

The patient has left the building – what next? The success of a web-based patient follow up system

Adriaan Ackers¹, Antoine Driessen², Wim Jan van Boven³

1. Introduction

The Cardio-Thoracic Surgery Group (CTC) at the Nieuwegein based St Antonius Hospital is highly renowned for its innovation and expertise in the field of pulmonary and cardiac surgery. Being one of the leading cardiac centers in Europe from the 1950's on, it has a nation wide referral pattern of cardiac, pulmonary and thoracic-vascular pathologies. The center is continuously adopting new operations and innovative techniques into its daily practice. It is still increasing its turnover, and operates more than 2000 cases each year. Meanwhile, the center is training more new surgeons than any other center in the Netherlands. To perform as a teaching center, the CTC has an established scientific research program, both conducting its own studies as well as participating in large international studies; and therefore is a foremost teaching center. Follow-up of patients after surgery is crucial to good after care, however, due to the numbers of patients being treated it has become almost impossible to conduct this as desired.

Cardio-thoracic operations are generally performed on the elderly; the average patient age in 2004 was 65. These patients are exposed to a high-risk procedure, which is followed by a long and slow recovery period. These kinds of high-risk procedures, including the postoperative time, have an accepted mortality and morbidity rate. The primary goal in each procedure is to prolong the average lifespan of the patient and to improve their quality of life.

ADV Market Research is a Dutch based market research agency that specializes in innovative online research systems. In recent years it has contributed to the growing acceptance of online market research as a reliable research method in the Netherlands. Online monitoring is a special expertise of ADV Market Research, where changes in the client's operational database trigger customized online surveys, creating information that is fed back into the client's organisation.

2. Background

At this moment the Dutch Health Care segment is in a state of flux. In the near future, the government will force the hospitals to become more and more transparent, making after care a necessity instead of a luxury.

One of the expected changes following realization of this government plan will be the implementation of detailed patient outcomes in annual reports. Treatment follow-up data in terms of survival and quality of life will be of utmost importance. In this way it will become possible to reveal differences in quality, volumes and prices between different health care

¹ ADV Market Research, Zeist, The Netherlands

² Cardio-Thoracal Surgery Group at the St Antonius Hospital, Nieuwegein, The Netherlands

³ Cardio-Thoracal Surgery Group at the St Antonius Hospital, Nieuwegein, The Netherlands

facilities. Health care insurance companies will be able to use these data while in the process of contracting hospitals. On the other hand, patients can decide in which institution they want to be treated.

The government has implemented a new treatment-based system of financing health care. In contrast to the previous system, the patient has become the center of importance. In this way, the government is achieving its aims of creating a more market oriented health care system as well as increasing competition between health care providers. Efficiency, effectiveness and quality control have become the new keywords in the health care sector.

As a result of these changed circumstances, first and second line health care professionals have regained interest in patients from a non-medical point of view. Patients are now being viewed as customers, and customer care, especially aftercare, has become vital. 'New' phenomena like patient satisfaction and quality of life, are being embraced.

The way health care has been organized over the last few decennia in the Netherlands has led to a general feeling that health care is being paid for by the government. Modern state-of-the-art healthcare however has become a high level technical enterprise. This has led to a major increase in overall health care costs. Some first steps toward a major breakthrough have been achieved: new insurance models for the patients have been developed, which, for example, also give the patient the opportunity to select more expensive contracts, enabling the patients to choose their preferred health care supplier.

Meanwhile, insurance companies are in transition; moving towards a new role as health care providers. Instead of managing the financial part of the health care system, they have started to manage the complete process: from sickness to health. This means that the insurance companies are increasingly taking on the role of clients: demanding concrete performance indicators from the health care professionals. They are now looking for bargains in the health care segment by trying to match these indicators with the costs they are making.

As a boost to this new system, the media started their own competitive hospital listings several years ago, placing themselves in the position of the patient or customer. The outcome of these polls shocked both the health care sector and the hospital boards. The St. Antonius hospital, for example, ended up in the middle of the list, instead of at the top as had been expected. This made it clear that treating a patient is more than performing good surgery alone. The effect of these highly profiled public lists is that the patient develops his own preferences for certain hospitals or medical centers. Being at the top of these lists has therefore become very important, as it has a direct effect on the revenues of the medical centers.

