire.
Reminders	Two reminders.
Response rate	38%.

3 Reporting of results

Media	Report.
Adjustments	

4 References

Healthcare Commission. Survey of users 2005. Mental health services. Healthcare Commission, 2005.
Healthcare Commission. Survey of users of services 2006. Community mental health services. Healthcare Commission, 2006.

Osborn C, Reeves R, Howell E et al. Development and pilot testing of the questionnaire for use in NHS Trust-based Mental Health service user survey. Picker Institute Europe, 2004.
Picker Institute Europe. Preparation of service user questionnaire for mental health survey 2005. Picker Institute Europe, 2004.
Reeves R, Howell E, Graham C. Patient survey report 2004 – mental health. Healthcare Commission, 2004.

Picker Institute Europe – cross-national surveys

Table 47 Picker Institute Europe Inpatient experiences in five countries	Five countries
1 Background to survey	
Organisation(s)	Picker Institute Europe.
Funding	
Objectives	To describe the nature and frequency of problems reported by hospital patients in Germany, Sweden, Switzerland, UK and USA (Coulter and Cleary 2001), and to develop and test a core set of questions to measure patients' experiences of in-patient care (Jenkinson et al 2002).
Countries	Germany, Sweden, Switzerland, UK and USA.
Recipients of results	
History	This cross-sectional survey validates and compares the Picker questionnaire data collected between 1998 and 2000 in the US and four European countries.
2 Design	
Setting	Adult inpatient acute health care.
Population	
Inclusion/exclusion criteria	Inpatients over a twelve-month period in each country during 1998-2000. Outpatients, obstetric care or primary care patients were excluded.
Questionnaire	Picker Institute Adult In-patient Survey and the 15-item Picker Patient Experience Questionnaire (PPE-15).
Length	The PPE-15 consists of 15-items from the longer Picker in-patient survey which includes 40 items and other items, the exact number being country specific.
Scales (items)	Continuity and transition (4), coordination of care (6), emotional support (4), information and education (5), involvement of family and friends (3), overall impression (8), physical comfort (5), respect for patient preferences (4). There were also two global items relating to an overall evaluation of care and recommendation to others.
Item scaling	Three-point scales, dichotomised into 'problem scores' for purposes of analysis.
Development	The Picker Institute Adult In-patient Survey was initially developed following an expert advisory group, a literature review, in-depth interviews, focus groups with patients to determine their priorities, testing the questionnaire through cognitive interviews with patients, redrafting and piloting the questionnaire before a final version was ready. This was refined after two US national surveys. Criteria for the items included in the PPE-15 were that they should have: wide applicability, high correlations with the original questionnaire, internal consistency over 0.70, and item-total correlations over 0.3.

Translation	The questionnaire was translated from the US version and tested with patients for cultural and linguistic relevance and comparability of meaning.
Data quality	
Reliability	Cronbach's alpha for the PPE-15 were in the range 0.80-0.87 for Sweden and US respectively. One item relating to doctor communication did not meet the criterion for an item-total correlation over 0.3 (Sweden and US).
Validity	The PPE-15 index had correlations over 0.9 with the total numbers of items selected as problems in the longer questionnaire which is evidence for criterion validity.
Data collection	
Sampling	Hospitals included were self-selected, and represented a small sample of hospitals from each country. Either all patients or a random sample of patients within a specific period were selected for participation. The samples were however, selected in a similar way in all countries (Coulter and Cleary, 2001). Questionnaires were mailed to patients' homes within one month following discharge. There were some differences across country samples in demographic characteristics, hospital size and hospital type. Net samples were UK (3592), Germany (3716), Sweden (5306), Switzerland (13 939) and USA (103 426).
Sampling period	1998-2000.
Survey administration	Postal questionnaire.
Reminders	Two reminders.
Response rate	Germany 74%, Sweden 63%, Switzerland 52%, UK 65% and USA 46%.
3 Reporting of results	
Media	Journal article.
Adjustments	Direct standardization by age and sex regarding reporting the mean score from 0-100 on each of 7 scales and global measures.
4 References	
Coulter A, Cleary P. Patients' experiences with hospital care in five countries. Health Affairs 2001;20:244-252. Jenkinson C, Coulter A, Bruster S. The Picker Patient Experience Questionnaire: development and validation using data from in-patient surveys in five countries. International Journal for Quality in Health Care 2002;14:353-358.	

Table 48 Picker Institute Europe — Eight countries

Patients' views on the responsiveness of health systems and health care providers in eight countries

1 Background to survey	
Organisation(s)	Picker Institute Europe.
Funding	Merck Sharp & Dohme.
Objectives	To learn more about European people's views on the responsiveness of their country's health system and healthcare providers.
Countries	Germany, Italy, Poland, Slovenia, Spain, Sweden, Switzerland, UK.
Recipients of results	
History	This was not a traditional Picker survey differing in its sampling of the general population and use of computer-assisted telephone interviewing.

2 Design	
Setting	General population.
Population	
Inclusion/exclusion criteria	General population aged 16 and over. Those who did not have any care, treatment or tests within the previous 12 months were excluded.
Questionnaire	
Length	
Scales (items)	Choice of health care provider (yes/no), doctor explained things understandably, doctor gave time to ask questions, doctor listening skills, expectation of involvement in treatment decisions, overall communication rating, rating of opportunity to make a choice about health care, reported involvement in treatment decision.
Item scaling	Item scaling was variable with yes/no, four- and five-point scales.
Development	
Translation	
Data quality	
Reliability	
Validity	
Data collection	
Sampling	Data collection was organised by NIPO, a Netherlands-based market research institute. Approximately 1000 interviews were conducted in each country (n=8119): Italy (n=1021), Germany (n=1026), Poland (n=1050), Slovenia (n=1014), Spain (n=1000), Sweden (n=1000), Switzerland (n=1000), UK (n=1008).
Sampling period	July 2002.
Survey administration	Computer-assisted telephone interviewing (random digit dialling).
Reminders	
Response rate	Sweden 60%, Germany 45%, Switzerland 41%, Spain 40%, Poland 32%, Italy 18%, Slovenia 18%, UK 13%.
3 Reporting of results	
Media	Journal article.
Adjustments	Weighted percent by age and sex and age-standardized scores. Differences between weighted and unweighted results were minimal.
4 References	
Coulter A, Jenkinson C. European patients' views on the responsiveness of health systems and healthcare providers. European Journal of Public Health 2005;15:355-360.	

Unit of Patient Evaluation, Denmark

The Unit of Patient Evaluation was established in 1998 to assist departments at the Copenhagen county hospital undertaking patient satisfaction and evaluation surveys. The Danish Regions responsible for hospital administration finance the surveys with agreement from the national government. A professional working group and steering committee comprises regional representatives and the Ministry of the Interior and Health.

The Unit has had responsibility for the Danish National Survey of Patient Experiences since 2000 which takes place every two years. The aim of the survey is to identify and compare differences in patient experiences at the hospital and unit level within hospitals longitudinally and assesses clinical services and patient safety, patient and personnel continuity, inclusion and communication, information, care process, discharge, transitions between sectors, physical resources, waiting time and hospital choice.

Hospital inpatients over one year of age attending one of the 53 public hospitals within Denmark have been included in the surveys. Approximately 30 000 patients are selected for participation in each survey. Patients must also have a diagnosis within one of the basic specialties of internal medicine, orthopaedic or organ surgery and obstetrics/gynaecology. The patient details are retrieved from the national patient registry and 660 patients from each hospital are recruited with 220 coming from each of three diagnostic or treatment groups. The survey is postal with a facility for internet completion.

The questionnaire was developed following a review of the literature and patient interviews. It comprises 34 items that are not part of summated rating scales with reporting at the individual item level. Data are adjusted for age, sex and type of admission. Results are reported in journal articles and reports and are available on a website.

The unit has conducted many qualitative and quantitative studies of patient experiences, usually in cooperation with or on behalf of regions/communities, the Ministry of the Interior and Health, the Danish Cancer Society, the Danish Rheumatism Association, and hospitals both within and outside the Copenhagen region. The regional and cross-regional surveys are a continuation of the national patient experience survey. The unit also participates in several research, development and cooperation projects with a focus on patient experiences.

The fourth national survey took place in 2006 and its results were published in February 2007. The 2004 and 2006 survey methodology and results are summarised in two English written reports available on the website. Further information and links to their national reports and other documents are available at the Unit website www.patientoplevelser.dk.

Table 49 Unit of Patient Evaluation Hospital inpatients	Denmark
1 Background to survey	
Organisation(s)	Unit of Patient Evaluation, Danish government, Danish Regions. Representatives of the Regions and the Ministry of the Interior and Health constitute a working group and steering committee.
Funding	The 14 Danish Regions which operate the hospitals.
Objectives	Cross-sectional and longitudinal comparisons of patient experiences at the hospital and medical specialties level.
Recipients of results	Hospitals, Regions, Danish Ministry of the Interior and Health.
History	The survey started in 2000 and takes place every second year.
2 Design	
Setting	Hospital inpatients attending all 53 public hospitals with a diagnosis within the basic specialties of internal medicine, orthopaedic surgery, organ surgery and obstetrics/gynaecology.
Population	
Inclusion/exclusion criteria	Patients aged one and over. Patients under one year of age are excluded together with disease code DZ763 relating to healthy companions and healthy newborns.
Questionnaire	
Length	34 items.
Scales (items)	The questionnaire does not comprise scales, results being reported at the item level. Themes include: care, communication, continuity and coordination, free hospital choice, information, involvement of family, patient involvement.
Item scaling	Items are scaled with between two- and five-point descriptive scales.
Development	Review of existing questionnaires, literature review and cognitive interviews with patients.
Data quality	
Reliability	
Validity	
Data collection	
Sampling	Samples are drawn from the Danish National Patient Register comprising 660 patients from each hospital with 220 patients from each of internal medicine, orthopaedic surgery, organ surgery and obstetrics/gynaecology. Organ surgery and obstetric/gynaecology were merged because of the small number of patients during

	the inclusion period for the latter. For hospitals with a mix of medical and surgical departments, a random selection of 660 patients meeting the inclusion criteria was made. This gave 26 313 representative patients from all public hospitals in Denmark.
Sampling period	16 March 2006 to 15 June 2006.
Survey administration	Postal with internet provision through information included with the questionnaire. Questionnaires were mailed at the end of August 2006.
Reminders	Mailed at 14 days in mid-September 2006.
Response rate	58%.
3 Reporting of results	
Media	Journal article, report and website.
Adjustments	Age, sex, admission type.
4 References	
Mathieson TP, Freil M, Willaig I et al. So patients differentiate between aspects of healthcare quality. Journal for Healthcare Quality 2007;29:W1-3-W1-10. Østerbye T, Sevaldsen J, Hansen KS et al. Patients experiences in Danish hospitals 2006: questionnaire among 26 045 hospitalised patients. Unit of Patients Evaluation: Denmark, 2007.	

World Health Organization

The WHO's Health Systems Responsiveness program was developed as part of WHO's broader conceptual framework on health systems in 2000, which identified three focuses for health system goals, namely health, responsiveness and financing fairness (86). The concept of responsiveness is very similar to that of patient experiences, the aim of the responsiveness surveys being to assess what actually happens when the health care system comes into contact with a patient (60).

The Responsiveness program is designed to implement patient experiences as a further aspect of the WHO's cross-national evaluation of health systems. The aims of the program are firstly, to develop tools to assess, monitor and increase awareness of patient experiences or responsiveness of health care and, secondly, to produce norms or standards for assessing responsiveness with a focus on patient questionnaires. There is also a focus on inequitable treatment associated with social class. The program started in 1999 and is scheduled to run until the end of 2007.

The program period has been divided into three milestones. The objectives of the first which took place between 1999 and 2004, were the development of two questionnaires and production of national reports for each country participating in the WHO Multi-Country Survey Study on Health and The Health System Responsiveness study collected in 2000-2001. For the second milestone in 2005, specific country reports were developed for the World Health Survey (WHS) together with a cross-national summary implementation report. It also published analytical guidelines for analysing user-based questionnaires on responsiveness and tested the reliability and validity of the WHS responsiveness module and reported a short-list of items to measure responsiveness. For the third milestone, which took place during 2006 and 2007, there was a review and recommendations relating to the methodology of scale adjustment. Regional technical capacities were developed to help governments undertake their own health system responsiveness evaluations, including how to develop questionnaires and analyse results. Furthermore, processes for information sharing relating to health system responsiveness across regions and countries were developed and supported. Finally, technical leadership within the WHO was designed to advise countries on the implications of health policies and programs for health system responsiveness.

Three pilot and two cross-national cross-sectional surveys have been conducted. These included the Three Country Household Health Survey (1999), Key Informant Survey for the 2000 World Health Report (1999) which included 35 countries, Multi-Country Study Pilot in Eight Countries on Health and Health System Responsiveness (2000), WHO Multi-country Survey Study on Health and Health System Responsiveness (2000-2001) which included 60 countries and The World Health Survey implemented 2002-2004 in 71 countries. The Table below gives further details for the Multi-country Survey.

The World Health Survey from 2002 included 142 questions in the long questionnaire and 78 questions in the short questionnaire covering responsiveness through the same eight domains included in the multi-country study in 2000-2001. The brief version included half the number of questions in each of the eight domains and was used in 17 countries. The target population in each country was adults aged 18 and over with randomly drawn samples of between 1000 and 10 000 individuals. The 71 surveys involved either face-to-face, computer assisted telephone or computer assisted personal interviews. Country specific reports as well as an overall report of the health responsiveness results were planned for April 2006 and December 2005 respectively, however, these reports were not available while the review was being undertaken. Therefore information relating to the survey methodology used for measuring responsiveness in the World Health Survey from 2002 is not described in detail. In addition to the surveys asking patients about their health care experiences, the Key Informant Survey on Health and Health System Responsiveness (2000) was conducted in 41 countries. Further information relating to WHO's responsiveness surveys can be found at www.who.int/responsiveness/en/.

Table 50 World Health Organization WHO multi-country survey study on health and responsiveness 2000-2001	60 countries
1 Background to survey	
Organisation(s)	World Health Organization, INRA, GALLUP and 43 single country survey operators.
Funding	World Health Organisation.
Objectives	To develop various methods of comparable data collection on health and health system responsiveness.
Countries	60 countries.
Recipients of results	
History	The WHO's work on responsiveness is one component of its cross-national evaluation of health systems which started in 1999 and is scheduled to run until 2007.
2 Design	
Setting	General population survey relating to aspects of outpatient, inpatient and home health care.
Population	General population.
Inclusion/exclusion criteria	Adults aged 18 and over from private households having been in contact with the health care system during the 12 months prior to interview. Institutionalised individuals were excluded.
Questionnaire	Long Face-to-Face Questionnaire and the Brief Questionnaire for the multi-country survey study.
Length	Responsiveness module of surveys has 126 items (long form) and 87 items (brief).
Scales (items)	Respect for persons: autonomy, clear communication, confidentiality, dignity. Client orientation: access to social support networks, choice of health care provider, prompt attention, quality of basic amenities. Respondents that had been hospital inpatients were asked all questions. Ambulatory care patients were not asked about social support. Home care patients were not asked about social support and quality of basic amenities. All respondents were asked about: discrimination, non-utilisation, importance, reason and services, vignettes. There were also socio-demographic and healthstatus questions.
Item scaling	Item scaling is dependent on item content and varies from yes/no to five-point scaling.
Development	Development was based on a literature review. Seven domains were identified following the application of criteria and the review experts added the eighth domain of communication. Nine questions from the Consumer Assessment of Health PlanS (CAHPS) survey were included in the WHO survey with a few changes. The first pilot surveys took place in Colombia, the Philippines and Tanzania in 1999. Six domains were assessed using face-to-face interviews (n=150). A second pilot was part of the 35 country key informant survey in 1999, with seven domains of responsiveness (n=1791; range 24-72 per country). The third pilot for the multi-country household questionnaire, took place in China, Colombia, Egypt, Georgia, India, Nigeria, Slovakia, Turkey. This included all eight responsiveness domains (n=811; range 59-152 per country).
Translation	Questions were translated into at least one official language per country according to WHO Translation Guidelines. National expert groups checked translations and back-translations.

Data quality	Psychometric guidelines were developed which followed classical test theory. Two items had missing responses above the criterion of 20%. Average item non-response after excluding these two items was 4%.
Reliability	Criteria for item-total correlation and Cronbach's alpha were 0.4 and 0.8 respectively. Cronbach's Alpha for all items was 0.75 for the total sample. In the Australian sample the scale of prompt attention had an alpha of 0.60, while all other scales were larger than 0.75. For purposes of assessing test-retest reliability respondents in 9 countries (China, Colombia, Egypt, Georgia, Indonesia, India, Nigeria, Slovakia, Turkey) were approached one week after their first questionnaire had been administered. This gave 4625 retest interviews of which 2174 reported to have had ambulatory care experience during the previous 12 months, 183 had home care, and 283 were inpatients. The other respondents had no care experience. Kappa values showed moderate to excellent reliability with an average of 0.67 (range 0.43-0.87).
Validity	Internal construct validity was assessed through factor analysis. For patients with ambulatory care experiences, factor loadings for the 24 items were large across seven identified factors of autonomy, choice, communication, confidentiality, dignity, prompts attention, and quality of basic amenities. Two items relating to waiting time had factor loadings below 0.6.
Data collection	
Sampling	70 surveys were completed in 60 countries with 4 different types of questionnaire; one long version and three brief versions (Üstün et al, 2001). The household long face-to-face and household brief face-to-face interviews included all the responsiveness questions. For the household mode surveys the sample size was 5000-10 000 and the sampling frame used census data or electoral rolls. Samples were multistage stratified and nationally representative for urban and rural areas. The "Kish table" method was used to select one respondent from a household. Surveys collected using the brief face-to-face mode had a sample size of 1000-1500 selected from a sampling frame reasonably representative of the country's population. The sampling strategy was multi-stage random probability sampling, selected proportionally to the population distribution in metropolitan, urban and rural areas. Most postal surveys had a sample size of 5000 selected from a sampling frame reasonably representative for the national population. Telephone directories, partial coverage registries, post office listing, etc were considered as sampling frames if an up-to-date register of the entire population was not available. Where possible, eligible individuals were mailed a questionnaire. When an acceptable sampling frame was not available a household was selected and the "last birthday" method was applied to select an individual. Additional questions relating to the number of household members were included so that weights could be developed for the data. For the two countries using computer assisted telephone interviews a sample size of 1000 was taken from recently published telephone directories and individuals were contacted using the random digit dialling method. The sample sizes were from 348 to 9952 per survey. Survey response target was set at 30% (Üstün et al, 2001).
Sampling period	Towards the end of 2000 and 2001.
Survey administration	In-person household interviews (14 countries), brief face-to-face interviews (27 countries), computerized telephone interviews (2 countries) and postal survey (28 countries). The latter three modes were used by GALLUP and independent survey operators hired for specific countries. In 10 countries different modes were purposely chosen so to estimate the mode effect. Egypt and Turkey used a drop-off mode, where the interviewer dropped off the questionnaire at respondent homes and picked it up a few days later.
Reminders	

Response rate	93% for the long face-to-face administration (10 countries, range 82-99%), 59% for the brief face-to-face administration (27 countries, range 25-88%), 48% for the postal administration (28 countries, range 24-92%), and for the two countries using computer assisted telephone interview administration, Canada and Luxembourg, the response rates were 25% and 55% respectively. Egypt and Turkey, using drop-off mode, were counted among the postal surveys.
3 Reporting of results	
Media	Report.
Adjustments	Age-sex standardized population weights were used (Letkovicova et al, 2005). The methods used by the WHO in data analysis of self perceived health to adjust for expectation were as of December 2005, under development for being applied in the analysis of responsiveness data.
4 References	

Letkovicova H, Prasad A, La Vallèe R et al. The Health Systems Responsiveness Analytical Guidelines for Surveys in the Multi-country Survey Study. World Health Organization, 2005.
Üstün TB, Chatterji S, Villanueva M et al. WHO Multi-country Survey Study on Health and Responsiveness 2000-2001. World Health Organization, 2001.

Table 51 Maternity care (Hundley et al, 2000)	Scotland
1 Background to survey	
Organisation(s)	Centre for Advanced Studies in Nursing, Aberdeen University, Scotland.
Funding	Clinical Resource and Audit Group of the Scottish Executive Health Department.
Objectives	
Recipients of results	Scottish Programme for Clinical Effectiveness in Reproductive Health.
History	
2 Design	
Setting	Maternity care.
Population	
Inclusion/exclusion criteria	Women giving birth in Scotland in September 1998 unless the midwife deemed it inappropriate. Excluded women included those unable to complete a questionnaire in English, if the midwife deemed it inappropriate and women who delivered but no longer resided in Scotland on their tenth postnatal day.
Questionnaire	
Length	Results related to 28 variables.
Scales (items)	Items related to access/location of care, antenatal classes, continuity of care, intrapartum care, postnatal communication.
Item scaling	Item scales were descriptive and varied according to item content.
Development	Developed by the survey team and based on criteria agreed by the Standard Setting Group and several validated questionnaires (Mason, 1989; Lamping and Rowe, 1996, Audit Commission and Institute of Child Health, 1996; Hundley et al, 1997, Rennie et al, 1998). Tested with ten postnatal women to review acceptability and validity. Pilot survey with 52 women attending five Scottish hospitals.
Data quality	
Reliability	
Validity	
Data collection	
Sampling	Posters in the postnatal ward and leaflets given after delivery provided information to potential respondents. Information sheets were sent to all midwives who were required to assist in the distribution of the questionnaire. They were instructed to give the mother the questionnaire on the tenth postnatal day, however some gave the questionnaire on day 0. Gross sample was 1639 and net sample was 1152 with 1137 responses suitable for analysis. 38 respondents submitted their questionnaire after the end of October, and were not included.
Sampling period	Women giving birth in Scotland from 14 to 23 September 1998.

Survey administration	Self-completed questionnaires distributed by midwives were returned directly to the study team in prepaid envelopes.
Reminders	Reminders within two weeks.
Response rate	69% is a conservative estimate because the calculation of the response rate was not straightforward.
3 Reporting of results	
Media	Journal article.
Adjustments	
4 References	

Audit Commission & Institute of Child Health. Maternity Care Survey. Audit Commission/Institute of Child Health, Bristol, 1996.
Hundley V, Milne J, Glazener C et al. Satisfaction and the three Cs-continuity, choice and control - women's views from a randomised controlled trial of midwife-led care. British Journal of Obstetrics and Gynaecology 1997;104:1273-1280.
Hundley V, Rennie AM, Fitzmaurice A et al. A national survey of women's views of their maternity care in Scotland. Midwifery 2000;16:303-313.
Lamping DL, Rowe P. Users' manual for purchasers and providers: survey of wonen's experience of maternity services. (Short form). London: Health Services Research Unit, School of Hygiene and Tropical Medicine, 1996.
Mason V. Women's experience of maternity care – a survey manual. Office of Population Censuses and Surveys. London: HMSO, 1989.
Rennie AM, Hundley V, Gurney E et al. Women's priorities for care before and after delivery. British Journal of Midwifery 1998;6:434-438.

Table 52 Osteopathy (Licciardone and Herron, 2001)	USA
1 Background to survey	
Organisation(s)	Department of Family Medicine, Texas College of Osteopathic Medicine, Fort Worth, USA; Survey Research Centre of the University of North Texas.
Funding	Carl Everett Charitable Lead Trust Fund.
Objectives	To describe patients who visit osteopathic physicians, their satisfaction with care, asses their perceptions of osteopathic medicine and to compare them with patients who visit allopathic physicians and non-physician clinicians. Subsequent administrations of the survey will provide longitudinal data on osteopathic medicine as well as other healthcare topics.
Recipients of results	
History	The work described here relates to the measurement of patient satisfaction. A follow-up survey assessed public awareness of osteopathic services together with the use of such services.
2 Design	
Setting	Osteopathic medicine.
Population	
Inclusion/exclusion criteria	General population for the USA aged 18 and over with telephones in their household.

Questionnaire	The first Osteopathic Survey of Healthcare in America (OSTEOSURV-I) included the Patient Satisfaction Questionnaire (Ware et al, 1983; Licciardone JC, 2003).
Length	139 items including 11 items of patient satisfaction addressing 8 aspects of healthcare from the Patient Satisfaction Questionnaire (PCQ).
Scales (items)	PCQ: access (2), convenience of services (1), continuity of care (1), cost of care (1), emergency care (1), interpersonal manner (2), overall satisfaction (1), quality of care (2).
Item scaling	Five-point Likert scale.
Development	The OSTEOSURV-I was developed following a literature review.
Data quality	
Reliability	Test-retest percentage agreement and kappa were 41-72% and 0.11-0.46 at the item level and 56% and 0.26 at the scale level respectively.
Validity	The authors state that the process of development lends the questionnaire content validity.
Data collection	
Sampling	Random digit dialling was used to generate the sample using proportional population estimates from all telephone exchanges in the USA. Numbers were tried a minimum of five times using different times and weekday or weekend combinations. Of the initial 9994 telephone numbers, 1792 were non-working, 1303 were not assigned to households, 185 were not primary telephone lines or were assigned to individuals under 18 years of age. Of the remaining 6714 numbers, 2994 generated no contacts and 181 individuals did not speak English or were incapable of completing an interview. Of the 3539 eligible contacts, 1041 (29.4%) completed an interview on initial request.
Sampling period	Telephone interviews took place during September and October 1998.
Survey administration	Telephone interview.
Reminders	2192 attempts were made to convert a random sample of refusers, resulting in 1371 contacts of which 127 (9.3%) were willing to participate.
Response rate	36.0% weighted response rate following extrapolation of a refusal conversion rate to all eligible contacts.

