

Linking a breast cancer screening data base with a cancer registry in Antwerp, Belgium

by

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Abstract

The effect of well organized breast cancer screening on breast cancer mortality has been demonstrated for more than 20 years. However, since the success of a screening programme is not unconditional, evaluation of its effect is always necessary. For an effect evaluation of a breast cancer screening programme, a cancer registry is indispensable. In several European countries evaluation of the effect of breast cancer screening can be performed using routinely available cancer registry data. The main objective of our study was to assess the possibilities and difficulties of linking a cancer registry with a screening data base in the Rupelstreek, Flanders/Belgium.

The study population comprised 50 to 70 year old women (n = 9,321), invited to the 1st round (1991-1992) and/or the 2nd round (1994) of the screening programme. Of these women, 4,267 participated in at least one round (45.8%). There were 41 women with a screening detected

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breast cancer and 107 women who sent back a reply card indicating they were breast cancer patients.

To collect as much information as possible on breast cancer patients, all GPs in the region ($n = 60$) were sent a questionnaire in 1996. In addition, the Screening Data Base (SDB) was linked to the Antwerp Cancer Registry (ACR), which, especially in its early years, stressed the registration of breast cancer.

Six women with breast cancer could not be retrieved by the ACR or by the SDB and could only be traced thanks to the GP survey.

The linking of the ACR with the SDB showed that of the 148 breast cancer patients who were registered in the SDB, 75 were also recorded in the ACR (50.7%). Furthermore, we could register 13 screening participants whose breast cancers only showed up in the meantime between 2 consecutive screening rounds and another 34 breast cancer patients only thanks to the ACR.

The linking of the SDB with the ACR seems very promising but is very labour intensive and until further notice, the privacy laws make it impossible to use nominative data for linking. In addition, there is currently no watertight cancer registry.

Our study clearly indicated that the amount of manpower, time and financial support needed for permanent surveillance and quality control of organised breast cancer screening must certainly not be underestimated.

Keywords

Belgium, feasibility studies, mammary neoplasms, mass screening, medical record linkage, program evaluation, registries.

1. Introduction

On December 19, 1997 the Flemish Government published an Order concerning the preventive health care structure in Flanders. In this Order, new geographical divisions were delineated for the co-ordination of preventive health care on a local level, the so called Logo's (**L**okaal **G**ezondheids**o**verleg) (1). Since 1998 the Flemish Government has considered breast cancer screening, together with four other health care themes, a health care priority for these Logo's. The beneficial effect of

well organized breast cancer screening on breast cancer mortality has been demonstrated for more than 20 years (2-6). More recent data seem to confirm these findings (7-10). However, the success of screening is not unconditional. Since screening is targeted essentially at asymptomatic women, the narrow balance between benefits and undesirable effects is completely dependent on programme quality (11). For this reason, the Flemish Government has put forward several criteria to assure quality, mainly based on the European guidelines (11). It is beyond dispute that the screening must be carried out impeccably, but it is also essential for it to ultimately lead to a real reduction in breast cancer mortality. For a short term effect evaluation of a breast cancer screening programme, the following data are needed:

- The stage of screening detected breast cancers
- Interval cancers
- The number and stage of breast cancers detected outside the screening programme.

These data should be found in a cancer registry. In some European countries, evaluation of the effect of breast cancer screening can be performed using routinely available cancer registry data (12-14). The short term objective of our study was to assess the possibilities and difficulties of linking a cancer registry with a screening data base in the Rupelstreek, Flanders/Belgium. The article below reports the results of this feasibility study. The long term objective is to use the cancer registry as an instrument in evaluating the breast cancer screening programme and more especially:

- Evaluation of the validity parameters (sensitivity/specificity) of the screening mammography;
- Comparison of the stage distributions of screening detected cancers, interval cancers and cancers detected outside the screening programme.

This long term objective is not dealt with in this article.