Entering new fields of treatments makes it essential to follow patients after discharge.

"Quality of Life" has become an essential criterion in evaluating success, as reflected by the exponential increase in the number of papers written in the medical journals on this subject. In 1973 only 5 articles listed "quality of life" as a reference key in MEDLINE. In the subsequent 5-year periods, there were 195, 273, 490 and 1252 articles listed. (ref: [M.A. Testa, D.C. Simonson \(1996\), Assessment of Quality-of-Life Outcomes \(1996\), NEJM, 334:835-40](#)) Our own, quickly executed, research revealed an even more striking increase, listing 154 articles in 1970-1975 and up to 33.541 articles in the period 2000-2005. This illustrates that prolonging life alone, is as such not enough to be rated as successful anymore.

Health care professionals have always shown a high interest in patient follow-up research from both a medical and scientific point of view. The effectiveness of procedures and innovative techniques is of vital importance to the professionals. This forced the Cardio-Thoracic Surgery Group of the St Antonius Hospital to look for a reliable way of following-up their patients, by evaluating the patient's quality of life whilst at the same time improving the standard of treatment by scoring and reflecting the patient satisfaction.

3. Patient follow-up

Although extensive patient-driven follow-up is of vital importance to health care professionals, this has often been neglected because of the time-consuming and expensive nature of the research. To start with, follow-up research can be conducted by contacting the referring cardiologist or the general practitioner. Although this is likely to provide an adequate survival curve and will provide reliable information about the health care consumption, it will mean bypassing the most valuable source of information, the patient himself. Therefore it will neither provide a reliable Quality of Life score nor will it reflect the patient's satisfaction.

Alternatively, requesting the patients return to the outpatients clinic will provide both the opportunity to score the patient's Quality of Life, and the ability to reflect on patient satisfaction. However, this is a time-consuming and expensive process. It also introduces a possible interview bias on patient satisfaction resulting from the confrontation with the patient's health professionals. Telephone interviews are also time-consuming and expensive, and we have the same concerns about the possible interview bias. On the other hand, achieving an adequate survival curve through telephone research is relatively easy to accomplish.

These issues made us (re-)consider the use of written and online questionnaires. Although written questionnaires are commonly used, we were specifically looking for a new approach. Online research has proven itself a cost-effective and reliable research method in the field of commercial market research. Other reasons to prefer online surveying are the user-friendliness of the method, the possibility to include automatic routing and the absence of interviewer bias. We therefore decided to conduct research to establish whether online research techniques could be applied to the specific area of medical patient follow-up programs.

We were looking for a cost effective research method that includes the patient in the follow-up. Considering the advantages of online surveying, we set up a pilot to determine whether a web-based follow-up system could be feasible for use amongst this specific research population.

The need for a follow-up with the above-described possibilities has led to our pilot, in which our primary aim was to establish the feasibility of this method.

4. The pilot: research questions

The main objective of the pilot study was to establish the feasibility of a web-based follow-up system for cardiac surgery patients. We wanted to establish whether it is possible to use the

Internet as the main medium for gathering data on the patient's condition during the year following the patient's discharge from hospital.

In the pilot study we looked at four outcomes of follow-up:

- Patient satisfaction concerning the hospital stay
- Quality of life after discharge
- Specific medical questions (e.g. on complications, medicine use)
- Survival curve (mortality rate)

The outcome of the mortality rate has a special bearing on the research method: it requires completeness of follow-up, meaning simply that a result from every respondent is required. Early on, we agreed that a web-based system, on its own, is insufficient in creating the necessary completeness of a case. In order to address this issue we needed to enlist the aid of a call center, to be used for contacting the non-response of our web survey. This underlines the importance of a high online response: the less the non-response, the less effort and costs of the call centre will be needed for the survey to be completed.

The other three types of follow-up can be statistically valid without completeness. The main question was to see if a web-based research under this population would yield a representative response pattern.