3 Reporting of results

Media	Journal article.
Adjustments	

4 References

Licciardone JC, Herron KM. Characteristics, satisfaction, and perceptions of patients receiving ambulatory healthcare from osteopathic physicians: a comparative national survey. Journal of the American Osteopathy Association 2001;7:374-385.

Licciardone JC. Validity and reliability of the Osteopathic Survey of Health Care in America (OSTEOSURV). Journal of the American Osteopathy Association 2003;103:89-101.

Licciardone JC. Awareness and use of osteopathic physicians in the United States: results of the second Osteopathic Survey of Health Care in America (OSTEOSURV-II). Journal of the American Osteopathy Association 2003;6:281-289.

Ware JE Jr, Snyder MK, Wright WR et al. Defining and measuring patient satisfaction with medical care. Evaluation and Program Planning 1983;6:247-263.

Table 53 Breast health practices (Stamler et al, 2002)	Canada
1 Background to survey	
Organisation(s)	Nipissing University in North Bay, Ontario, Canada; University of Windsor, Windsor, Ontario; Social Science Research Unit, York University.
Funding	Canadian Breast Cancer Foundation, Ontario Chapter and the CAW Social Justice Fund.
Objectives	To study the satisfaction, knowledge and usage of organized breast screening clinics among Canadian women.
Recipients of results	
History	
2 Design	
Setting	Breast cancer screening services.
Population	
Inclusion/exclusion criteria	Canadian women aged 25 and over. Excluded women included those diagnosed with breast cancer, those living in the territories, non-English and non-French speakers and those that could not be reached by telephone.
Questionnaire	
Length	Ten items relating to knowledge, use and satisfaction with organized breast screening in their geographic area.
Scales (items)	
Item scaling	Nominal level categorical variables.
Development	
Data quality	
Reliability	
Validity	
Data collection	
Sampling	Canada's ten provinces were divided into five weighted regions. Women were contacted through random-digit dialling generated by area code. A female interviewer interviewed one woman in each household in English or French and 49.5% answered following one or two calls. Answers were entered into a computer-assisted telephone interview program during the interview.
Sampling period	1997.
Survey administration	Computer-assisted telephone interview.
Reminders	Two telephone calls were made.
Response rate	1224 (49.5%) women were interviewed.
3 Reporting of results	
Media	Journal article.
Adjustments	

4 References
Kurtz ME, Given B, Given CW et al. Relationships to barriers and facilitators to breast self-examination, mammography, and clinical breast examinations in a worksite population. Cancer and Nursing 1993;16:251-259. Stamler LL, Lafreniere K, Thomas B et al. A national survey of Canadian women: breast health practices, influences, and satisfaction. Canadian oncology nursing journal 2002:218-228.

Table 54 National Centers of Excellence in Women’s Health (Anderson et al, 2002)	USA
1 Background to survey	
Organisation(s)	Department of Public Health Sciences, Wake Forest University School of Medicine, Winston-Salem, North Carolina, USA; University of Michigan School of Public Health, Ann Arbor, Michigan; University of South Carolina Survey Research Laboratory.
Funding	The study was supported by contracts from the DHHS Office on Women’s Health and a grant from the Agency for Healthcare Research and Quality.
Objectives	To evaluate the quality of primary care services provided in National Centers of Excellence in Women’s Health (CoE) in comparison with quality of care benchmarks from national and local surveys.
Recipients of results	
History	
2 Design	
Setting	Clinical care centers.
Population	
Inclusion/exclusion criteria	Women aged 18 and over having made at least one primary care visit to the CoE within the previous year. Women were excluded whose last visit to the CoE was solely for an emergency, dropping off a specimen, a single procedure such as contraceptive injection, flu shot, a mammogram, allergy shot, or a visit with an allied health service such as physical therapy. Women were also excluded who during their last visit to the CoE did not see a doctor, nurse practitioner, nurse midwife or physician’s assistant.
Questionnaire	
Length	Ten items relating to primary care satisfaction and one global measure of satisfaction.
Scales (items)	The 10-item Primary Care Satisfaction Survey (PCSSW) for Women (Scholle et al, 2000) and a single item measure of global patient satisfaction from the 1999 Consumer Assessment of Health Plans Survey (National Committee for Quality Assurance, 1999).
Item scaling	Global satisfaction was scaled from 0 to 10, where 0 is the worst and 10 the best health care possible. PCSSW items used a 5-point scale from not at all satisfied to extremely satisfied.
Development	The development of the PCSSW was based on focus groups and cognitive interviews with women (Scholle et al, 2000).
Data quality	

Reliability	Cronbach’s alpha for the PCSSW was 0.95.
Validity	PCSSW discriminates well among women with high versus low comprehensiveness of services, and adds substantially to explaining statistical variation in global satisfaction (Scholle, Anderson and Weisman, unpublished data).
Data collection	
Sampling	200 completed surveys were sought for each CoE. The sampling frame was all patient visits during the last three months and a random sample of 400 was selected from each CoE for telephone contact and eligibility screening. Three centres required an “opt out” process enabling individuals to be deleted from the recruitment database; 1% to 11% requested this. One centre gave patients a form asking them to make contact should they wish to participate in the survey; 37% did not respond to the form. Each telephone interview lasted about 15 minutes. There was a minimum of 15 attempts at varying times of the day or different days within the week. There was a call back schedule for when the respondent was unable to participate when initial contact was made. 3111 women were sampled in total.
Sampling period	August 2001 to January 2002.
Survey administration	Computerized telephone interview.
Reminders	Two telephone calls were made.
Response rate	70.7% varying from 57.7-84.7% across sites.

3 Reporting of results

Media	Journal article.
Adjustments	Region, age, education, perceived health status and managed care enrollment were included as covariates to enable comparability and to adjust for design features in the CoE sample versus each benchmark sample.

4 References

Anderson RT, Barbara AM, Weisman C et al. A qualitative analysis of women’s satisfaction with primary care from a panel of focus groups in National Centers of Excellence in Women’s Health. Journal of Women’s Health and Gender-based Medicine 2001;10:637-647.
Anderson RT, Weisman CS, Scholle SH et al. Evaluation of the quality of care in the clinical care centers of the National Centers of Excellence in Women’s Health. Women’s Health Issues 2002;12:309-326.
National Committee for Quality Assurance. HEDIS 1999 Volume 3: HEDIS protocol for administering CAHPS 2.0H survey. Washington, DC: NCQA, 1998.
Scholle SH, Weisman C, Anderson RT et al. Women’s satisfaction with primary care: a new measurement effort from the PHS National Centers of Excellence in Women’s Health. Women’s Health Issues 2000;10:1.

Table 55 HIV inpatient and outpatient care (Wilson et al, 2002)	USA
1 Background to survey	
Organisation(s)	Division of Clinical Care Research and the Department of Medicine, Tufts New England Medical Center, Boston, Massachusetts, USA.
Funding	Agency for Health care Research and Quality, Health Services Resources Administration, National Institute for Mental Health, National Institute on Drug Abuse, National Institutes of Health Office of Research on Minority Health through the National Institute of Dental Research, National Institute for Child Health and Human Development, and the Robert Wood Johnson Foundation.
Objectives	To assess care experiences and patient characteristics associated with these experiences among HIV patients in the USA.
Recipients of results	
History	
2 Design	
Setting	Inpatient and outpatient care among HIV patients.
Population	
Inclusion/exclusion criteria	Patients age 18 and over with HIV infection. Patients at a military, prison or emergency department were excluded.
Questionnaire	Picker survey on quality of hospital care and Picker Ambulatory Care Questionnaire (Cleary et al, 1991; Keating et al, 2002).
Length	11 items relating to patient experiences.
Scales (items)	For patients reporting an inpatient stay there were two items from each of five dimensions in the Picker survey on quality of hospital care relating to: coordination and integration; emotional support; information and education; physical comfort; and, respect for patient' values, preferences and needs. A single item asked about overall care quality. Patients completing the first interview were administered a further ten items from the Picker Ambulatory Care Questionnaire relating to coordination and continuity, information and education, and patient respect. A single item asked about overall care quality.
Item scaling	The Picker items use three-point scales of yes always, yes sometimes, no. The overall quality items have a five-point scale of poor, fair, good, very good, excellent. The percentage of patients having problems for each item was calculated, for each scale and for all ten items.
Development	Regression analysis was used to select items from the Picker survey of quality of hospital care using a national database of hospitalised patients who did not have HIV. The piloting of 132 items was done at a hospital based ambulatory care practice to select items for the final questionnaire from the Picker Ambulatory Care Questionnaire.
Data quality	
Reliability	
Validity	
Data collection	
Sampling	Multistage national probability sample of persons in care for HIV from the HIV Cost

	and Services Utilization Study. First, areas and rural counties containing nearly 70% of all US AIDS cases were selected. Second, 86 providers known to care for patients with HIV infection and 116 other providers who had confirmed care for eligible patients in a screening survey of approximately 4000 physicians in relevant specialties identified from the American Medical Association Master File were selected. Third, patients receiving inpatient or outpatient care in January to February 1996 were drawn. Agreement to participate was obtained from 100% urban providers, 79% of rural providers, 70% of other urban providers and 83% of other rural providers. 84% of patients selected agreed to participate. The net sample represented 68% of everyone selected after taking the multistage sampling selection into account. Short-form and proxy respondents were used when those selected to participate were too ill or unable to complete the full interview. Only full interview respondents were included in the data analysis (Wilson et al, 2002). Data were collected as a cohort study, with three interviews. Patients were approached only after providers or their agents obtained permission. If a full interview was not completed at the first or second interview the patient was not re-interviewed.
Sampling period	Probability sample based on those who were patients between 5 January 1996 and 29 February 1996. The first interviews were from January 1996 to April 1997, the second from December 1996 to July 1997 and the third from August 1997 to January 1998.
Survey administration	Face to face interview.
Reminders	
Response rate	2864 (71% of those sampled) patients completed a first interview, 2466 a second and 2267 a third (65% of those surviving who were sampled).

3 Reporting of results

Media	Journal article.
Adjustments	Baseline analytical weight for each respondent used to adjust for sampling and non-response. Missing values imputed for essential covariates, using a standard “hot-deck” strategy. To adjust standard errors and statistical tests for the differential weighting and complex sample design, the linearization methods were used.

4 References

Cleary PD, Edgman-Levitan S, Roberts M et al. Patients evaluate their hospital care: a national survey. Medical Care 1991;4:254-267.
Keating NL, Green DC, Kao AD et al. How are patients’ specific ambulatory care experiences related to trust, satisfaction, and considering changing physicians? Journal of General Internal Medicine 2002;17:29-39.
Wilson IB, Ding L, Hays R et al. HIV patients’ experiences with inpatient and outpatient care. Results of a national survey. Medical Care 2002;40:1149-1160.

Table 56 Health care for patients with cystic fibrosis (Walters, 2002) UK

1 Background to survey

Organisation(s)	Cystic Fibrosis Trust, Clinical Standards Advisory Group, Deparment of Public Health and Epidemiology, University of Birmingham.
Funding	
Objectives	Review of three surveys of adults with cystic fibrosis and two surveys of children with cystic fibrosis collected by the Cystic Fibrosis Trust to study access to specialist care, differences between specialist and non-specialist care, satisfaction with care,

	problems with hospital care and satisfaction with primary care in the UK.
Recipients of results	
History	The surveys that were reviewed by this study were undertaken for the Clinical Standards Advisory Group in 1990, 1992 and 2000 for adults and in 1992 and 1995 for children.
2 Design	
Setting	Health care for cystic fibrosis patients.
Population	
Inclusion/exclusion criteria	Members of the Cystic Fibrosis Trust aged 16 and over participating in the adult survey in 1990, 1994 or 2000. Parents known to the Cystic Fibrosis Trust participating in the children survey in 1992 or 1995.
Questionnaire	
Length	The three scales of hotel and professional aspects of patient satisfaction, facilities at cystic fibrosis clinics and general practice comprise 26 items. There were also items relating to access to care and investigations.
Scales (items)	Hotel and professional aspects of patient satisfaction (11), facilities at cystic fibrosis clinics (12), general practice (3). There were also items relating to access to care and investigations. Items relating to hotel and professional aspects of patient satisfaction are summed to produce two scales.
Item scaling	5-point scales.
Development	
Data quality	
Reliability	
Validity	
Data collection	
Sampling	Net versus gross samples were 866/1052 (1990), 1069/1870 (1994) and 1245/2283 (2000) for the three adult surveys and 542/1000 (1992) and 488/900 (1995) for the two child surveys.
Sampling period	Adults with cystic fibrosis were recruited in 1990, 1994 and 2000 and parents with children with cystic fibrosis were recruited in 1992 and 1995.
Survey administration	Postal questionnaire.
Reminders	
Response rate	Response rates for adults were 82.7%, 57.2% and 54.5% in 1990, 1994 and 2000 respectively. Response rates for children were 54.2% for both 1992 and 1995.
3 Reporting of results	
Media	Journal article.
Adjustments	
4 References	
Walters S. National Health services for patients with cystic fibrosis: the good, the bad and the ugly. Journal of the Royal Society of Medicine 2002;95(suppl):32-40.	

Table 57 Hospital inpatients (Sweeney et al, 2003)	Ireland
1 Background to survey	
Organisation(s)	Irish Society for Quality in Healthcare; Royal College of Surgeons in Ireland; Beaumont Hospital, Dublin.
Funding	
Objectives	Comparison of hospitals to stimulate quality improvement, while enhancing quality of care.
Recipients of results	Hospital staff.
History	
2 Design	
Setting	Hospitals including medical and surgical specialities.
Population	
Inclusion/exclusion criteria	Medical and surgical patients. Patients were excluded who were deemed incapable of completing a questionnaire or were discharged to a place other than their own home. Paediatric, psychiatric, severe cognitive impairment and detoxification patients were also excluded.
Questionnaire	
Length	95 items.
Scales (items)	Eight scales of satisfaction with health care: admission procedure, care and assistance, discharge procedure, information given, overall impression, pain management, physical environment, tests and operations.
Item scaling	Scaling varied across items with two or more descriptive categories.
Development	A steering committee with six members from a cross-section of health disciplines had responsibility for planning the development of the questionnaire which included a literature review, a review of existing questionnaires and patient focus groups. Piloting included recently discharged patients from two hospitals.
Data quality	
Reliability	
Validity	
Data collection	
Sampling	Random sample of 150 patients without replacement within each hospital. Total number of eligible patients was 3276.
Sampling period	January 2000 to October 2000, covering two months for each hospital.
Survey administration	Computer-aided telephone interview system conducted by trained members of the Irish Society for Quality in Healthcare and medical students 3-6 weeks after discharge. Three attempts at contact were made.
Reminders	
Response rate	1950 (59.5%).
3 Reporting of results	
Media	Journal article.

Adjustments	
4 References	
Sweeney J, Brooks AM, Leahy A. Development of the Irish National Patient Perception of Quality of Care Survey. International Journal for Quality in Health Care 2003;15:163-168.	

Table 58 Physician-patient interaction for African-American women with depression (Scarinci et al, 2004) USA

1 Background to survey	
Organisation(s)	National Black Women's Health Project (NBWHP) and University of Memphis Center for Community Health, Memphis, Tennessee, USA.
Funding	The Memphis Alliance for Public Health Research at the University of Memphis.
Objectives	To assess the relationship between physician-patient interaction and depression among African-American women.
Recipients of results	
History	
2 Design	
Setting	General practice.
Population	
Inclusion/exclusion criteria	African-American women from the NBWHP mailing list. Women were excluded who indicated that a nurse practitioner or physician assistant was the usual person they saw, that they did not see a particular individual for care or who did not know or were not sure.
Questionnaire	
Length	12 items related to patient experiences, specifically physician-patient interaction. The questionnaire also included the 20-item Center for Epidemiologic Studies Depression Scale (CES-D).
Scales (items)	The physician-patient interaction scale was taken from The Commonwealth Fund survey of mens and womens health (Schoen et al, 2003). Four items related to the patient's relationship with her provider: difficulty talking, problems not discussed, changed doctor due to dissatisfaction, offensive or inappropriate comments by doctor.
Item scaling	Physician-patient interaction items were on a five-point scale from excellent to very poor. The first of the physician-patient interaction items is scaled from very difficult to not difficult while the remainder are scales yes, no or not sure.
Development	The questionnaire was reviewed by a panel of experts. Survey procedures were pilot-tested among 100 African-American women attending a local church.
Data quality	
Reliability	Cronbach's alpha for the physician-patient interaction was 0.94.
Validity	
Data collection	
Sampling	Sampling was based on a mailing list from the NBWHP comprising 6000 individuals,

	of which 4848 were eligible. Among the 1821 completed surveys, 1411 respondents answered all items and reported a physician as their usual source of medical care.
Sampling period	
Survey administration	Questionnaires were sent by post, accompanied with a stamped addressed envelope, a consent form and a cover letter from NBWHP.
Reminders	Two postal reminders with respondents asked to complete the survey within 2 weeks. The second reminder was sent to non-respondents one month after the first reminder.
Response rate	38%.
3 Reporting of results	
Media	Journal article.
Adjustments	Linear or logistic regression with age, income, marital status and education as covariates.
4 References	
Scarinci IC, Beech BM, Watson JM. Physician-patient interaction and depression among African-American women: A national study. Ethnicity & Disease 2004;14:567-573. Schoen C, Simantov E, Gross R et al. Disparities in women's health and health care experiences in the United States and Israel: Findings from 1998 national women's health surveys. Women and Health 2003;37:49-70.	

Table 59 Antenatal care (Hildingsson and Rådestad, 2005)	Sweden
1 Background to survey	
Organisation(s)	Department of Health Sciences, Mid-Sweden University, Sundsvall, Sweden.
Funding	
Objectives	To report how satisfied Swedish women are with their antenatal care.
Recipients of results	
History	
2 Design	
Setting	Antenatal care.
Population	
Inclusion/exclusion criteria	Pregnant Swedish women. Miscarriages, non-Swedish-speaking women, women from non-participating clinics were excluded.
Questionnaire	
Length	The questionnaire included items relating to medical and emotional aspects of care: access to care, attention to needs, continuity, support from midwife.
Scales (items)	Items related to access/location of care, antenatal classes, continuity of care, intrapartum care, postnatal communication.
Item scaling	Satisfaction with medical and emotional aspects was assessed with a five-point scale from very satisfied to very dissatisfied. Assessment of the midwife regarding ability to give support and pay attention to partner's needs was assessed with a four-point scale from totally agree to totally disagree. Content of care was assessed with a three-point scale of not enough time, enough time, too much time.

Development	The questionnaire was based on existing questionnaires (Waldenstrom et al, 1993; Brown et al, 1994; Waldenstrom et al, 2000) and also included some new questions. A pilot study on 13 women assessing face validity resulted in minor changes in the wording of questions.
Data quality	
Reliability	
Validity	
Data collection	
Sampling	593 of the 608 antenatal clinics in Sweden participated. Pregnant women were invited to participate at their first booking visit and 3293 of 4600 (72%) meeting the inclusion criteria agreed to participate. Among these 2746 (83%) answered two postal questionnaires, in early pregnancy and two months after birth.
Sampling period	Three weeks evenly spread over the period of 1 year from 1999 to 2000.
Survey administration	Postal questionnaire.
Reminders	Up to two postal reminders.
Response rate	72% responded and 83% answered both questionnaires.
3 Reporting of results	
Media	Journal article.
Adjustments	Maternal age, parity and medical conditions.
4 References	
Brown S, Lumley J. Satisfaction with care in labour and birth: a survey of 790 Australian women. Birth 1994;21:4-13. Hildingsson I, Rådestad I. Swedish women's satisfaction with medical and emotional aspects of antenatal care. Journal of Advanced Nursing 2005;52:239-249. Waldenstrom U, Brown S, McLachlan H et al. Does team midwife care increase satisfaction with antenatal, intrapartum, and postpartum care? A randomised, controlled trial. Birth 2000;156-167. Waldenstrom U, Nilsson CA. Women's satisfaction with birth center care: a randomised, controlled study. Birth 1993;20:3-13.	

Table 60 Maternity care (Redshaw et al, 2007)	England
1 Background to survey	
Organisation(s)	National Perinatal Epidemiology Unit (NPEU), Oxford University; Department of Health; Healthcare Commission; Information Centre for Health and Social Care.
Funding	Department of Health, Healthcare Commission, Information Centre for Health and Social Care.
Objectives	Three research questions were specified: first, what is the current clinical practice in England from the perspective of women needing maternity care; second, what are the key areas of concern; and third, to assess changes in maternity care over the last ten years. Furthermore, the study's information was to be used as a benchmark of current practice, a baseline for measuring change over time in maternity health care, to inform policy in maternity care and support implementation of change and to serve as a point of comparison for local audits of user views and experiences in individual trusts.

Recipients of results	
History	A 1995 survey used the same sampling methodology.
2 Design	
Setting	Maternity health care.
Population	
Inclusion/exclusion criteria	Mothers who gave birth during one week in March 2006. Women who were aged under 16 and women whose babies had died were excluded.
Questionnaire	
Length	27 pages.
Scales (items)	Antenatal care, babies born at home, babies needing special care, care at home after the birth, care in hospital after the birth, dates and your baby, feeding your baby, hospital environment, labour and the birth of your baby, previous pregnancies and childbirth, you and your household.
Item scaling	Three-, four- and five-point scales.
Development	Experts from the Department of Health and the Healthcare Commission were represented in one project team and one project management group. In addition there was an expert stakeholders group which included professionals and user group representatives. A 1995 survey was the starting point for the development of the 2006 survey. The draft version of the new questionnaire was tested in a series of cognitive interviews. Mothers of young babies who had been recruited through community groups and personal contacts completed the questionnaire while commenting on it to a researcher who was present. Some changes were made based on the information from the cognitive interviews, especially in relation to difficulties with items relating to choice. The questionnaire was reduced from 43 to 27 A4 printed pages. The Office for National Statistics selected the random sample of 400 for the pilot survey and 238 responded (60%).
Data quality	
Reliability	
Validity	
Data collection	
Sampling	The survey used similar methodology as the 1995 survey and pilot survey. Instructions were available in 18 languages. A Language line interpreter could be used if necessary as part of a three-way telephone call. Using birth registrations during 4-10 March 2006 the Office for National Statistics selected a sample of 4800 women. Questionnaires were sent three months after the birth. Women whose babies had died were excluded and replaced. Questionnaires were returned to the National Perinatal Epidemiology Unit (n=2960). 10% of the questionnaires were checked and verified for data entry accuracy. Compared to non-respondents, respondents were more likely to be married, born in the UK, living in areas with lower deprivation and having the highest socio-economic classification. Non-respondents were more likely to have registered their baby jointly while living at different address from their partner or registered their baby alone, to be born outside the UK, to live in areas with high deprivation and to be classified as ‘occupation not stated or inadequately described’. Compared with national statistics for England and Wales sample respondents were more likely to be older and born in the UK than women in general who had given birth. Similar to the demographic changes since 1995, the 2006 sample was older and more ethnically diverse (13% as compared to 8% black and minority ethnic women). The mean age of babies at the time of

	questionnaire completion was 15.5 weeks (range 13-28). The Freephone helpline received 86 calls, and 11 of these were from women who needed help or advice in their own language. Three interviews were conducted by phone with an interpreter.
Sampling period	June 2006.
Survey administration	Postal questionnaire.
Reminders	Two postal reminders.
Response rate	63%.
3 Reporting of results	
Media	Report.
Adjustments	In comparisons of different groups adjustments were made for born in the UK, Index of Multiple Deprivation, mode of delivery, mother's age, parity and partner status.
4 References	
Redshaw M, Rowe R, Hockley C et al. Recorded delivery: a national survey of women's experience of maternity care. University of Oxford: National Perinatal Epidemiology Unit, 2007.	