2. Material and methods

2.1. Study population

The study population comprised women between 50 and 70 years of age who were living in the region of the river Rupel ("Rupelstreek") and were invited for the first and/or second round of the breast cancer

screening programme in 1991-1992 and/or 1994. The Rupelstreek consists of six municipalities south of the city of Antwerp: Aartselaar, Boom, Hemiksem, Niel, Schelle and Rumst. The total number of inhabitants by the end of 1999 was approximately 69,000 (15). In the first and second screening round, 9,321 women were invited to have a screening mammography performed. Of all invited women, 45.8% participated at least once ($n = 4,267$). The participation rate increased between the first and the second round from 32.1% (2, 656/8, 268) to 43.3% (3, 511/8, 112). In the first round, 166 women were referred for further diagnostic follow up (6.2%); in the second round 83 women were referred (2.4%). In total, there were 41 screening detected breast cancers (11.3/1,000 in the prevalent/first round and 3.1/1,000 in the incident/second round). In addition, 107 women sent back the reply form that was enclosed with the invitation letter, reporting they had breast cancer. To analyse the data according to the Belgian law safeguarding personal privacy in relation to the processing of personal details (see further), written permission was obtained from all women.

The linking of the cancer registry and the breast cancer screening data base (SDB) was based on the birth date and the post code of the woman's place of residence. There were three possible outcomes of the linking with respect to breast cancer patients:

- The patient was registered in the cancer registry and not in the SDB;
- The patient was registered in the SDB and not in the cancer registry;
- The patient was registered in the cancer registry and in the SDB.

2.2. Data collection from GPs

To get as much information as possible on breast cancer patients, we also designed a form to collect data from the GPs. All GPs with a practice in the Rupelstreek ($n = 60$), were contacted by telephone to inform them about the project and to ask for their co-operation. The form was then sent to these GPs, together with a covering letter. If there was no response after 4 weeks, the GP was again contacted by telephone.

2.3. The Antwerp Cancer Registry (ACR)

The Belgian National Cancer Registry is a population-based registry which is founded on the participation of the sickness insurance funds (16). This method of registration enables fairly simple and easy collection of data. So far, however, the data collected are far from complete, the

quality and diversity of the information is limited and there is a considerable time delay (17).

For this reason, regional cancer registries were set up which, together with the National Cancer Registry, constituted a Flemish Network of Cancer Registries. The Antwerp Cancer Registry (Antwerps Kanker Register – AKR) is one of the regional cancer registries belonging to this Network. This cancer registry, which was used for the linking with the breast cancer SDB in the study described below, started in 1989 as a hospital based cancer registry at provincial level. The target population are all newly diagnosed cancer patients, inhabitants of the province of Antwerp. In 1991, the first reported incidence year of the registry, 2,502 new cancer cases were included. For the incidence year 1997, 5,137 new cancer cases were registered. The increase in the number of registered cancer cases is at least partly due to the increase in the number of cooperating hospitals ($n = 7$ in 1993; $n = 9$ in 1997). In the year 2000, there will be a full coverage of all Antwerp hospitals ($n = 31$) for the first time.

Another element which explains the increasing number of registered new cancer cases is experience, and manpower becoming more and more efficient.

2.4. The Breast Cancer Screening Data Base (SDB)

The SDB contains data of those women who were invited for the first and/or second screening round of the breast cancer screening programme in the Rupelstreek (see 2.1. Study population). Details of this breast cancer screening programme are published elsewhere (18, 19).

The input of this SDB consists of two kinds of breast cancer data:

- Reply forms with self reporting of breast cancer;
- Referred women who were found to have breast cancer and for whom follow-up data were collected from their GP after six months.

2.5. The linking itself

To link the ACR with the above-mentioned SDB of the Rupelstreek, several activities had to be undertaken:

- A file was made for every woman with breast cancer (known via reply form or via follow up after referral);

- A search for “couples” on the basis of birth date and post code of the woman’s place of residence: for each known breast cancer patient in the SDB, it was checked whether the woman was registered in the cancer registry. Conversely, for each breast cancer patient in the cancer registry, there was a check to see whether she was also known as such in the SDB;
- Information concerning breast cancer was compared for each couple.