In any case, the response rate of the web-based survey system is one of the more important research questions of the pilot study. Does online follow-up provide a representative response in patient follow-up?

This is especially relevant when regarding the population of cardiac surgery patients. The majority of cardiac patients are elderly. Although they are the fastest growing group on the Internet (ref: [CBS Statline Database, 2000-2004](#)), they are currently still not represented on the Internet as much as the younger age groups. Furthermore, because of cardiac surgery, the respondents are usually in a lesser physical state than other people of the same age, especially during the first months after surgery. Does the research method yield differences in age groups in response rate? Does the method yield differences in different types of cardiac or pulmonary surgery?

Another research question we put to the test in our pilot was to see if it would be possible to include patients in the survey that do not have an Internet connection. We asked these patients to provide an e-mail address of a relative or friend, to whom we could send the e-mail invitation and a hyperlink to the online questionnaire. We wanted to find out if it would be possible to reach all patients by online surveying, including the ones without an Internet connection. The derivative research question was to find out if there is a difference in response rate between the 'online' patients and the 'off-line' patients.

Finally, we wanted to test if the survey response was dependent on the time between discharge from the hospital and the moment of survey. The pilot set-up had multiple research moments during the year following the discharge of the patient, making it possible to detect a possible decline in survey participation over time.

5. The pilot set up

5.1 The process

The pilot was set up as follows. Starting from 1-1-2005, all patients were asked to participate in the follow-up study. No distinction was made on age group, physical condition, or type of cardiac surgery. The only precondition used was the availability of an e-mail address. Emergency operations were not included in the pilot. All scheduled patients had an equal participation opportunity.

If patients accepted the invitation to participate, they were asked to sign an informed consent form declining the anonymity of the results, allowing ADV Market Research as executive research agency to pass on individual results to the medical staff at the St Antonius Hospital.

During the year after discharge from hospital, every patient included in the pilot was asked to participate in a cycle of five different web-based surveys. The patients received an e-mail invitation that has a direct personal hyperlink to a secure web environment where the patient could fill in the questionnaire.

The first survey was conducted two weeks after discharge from hospital and consisted of a patient satisfaction questionnaire concerning the hospital stay. The four surveys following the first are identical; these were conducted every three months following discharge from hospital (longitudinal study).

It is noteworthy that the entire cycle of surveys is “event-driven”, meaning that the date of discharge determines the 5 moments that an e-mail invitation for each of the successive surveys will be sent. As most of the respondents have different moments of discharge, the moment of invitation will differ accordingly. In this pilot study, this means that the first group of respondents will have completed the entire survey cycle in January 2006, and the last patient will be asked to fill in the final questionnaire in June 2006.

As mentioned above, one of the reasons to have multiple research moments in the follow-up pilot is to find out if there is a decline in survey participation as the pilot advances. Will there be a lesser involvement of the patient to the follow-up when his physical health improves and the moment of surgery is further back? Another reason for the multiple research moments is that they provide us with opportunities to adapt the process or the questionnaire during the study, giving us flexibility in testing the optimal approach. From a scientific point of view, the longitudinal nature of the study enables an assessment of the Quality of Life curve.

Each research moment has the same procedure:

- an e-mail is sent to the patient inviting them to participate in the survey, containing a personal hyperlink to a secure web site with the patient's questionnaire.
- after the patient has answered the questions, the data is transmitted to the ADV database.
- if the patient does not respond to the e-mail invitation, a reminder is sent one week after the original e-mail.
- If the patient does not react to the reminder, the St Antonius Hospital is alerted. The hospital contacts the patient or the patient's GP by telephone in order to close the loop necessary for the survival curve.

5.2 The questionnaire

The follow-up pilot questionnaire contains three parts:

- Patient Satisfaction Survey
- Quality of Life
- Specific medical questions (e.g. on complications, medicine use)

The Patient Satisfaction Survey was developed in cooperation with the St Antonius hospital board. We conducted the Patient Satisfaction Survey early on in the follow-up; two weeks after discharge, based on the idea that determining satisfaction would be more reliable in this way. It will be interesting to find out whether these results will be consistent with the results of the final survey after one year, when we conduct the same Patient Satisfaction Survey again.