Table 61 European Psychiatric Services: Inputs Linked to Outcome Domains and Needs (EPSILSON)
Mental health care for schizophrenia (Becker et al, 2000) Five countries

1 Background to survey	
Organisation(s)	Institute of Psychiatry, King’s College, London, UK; The EPSILON Study Group.
Funding	European Commission BIOMED-2 Programme with additional funding from National Fonds Geestelijke Volksgezondheid and Netherlands Organisation for Scientific Research, Spanish Institute of Health, and in Italy from Regione del Veneto, Giunta Regionale, Ricerca Sanitaria Finalizzata.
Objectives	The aim was to produce standardised European versions of five instruments in five languages in key areas of mental health service, and to compare data from five cross-national centres regarding patients with schizophrenia and mental health care provision and costs.
Countries	Denmark, Italy, Spain, The Netherlands, UK.
Recipients of results	
History	The EPSILON (European Psychiatric Services: Inputs Linked to Outcome Domains and Needs) study is a comparative, cross-sectional study of the characteristics, needs and life qualities of people with schizophrenia in five European countries and of the services they receive and associated costs and satisfaction levels.
2 Design	
Setting	Mental health care for patients with schizophrenia.
Population	
Inclusion/exclusion criteria	Adults aged 18-65 years with ICD-10 diagnosis F20 who had contact with mental health services during the three month period preceding the start of the study. Excluded patients included those resident in prison, secure residential services or hostels for long term patients, the presence of coexisting learning disability, primary dementia or other severe organic disorder, the patient having received extended in-patient treatment episodes lasting longer than a year.
Questionnaire	Several instruments were used with the Verona Service Satisfaction Scale (VSSS) being used to assess patient satisfaction.
Length	There are three versions of the VSSS; VSSS-82, VSSS-54 and VSSS-32 with 82, 54 and 32 items respectively. The European version, VSSS-EU, was developed from the Italian 54-item version.
Scales (items)	Access (2), efficacy (8), information (3), overall satisfaction (3), professionals’ skills and behaviour (16), relative’s involvement (5), types of intervention, (17), total score (54).
Item scaling	VSSS-EU items use a five-point scale of terrible, mostly dissatisfactory, mixed, mostly satisfactory, excellent.
Development	The development of the original VSSS has been described (Ruggeri and Dall’Agnola, 1993; Ruggeri et al, 1994).
Translation	Forward-back translation into the other four languages from Italian. Back transla-

	tions were assessed by the Italian authors.
Data quality	
Reliability	Across the five countries Cronbach’s alpha for total scores ranged from 0.92-0.96 and test-retest intraclass correlations for total scores ranged from 0.73-0.93.
Validity	
Data collection	
Sampling	An administrative prevalence sample of people with schizophrenia; 52 to 107 patients per site with a total of 404.
Sampling period	Three months prior to the start of the study.
Survey administration	Interview with interviewers receiving training in SCAN in Santander and at the Institute of Psychiatry in London, with regular follow-up meetings.
Reminders	
Response rate	Excluding Denmark the response rate for the other 4 samples combined was 63.42%.
3 Reporting of results	
Media	Journal article.
Adjustments	
4 References	

Becker T, Knapp M, Knudsen HC et al. The EPSILON study of schizophrenia in five European countries British Journal of Psychiatry 1999;175:514-521.
Becker T, Knapp M, Knudsen HC et al. Aims, outcome measures, study sites and patient sample. British Journal of Psychiatry 2000;177:s1-s7.
Knudsen HC, Vazquez-Barquero JL, Welcher B et al. Translation and cross-cultural adaptation of outcome measurements for schizophrenia. EPSILON Study 2. European Psychiatric Services: Inputs Linked to Outcome Domains and Needs. British Journal of Psychiatry 2000;39:s8-14.
Ruggeri M, Dall’Agnola R. The development and use of the Verona Expectations for Care Scale (VECS) and the Verona Service Satisfaction Scale (VSSS) for measuring expectations and satisfaction with community-based psychiatric services in patients, relatives and professionals. Psychological Medicine 1993;23:511-523.
Ruggeri M, Dall’Agnola R, Agostini C et al. Acceptability, sensitivity and content validity of the VECS and VSSS in measuring expectations and satisfaction in psychiatric patients and their relatives. Social Psychiatry and Psychiatric Epidemiology 1994;29:265-276.

Table 62 Netherlands Institute for Health Services Research (NIVEL) Primary care (Kerssens JJ et al, 2004)	12 countries
1 Background to survey	
Organisation(s)	NIVEL, Netherlands Institute for Health Services Research, Utrecht, Netherlands.
Funding	ZonMw “Netherlands Organization for Health Research and Development” project number 240-20-205.
Objectives	Quality of care Through patients’ Eyes (Quote) instruments were used to compare health care quality among patients in 12 countries and to correlate these patient evaluations with World Health Organization (WHO) measures of achievement.
Countries	Belarus, Denmark, Finland, Greece, Ireland, Israel, Italy, the Netherlands, Norway, Portugal, Ukraine.
Recipients of results	World Health Organization.
History	
2 Design	
Setting	Primary care.
Population	
Inclusion/exclusion criteria	Patient group varies by country according to diagnosis. General practice patients were recruited from Belarus and Ukraine. Patients with inflammatory bowel disease came from Denmark, Greece, Ireland, Israel, Italy, Norway, Portugal. Elderly patients came from Finland, Ireland, the Netherlands. Disabled patients came from the Netherlands, UK. Patients with diabetes, migrants, chronic obstructive pulmonary disease, rheumatism came from the Netherlands.
Questionnaire	Quote (Quality of care Through patients’ Eyes) instrument (Sixma et al, 1998, 2000; Calnan et al 2000; Van der Eijk et al, 2001).
Length	10 items.
Scales (items)	The ten Quote instrument items relating to the general practitioner or primary care provider and each comprised a scale.
Item scaling	Performance items are scaled no, not really, on the whole yes, and yes.
Development	Focus group interviews tailored to various patient groups (chronic obstructive pulmonary disease, diabetes, rheumatism) or providers (general practice, occupational therapy services).
Translation	The Finnish Quote-elderly questionnaire was translated after double forward-backward procedure.
Data quality	Reported for longer-form parent questionnaire.
Reliability	Reported for longer-form parent questionnaire.
Validity	Reported for longer-form parent questionnaire.
Data collection	
Sampling	In the Ukraine the sampling was opportunistic. In Belarus a random sample of 500 was drawn from 2000 patients. Patients with inflammatory bowel disease were randomly selected from patient lists in Greece, Ireland, Israel, Italy, Norway, the Netherlands. Elderly patients were selected from primary health care centres and home care organisations in Finland and Ireland respectively. In the Netherlands all but the inflammatory bowel disease patients were chosen randomly from GP files. In

	the UK the disabled patients were chosen from files of occupational therapy services. 5133 patients participated: Belarus (500), Denmark (102), Finland (143), Greece (96), Ireland (73), Israel (46), Italy (201), the Netherlands (2873), Norway (93), Portugal (36), Ukraine (490), UK (480).
Sampling period	
Survey administration	Postal questionnaire.
Reminders	
Response rate	Netherlands: 50-60% (Rheumatology), 35% (elderly).
3 Reporting of results	
Media	Journal article.
Adjustments	Age and sex in the random effects analyses to see the size of rho before and after correction. Means for each scale in each country were not adjusted.
4 References	

Calnan S, Sixma HJ, Calnan MW et al. Quality of local authority occupational therapy services: developing an instrument to measure the user's perspective. British Journal of Occupational Therapy 2000;63:155-62.
Kerssens JJ, Groenewegen PP, Sixma HJ et al. Comparison of patient evaluations of health care quality in relation to WHO measures of achievement in 12 European countries. World Health Organisation. Bulletin of the World Health Organisation 2004;82:2.
Sixma HJ, Kerssens JJ, van Campen C et al. Quality of care from the patients' perspective: from theoretical concept to a new measuring instrument. Health Expectations 1998;1:82-95.
Sixma HJ, van Campen C, Kerssens JJ et al. Quality of care from the perspective of elderly people: the QUOTE-elderly instrument. Age and Ageing 2000;29:173-178.
Van der Eijk I, Sixma HJ, Smeets T et al. Quality of health care in inflammatory bowel disease: development of a reliable questionnaire (QUOTE-IBD) and first results. American Journal of Gastroenterology 2001;96:3329-3336.

Table 63 European Task Force on Patient Evaluations of General Practice (EUROPEP) General practice (Wensing et al, 2004)	17 countries
1 Background to survey	
Organisation(s)	European Task Force on Patient Evaluations of General Practice (EUROPEP).
Funding	European Community (BiomedII).
Objectives	To examine associations between patient satisfaction and characteristics of health systems.
Countries	Austria, Belgium, Denmark, Finland, France, Germany, Iceland, Israel, The Netherlands, Norway, Portugal, Slovenia, Spain, Sweden, Switzerland, Turkey, UK.
Recipients of results	
History	The EUROPEP group has assessed patient priorities relating to different aspects of general practice care across eight countries (Wensing et al, 1998; Grol et al, 1999). Patient evaluations of general practice care have been compared across ten (Grol et al, 2000) and nine (Wensing et al, 2002) countries, the latter focusing on availability of services. These data were then supplemented with data for a further seven countries in a comparison of 17 countries (Wensing et al, 2002; Wensing et al, 2004).
2 Design	
Setting	General Practice.
Population	
Inclusion/exclusion criteria	Patients aged 18 and over who had recently visited the GP and were able to understand the national language.
Questionnaire	EUROPEP instrument.
Length	23 items.
Scales (items)	Clinical behaviour (16), organisation of care (7) and the sum of number of times the two most positive categories were endorsed for the 23 items.
Item scaling	Five-point end-anchored only scale of poor to excellent.
Development	Literature review and pilot studies in participating countries including qualitative and quantitative work. The EUROPEP is currently undergoing revision and is due to be finished and approved in May 2007.
Translation	Forward translation of the English version to national languages was independently performed by two researchers and one professional translator. The three of them then achieved consensus. Back translation was performed by two independent translators. Their results were then compared with the original English questionnaire in a meeting and a final translated version established (Grol and Wensing, 2000; Wensing et al, 2000).
Data quality	Missing data and score variation informed final item selection (Grol and Wensing, 2000; Wensing et al, 2000).
Reliability	Cronbach's alpha was 0.96 for clinical behaviour and 0.87 for organisation of care with little variation across countries (Wensing et al, 2000).
Validity	The authors state that the process of item selection guarantees content validity. Factor analysis identified the two scales of clinical behaviour and organisation of care (Wensing et al, 2000). EUROPEP scores were significantly associated with patients' recommending the GP to others, whether they had reasons for changing

	their GP, age, number of GP visits, health status (Wensing et al, 2000).
Data collection	
Sampling	The research teams for each country were responsible for the recruitment procedure. In each country, a stratified sample of approximately 36 practices was sought. Flanders and Wallonia in Belgium were treated as two countries. In each country the sample of practices was stratified by practice size and urbanisation. Only one GP from each practice could participate to reduce statistical clustering of data in Belgium, Denmark, Slovenia, Spain, Switzerland. GPs were randomly selected where feasible. The aim was to have at least 1080 patients for each country. The number of patients asked to participate varied from 45-80 per practice depending on the response rate predicted for each country. Patients were recruited consecutively.
Sampling period	Consecutive patients were asked to participate after chosen start dates in 1998 and 1999.
Survey administration	GPs' handed out the questionnaire following a consultation and patients' were asked to complete it at home and return it in a reply paid envelope.
Reminders	Postal at three weeks where feasible.
Response rate	Total sample was 25 052. Response rates available for individual countries ranged from 67-89% for Iceland and Norway respectively.
3 Reporting of results	
Media	Journal article.
Adjustments	
4 References	

Grol R, Wensing M, Mainz J et al. Patients' priorities with respect to general practice care: an international comparison. Family Practice 1999;16:4-11.
Grol R, Wensing M for the EUROPEP group. Patients evaluate general/family practice: the EUROPEP instrument. The Task Force on Patient Evaluations of General Practice Care, 2000.
Grol R, Wensing M. Patients evaluate general/family practice. The EUROPEP instrument. EQuiP, WONCA Region Europe, 2000.
Grol R, Wensing M, Mainz J et al. Patients in Europe evaluate general practice: an international comparison. British Journal of General Practice 2000;50:882-887.
Wensing M, Mainz J, Ferreira et al. General practice care and patients' priorities in Europe: an international comparison. Health Policy 1998;175-186.
Wensing M, Mainz J, Grol R for the EUROPEP group. A standardised instrument for patient evaluations of general practice care in Europe. Eurpean Journal of General Practice 2000;6:82-87.
Wensing M, Vedsted P, Kersnik J et al. Patient satisfaction with availability of general practice: an international comparison. International Journal for Quality in Health Care 2002;14:111-118.
Wensing M, Baker R, Szecsenyi J et al, on behalf of the EUROPEP Group. Impact of national health care systems on patient evaluations of general practice in Europe. Health Policy 2004;68:353-357.

Table 64 Diabetes Attitudes, Wishes and Needs (DAWN) study Diabetes care (Peyrot et al, 2006)	13 countries
1 Background to survey	
Organisation(s)	Diabetes Attitudes, Wishes and Needs (DAWN) study and Department of Sociology, Loyola College, Baltimore, USA. Fieldwork firms in each country undertook the surveys including translation.
Funding	Novo Nordisk Pharmaceuticals.
Objectives	To assess country-level and individual-level patterns in patient perceptions of care.
Countries	Australia, Denmark, France, Germany, India, Japan, the Netherlands, Norway, Poland, Spain, Sweden, UK and USA.
Recipients of results	
History	Data came from the DAWN study which was designed to identify attitudes, needs and wishes among patients with diabetes in order to inform the improvement of care.
2 Design	
Setting	Diabetic care.
Population	
Inclusion/exclusion criteria	Adults with type 1 or type 2 diabetes. Patients with serious illness or depression were excluded.
Questionnaire	
Length	Nine items relating to patient experiences.
Scales (items)	Ease of access to providers (3), financial barriers to care (1), quality of provider team collaboration (1), quality of patient-provider interaction (4).
Item scaling	Item scaling varied in terms of scale length and descriptors.
Development	The questionnaire was developed by the DAWN Advisory Panel following a review of diabetes-related questionnaires and focus groups comprising patients, providers and policy makers in eight countries.
Translation	Fieldwork firms in each country undertook the translation.
Data quality	
Reliability	Cronbach’s alpha for the two multi-item scales were 0.62 and 0.78.
Validity	
Data collection	
Sampling	Patients were randomly sampled. Sampling frames varied by country, but all were designed to give heterogeneous samples from the whole country, however the sample for India was limited to five regions. Scandinavia was viewed as one region. The quota was 500 patients for each region giving a total of 5500.
Sampling period	2001.
Survey administration	Face-to-face or telephone interviews taking 30-50 minutes.
Reminders	
Response rate	Respondents not providing demographic information were not included in the study giving 5104 (92.8%) patients.

3 Reporting of results

Media	Journal article.
Adjustments	Age, gender, education, marital status, occupation, residential location, diabetes complications, type of diabetes.

4 References

Alberti G. The DAWN (Diabetes Attitudes, Wishes and Needs) study. Practical Diabetes International 2002;19:22-24.

Peyrot M, Rubin RR, Lauritsen T et al. Psychosocial problems and barriers to improved diabetes management: results of the cross-sectional Diabetes Attitudes, Wishes and Needs (DAWN) study. Diabetes Medicine 2005;22:1379-1385.

Peyrot M, Rubin RR, Lauritsen T et al. Patient and provider perceptions of care for diabetes: results of the cross-national DAWN Study. Diabetologia 2006;49:279-288.

Skovlund SE, Peyrot M on behalf of the DAWN International Advisory Panel. The Diabetes Attitudes, Wishes, and Needs (DAWN) Program: a new approach to improving outcomes of diabetes care. Diabetes Spectrum 2005;18:136-142.

Table 65 European Organisation for Research into the Treatment of Cancer (EORTC) Inpatient cancer care (Bredart et al, 2007)

Six countries

1 Background to survey

Organisation(s)	European Organisation for Research into the Treatment of Cancer (EORTC).
Funding	National Agency for Accreditation and Evaluation in Health Care (France); Deutschr Krebshilfe, Germany; EORTC Quality of Life Group; National Cancer Institute, USA.
Objectives	To identify factors associated with hospitalised cancer patients' satisfaction with care.
Countries	France, Germany, Italy, Spain, Sweden, Taiwan.
Recipients of results	EORTC.
History	Follows work by the EORTC to develop a questionnaire to assess cancer patients' satisfaction with hospital-based care. Earlier work using the Comprehensive Assessment of Satisfaction with Care scales which included four of the above countries also followed EORTC guidelines for cross-cultural translation (Bredart et al, 2001).

2 Design

Setting	Cancer inpatients.
Population	
Inclusion/exclusion criteria	Patients aged 18 years or over, hospitalised for at least three days and mentally fit to complete a questionnaire.
Questionnaire	EORTC IN-PATSAT32.
Length	32 items.
Scales (items)	Eleven multi-item and three single-item scales: comfort (1), doctors availability (2), doctors information provision (3), doctors interpersonal skills (3), doctors' technical skills (3), exchange of information (1), general satisfaction (1), hospital access (2), nurses availability (2), nurses information provision (3), nurses interpersonal skills (3), nurses technical skills (3), other hospital staff interpersonal skills and information provision (3), waiting time (2).

Item scaling	Five-point scale of poor, fair, good, very good, excellent.
Development	Development followed EORTC Quality of Life Group guidelines. It is based on existing patient satisfaction questionnaires and interviews with oncology specialists and cancer patients. Initial testing took place in four countries.
Translation	Translated followed EORTC Quality of Life Group guidelines.
Data quality	Median percentage item omission was 2% (range 1-1.6%).
Reliability	Item-total correlations were over 0.40 and with the exception of the hospital access scale (alpha = 0.67), Cronbach's alpha coefficients ranged from 0.80 to 0.96. With the exception of the general satisfaction scale (ICC = 0.66) the test-retest ICCs were above 0.70.
Validity	Moderate correlations with the Oberst perception of care quality and satisfaction scales, intention to recommend the hospital item. Discrimination between groups whose expectations were or were not met (p<0.01) and different levels of intention to recommend the hospital, levels of treatment toxicity (p<0.01).
Data collection	
Sampling	Patients were contacted before discharge from hospital and asked to complete a questionnaire. 762 patients met the inclusion criteria.
Sampling period	The study began in May 2002 and finished in June 2004.
Survey administration	Patients were given the questionnaire before discharge and asked to complete it at home within six weeks.
Reminders	Postal reminder letters and if necessary, a telephone reminder.
Response rate	Of the 762 patients meeting the inclusion criteria, 115 did not complete the questionnaires giving a response rate of 84.9%.
3 Reporting of results	
Media	Journal article.
Adjustments	
4 References	
Bredart A, Roberston C, Razavi D et al. Patients' satisfaction ratings and their desire for care improvement across oncology settings from France, Italy, Poland and Sweden. Psycho-Oncology 2003;12:68-77. Bredart A, Bottomley A, Blazeby JM et al. An international prospective study of the EORTC cancer in-patient satisfaction with care measure (EORTC IN-PATSAT32). European Journal of Cancer 2005;41:2120-2131. Bredart A, Coens C, Aaronson N et al. Determinants of patient satisfaction in oncology settings from European and Asian countries: preliminary results based on the EORTC IN-PATAT32 questionnaire. European Journal of Cancer 2007;43:323-330. Bredart A, Razavi D, Robertson C et al. A comprehensive assessment of satisfaction with care: preliminary psychometric analysis in French, Polish, Swedish and Italian oncology patients. Patient Education and Counselling 2001;43:243-252.	

Table 66 Primary care for patients with spinal cord injuries (Donelly et al, 2007)	Canada, UK, USA
1 Background to survey	
Organisation(s)	School of Rehabilitation Sciences, Queen’s University, Canada.
Funding	Ontario Neurotrauma Foundation.
Objectives	Cross-sectional survey to describe the utilization, accessibility and satisfaction of primary and preventive health care services to individuals with long-term spinal cord injuries in three countries.
Countries	Canada, UK, USA.
Recipients of results	
History	
2 Design	
Setting	Primary and preventive health-care.
Population	
Inclusion/exclusion criteria	Patients with a spinal cord injury at least 20 years ago, aged 15 to 55 years at the time of interview who were admitted to rehabilitation within one year of injury.
Questionnaire	The Health Care Questionnaire which comprises two published measures, the Primary Care Questionnaire (Grumbach et al, 1999) and the Patient Satisfaction with Health Care Provider Scale (Marsh ,1999).
Length	46 items with two questionnaires for specialist and primary care.
Scales (items)	Access (14), counselling (12), prevention (9) and satisfaction (11).
Item scaling	Eight of the access items and all of the counselling and prevention items have yes/no responses. The remainder of the access items and satisfaction items are scaled “always, sometimes and never” and with a five-point Likert scale respectively.
Development	The Primary Care Questionnaire has not previously been assessed for reliability and validity. The Patient Satisfaction with Health Care Question Scale was based on existing questionnaire and according to the authors has evidence for internal consistency reliability and construct validity.
Translation	
Data quality	
Reliability	Cronbach’s alpha for the Health Care Questionnaire ranged from 0.55-0.88. Factor analysis supported unidimensionality, with factor loadings above 0.30 for most items.
Validity	
Data collection	
Sampling	373 individuals with a spinal cord injury of whom 127 were Canadians from the member database of the Canadian Paraplegic Association; 162 were British patients recruited from Northwest Regional Spinal Injuries Centre in Southport or the National Spinal Injuries Centre at Stoke Mandeville Hospital in Aylesbury; 84 were US patients recruited through Craig Hospital in Englewood, CO, US.
Sampling period	Between 2001 and 2003.

Survey administration	Postal contact to request participation. Postal questionnaire completed by respondent, interview or telephone interview.
Reminders	
Response rate	
3 Reporting of results	
Media	Journal article.
Adjustments	
4 References	

Donelly C, McColl MA, Charlifue S et al. Utilization, access and satisfaction with primary care among people with spinal cord injuries: a comparison of three countries. Spinal Cord 2007;45:25-36.
Grumbach K, Selby JV, Scmittdiel JA et al. Quality of primary care practice in a large HMO according to physician specialty. Health Service Research 1999;43:485-499.
Marsh GW. Measuring patient satisfaction outcomes across provider disciplines. Journal of Nursing Management 1999;7:47-62.

QUESTIONNAIRE FOR CONTACT PERSONS

Members of the OECD's Health Care Quality Indicator Project from Canada, France, Iceland, Italy, Japan, the Netherlands, New Zealand, Switzerland and Turkey identified contact persons that were emailed a link to the electronic questionnaire. France did not respond to the questionnaire. National programs of work for Canada and the Netherlands are described in detail on the preceding pages. Italy and Switzerland have not undertaken national surveys but have undertaken questionnaire development, local or small scale surveys and larger surveys covering a region or large number of health providers, hospitals or clinics.

Tables 12-15 below show the questionnaire responses for Iceland, Japan, New Zealand and Turkey, the countries that have undertaken national surveys. Japan and New Zealand have also been a part of cross-national surveys. All four countries have surveys are taking place at regular intervals or ongoing programs of work. All four countries have undertaken national surveys of the general population. Iceland and Japan have undertaken national surveys of patients. Japan and New Zealand have been included in cross-national surveys of the general population. New Zealand was also part of a cross-national comparison of patients. The most recent survey for Iceland included hospital inpatients. The most recent survey for Japan included hospital inpatients, hospital outpatients and general practice/primary care patients. The most recent survey for New Zealand was part of a cross-national comparison involving hospital inpatients, hospital outpatients and general practice/primary care patients which was funded The Commonwealth Fund, the results for which were not available when the literature review was undertaken. Finally, the survey for Turkey included members of the general population.