2.6. Verification of the linking

To verify the linking, the following steps were undertaken:

- For each couple, confirmation was sought on the basis of family name and first name;
- Confirmation was also sought when a breast cancer patient could only be found in one data base. This was done by means of a manual search, making it possible to compare birth date and post code;
- When a breast cancer patient could be found in the SDB and not in the cancer registry, the GP of this patient or the hospital where that patient had been treated, was traced. To this end, the reply form or the follow-up data were checked to find out by which physician or in which hospital the woman was treated. If it concerned a breast cancer patient, the cancer registry was completed or adjusted. If birth date and post code did not lead to a file for that woman in the hospital, the search was continued under name.

3. Results

3.1. Survey from GPs

Although 60 GPs in the Rupelstreek were selected because they were registered as still having a practice, one replied that he no longer had a practice, one had died and one said he did not have any breast cancer patients. Thus, eventually, 57 GPs were contacted by mail.

At the time the survey with the GPs took place (April 1996), the 3rd breast cancer screening round in the Rupelstreek had just finished. Forty seven of the 57 GPs who received a form, had to be contacted again in order to obtain all the necessary data. One GP did not want to co-operate because it would take too much time and energy to retrieve the required data. One GP did not want to communicate the names of breast cancer

patients for privacy reasons. No form could be collected from 4 GPs. A few GPs informed us that they had not seen breast cancer patients during the period under study.

Eventually, 36 names of breast cancer patients were collected. Although the survey was only aimed at patients diagnosed with breast cancer from 1991 on, who were between 50 and 70 years of age at the time of diagnosis, 7 women did not match these criteria. The other 29 names were checked in the SDB, with the following results:

- 10 women were known because they were diagnosed following the screening (1st, 2nd or 3rd screening round);
- 8 women were already registered because they sent back the reply form indicating they were breast cancer patients;
- 5 women were known by means of the record linkage with the ACR;
- 6 women could not be found in the ACR or in the SDB and could only be traced thanks to the GP survey.

One woman was reported by a GP while the SDB did not indicate that this woman was a breast cancer patient. She was referred in the 1st screening round and afterwards diagnosed with sclerocystic mastopathy. She participated in the 2nd and the 3rd screening round and was not referred anymore.

Of all screening detected breast cancers in the 1st round ($n = 30$), only 3 were reported, all by the same GP. Eight GPs reported a total of 18 names of breast cancer patients but not the names of their 9 patients with a screening detected breast cancer in the 1st screening round. Subsequently, 2 GPs reported not having had breast cancer patients during the period concerned. Nevertheless, they filled in follow-up forms for 3 screening detected breast cancers (1st round) some years earlier. For one woman with a screening detected breast cancer, the GP was not known because the woman did not want to give the name of a GP at the time of the mammographic screening. The GPs of the other women with a screening detected breast cancer ($n = 14$ patients) did not co-operate in the survey (4 GPs did not return the survey – 7 patients –, 3 GPs were not contacted because they did not appear on the official list of medical doctors – 4 patients –, 2 GPs did not have their place of residence in the Rupelstreek – 2 patients – and 1 GP did not want to communicate the names of breast cancer patients for privacy reasons – 1 patient –).

A closer look on the date of diagnosis of all 36 reported breast cancer patients revealed that this date was lacking for 6 women and that it lay

outside the study period for another 2 women. As far as the remaining 28 women is concerned, an imbalance was noticed in favour of the most recent diagnoses: in the period from 1991 to 1994 12 breast cancer patients were reported. In the period from 1995 to mid 1996 (ending of the survey) 16 breast cancer patients were reported.

3.2. Record linkage of the ACR and the SDB

There were 148 women with breast cancer known via the SDB: 41 screening detected and 107 via reply form. Of these 148 breast cancer patients, 75 (50.7%) could also be found in the ACR.

The cancer registry revealed that 13 women who participated in the first or second screening round, developed a breast cancer before the next round started (interval cancers).

There were also 34 women with breast cancer who could only be found in the cancer registry.

Thanks to the linking with the SDB, it could be seen that several women's birth dates or post codes as recorded in the ACR, were incorrect. On the other hand, cancers missed by the SDB could be revealed and clinical tumor specific information could be added to this SDB.