The SF-36 Health Survey is the most appropriate, currently available, measure of Health Related quality of life (Ref: Dempster M, Donnelly M.: [Measuring the health related quality of life of people with ischaemic heart disease. Heart 2000 Jun; 83\(6\): 641-4](#)). The major disadvantage of this questionnaire is its length (36 items). Because we also wanted to ask several questions concerning patient satisfaction and health care consumption we had to resort to a shorter list. Choosing the SF-12 was a logical step. It will not provide an accurate Quality of Life level for each patient, but for larger groups it is comparable and interchangeable with the SF-36. The pilot sample is not large enough to use the SF-12 survey as a reliable measurement of Quality of Life. Then again, this was not our objective: We wanted to test the feasibility of conducting an SF-12 survey via the Internet. Besides this, the ethical committee at the St Antonius hospital gave us limitations concerning time: Patients are not allowed to exceed 20 minutes of response-time.

Specific medical questions: this part of the questionnaire relates to medicine use, complications, re-admission, general well being, and progress in health and independence. This questionnaire has been developed by the ADV Market Research in cooperation with the Cardio-Thoracic Surgery Group.

Not all the same questions are asked at every research moment: The first research moment takes place two weeks after patient discharge and consists solely of the Patient Satisfaction Survey (20 questions). The following surveys are conducted every three months following the discharge, and consist of the SF12 and the specific questions (28 questions). In the fifth and final survey, one year after discharge from hospital, the patient satisfaction survey is again added to the SF12 and the medical questionnaire, to see how the intermittent period influences the perception of the hospital stay.

The questionnaire is designed to be completed in 15 minutes or less.

5.3 Monitoring results

All the survey results can be viewed by the members of the Cardio-Thoracic Surgery Group on a web-based monitor. This monitor is available 24/7 using a login name/password combination. In the monitor on the website, only depersonalized aggregated data is used, protecting patient's privacy against unauthorized onlookers.

The hospital staff is able to conduct cross analyses on the web, because background information from the hospital's operational database is added to the survey results.

Because of the delicate nature of personalised medical data, special emphasis has been placed on the security of the Internet environment. To name some of the measures taken, every data transmission uses encryption/decryption procedures over an SSL connection, and the data is stored in a secure data centre.

6. Results

In total 127 patients were included in the pilot study between January 2005 and June 2005. The procedure for inviting patients differed over this period: we started off by approaching patients in the hospital wards and changed to providing the patient with information about the pilot before admittance. The latter approach turned out to be the most efficient, in combination with the attention of a nurse practitioner, yielding an inclusion of approximately 1 out of every 2 people asked.

Of the 127 patients 7 turned out to have an incorrect e-mail address during some stage of the research, and were excluded from the pilot.

6.1 Representativity of pilot sample

As stated above, the pilot sample selection was not stratified but based on voluntary inclusion. Nevertheless, the make-up of the pilot sample turned out to be similar, though not equal, to the total population of cardio-thoracic patients on gender, age and type of heart failure.

Of all the heart patients treated⁴ 68.1% were male. In our sample **76.7%** were male. The mean age of all treated patients is 65.4 years and 37.4% of the population is over the age of 70. In the pilot sample the patients have a mean age of **62.2** years and **29.4%** of the patients being over the age of 70. Five patients aged over 80 were also included in the pilot sample.

Heart surgery can be divided into 4 groups: CABG, Valve, CABG/Valve combination and Other. The dispersion of pilot patients over these 4 types of operation is representative of that of the total population (Figure A).

⁴ Based on aggregated data of 2004.