Table 67 Questionnaire results for Iceland

A Background	
1. Survey work that has taken place or is ongoing	Development, smaller scale survey, national surveys of patients and general population
2. Respondent's role in the work	All aspects except data analysis
B National surveys	
3. Year of most recent national survey	2005
4. Year of first survey	2002
5. Frequency of survey	Every 3 years
6. Organisation(s) involved – development, organisation, running	Ministry of Health, Medical Directorate, market research organsation
7. Organisation(s) funding the survey	Ministry of Health
8. Survey aims	National comparison of providers, quality information – patients, health professions, managers, government
C Patients	
9. Patient groups taking part in the survey	Hospital inpatients
10. Min and max age of patients	18 years and over
11. Information used to contact patients	Health care information systems
D Data collection	
12. Random sampling	No
13. Organisation(s) undertaking survey	Providers, private research organisation
14. Method of determining number of patients for each provider	Dependent on provider size
15. Questionnaire administration	Telephone interview
16. Time lag between care and receipt of questionnaire	2-4 weeks after care
17. Use/type of reminders	-
18. Sample size	Approx 535
19. Number of respondents	519
20. Testing for response bias	No
E The questionnaire	
21. Methods of development	Existing questionnaire, literature review, patient interviews, pilot survey
22. Number of items	24
23. Methods of testing	Content validity, data quality, factor analysis, internal consistency, test-retest, construct validity
F Reporting of results	
24. Who received the results	Government, health care organisations, public
25. Level(s) at which results were reported	Institution, national
26. Case-mix adjustment	No
G Other patient surveys	
27. Developmental work and national surveys relating to other groups	-
28. Ongoing national program	-

Table 68 Questionnaire results for Japan

A Background	
1. Survey work that has taken place or is ongoing	Development, smaller scale survey, national survey of patients and general population, part of cross-national survey of general population
2. Respondent's role in the work	Researcher, consultant
B National surveys	
3. Year of most recent national survey	2005
4. Year of first survey	1996
5. Frequency of survey	Every 3 years
6. Organisation(s) involved – development, organisation, running	Statistics and Information Division, Ministry of Health; Labour and Welfare
7. Organisation(s) funding the survey	Ministry of Health, Labour and Welfare
8. Survey aims	To improvement health care administration nationwide
C Patients	
9. Patient groups taking part in the survey	Hospital inpatients, hospital outpatients, general practice/primary care
10. Min and max age of patients	Up to 75 years
11. Information used to contact patients	Central or national information system
D Data collection	
12. Random sampling	Yes
13. Organisation(s) undertaking survey	Surveyers from public health centres from the 47 Prefecturers and Ministry of Health, Labour and Welfare
14. Method of determining number of patients for each provider	-
15. Questionnaire administration	Given to patient for self-completion at the clinic or home
16. Time lag between care and receipt of questionnaire	Given to patient for self-completion at the clinic or home
17. Use/type of reminders	No
18. Sample size	218 393
19. Number of respondents	-
20. Testing for response bias	-
E The questionnaire	
21. Methods of development	-
22. Number of items	-
23. Methods of testing	-
F Reporting of results	
24. Who received the results	-
25. Level(s) at which results were reported	-
26. Case-mix adjustment	-
G Other patient surveys	
27. Developmental work and national surveys relating to other groups	-
28. Ongoing national program	-

Table 69 Questionnaire results for New Zealand

A Background	
1. Survey work that has taken place or is ongoing	Development, smaller scale survey, national survey of general population, part of cross-national survey of patients and general population
2. Respondent's role in the work	Position with Ministry of Health
B National surveys	
3. Year of most recent national survey	2006
4. Year of first survey	1997
5. Frequency of survey	Annual
6. Organisation(s) involved – development, organisation, running	Ministry of Health, health care providers, University
7. Organisation(s) funding the survey	Government, health care providers, research funding
8. Survey aims	National or cross-national comparison of health care providers, research, quality information - managers, government
C Patients	
9. Patient groups taking part in the survey	Hospital inpatients, hospital outpatients, general practice/primary care, general population
10. Min and max age of patients	18 years and over
11. Information used to contact patients	-
D Data collection	
12. Random sampling	Yes
13. Organisation(s) undertaking survey	The Commonwealth Fund
14. Method of determining number of patients for each provider	General population survey
15. Questionnaire administration	Telephone interview
16. Time lag between care and receipt of questionnaire	General population survey
17. Use/type of reminders	-
18. Sample size	1000
19. Number of respondents	1000
20. Testing for response bias	-
E The questionnaire	
21. Methods of development	Existing questionnaire, literature review
22. Number of items	100
23. Methods of testing	-
F Reporting of results	
24. Who received the results	Funding organisation, health care providers, public
25. Level(s) at which results were reported	Diagnoses/health problems, type of care/treatment, individual professional level, national, cross-national
26. Case-mix adjustment	No
G Other patient surveys	
27. Developmental work and national surveys relating to other groups	National surveys of hospital inpatients, hospital outpatients, general practice/primary care, specific diagnoses/health problems, specific types of health care, general population
28. Ongoing national program	Yes

Table 70 Questionnaire results for Turkey

A Background	
1. Survey work that has taken place or is ongoing	Development, smaller scale survey, national survey of general population
2. Respondent's role in the work	Consultant
B National surveys	
3. Year of most recent national survey	2006
4. Year of first survey	2002
5. Frequency of survey	Annual
6. Organisation(s) involved – development, organisation, running	Turkish Statistical Institute, Ministry of Health, Universities
7. Organisation(s) funding the survey	Government
8. Survey aims	Other type of non-national comparison of providers, research, quality information – managers, government,
C Patients	
9. Patient groups taking part in the survey	General population
10. Min and max age of patients	15 years and over
11. Information used to contact patients	-
D Data collection	
12. Random sampling	Yes
13. Organisation(s) undertaking survey	Public or state funded research organisation
14. Method of determining number of patients for each provider	General population survey
15. Questionnaire administration	Home interview
16. Time lag between care and receipt of questionnaire	General population survey
17. Use/type of reminders	-
18. Sample size	18 938
19. Number of respondents	12 842
20. Testing for response bias	-
E The questionnaire	
21. Methods of development	Literature review, expert group, pilot survey
22. Number of items	114
23. Methods of testing	-
F Reporting of results	
24. Who received the results	Government
25. Level(s) at which results were reported	Type of care/treatment, individual professional level, Institution, department/specialty level, national
26. Case-mix adjustment	-
G Other patient surveys	
27. Developmental work and national surveys relating to other groups	General population survey
28. Ongoing national program	Yes

Discussion

The review was designed to identify and describe national and cross-national surveys of patient experiences that have taken place within the last ten years in OECD and non-OECD EU member countries. The review was structured and used a search strategy based on published reviews within the field of patient experiences measurement (24, 32-35, 78, 79). The information extracted was designed to give a sufficiently detailed description of the programs of survey work together with individual surveys that have taken place across the different countries.

The search strategy produced a large number of individual surveys which met the inclusion criteria, 42 of which were national and 13 were cross-national. Nine programs of ongoing work relating to patient experiences were responsible for 39 surveys, 32 of which were national and 7 were cross-national. These programs include the Canadian Community Health Survey (CHHS) (40), The Commonwealth Fund in the USA (73), Consumer Assessment of Healthcare Providers and Systems (CAHPS) in the USA (4), Department of Quality Measurement in Denmark (57), Dutch Centre for Consumer Experience in Health Care (7, 27), Norwegian Knowledge Centre for the Health Services (32-35), Picker Institute Europe (23), Unit of Patient Evaluation in Denmark (87), and the World Health Organisation (WHO) program The Health Systems Responsiveness (86). The programs of work undertaken by the Canadian Community Health Survey, The Commonwealth Fund and WHO are all based on surveys of the general population. The remainder of the programs relate to patients who have received care and for the CAHPS and one survey undertaken by the Dutch centre, members of health plans and health insurance enrolees respectively.

The Commonwealth Fund, Picker Institute Europe and the WHO have undertaken cross-national surveys of patient experiences. The Norwegian Knowledge Centre for the Health Services and the Unit for Patient Evaluation in Denmark have started development work relating to a future cross-national comparison of patient experiences for the Nordic countries (66).

Both the Norwegian Knowledge Centre for the Health Services and Picker Institute Europe have undertaken national surveys of several patient groups. The work of The Commonwealth Fund has involved surveys of the general population but filter questions that are part of the telephone interviews have meant that the health care experiences of specific groups, including the elderly and sicker adults, have been assessed. The Unit for Patient Evaluation in Denmark has surveyed patients receiving hospital inpatient care every two years (87). The Department of Quality Measurement in Denmark has undertaken national surveys relating to different aspects of psychiatry services (57). The Dutch Centre for Consumer Experience of Health Care has undertaken national surveys of enrolees of health insurance and people with disabilities (7, 27).

There were ten national surveys of patient experiences that were not ongoing national programs relating to acute care hospitals in Ireland (81), antenatal care in Sweden (51), breast health practices in Canada (80), Centers' for Womens's Health in the USA, (6), cystic fibrosis in the UK (83), depression among African-American women in the USA (71), HIV infection in the USA (84), maternity care in the UK (52, 69) and osteopathy in the USA (61). Finally, six cross-national surveys were identified that were not part of programs of work. These include large studies that have developed, translated and evaluated questionnaires for assessing patient experiences with cancer care (15, 16), diabetes care (67), general practice and primary care (56, 85), mental health care (9), and care relating to spinal cord injury (28).

The majority of the cross-national work has included Canada, European countries and the USA with between 4 and 17 countries participating. The exception is the work of the WHO relating to responsiveness involving 60 countries. The surveys undertaken by The Commonwealth Fund and Picker Institute Europe have included up to six and eight countries respectively.

There have been relatively more published reports including peer-reviewed scientific articles that describe cross-cultural questionnaire evaluation underpinning the cross-national work that was not part of programs. This may due to more of a focus on methodology on the part of such large research projects, notable examples being the European Psychiatric Services - Inputs Linked to Outcome Domains and Needs (EPSILON) study (9) and the European Organisation for Research and Treatment for Cancer (EORTC) work (15, 16). These research projects have a history of development and testing including cross-cultural evaluation relating to patient-reported outcomes more generally. The WHO's cross-national program is the main exception to this (86). The CAHPS questionnaires have also undergone cross-cultural evaluation for different ethnic groups within the USA (4).

The focus on English and Scandinavian literature and websites is the most obvious limitation of the review. Abstracts written in English were considered for inclusion but it was not possible within available resources to extend the searches to non-English language journals and websites which would have increased the chances of finding further national work relating to the measurement of patient experiences. It is also highly probable that surveys have been undertaken that have not been published in scientific journals and that reports have not been made available on websites. The electronic questionnaire that was emailed as a link to contact persons identified through the OECD Health Care Quality Indicators Project group was designed to identify such work not included in the main review. In addition to the work described above, Iceland, Japan, New Zealand and Turkey have undertaken national surveys that are ongoing or are part of national programs. Japan and New Zealand have also been a part of cross-national surveys.

The information that was available for retrieval from journal articles, reports and websites was often limited in terms of the detail relating to three broad headings of data extraction: background, survey design and reporting of results. In terms of background, information relating to survey objectives was for many surveys, very brief. In terms of design, information relating to the questionnaire content together with the methods and results of development and testing was often lacking. Scientific articles and reports from cross-national surveys often failed to give sufficient information relating to translation methodology and the results of testing for cross-cultural equivalence. The main emphasis of much of the work was on reporting of survey results in terms of reports to funding bodies and other recipients. The review has identified organisations and key persons responsible for the surveys and hence it is possible to build upon the findings by contacting these individuals for further information relating to the background, design and reporting of the surveys.

Conclusions

The review identified a large number of surveys that were national and cross-national in scope, the majority of which are part of ongoing programs of work relating to the measurement of patient experiences. Four further ongoing surveys or national programs of work were identified by means of an electronic questionnaire. The review is an information source for understanding the current status of large scale survey work relating to the measurement of patient views of health care quality. This includes the identification of expertise, infrastructure and organisations that will inform future national survey work and cross-national collaboration designed to provide information on patient views of health care quality.

References

1. Agency for Healthcare Research and Quality. 2006 National Healthcare Disparities Report. Rockville, MD: U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality, 2006.

2. Agency for Healthcare Research and Quality. 2006 National Healthcare Quality Report. Rockville, MD: U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality, 2006.

3. Agency for Healthcare Research and Quality. 2006 CAHPS® Health PlanSurvey Chartbook. Rockville, MD: U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality, 2006.

4. Agency for Healthcare Research and Quality. CAHPS® Health Plan Survey and Reporting Kit 2007. Rockville, MD: U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality, 2007.

5. Airey C, Becher H, Erens B et al. National surveys of NHS patients: Cancer: National Overview 1999/2000. Department of Health, 2002.

6. Anderson RT, Weisman CS, Scholle SH et al. Evaluation of the quality of care in the clinical care centers of the National Centers of Excellence in Women's Health. Women's Health Issues 2002;12:309-326.

7. Arah OA, ten Asbroek AH, Delnoij DM et al. Psychometric properties of the Dutch version of the Hospital-level Consumer Assessment of Health Plans Survey instrument. Health Services Research 2006;41:284-301.

8. Arraras JI, Wright S, Greimel E et al. Development of a questionnaire to evaluate the information needs of cancer patients: the EORTC questionnaire. Patient Education and Counselling 2004;54:235-241.

9. Becker T, Knapp M, Knudsen HC et al. Aims, outcome measures, study sites and patient sample. EPSILON Study 1. European Psychiatric Services: Inputs Linked

to Outcome Domains and Needs. British Journal of Psychiatry Supplement 2000;39:s1-s7.

10. Bedi R, Gulati N, McGrath C. A study of satisfaction with dental services among adults in the United Kingdom. British Dental Journal 2005;198:433-437.

11. Bethell C, Peck C, Abrams M et al. Partnering with parents to promote the health development of young children enrolled in Medicaid. The Commonwealth Fund, 2002.

12. Bethell C, Peck C, Schor E. Assessing health system provision of well-child care: the promoting Health Development Survey. Pediatrics 2001;107:1084-1094.

13. Bjertnaes AØ, Garratt A, Nessa J. The GPs' Experiences Questionnaire (GPEQ): Reliability and validity following a national survey to assess GPs' views of district psychiatric services. Family Practice 2007; June 24.

14. Bradley C. Translation of questionnaires. In *Handbook of Psychology and Diabetes*. C Bradley Ed. Switzerland: Harwood, 1994.

15. Brédart A, Coens C, Aaronson N et al. Determinants of patient satisfaction in oncology settings from European and Asian countries: preliminary results based on the EORTC IN-PATSAT32 questionnaire. European Journal of Cancer 2007;43:323-330.

16. Brédart A, Robertson C, Razavi D et al. Patients' satisfaction ratings and their desire for care improvement across oncology settings from France, Italy, Poland and Sweden. Psycho-Oncology 2003;12:68-77

17. Cheng SH, Wei, YJ, Chang HJ. Quality competition among hospitals: The effects of perceived quality and perceived expensiveness on health care consumers. American Journal of Medical Quality 2006;21:68-75.

18. Cleary PD, Edgman-Levitan S. Health care quality: Incorporating consumer perspectives. JAMA 1997;278:1608-1612.

19. Collins SR, Davis K, Doty MM et al. Gaps in health insurance: an all-American problem. The Commonwealth Fund, 2006.

20. Collins SR, Davis K, Schoen C et al. Health coverage for aging baby boomers: findings from the Commonwealth Fund Survey for older adults. The Commonwealth Fund, 2006.

21. Collins KS, Hughes DL, Doty MM et al. Diverse communities, common concerns: assessing health care quality for minority Americans. The Commonwealth Fund, 2002

22. Coulter A, Cleary PD. Patients' experiences with hospital care in five countries. Health Affairs 2001;20:244-252.

23. Coulter A, Jenkinson C. European patients’ views on the responsiveness of health systems and healthcare providers. European Journal of Public Health 2005;15:355-360.

24. Crow R, Gage H, Hampson S et al. The measurement of satisfaction with healthcare: implications for practice from a systematic review of the literature. Health Technology Assessment 2002;6:1-244.

25. Danielsen K, Garratt AM, Bjertnæs ØA et al. Patient experiences in relation to health care process and provider characteristics. Scandanavian Journal of Public Health 2007;35:70-77.

26. Darby C, Hays RD, Kletke P. Development and evaluation of the CAHPS hospital survey. Health Services Research 2005;40:1973-1976.

27. Delnoij D, ten Asbroek, Arah OA et al. Made in the USA: the import of American Consumer Assessment of Health Plan Surveys (CAHPS) into the Dutch social insurance system. European Journal of Public Health 2006;14:652-659.

28. Donelly C, McColl MA, Charlifue S et al. Utilization, access and satisfaction with primary care among people with spinal cord injuries: a comparison of three countries. Spinal Cord 2007;45:25-36.

29. Dunckley M, Osborn C, Magee H et al. Development and pilot testing of the questionnaire for use in NHS Trust-based Ambulance Emergency Services patient survey. Picker Institute Europe, 2004

30. Eisen SV, Shaul JA, Leff HS et al. Toward a National Consumer Survey: Evaluation of the CABHS and MHSIP Instruments. The Journal of Behavioral Health Services & Research 2001;28:347-369.

31. Fronstin P, Collins SR. Early experiences with high-deductible and consumer-driven health plans: findings from the EBRI/Commonwealth Fund consumerism in Health Care Survey. EBRI Issue Brief/Employee Benefit Research Institute Issue Brief 2005;288:4-28.

32. Garratt AM, Bjertnæs ØA, Krogstad U et al. The Outpatient Experience Questionnaire (OPEQ): data quality, reliability, and validity in patients attending 52 Norwegian hospitals. Quality and Safety in Health Care 2005;14:433-437.

33. Garratt A, Bjertnæs ØA, Barlinn J. Parent experiences of paediatric care (PEPC) questionnaire: reliability and validity following a national survey. Acta Paediatrica 2007;96:246-252.

34. Garratt A, Bjørngaard JH, Dahle KAa et al. The Psychiatric Out-Patient Experiences Questionnaire (POPEQ): data quality, reliability and validity in patients attending 90 Norwegian clinics. Nordic Journal of Psychiatry 2006;60:89-96.

35. Garratt AM, Danielsen K, Bjertnæs ØA et al. The Psychiatric In-Patient Experiences Questionnaire (PIPEQ): data quality, reliability and validity. Tidskrift for den Norske Laegeforening 2006;126:1478-1480.

36. Goldstein E, Farquahr M, Crofton C et al. Measuring hospital care from the patients' persepective: an overview of the CAHPS ® hospital survey development process. Health Services Research 2005;40:1977-1995.

37. Gross R. A consumer-based tool for evaluating the quality of health services in the Israeli health care system following reform. Health Policy 2004;68:143-158.

38. Halfon N, Inkelas M, Abrams M et al. Quality of preventative health care for young children: strategies for improvement. The Commonwealth Fund, 2005.

39. Hays RD, Shaul JA, Williams VAL et al. Psychometric properties of the CAHPS™ 1.9 survey measure: Consumer Asssessment of Health Plans Study (Cahps™). Medical Care 1999;37:MS22-MS31.

40. Health Canada. Healthy Canadians. A Federal Report on Comparable Health Indicators 2006. Health Canada, 2006.

41. Healthcare Commission. Coronary heart disease survey of patients 2004. Healthcare Commission, 2005.

42. Healthcare Commission. Patient Survey Programme 2004/5. Emergency Department: key findings. Healthcare Commission, 2005.

43. Healthcare Commission. Survey of patients 2005 Stroke. Healthcare Commission, 2005.

44. Healthcare Commission. Survey of users 2005. Mental health services. Healthcare Commission, 2005.

45. Healthcare Commission. Patient Survey Programme 2004/2005 Outpatient Department: key findings. Healthcare Commission, 2005.

46. Healthcare Commission. Survey of patients 2005. Primary care trust. Healthcare Commission, 2005.

47. Healthcare Commission. Survey of users of services 2006. Community mental health services. Healthcare Commission, 2006.

48. Healthcare Commission. Survey of patients 2006. Caring for people after they have had a stroke. Healthcare Commission, 2006.

49. Healthcare Commission. Inpatients. The views of hospital inpatients in England. Key findings from the 2006 survey. Healthcare Commission, 2007.

50. Healthcare Commission. Diabetes. The views of people with diabetes. Key findings from the 2006 survey. Healthcare Commission, 2007.

51. Hildingsson I, Rådestad I. Swedish women's satisfaction with medical and emotional aspects of antenatal care. Journal of Advanced Nursing 2005;52:239-249.

52. Hundley V, Rennie AM, Fitzmaurice A et al. A national survey of women's views of their maternity care in Scotland. Midwifery 2000;16:303-313.

53. Jenkinson C, Coulter A, Bruster S. The Picker Patient Experience Questionnaire: development and validation using data from in-patient surveys in five countries. International Journal for Quality in Health Care 2002;14:353-358.

54. Jurst J, Jee-Hughes M. Performance measurement and performance management in OECD halth systems. Labour Market and Social Policy Occasional Papers 47. Paris: OECD 2000.

55. Kersnik J. Determinants of customer satisfaction with the health care system, with the possibility to choose a personal physician and with a family doctor in a transition country. Health Policy 2001;57:155-164.

56. Kerssens JJ, Groenewegen PP, Sixma HJ et al. Comparison of patient evaluations of health care quality in relation to WHO measures of achievement in 12 European countries. World Health Organisation. Bulletin of the World Health Organisation 2004;82:106-114.

57. Kvalitsafdelingen i Arhus Amt. Beboerne og de pårørende har ordet: undersøgelse i de socialpsykiatriske borformer. Landsdaekkende Psykiatriundersøgelser, 2006.

58. Larsson BW, Larsson G, Chantereau MW et al. International comparisons of patients' views on quality of care. International Journal of Health Care Quality Assurance 2005;18:67-73.

59. Leplege A, Verdier A. The adaptation of health status measures: methodological aspects of the translation procedure. In Schumaker S, Berzon B (Eds). International Assessment of Quality of Life: Theory, translation, measurement and analysis. Oxford: Rapid Communications, 1995.

60. Letkovicova H, Prasad A, La Vallèe R et al. The Health Systems Responsiveness Analytical Guidelines for Surveys in the Multi-country Survey Study. World Health Organization, 2005.

61. Licciardone JC, Herron KM. Characteristics, satisfaction, and perceptions of patients receiving ambulatory healthcare from osteopathic physicians: a comparative national survey. Journal of the American Osteopathy Association 2001;7:374-385.

62. Merck Frosst Ltd. The 2005 Health Care in Canada Round Table. Toronto, Ontario: Mediresource Inc., 2005-2006.

63. Miseviciene I, Dregval L. Opinion of Lithuanian population about accessibility and quality of primary health care services. Medicina (Kaunas) 2002;38:1129-1135.

64. Mossialos, E. Citizens' views on health care systems in the 15 member states of the European Union. Health Economics 1997;6:109-116.

65. Murray C, Frenk J. A Framework for assessing the performance of health systems. Bulletin of the World Health Organization 2000;78:171-731.

66. Oltedal S, Garratt AM, Bjertnæs ØA et al. The NORPEQ patient experiences questionnaire: data quality, internal consistency and validity following a Norwegian inpatient survey. Scandinavian Journal of Public Health 2007;35:540-547.

67. Peyrot M, Rubin RR, Lauritsen T et al. Patient and provider perceptions of care for diabetes: results of the cross-national DAWN Study. Diabetologia 2006;49:279-288.

68. Ramm J, Reeves R, Graham C. Patient survey report 2004 – young patients. Healthcare Commission, 2004.

69. Redshaw M, Rowe R, Hockley C et al. Recorded delivery: a national survey of women's experience of maternity care. University of Oxford: National Perinatal Epidemiology Unit, 2007.

70. Reubsaet A, Lechner L, De Vries H. The Dutch cancer information helpline: More critical patients after 10 years. Patient Education and Counseling 2006;63:215-222.

71. Scarinci IC, Beech BM, Watson JM. Physician-patient interaction and depression among African-American women: A national study. Ethnicity & Disease 2004;14:567-573.

72. Schoen C, Blendon RJ, DesRoches CM et al. Comparison of health care system views and experiences in five nations, 2001. The Commonwealth Fund, 2002.

73. Schoen C, How SKH, Weinbaum I et al. Public views on shaping the future of the US health system. The Commonwealth Fund, 2006.

74. Schoen C, Osborn R, Huynh PT et al. Pimary care and health system performance: adults' experiences in five countries. Health Affairs 2004;W4:487-503.

75. Schoen C, Osborn R, Huynh PT et al. Taking the pulse of health care systems: experiences of patients with health problems in six countries. Health Affairs 2005;5:W509-W525.

76. Schoen C, Simantov E, Gross R et al. Disparities in women's health and health care experiences in the United States and Israel: Findings from 1998 national women's health surveys. Women and Health 2003;37:49-70.

77. Schoen C, Strumpf E, Davis K et al. The elderly's experiences with health care in five nations: Findings from The Commonwealth Fund 1999 International Health Policy Survey. The Commonwealth Fund, 2000.

78. Sitzia J. How valid and reliable are patient satisfaction data? An analysis of 195 studies. International Journal for Quality in Health Care 1999;11:319-328.

79. Sitzia J, Wood N. Response rate in patient satisfaction research: an analysis of 210 published studies. International Journal for Quality in Health Care 1998;10:311-317.

80. Stamler LL, Lafreniere K, Thomas B et al. A national survey of Canadian women: breast health practices, influences, and satisfaction. Canadian oncology nursing journal 2002:218-228.

81. Sweeney J, Brooks AM, Leahy A. Development of the Irish National Patient Perception of Quality of Care Survey. International Journal for Quality in Health Care 2003;15:163-168.

82. Üstün TB, Chatterji S, Villanueva M et al. WHO Multi-country Survey Study on Health and Responsiveness 2000-2001. World Health Organization, 2001.

83. Walters S. National Health services for patients with cystic fibrosis: the good, the bad and the ugly. Journal of the Royal Society of Medicine 2002;95(suppl):32-40.

84. Wilson IB, Ding L, Hays R et al. HIV patients' experiences with inpatient and outpatient care. Results of a national survey. Medical Care 2002;40:1149-1160.