4. Discussion

The data collection from GPs was very difficult, due to the following:

- It took a lot of time to bring the official list of medical doctors up to date and 3 GPs were still missed;
- Women belonging to the target population did not necessarily have a GP in one of the 6 municipalities of the Rupelstreek;
- The response of the GPs to the 1st telephone call and the ensuing mailing was low (10 GPs out of 57 reacted);
- A second telephone call resulted in information from 41 out of 47 GPs;
- The information gathered does not always reflect reality. Only 3 out of 30 patients with a screening detected breast cancer were reported. Maybe the GPs thought it was not necessary to report those patients who they knew were already registered in the SDB;

Although 6 breast cancer patients who could not be found in the ACR or in the SDB were revealed thanks to the survey from GPs, this kind of

data collection was very labour-intensive for both the Centre for Cancer Prevention and the GPs themselves.

The linking of the ACR with the SDB of the Rupelstreek seems promising but some points are not yet fully clear.

Linking of databases presupposes an identification up to the level of first names and surnames. The Belgian law safeguarding personal privacy in relation to the processing of personal details, makes it very difficult to start a data base with personal details, even for health care purposes (20). Following a European Recommendation, this law has been adapted so that screening is now seen as an exception to the rule. This new law should make it easier to start a data base with personal details when the purpose is screening. However, there are still no Implementation Orders, so until further notice, the "old law" is still in force (21).

Because of the number of manual searches needed to check whether it is the same woman in a "couple" that does not completely fit, linking data bases is a very labour-intensive process. This time consuming work is to a great degree due to the restrictions in working practices imposed by the privacy law.

There were 79 breast cancer patients who were identified by means of the SDB ($n = 73$) and the survey from GPs ($n = 6$) who could not be retrieved in the ACR. Because of the limited number of hospitals co-operating at that time, the ACR was far from being complete in the period 1991-1994. Moreover, experience and manpower were not yet fully efficient.

5. Conclusions

Follow up with GPs proved to be a very difficult and not very rewarding procedure for record linkage. It does not seem to be very easy for a GP to find all the required data. A possible solution could be a more frequent survey, for instance yearly. However, this would increase the pressure of work for the GPs as well as for the Centre for Cancer Prevention. A final decision in favour of or against a continuation of this process is dependent on further experience, i.e. when the ACR is complete.

To achieve a complete record linkage between a SDB and a cancer registry, a watertight registration system is needed. Other researchers

have already clearly stated that, for instance, ascertainment of interval cancers vitally depends on the availability of complete, accurate, and timely national cancer registration data (22). It could be of some help in this respect if the Cancer Registration Network Flanders could be widened.

The privacy law should not merely focus on the safeguarding of privacy. It has to be flexible enough for it to be used in a positive way in due time, so that women can take advantage of it whenever possible.

Our study clearly indicated that the amount of manpower, time and financial support for permanent surveillance and quality control in organised breast cancer screening must certainly not be underestimated.

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Samenvatting

Het gunstig effect van goed georganiseerde borstkankerscreening op de borstkankerssterfte wordt reeds sinds meer dan 20 jaar aangetoond. Aangezien het voorwaardelijke succes van screening echter, is effectevaluatie steeds noodzakelijk. Om een effectevaluatie van een borstkankerscreeningsprogramma uit te voeren, is een kankerregister onontbeerlijk. In verschillende Europese landen kan de effectevaluatie van een borstkankerscreeningsprogramma met behulp van een kankerregister routinematig worden uitgevoerd. Het voornaamste doel van ons onderzoek was de mogelijkheden en moeilijkheden na te gaan bij het koppelen van een kankerregister aan een screeningsbestand in de Rupelstreek, Vlaanderen/België.

De studiepopulatie bestaat uit 50- tot 70-jarige vrouwen ($n = 9.321$), uitgenodigd voor de 1^{ste} ronde (1991-1992) en/of de 2de ronde (1994) van het bevolkingsonderzoek. Hiervan namen 4.267 vrouwen aan minstens 1 ronde deel (45,8%). Bij 41 vrouwen werd borstkanker ontdekt tengevolge van de screening en 107 vrouwen stuurden hun antwoordkaartje terug met de vermelding dat ze borstkankerpatiënte zijn.