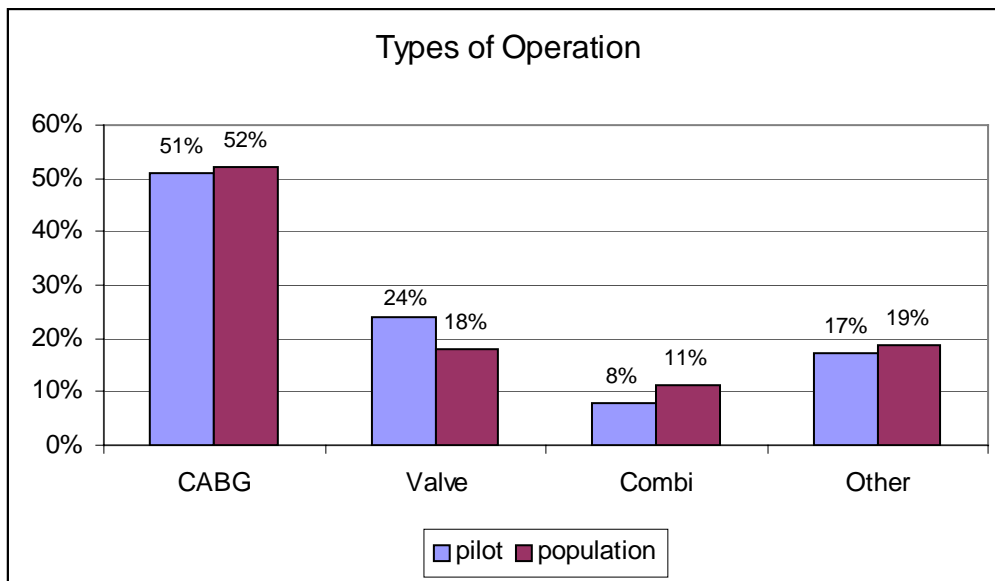


Figure A. Sample make-up over Operation Type

The pilot group can be considered to be a representative sample of the population, both in dispersion over age groups and surgery type⁵.

The availability of Internet access was another issue. As stated above, we have taken special care to include patients who do not possess their own e-mail address, but have access to e-mail via a friend or relative in order to participate in the follow-up. Henceforth we will refer to this group as the "offline" patients, as opposed to the "online" patients. The offline patients make up **31%** of the pilot group.

6.2 Preliminary results

Only the first two research moments have been concluded at the moment of writing this paper. The first group of patients will receive the invitation to the fifth and final survey in January 2006, but there is still a large group of respondents that have not yet been invited to the third survey. Therefore, the results presented here only relate to the first and the second survey moment; respectively two weeks and three months after the date of discharge from hospital.

The preliminary results show some remarkable findings⁶. Survey completion is high, above 85%, which is at the top of the range in response rates found by Gandek in 1998 (ref: [B. Gandek et al, Cross-Validation of Item Selection and Scoring for the SF-12 Health Survey in Nine Countries: results from the IQOLA Project \(1998\), J.C.Epid, 51:1171-8](#)). More noticeably, the response rate is consistent between the first and second survey moment (Figure B). About 75% of the respondents to the survey responded within the first week following the e-mail invitation. The remaining response was received after the reminder e-mail to the non-respondents was sent. (Figure C).