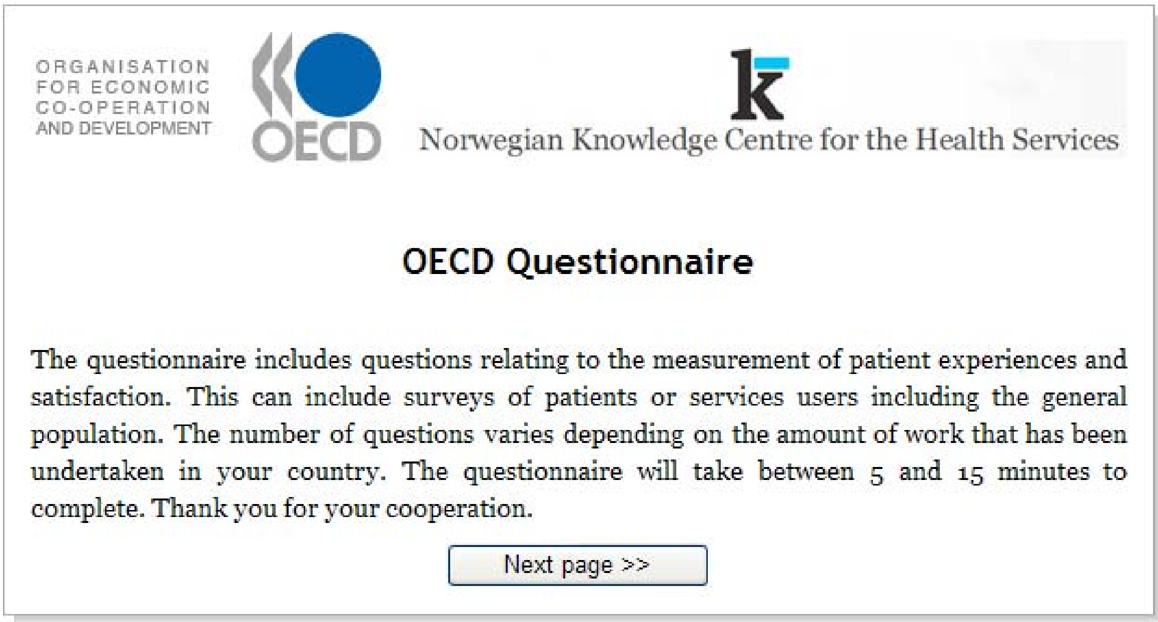
85. Wensing M, Baker R, Szecsenyi J et al, on behalf of the EUROPEP Group. Impact of national health care systems on patient evaluations of general practice in Europe. Health Policy 2004;68:353-357.

86. World Health Organization. The world health report 2000: health systems: improving performance. The World Health Organization 2000.

87. Østerbye T, Sevaldsen J, Hansen KS et al. Patients experiences in Danish hospitals 2006: questionnaire among 26 045 hospitalised patients. Unit of Patients Evaluation: Denmark, 2007.

Appendices

APPENDIX 1 QUESTIONNAIRE FOR CONTACT PERSONS



ORGANISATION FOR ECONOMIC CO-OPERATION AND DEVELOPMENT

Norwegian Knowledge Centre for the Health Services

OECD Questionnaire

The questionnaire includes questions relating to the measurement of patient experiences and satisfaction. This can include surveys of patients or services users including the general population. The number of questions varies depending on the amount of work that has been undertaken in your country. The questionnaire will take between 5 and 15 minutes to complete. Thank you for your cooperation.

ORGANISATION FOR ECONOMIC CO-OPERATION AND DEVELOPMENT

Password

1 Please write in your password that was included in the email you received (four digits + one letter).
2 Click "**Next page**" for authentication .

Password:

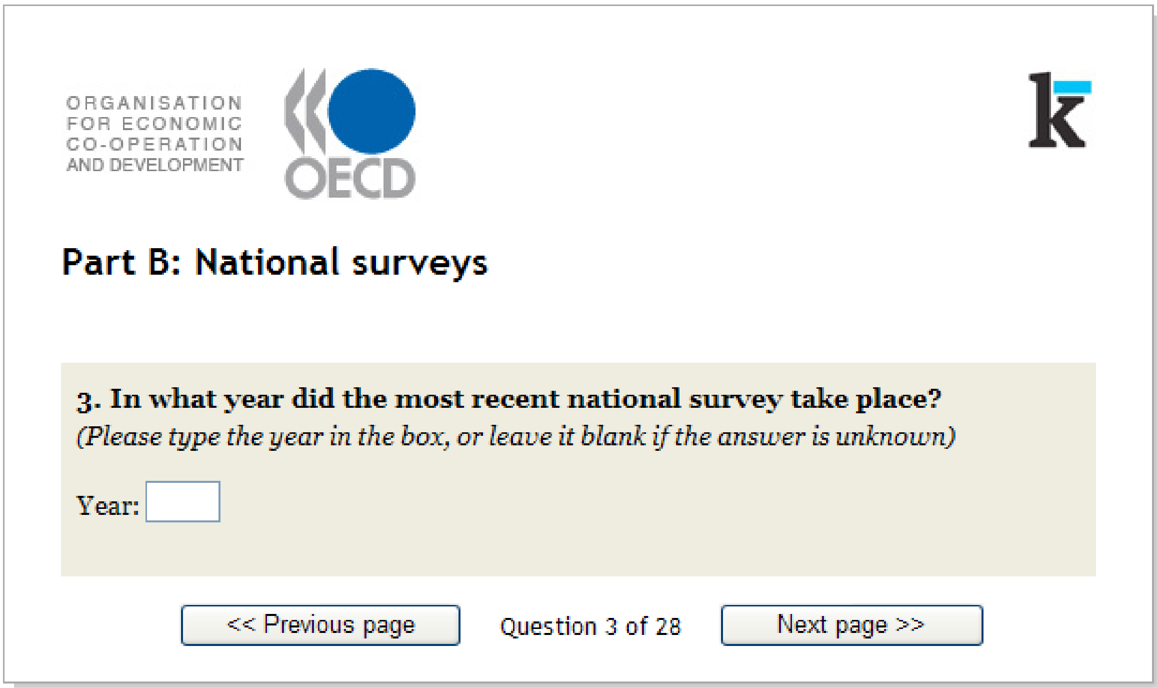
Part A: Background

1. What work has taken place or is ongoing within your country that relates to the measurement of patient experiences?
(Please mark all boxes that apply)

☐ Questionnaire development and testing including piloting and psychometric work
☐ Local or small scale surveys (e.g. including one or a small number of health care providers, hospitals or clinics)
☐ Larger, but not national surveys (e.g. covering a region or a large number of health care, providers, hospitals or clinics)
☐ National survey(s) of patients
☐ National survey(s) of the general population
☐ Part of an cross-national comparison of patient experiences
☐ Part of an cross-national comparison of general population
☐ Other

2. What was your role in this work?
(Please mark all boxes that apply)

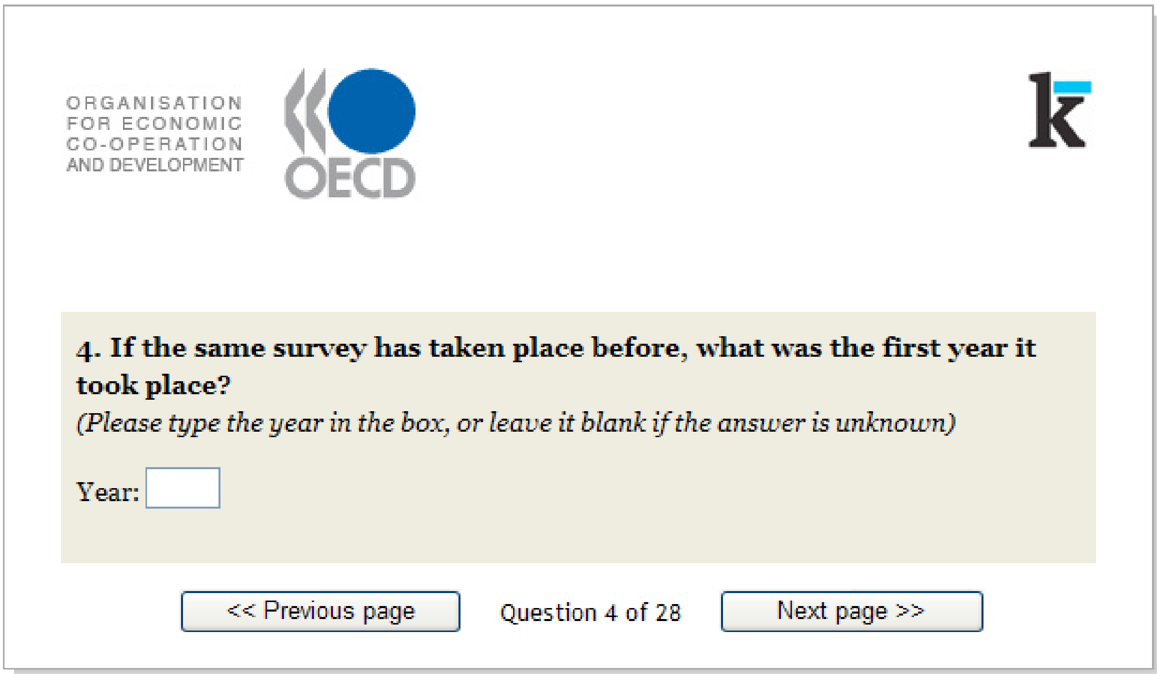
☐ Questionnaire development and testing
☐ Survey design
☐ Survey administration / carrying out the survey
☐ Data analysis
☐ Writing up and reporting of results
☐ Researcher
☐ Project manager
☐ Consultant
☐ Grantholder / fundholder
☐ Other



Part B: National surveys

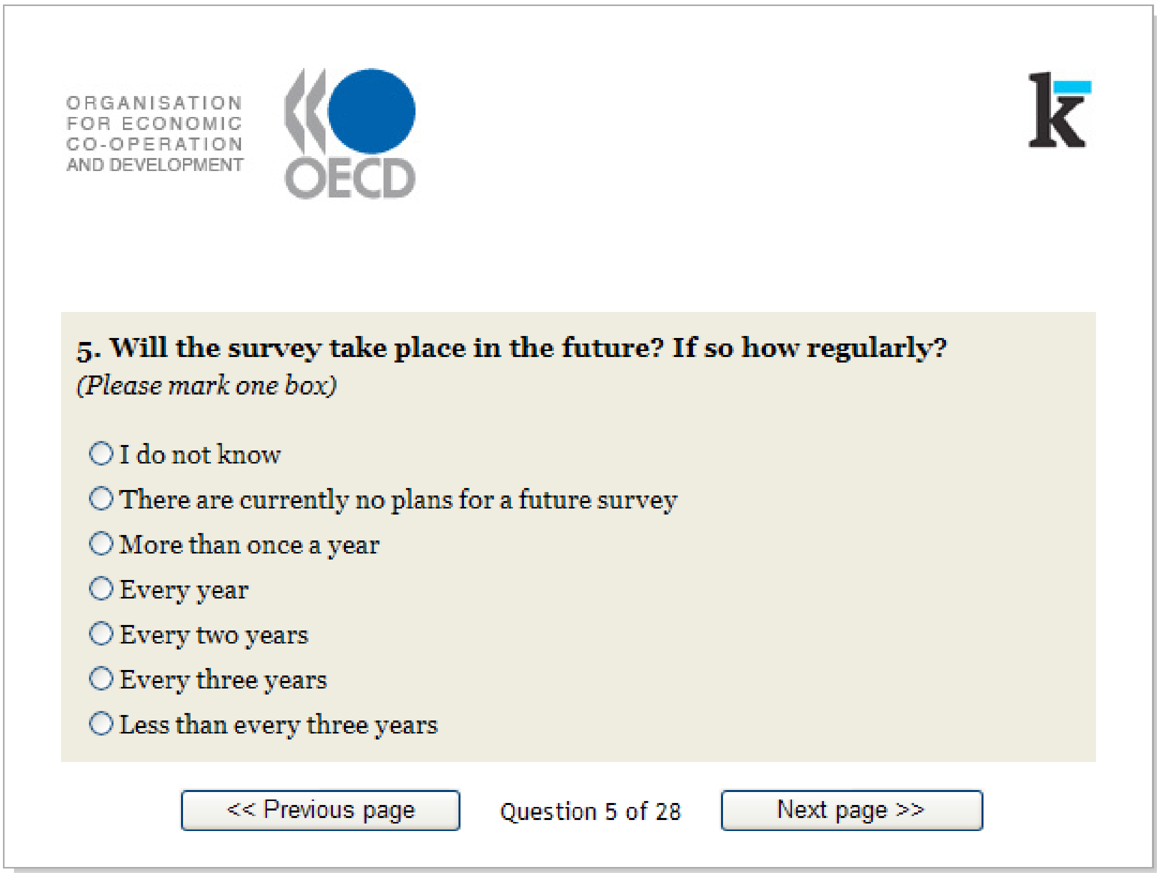
3. In what year did the most recent national survey take place?
(Please type the year in the box, or leave it blank if the answer is unknown)

Year: ☐



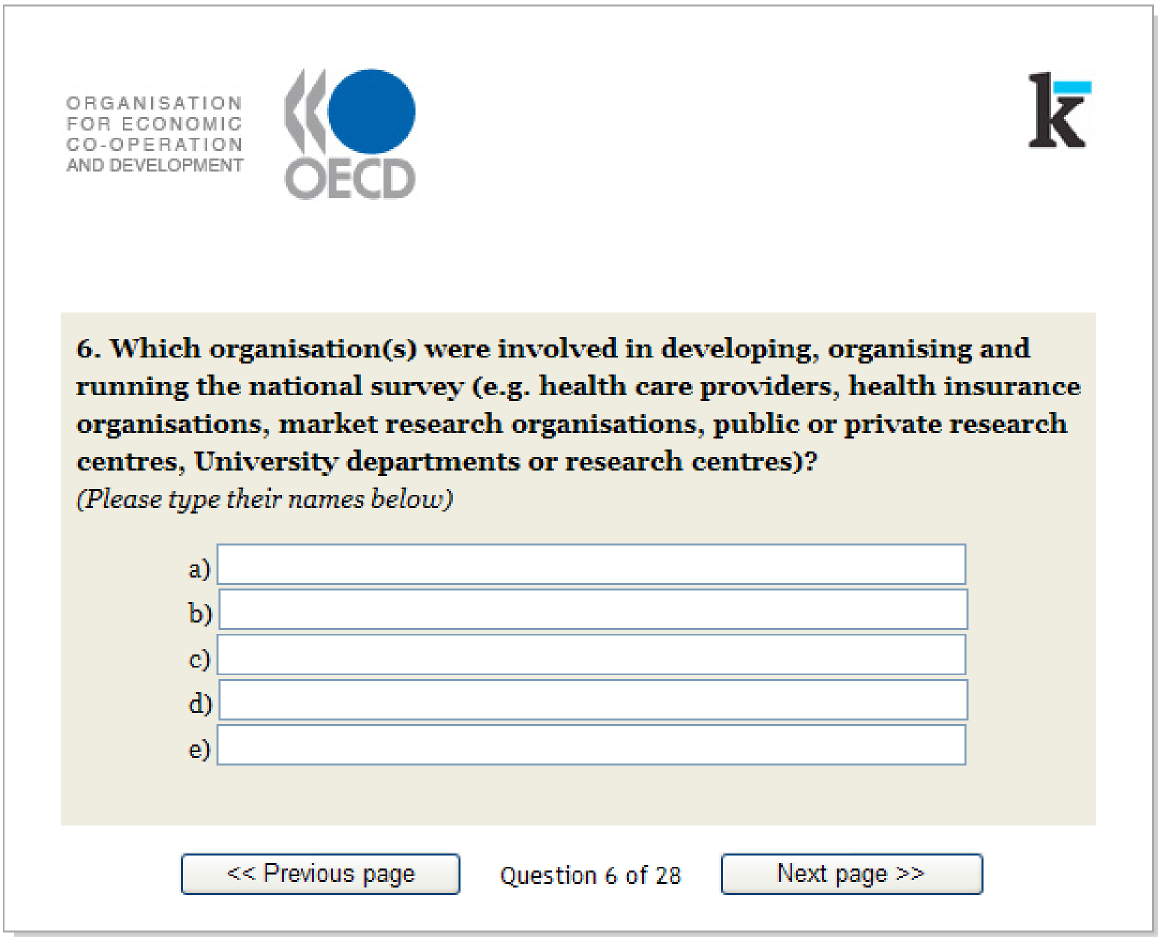
4. If the same survey has taken place before, what was the first year it took place?
(Please type the year in the box, or leave it blank if the answer is unknown)

Year: ☐



5. Will the survey take place in the future? If so how regularly?
(Please mark one box)

○ I do not know
○ There are currently no plans for a future survey
○ More than once a year
○ Every year
○ Every two years
○ Every three years
○ Less than every three years



6. Which organisation(s) were involved in developing, organising and running the national survey (e.g. health care providers, health insurance organisations, market research organisations, public or private research centres, University departments or research centres)?

(Please type their names below)

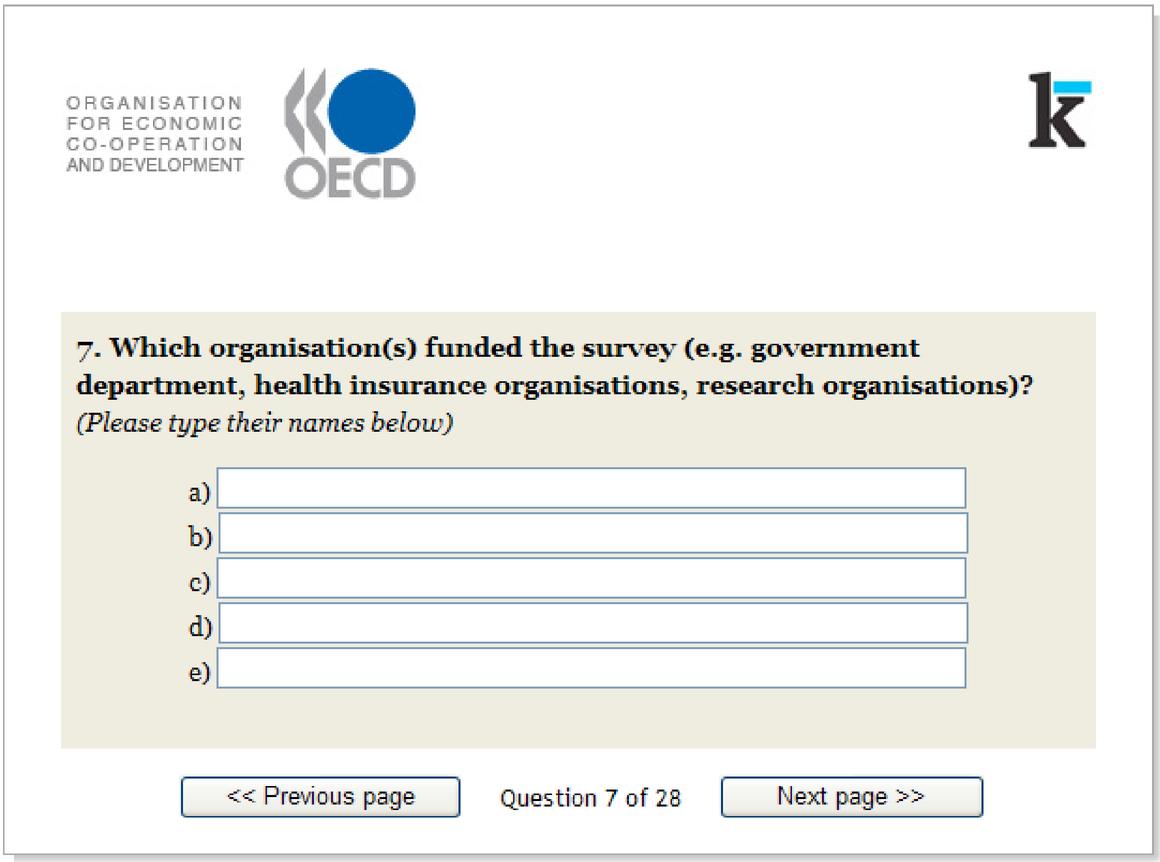
a) ______

b) ______

c) ______

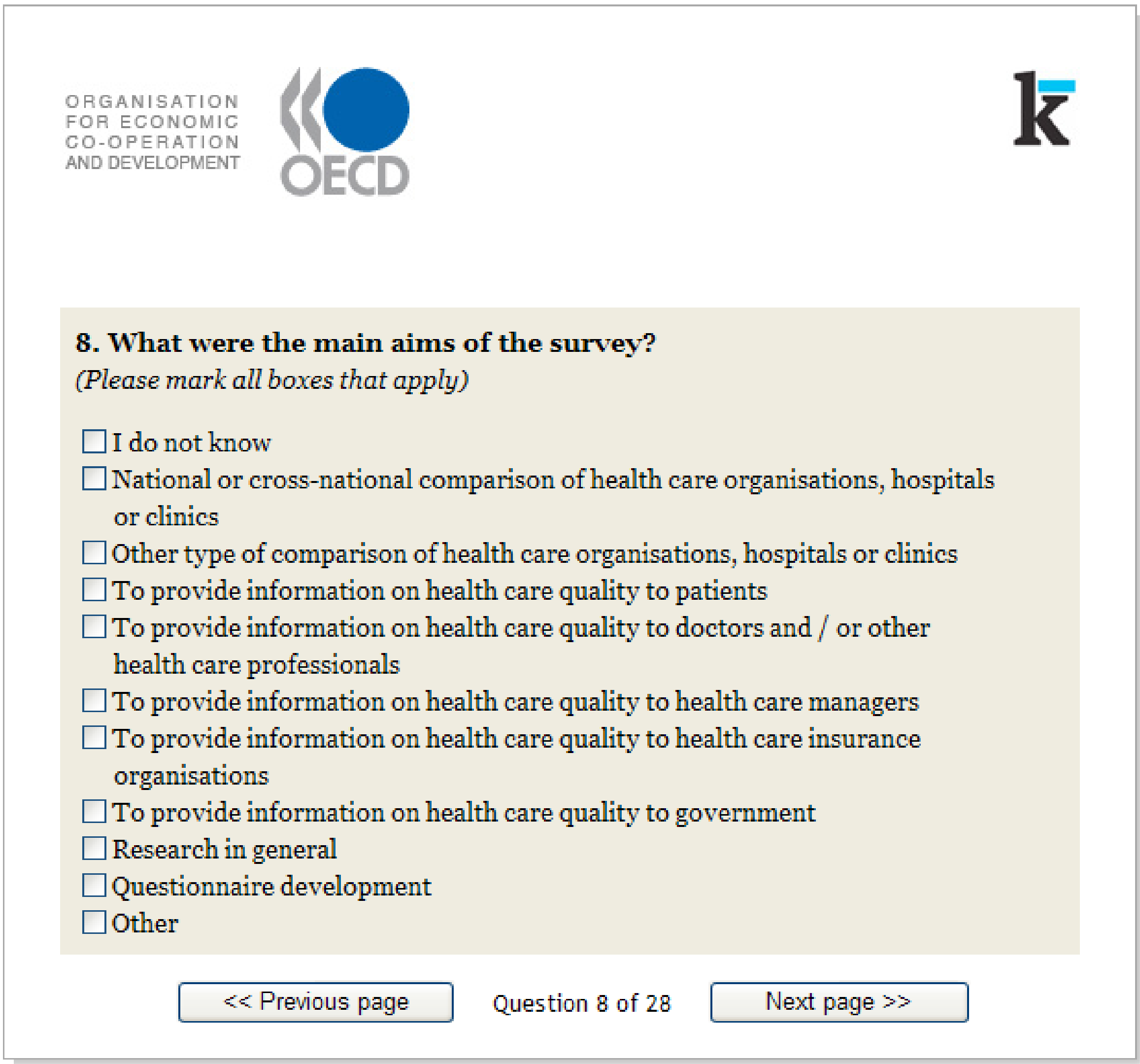
d) ______

e) ______



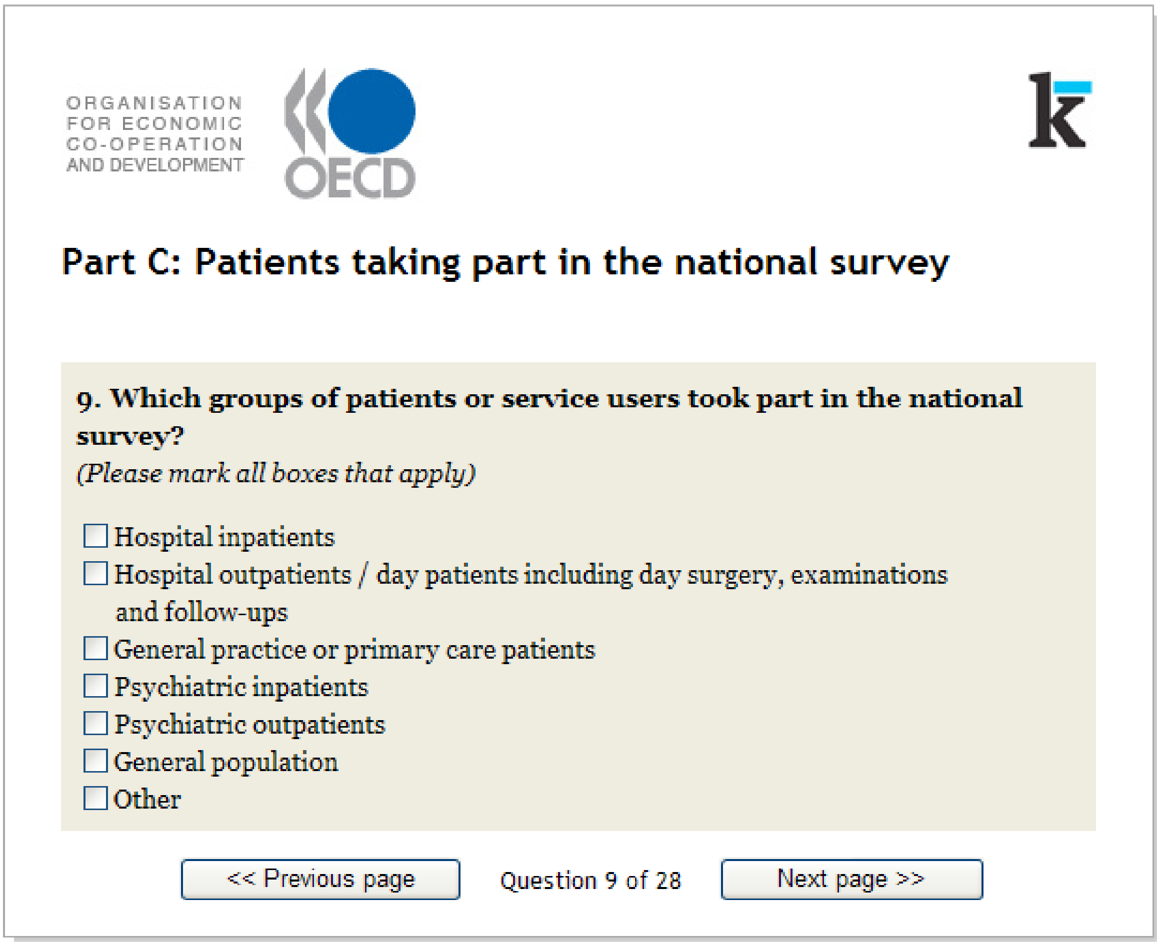
7. Which organisation(s) funded the survey (e.g. government department, health insurance organisations, research organisations)?
(Please type their names below)

a)
b)
c)
d)
e)