Om zoveel mogelijk informatie te verzamelen over borstkankerpatiënten, werden alle huisartsen uit de regio ($n = 60$) in 1996 schriftelijk bevroegd. Daarnaast werd het screeningsbestand gekoppeld aan het Antwerps Kankerregister (AKR), dat zich, zeker in de beginjaren, vooral toelegde op de registratie van borstkanker.

Zes vrouwen met borstkanker konden niet worden teruggevonden in het AKR noch in het screeningsbestand en konden enkel worden opgespoord dankzij de vragenlijst bij de huisartsen.

Uit de koppeling van het AKR aan het screeningsbestand bleek dat 75 van de 148 borstkankerpatiënten die bekend waren vanuit het screeningsbestand ook in het AKR waren terug te vinden (50,7%). Bovendien konden 13 intervalkankers worden geregistreerd en kwamen 34 vrouwen met borstkanker enkel voor in het kankerregister.

De koppeling van het screeningsbestand aan het kankerregister lijkt veelbelovend maar is arbeidsintensief en de wet op de privacy maakt koppeling via nominatieve gegevens voorlopig onmogelijk. Bovendien is er momenteel geen waterdicht kankerregister.

Hoedanook werd uit ons onderzoek duidelijk dat de omvang van mankracht, tijd en financiële middelen nodig voor de permanente opvolging en kwaliteitscontrole van georganiseerde borstkankerscreening zeker niet mag worden onderschat.

Résumé

Depuis plus de vingt ans, des études scientifiques ont démontré qu'un dépistage bien organisé du cancer du sein a un effet favorable sur la mortalité due au cancer du sein. Étant donné le succès conditionnel d'un dépistage de masse, il reste cependant toujours indispensable de faire une évaluation d'effet. Afin de pouvoir exécuter une évaluation d'effet pour un dépistage du cancer du sein, un registre du cancer est nécessaire. En différents pays de l'Europe ont est déjà capable d'exécuter de manière systématique une évaluation d'effet pour un dépistage du cancer du sein à l'aide d'un registre du cancer. Le but principal de cette étude était d'évaluer les possibilités et difficultés rencontrées lors de la liaison d'un registre du cancer à une banque de données du dépistage provenant du "Rupelstreek", Flandre/Belgique.

Les femmes de 50 à 70 ans ($n = 9.321$), invitées au premier tour (1991-1992) et/ou second tour (1994) du dépistage du cancer du sein forment la population d'étude. De ces femmes, 4.267 se sont présentées à au moins 1 tour (45,8%). Un cancer du sein a été diagnostiqués chez 41 femmes, grâce au dépistage et 107 femmes ont renvoyé leur carton réponse avec la mention d'avoir déjà été diagnostiquées avec un cancer du sein.

Afin de collectionner un maximum d'information sur les femmes du groupe-cible, diagnostiquées avec un cancer du sein, tous les médecins généralistes de la région ($n = 60$) furent interrogés en 1996, à l'aide d'un questionnaire. De plus, la banque de données du dépistage fut liée au registre du cancer anversoïis. Ce registre se consacrait, surtout au début, principalement à l'enregistrement des cancers du sein.

Six femmes diagnostiquées avec un cancer du sein, n'étaient répertoriées ni dans la banque de données du dépistage, ni dans le registre du cancer anversoïis et furent seulement découvertes grâce à l'enquête auprès des médecins généralistes.

De l'association des deux banques de données apparaît que 75 des 148 cancers du sein répertoriés dans le registre du dépistage, l'étaient aussi dans le registre du cancer anversoïis (50,7%). De plus, 13 cancers du sein qui se sont développés entre les deux tours de dépistage et 34 autres femmes avec un cancer du sein étaient uniquement répertoriées dans le registre du cancer anversoïis.

Lier la banque de données du dépistage à celle du registre du cancer anversoïis paraît très prometteur mais nécessite un travail intense. La loi protégeant la vie privée rend la

liaison avec des données nominatives pour le moment impossible. Par ailleurs, il n'existe pas encore de registre complet.

En tout cas, notre étude a clairement démontré que l'ampleur de la main-d'oeuvre, du temps et des moyens financiers nécessaire pour un suivi permanent ainsi qu'un contrôle de qualité du dépistage du cancer du sein, ne peut être sous-estimée.

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