⁵ Based on a Chi-square sample representativeness check

⁶ All results shown here are based on n=120

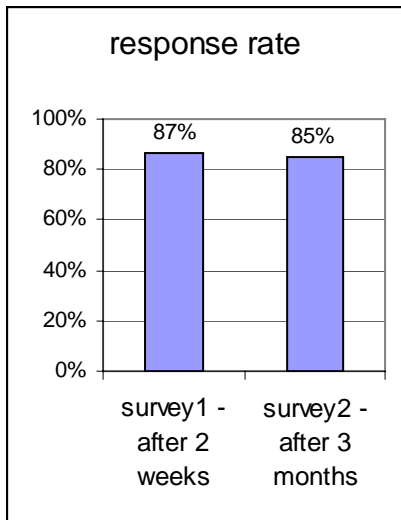


Figure B. Response rate

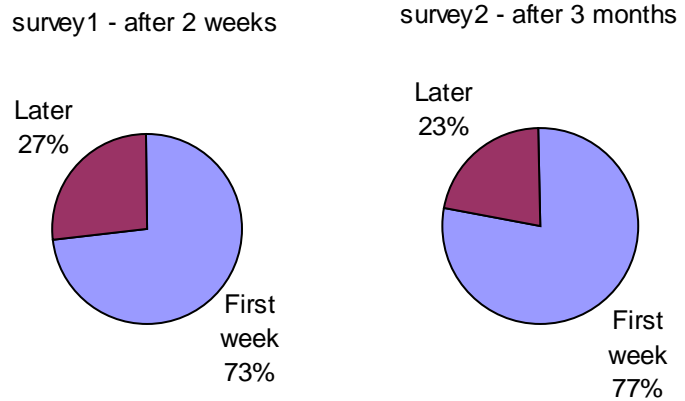


Figure C. Response Pattern

Another interesting finding is that only a small percentage (8%) of the respondents did not respond to either of the surveys (Figure D). Three quarters of the sample group have responded to both surveys.

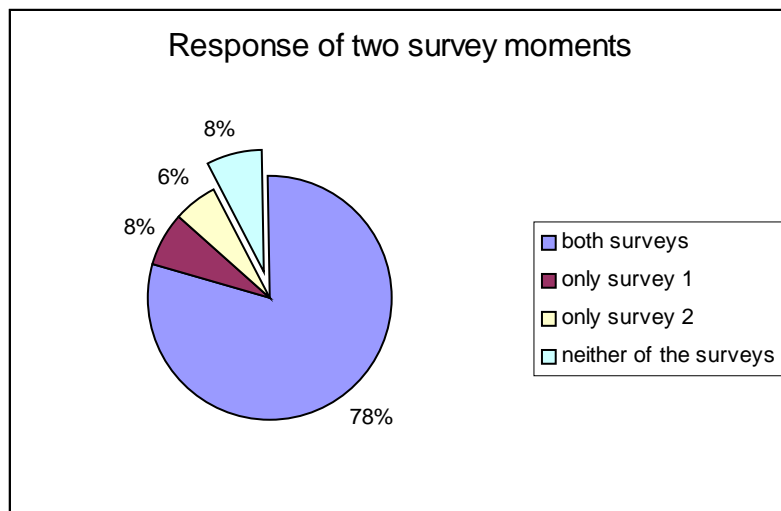


Figure D. Response rate over two moments combined

6.3 Cross analyses of the response

The pilot sample is too small to enable us to make incontestable statements about the response over sub-groups. Still, as an indication, we will briefly address the cross analyses of the response over operation type, age, gender and possession of e-mail.

The only real difference we have found is that between the online and off-line patients. As expected, the online patients show a higher response rate than the offline patients (Figure H). Nevertheless, we believe that the real result is in the fact that using online research, it is still possible to reach greater than two thirds of patients who have no direct access to Internet.

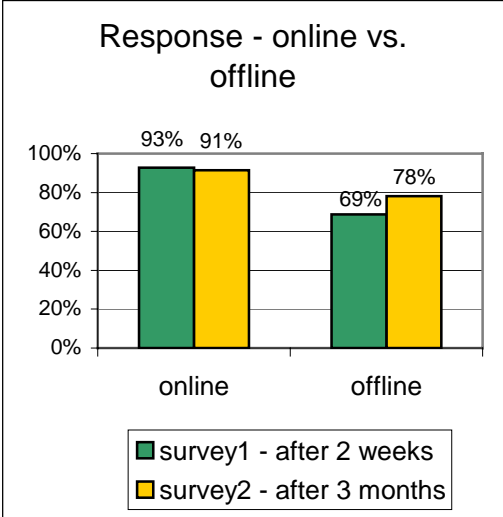


Figure E. Response rate – e-mail

Because of the nature of cardiac surgery, a relatively high proportion of the respondents are senior citizens. The response over age groups (Figure F) however, shows a smaller decline in response regarding the higher age groups than one might expect. As we see, four in five patients aged over 70 responded to the survey.