8. What were the main aims of the survey?
(Please mark all boxes that apply)

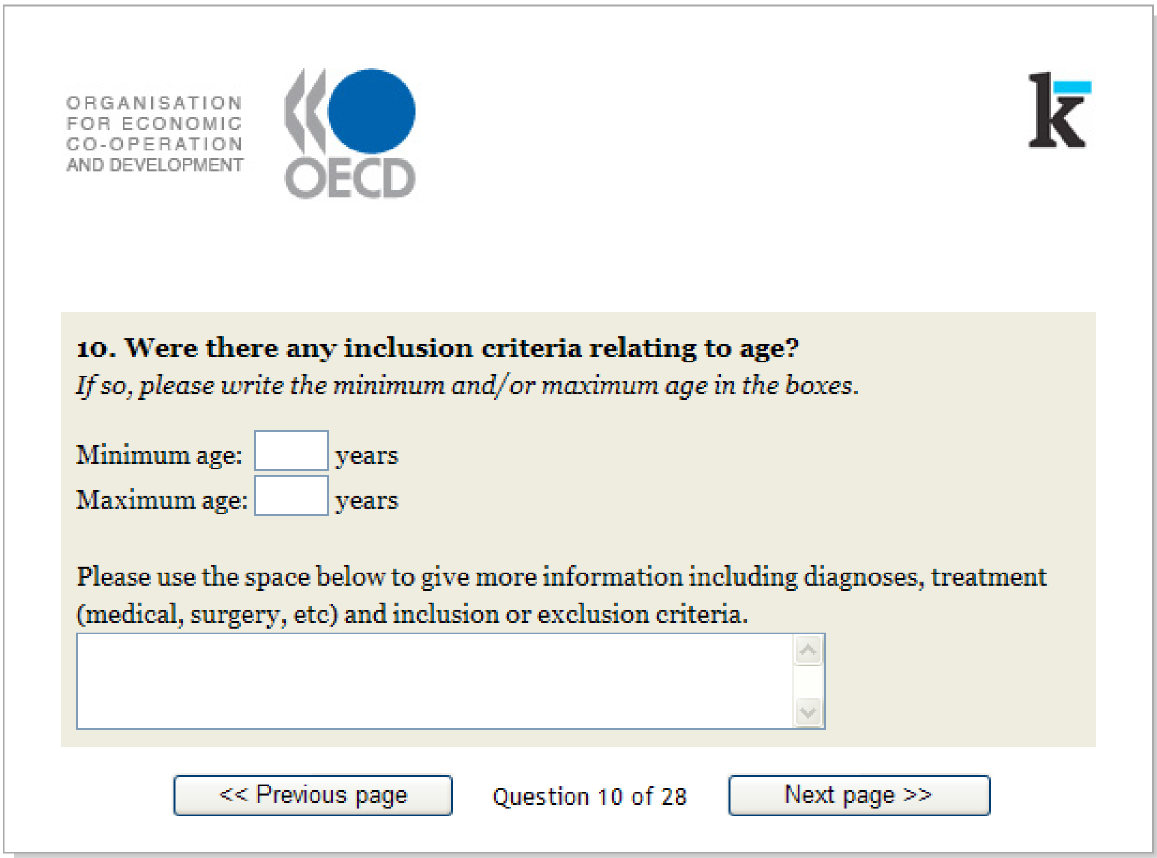
☐ I do not know
☐ National or cross-national comparison of health care organisations, hospitals or clinics
☐ Other type of comparison of health care organisations, hospitals or clinics
☐ To provide information on health care quality to patients
☐ To provide information on health care quality to doctors and / or other health care professionals
☐ To provide information on health care quality to health care managers
☐ To provide information on health care quality to health care insurance organisations
☐ To provide information on health care quality to government
☐ Research in general
☐ Questionnaire development
☐ Other



Part C: Patients taking part in the national survey

9. Which groups of patients or service users took part in the national survey?
(Please mark all boxes that apply)

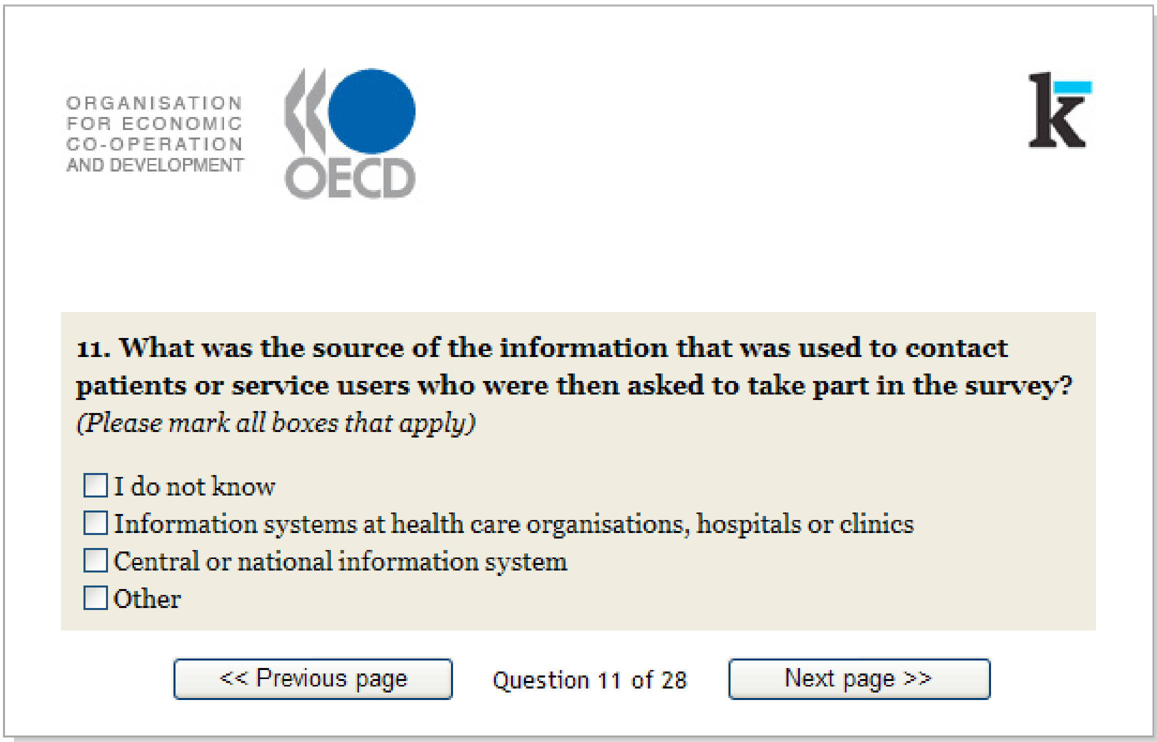
☐ Hospital inpatients
☐ Hospital outpatients / day patients including day surgery, examinations and follow-ups
☐ General practice or primary care patients
☐ Psychiatric inpatients
☐ Psychiatric outpatients
☐ General population
☐ Other



10. Were there any inclusion criteria relating to age?
If so, please write the minimum and/or maximum age in the boxes.

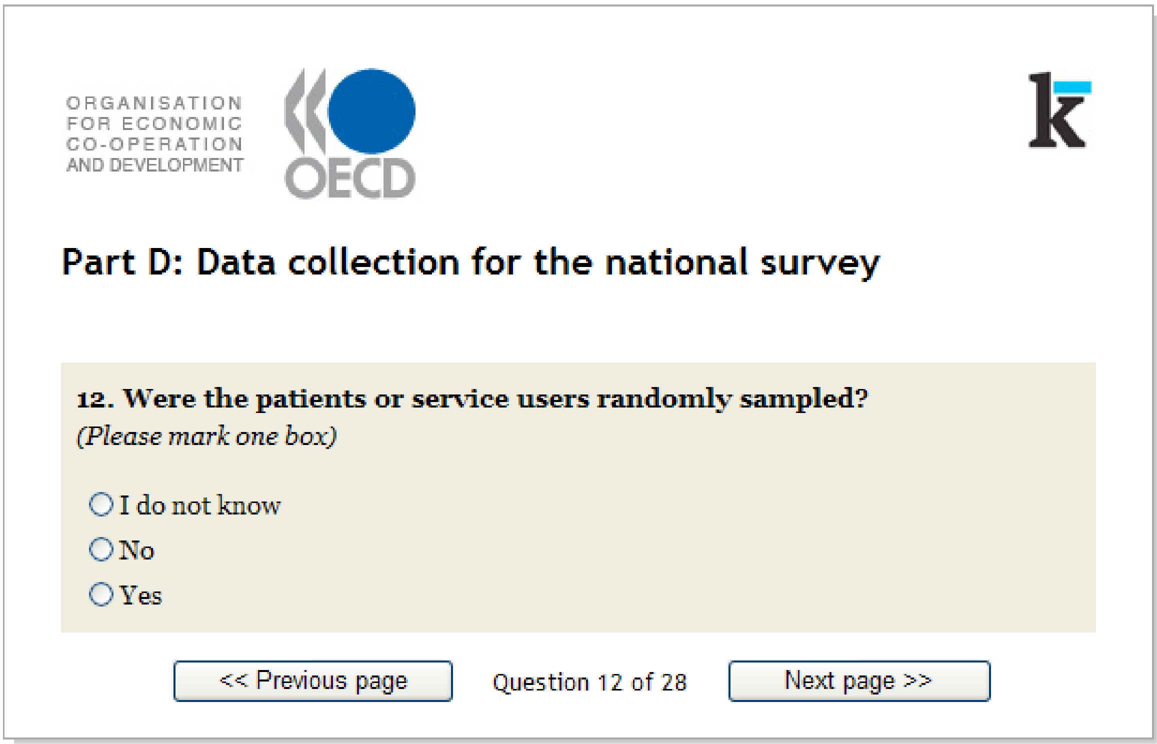
Minimum age: ☐ years
Maximum age: ☐ years

Please use the space below to give more information including diagnoses, treatment (medical, surgery, etc) and inclusion or exclusion criteria.



11. What was the source of the information that was used to contact patients or service users who were then asked to take part in the survey?
(Please mark all boxes that apply)

☐ I do not know
☐ Information systems at health care organisations, hospitals or clinics
☐ Central or national information system
☐ Other

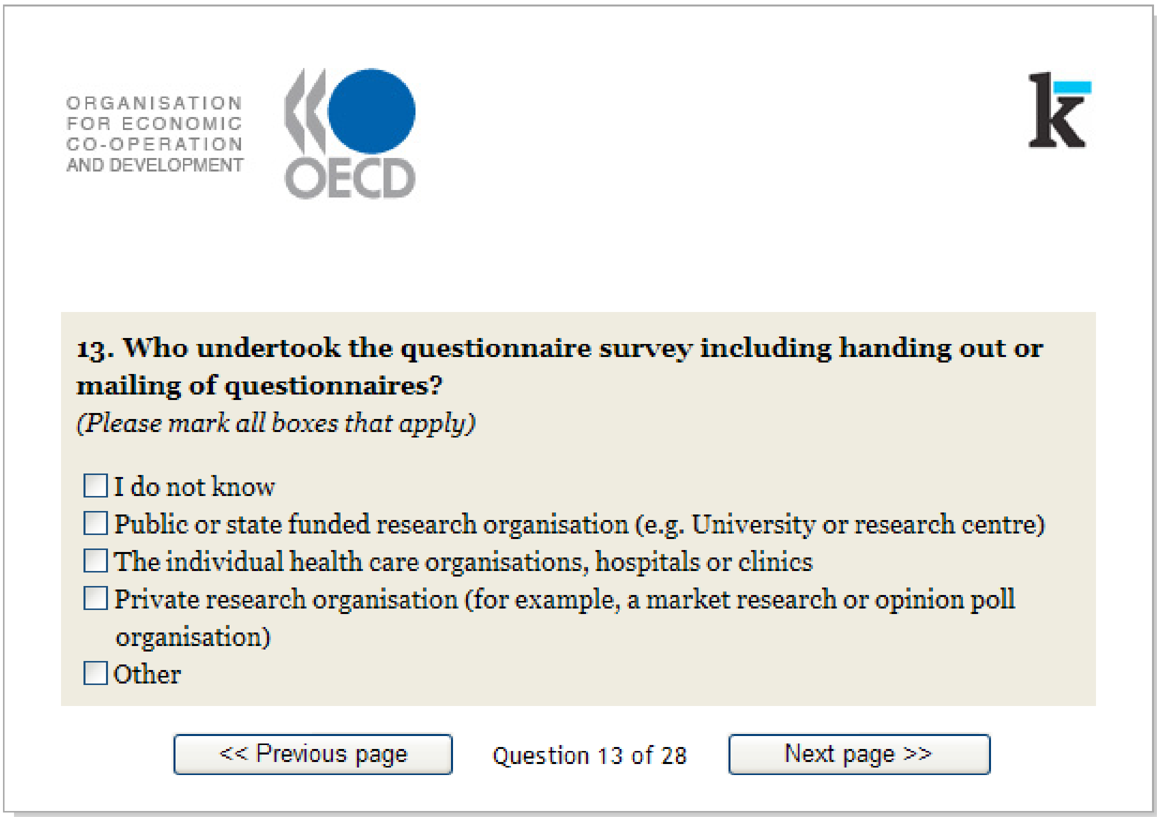


Part D: Data collection for the national survey

12. Were the patients or service users randomly sampled?
(Please mark one box)

○ I do not know
○ No
○ Yes

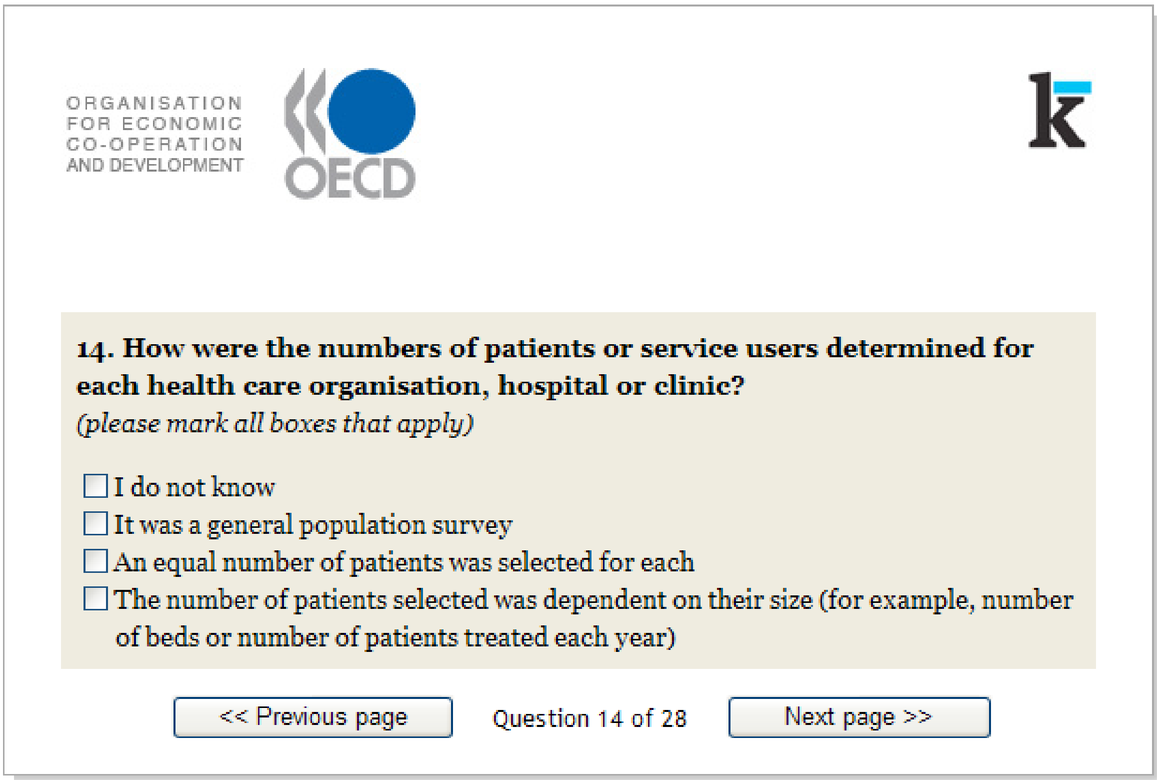
Question 12 of 28



13. Who undertook the questionnaire survey including handing out or mailing of questionnaires?
(Please mark all boxes that apply)

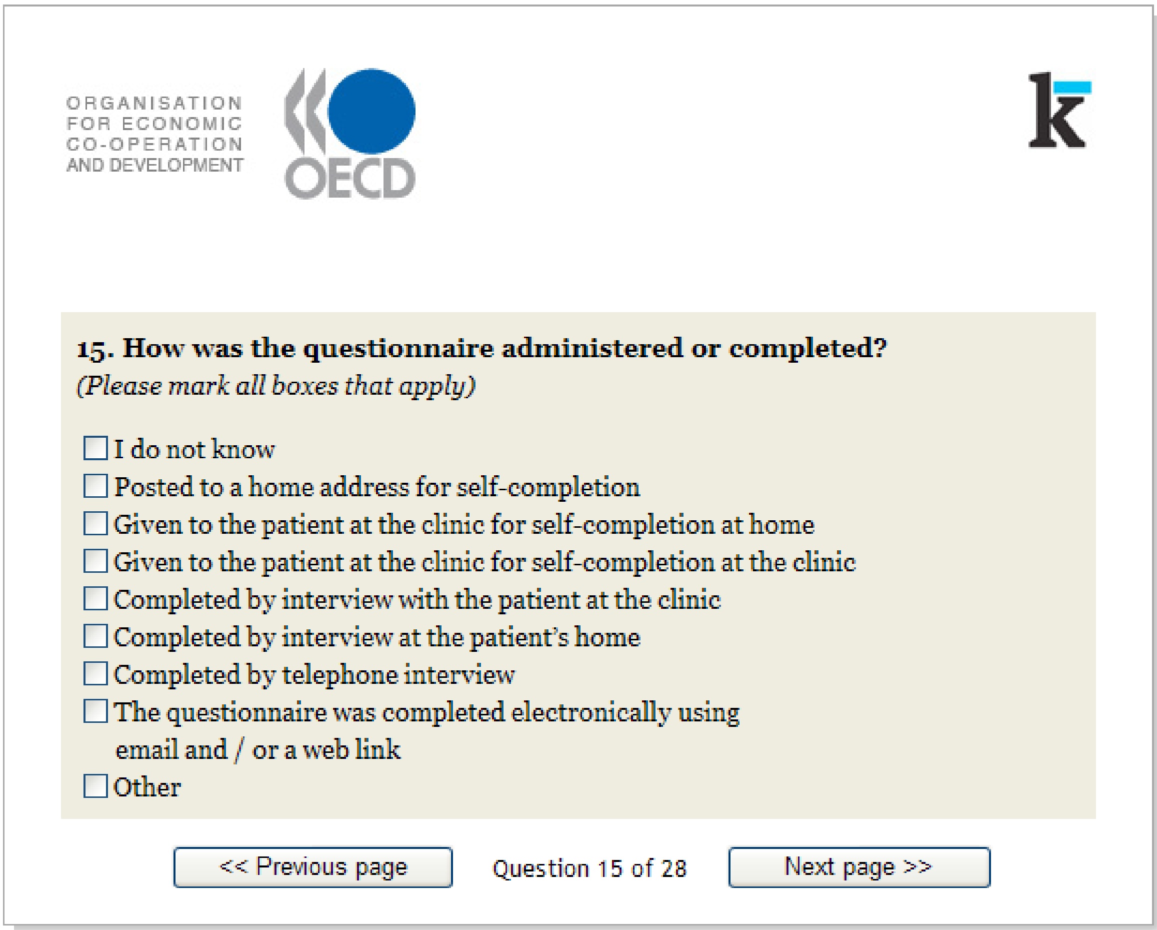
☐ I do not know
☐ Public or state funded research organisation (e.g. University or research centre)
☐ The individual health care organisations, hospitals or clinics
☐ Private research organisation (for example, a market research or opinion poll organisation)
☐ Other

Question 13 of 28



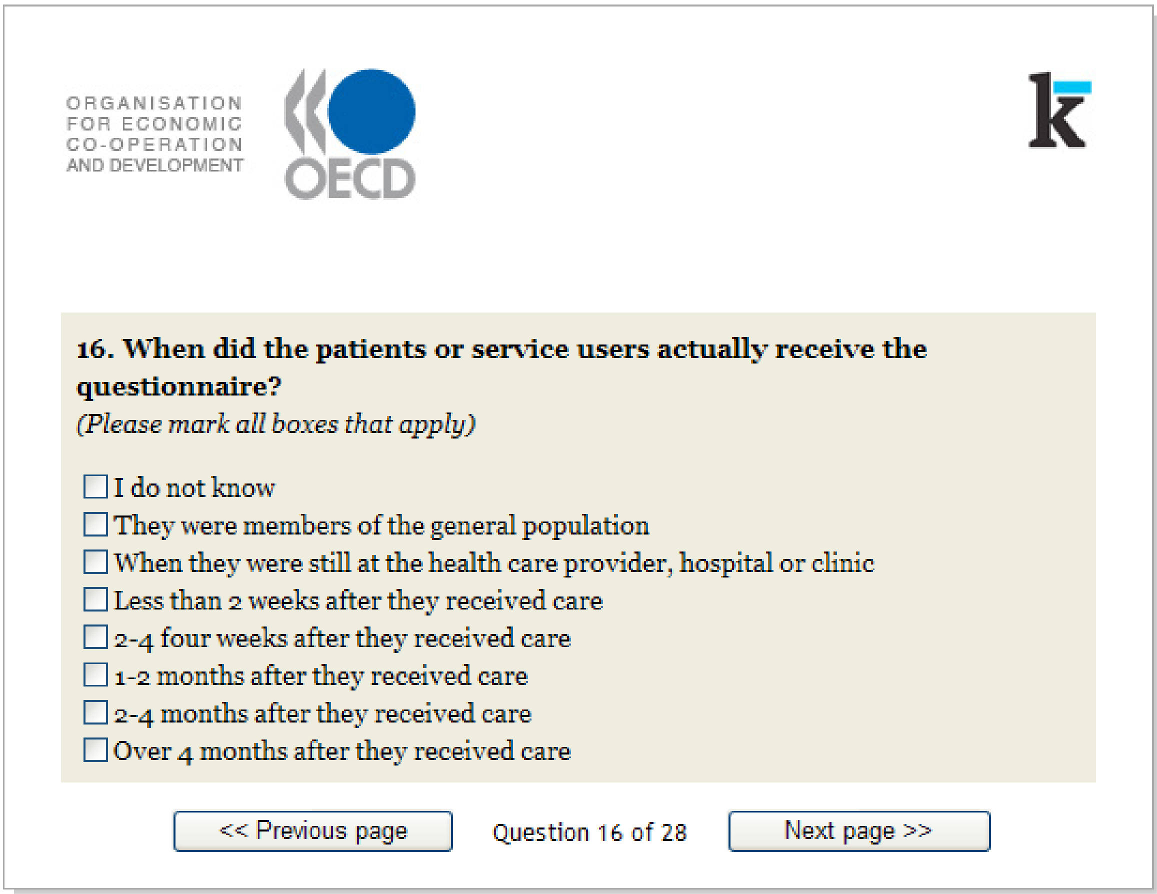
14. How were the numbers of patients or service users determined for each health care organisation, hospital or clinic?
(please mark all boxes that apply)

☐ I do not know
☐ It was a general population survey
☐ An equal number of patients was selected for each
☐ The number of patients selected was dependent on their size (for example, number of beds or number of patients treated each year)



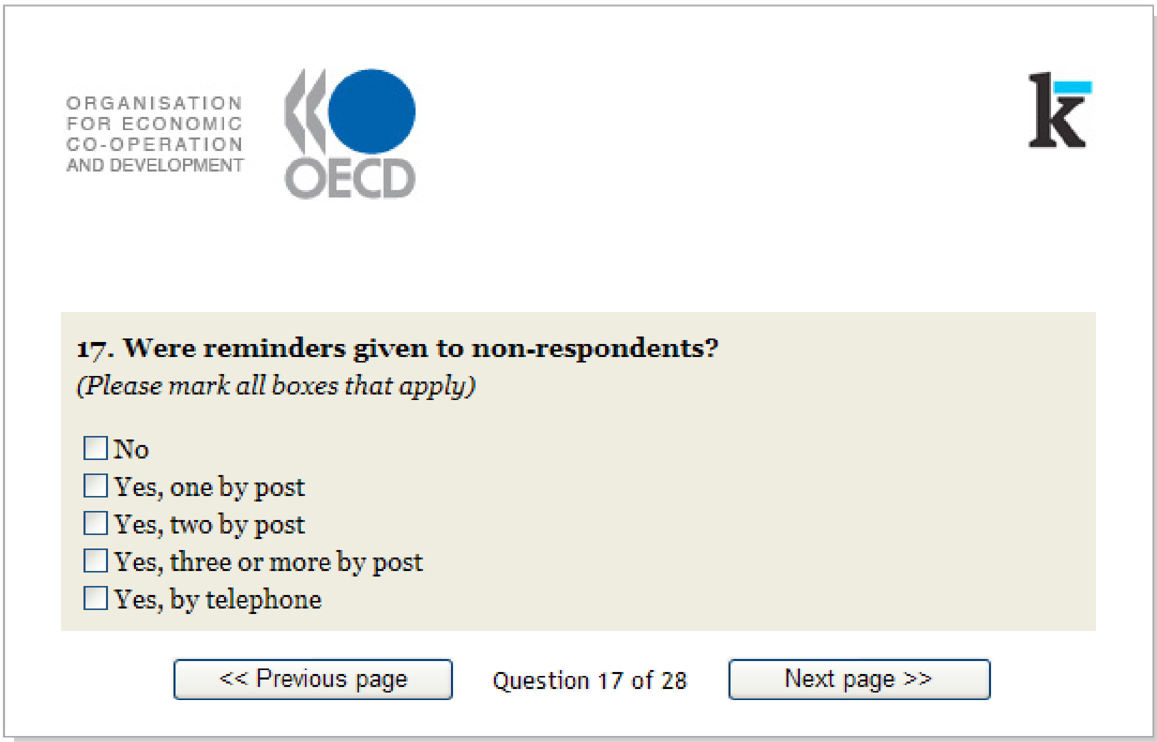
15. How was the questionnaire administered or completed?
(Please mark all boxes that apply)

☐ I do not know
☐ Posted to a home address for self-completion
☐ Given to the patient at the clinic for self-completion at home
☐ Given to the patient at the clinic for self-completion at the clinic
☐ Completed by interview with the patient at the clinic
☐ Completed by interview at the patient's home
☐ Completed by telephone interview
☐ The questionnaire was completed electronically using email and / or a web link
☐ Other



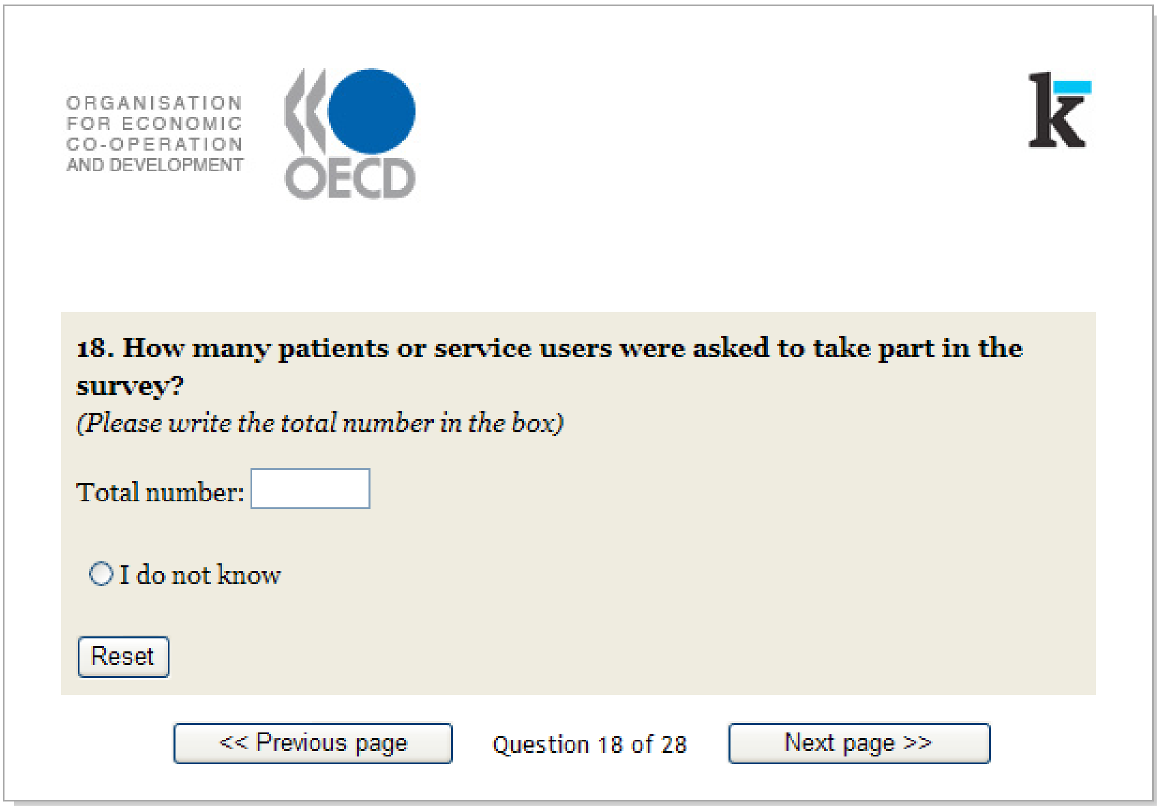
16. When did the patients or service users actually receive the questionnaire?
(Please mark all boxes that apply)

☐ I do not know
☐ They were members of the general population
☐ When they were still at the health care provider, hospital or clinic
☐ Less than 2 weeks after they received care
☐ 2-4 four weeks after they received care
☐ 1-2 months after they received care
☐ 2-4 months after they received care
☐ Over 4 months after they received care



17. Were reminders given to non-respondents?
(Please mark all boxes that apply)

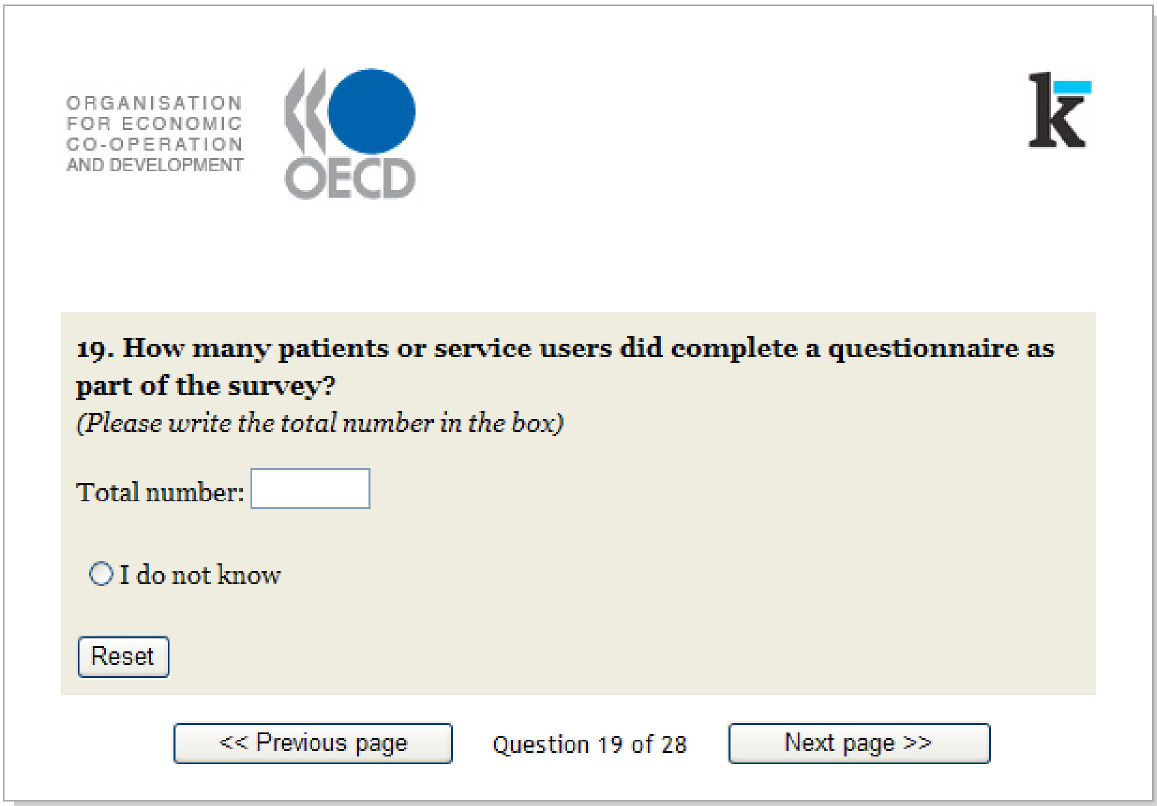
☐ No
☐ Yes, one by post
☐ Yes, two by post
☐ Yes, three or more by post
☐ Yes, by telephone



18. How many patients or service users were asked to take part in the survey?
(Please write the total number in the box)

Total number: ☐

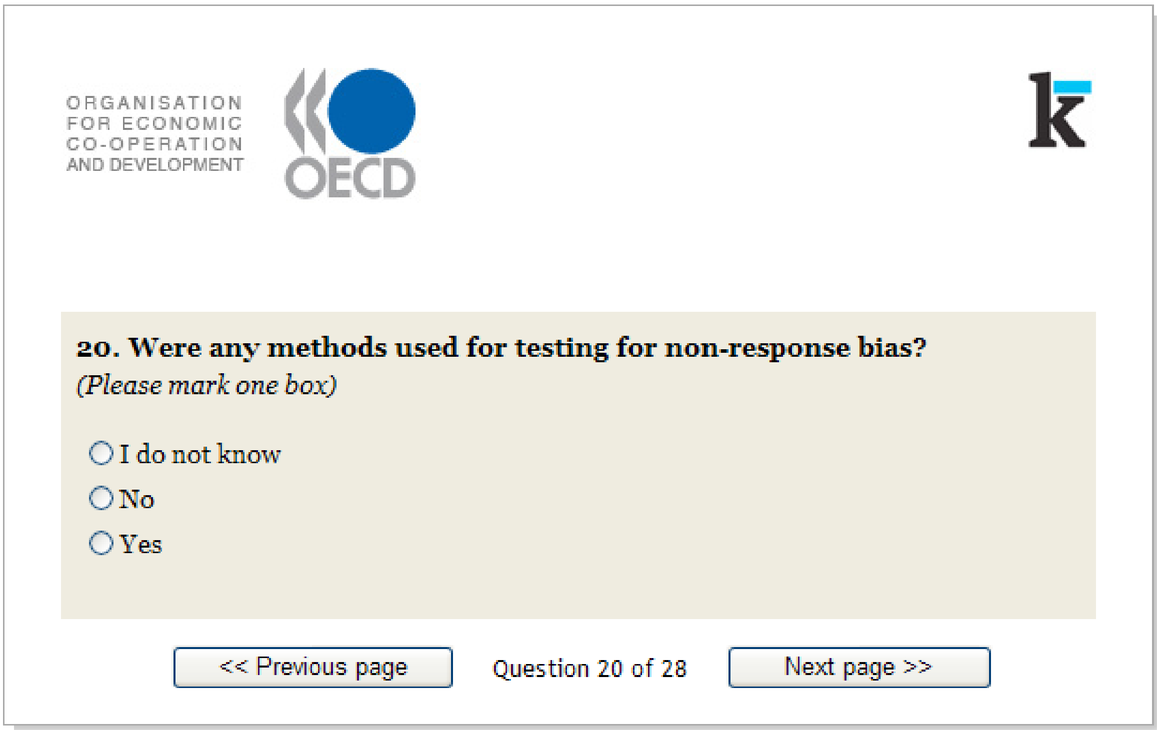
○ I do not know



19. How many patients or service users did complete a questionnaire as part of the survey?
(Please write the total number in the box)

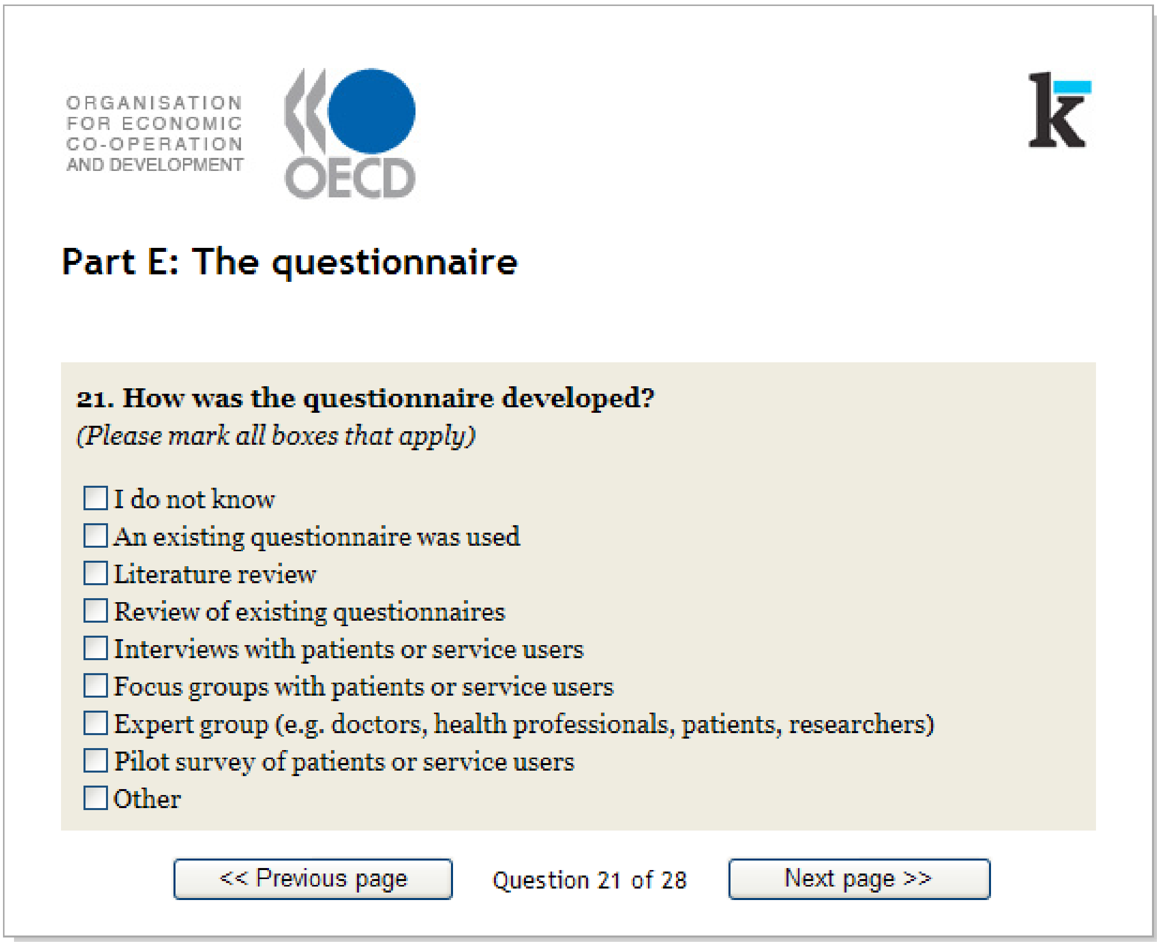
Total number: ☐

○ I do not know



20. Were any methods used for testing for non-response bias?
(Please mark one box)

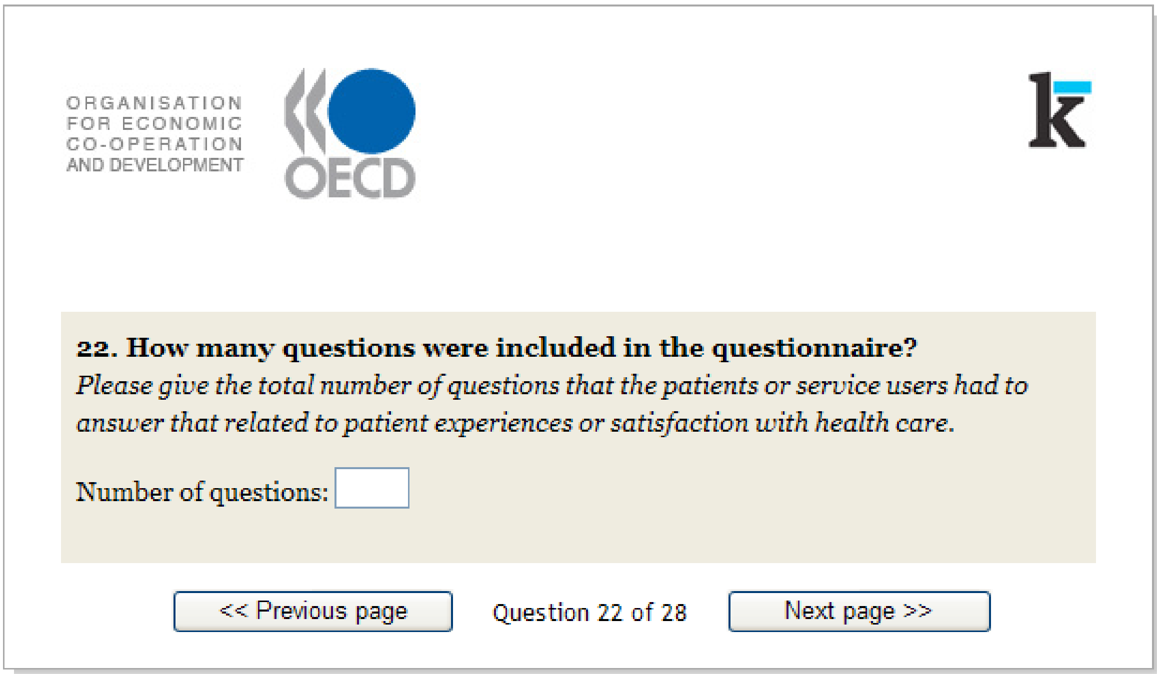
○ I do not know
○ No
○ Yes



Part E: The questionnaire

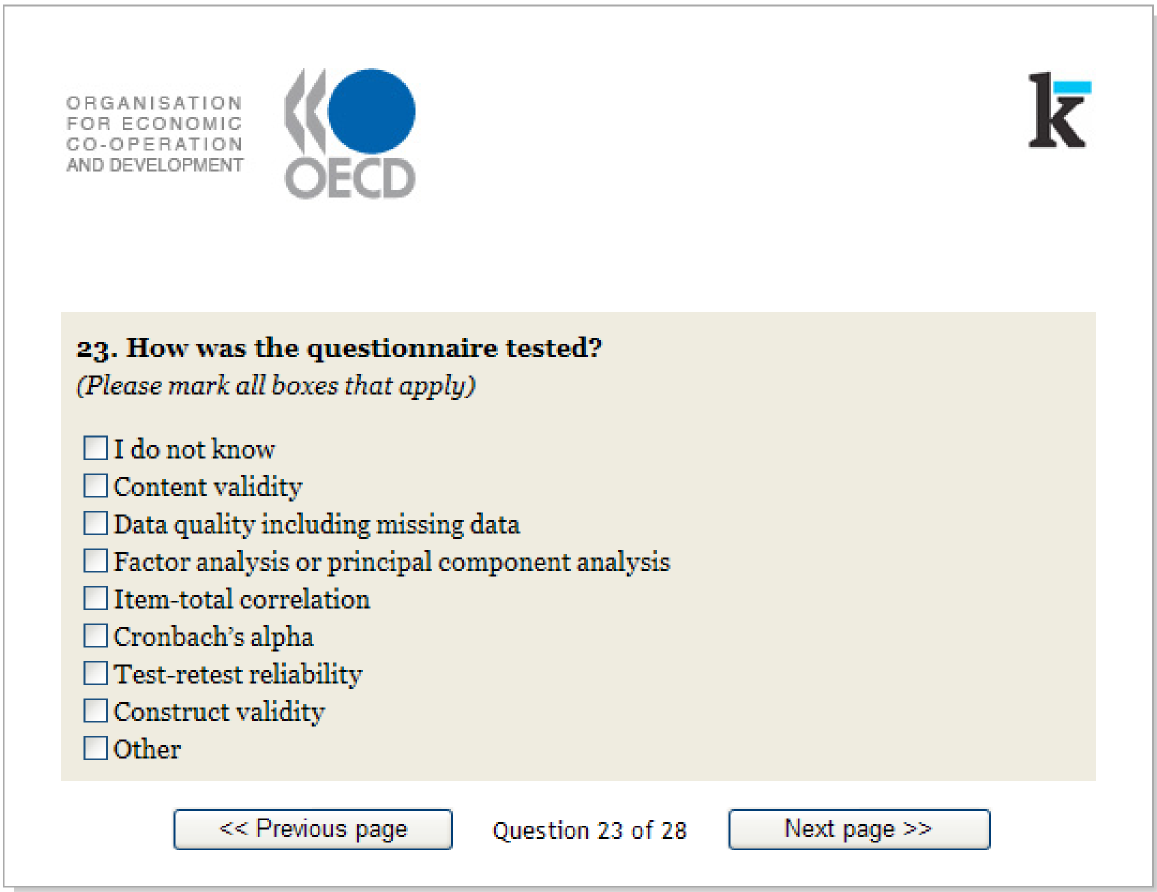
21. How was the questionnaire developed?
(Please mark all boxes that apply)

☐ I do not know
☐ An existing questionnaire was used
☐ Literature review
☐ Review of existing questionnaires
☐ Interviews with patients or service users
☐ Focus groups with patients or service users
☐ Expert group (e.g. doctors, health professionals, patients, researchers)
☐ Pilot survey of patients or service users
☐ Other



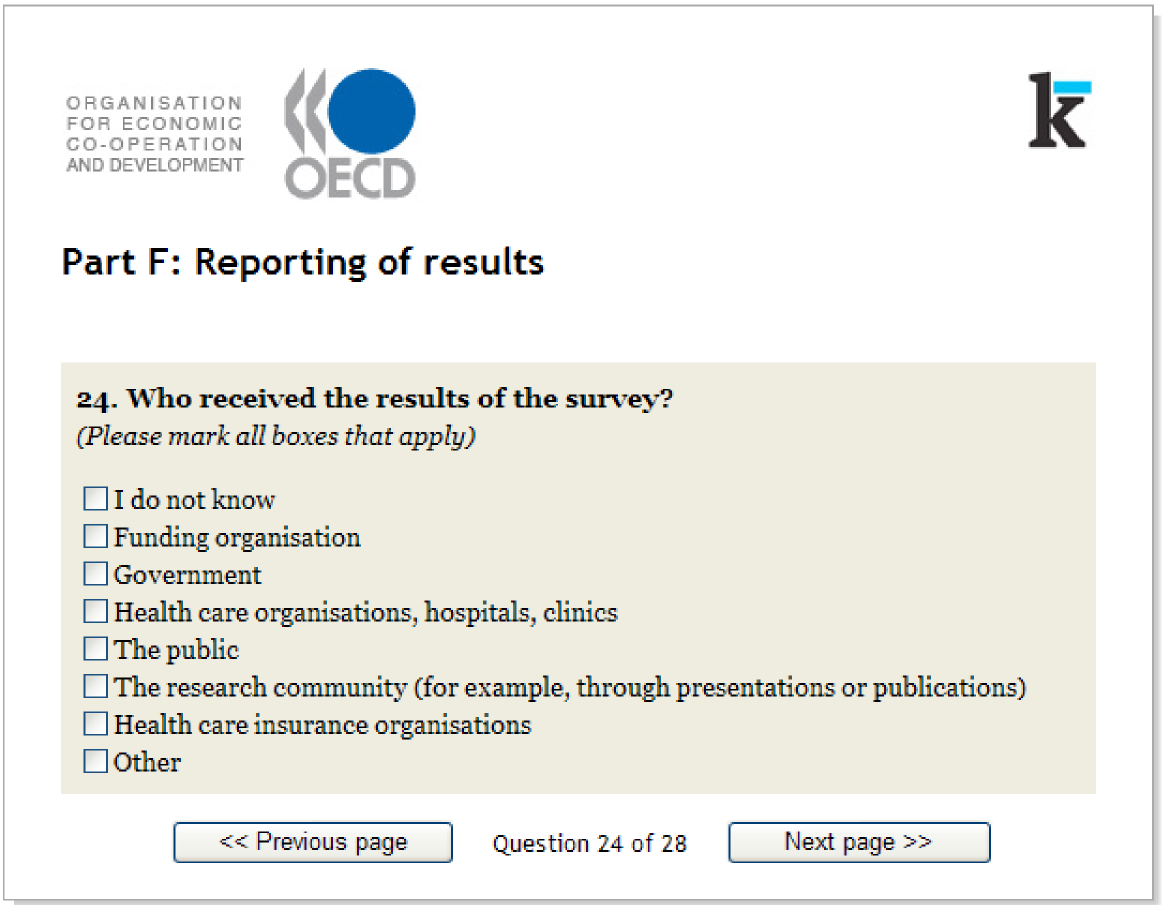
22. How many questions were included in the questionnaire?
Please give the total number of questions that the patients or service users had to answer that related to patient experiences or satisfaction with health care.