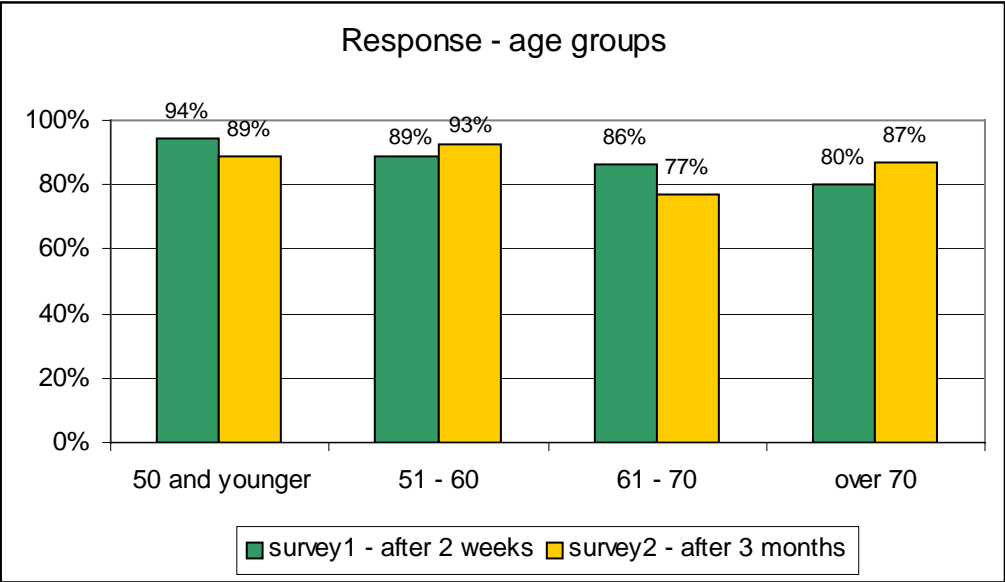


Figure F. Response rate over age

The response over operation type shows an almost equal response of the four operation types. The response over gender is also practically equal.

7. Discussion

7.1 Medical Ethics

Conducting scientific work on patients is increasingly restricted by medical ethical committees. The committees evaluate all scientific work that is performed on or with patients that is not part of a standard protocol. The committee approved our pilot. The only restrictions concerned the time taken by patients to complete the research. Taking unlimited amounts of a patient's time is no longer accepted. We adapted the research process to ensure that the time taken to respond to the questionnaire did not exceed the time-limits set by the medical ethical committees.

Two major advantages of this approach were the at-home approach and the self-administrative nature of the research. Informed consent was not conditional, but we expect this to be an advantage regarding patient commitment as well.

7.2 Completeness

Completeness of follow-up is essential to evaluate the effectiveness of medical procedures. Comparison of groups in medical-scientific work is justified by the completeness of data. In this pilot we focused on gathering data from the included patients via the Internet as a primary goal. Completeness of all the patients treated was not a primary goal. This is an issue to address in the future. The web-based method can serve as a low cost, easy to use start-up for any scientific work requiring completeness.

7.3 Future developments

We believe that web-based patient follow-up has a future and will become a corner stone of medical scientific work. In 2006, we will start to include all patients operated by the Cardio-Thoracic Group at the St Antonius Hospital, including emergency cases.

The first SF-12 will be sent pre-operatively, followed by two more lists post-operatively, 30 days and one year after surgery respectively. This will give us the opportunity to evaluate the effect on surgery on the well-being of patients more precisely.

In 2006 we will start to compare the effect of two different kinds of treatment: incorporating biometrical devices to enable online heart rhythm measurement. It will expand the frontiers of web-based monitoring, approaching the world of medicine from a completely new angle.

8. Conclusion

Results of the pilot study suggest that a fully web-based follow-up system is a feasible method for conducting patient follow-up. The response rate of over 80% is more than enough for many of the patient follow-up research objectives, for example Patient Satisfaction or Quality of Life. The enduring high response over time makes the online method appropriate for longitudinal studies. For studies that require completeness of results, like survival curve or medicine testing, the online follow-up method presents itself as a cost-effective way to collect the vast majority of response, thereby reducing the labor-intensive (and costly) written or telephone follow-up.

Furthermore, the online research method is not restricted to patients only with online access, as off-line patients can also be reached efficiently. This undermines any skepticism on representativity there might exist. Cross analyses over age, gender or type of operation also show the method to be suitable to all segments of the patient population.

In this pilot study, the web-based follow-up method has proven itself as a reliable, low-cost, highly effective, innovative way to reach all patients for follow-up purposes.