Number of questions: ☐



23. How was the questionnaire tested?
(Please mark all boxes that apply)

☐ I do not know
☐ Content validity
☐ Data quality including missing data
☐ Factor analysis or principal component analysis
☐ Item-total correlation
☐ Cronbach's alpha
☐ Test-retest reliability
☐ Construct validity
☐ Other

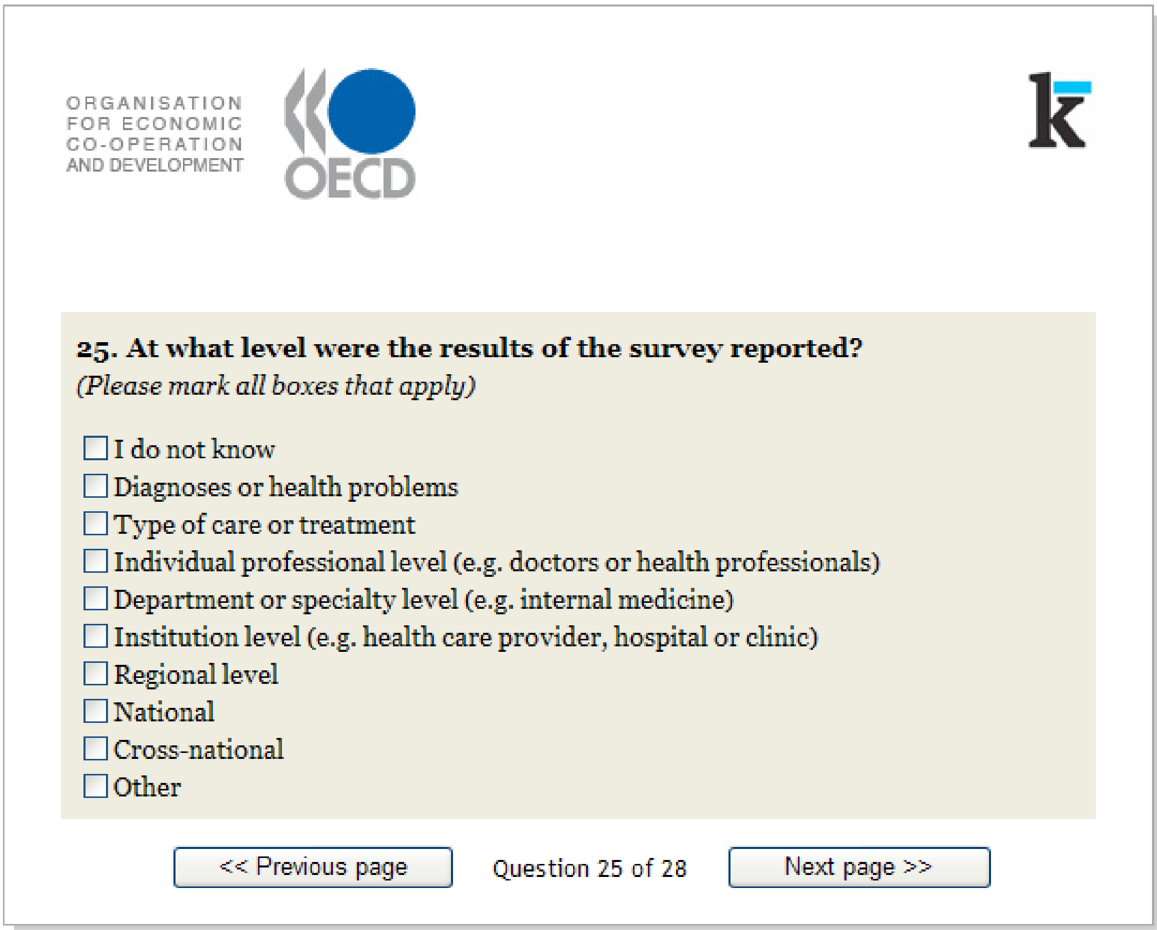


ORGANISATION FOR ECONOMIC CO-OPERATION AND DEVELOPMENT
OECD

Part F: Reporting of results

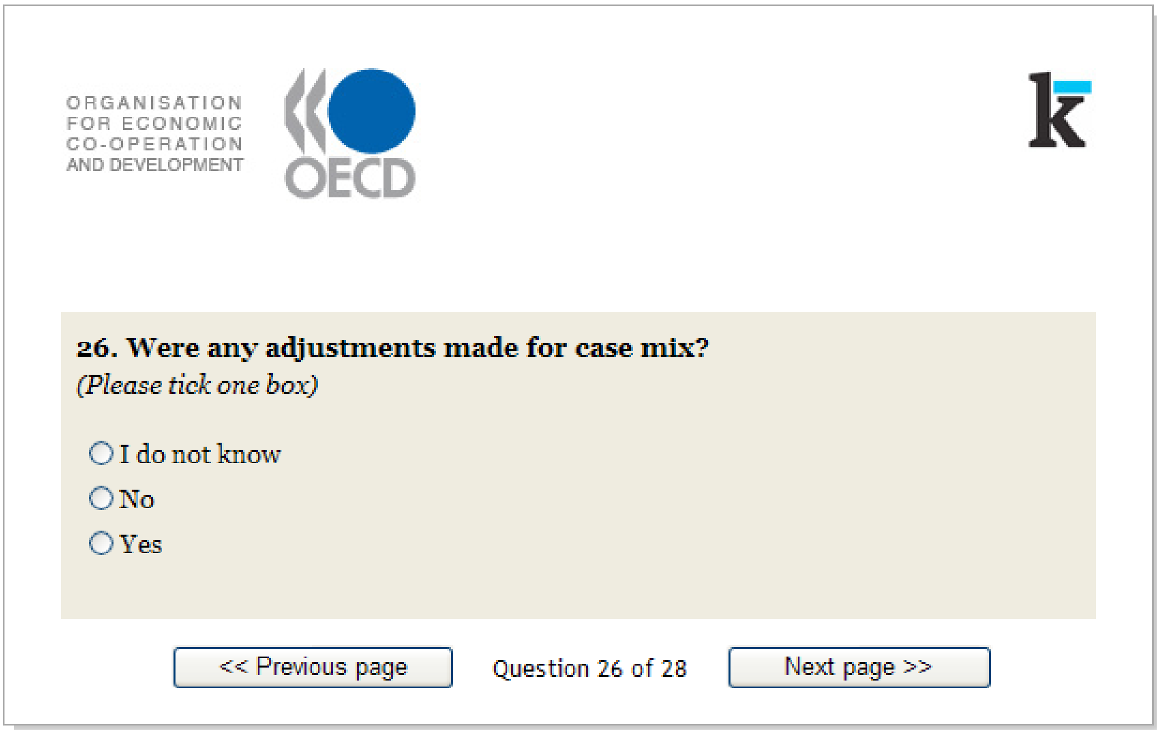
24. Who received the results of the survey?
(Please mark all boxes that apply)

☐ I do not know
☐ Funding organisation
☐ Government
☐ Health care organisations, hospitals, clinics
☐ The public
☐ The research community (for example, through presentations or publications)
☐ Health care insurance organisations
☐ Other



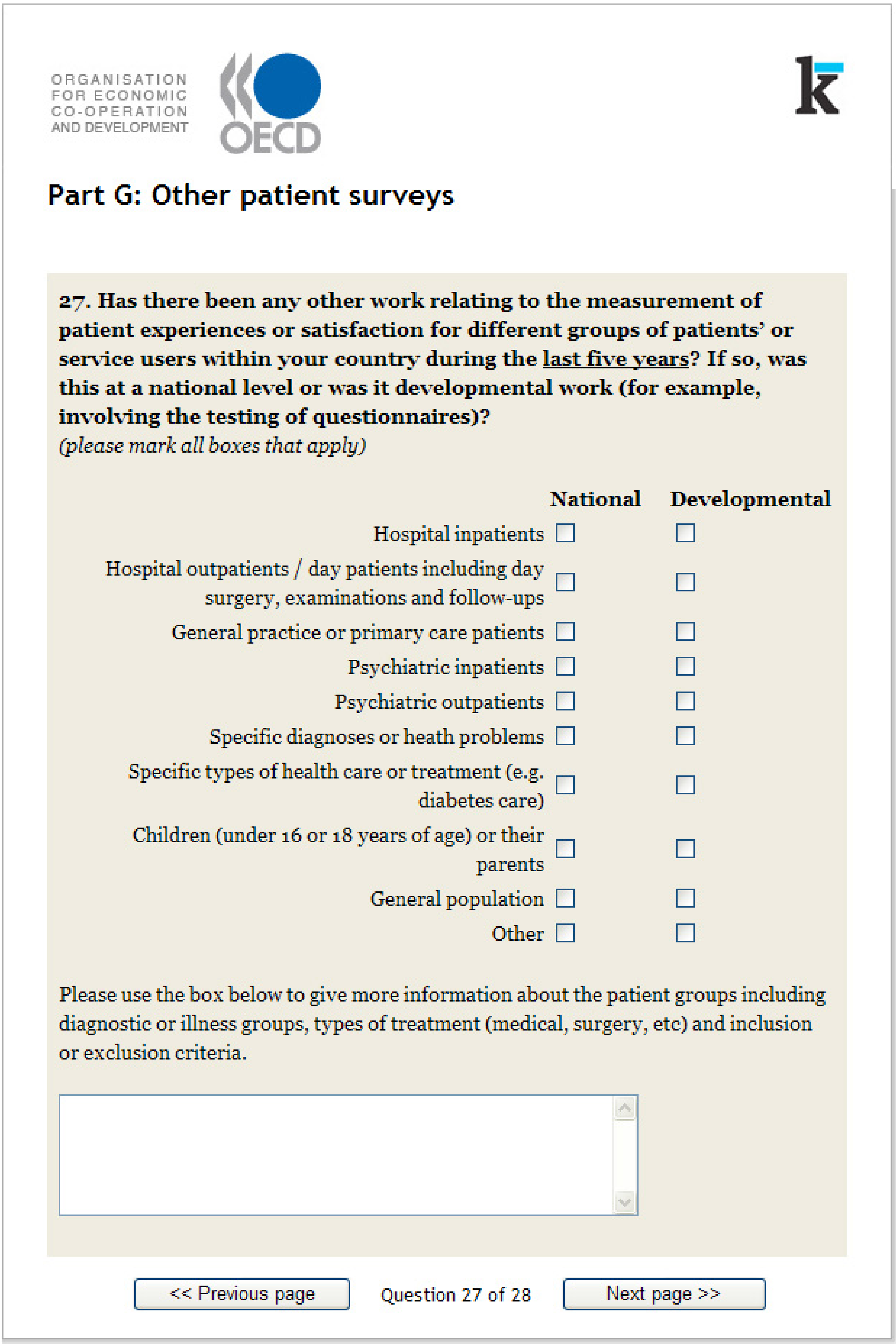
25. At what level were the results of the survey reported?
(Please mark all boxes that apply)

☐ I do not know
☐ Diagnoses or health problems
☐ Type of care or treatment
☐ Individual professional level (e.g. doctors or health professionals)
☐ Department or specialty level (e.g. internal medicine)
☐ Institution level (e.g. health care provider, hospital or clinic)
☐ Regional level
☐ National
☐ Cross-national
☐ Other



26. Were any adjustments made for case mix?
(Please tick one box)

○ I do not know
○ No
○ Yes



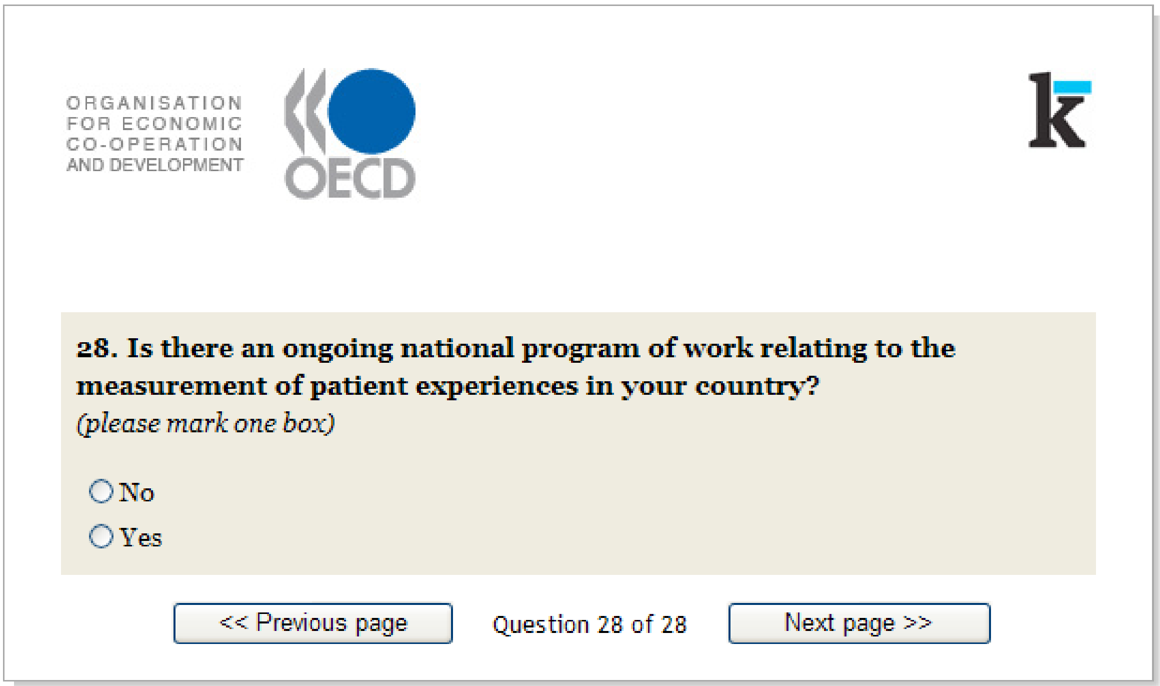
Part G: Other patient surveys

27. Has there been any other work relating to the measurement of patient experiences or satisfaction for different groups of patients' or service users within your country during the last five years? If so, was this at a national level or was it developmental work (for example, involving the testing of questionnaires)?
(please mark all boxes that apply)

	National	Developmental
Hospital inpatients	☐	☐
Hospital outpatients / day patients including day surgery, examinations and follow-ups	☐	☐
General practice or primary care patients	☐	☐
Psychiatric inpatients	☐	☐
Psychiatric outpatients	☐	☐
Specific diagnoses or heath problems	☐	☐
Specific types of health care or treatment (e.g. diabetes care)	☐	☐
Children (under 16 or 18 years of age) or their parents	☐	☐
General population	☐	☐
Other	☐	☐

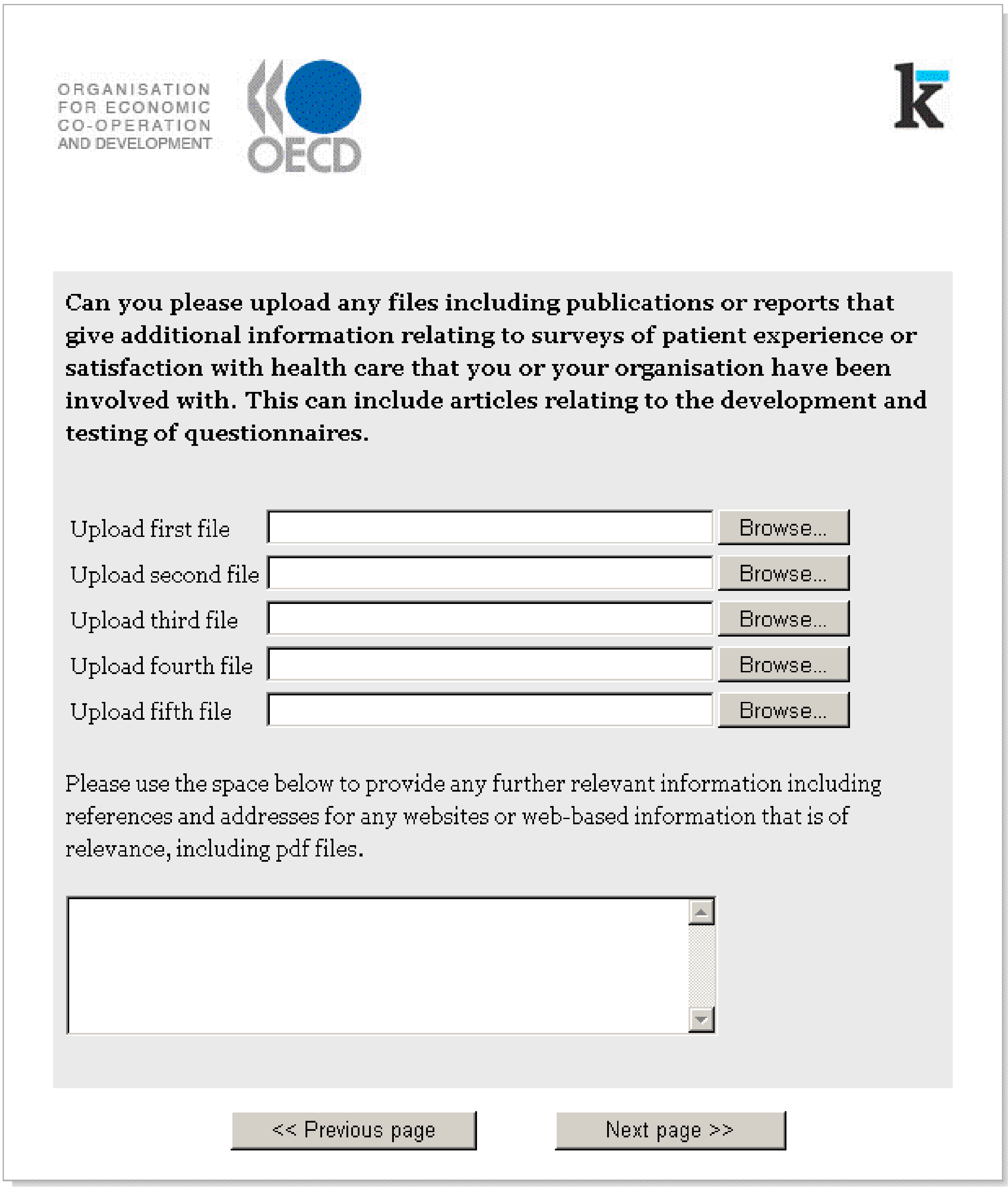
Please use the box below to give more information about the patient groups including diagnostic or illness groups, types of treatment (medical, surgery, etc) and inclusion or exclusion criteria.

Question 27 of 28



28. Is there an ongoing national program of work relating to the measurement of patient experiences in your country?
(please mark one box)

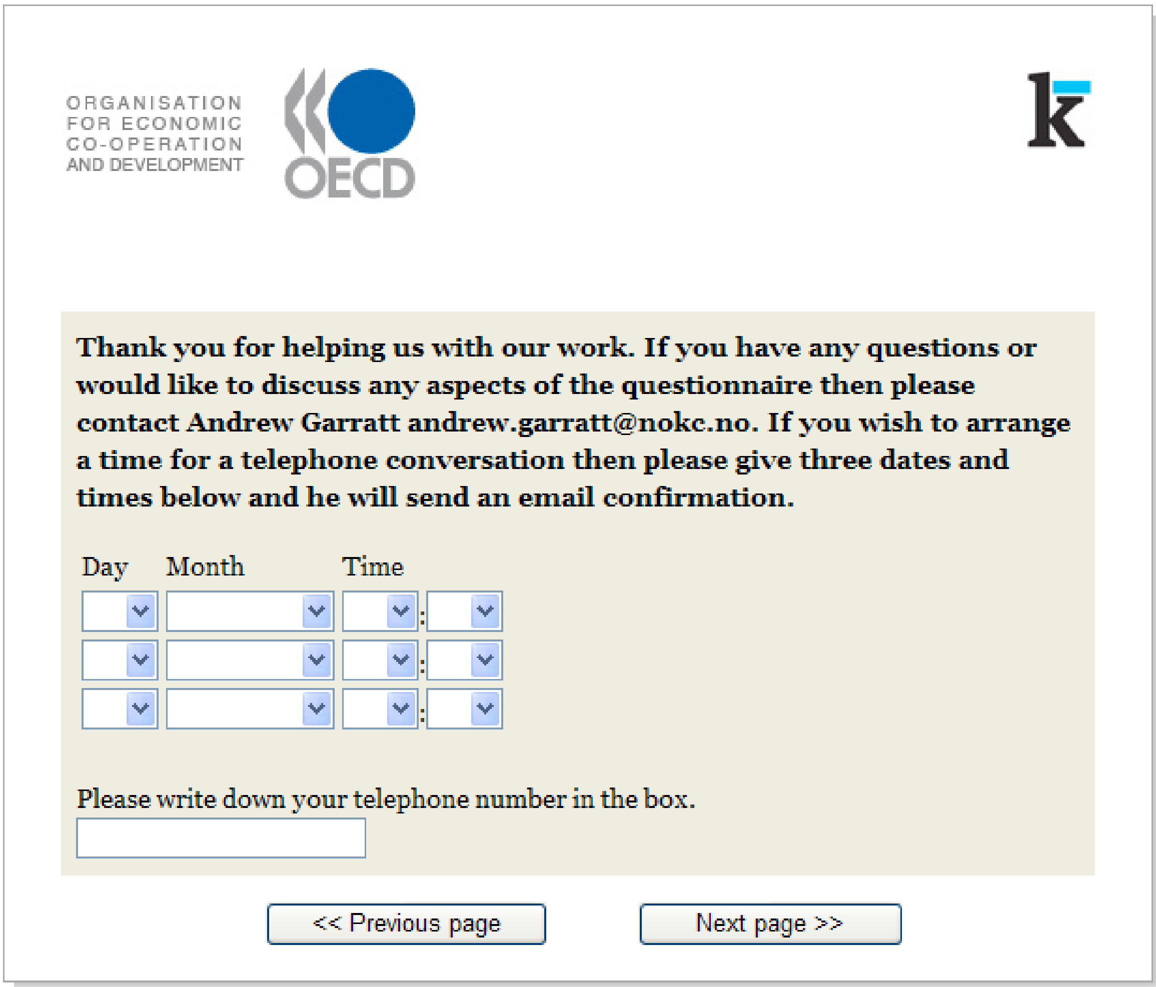
○ No
○ Yes



Can you please upload any files including publications or reports that give additional information relating to surveys of patient experience or satisfaction with health care that you or your organisation have been involved with. This can include articles relating to the development and testing of questionnaires.

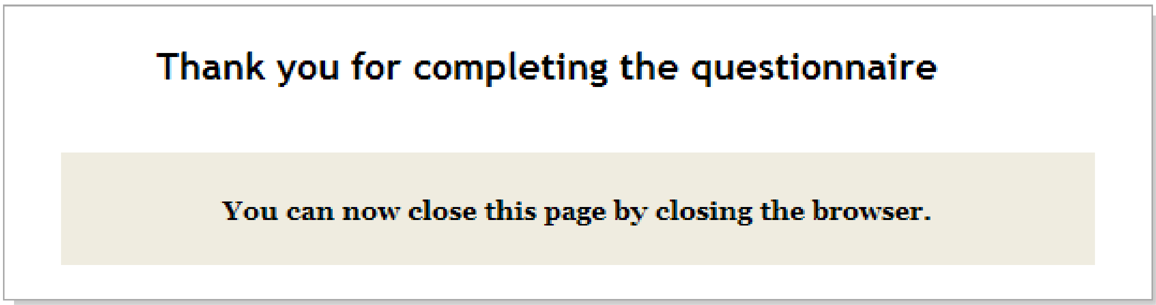
Upload first file
Upload second file
Upload third file
Upload fourth file
Upload fifth file

Please use the space below to provide any further relevant information including references and addresses for any websites or web-based information that is of relevance, including pdf files.



Thank you for helping us with our work. If you have any questions or would like to discuss any aspects of the questionnaire then please contact Andrew Garratt andrew.garratt@nokc.no. If you wish to arrange a time for a telephone conversation then please give three dates and times below and he will send an email confirmation.

Please write down your telephone number in the box.



Thank you for completing the questionnaire

You can now close this page by closing the browser.