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De Bock, Geertruida H.; Hesselink, Jan Willem; Roorda, Carriene; de Vries, Jaap; Hollema, Harry; Jaspers, Jan P. C.; Kok, Theo; Werker, Paul M. N.; Oosterwijk, Jan C.; Mourits, M.J.

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Model of care for women at increased risk of breast and ovarian cancer

Women with a family history of breast and/or ovarian cancer have a substantially higher risk of developing these cancers and at a much younger age when compared to the general population [1]. For women with a proven *BRCA1* or *BRCA2* mutation, this life time risk can reach up to 65% for breast cancer and up to 45% for ovarian cancer by the age of 70, according to two large meta-analyses [2,3].

In The Netherlands, the care for these high risk women is mainly concentrated in university hospitals because of the availability of highly specialized expertise. Our university hospital is situated in the North of The Netherlands, covering an area of 3.4 million inhabitants. In our hospital, the care for these women is provided by a multidisciplinary team consisting of clinical geneticists, surgical oncologists, gynecological oncologists, oncology nurses, a psychologist, a radiologist, plastic surgeons, and a pathologist. The team is supported by two epidemiologists.

Interventions comprise a four-stage approach consisting of risk assessment and genetic counselling, gene–mutation analysis, oncologic counselling and medical screening or intervention strategies (preventive surgery) [4]. When an increased cancer risk is assumed because of a personal or family history, women are referred to our family cancer clinic [5,6]. The clinical geneticists assess the breast and/or ovarian cancer risk based on a confirmation of the family history, and whether there is an indication for DNA-testing. The women are extensively counselled on the pros and cons of DNA-testing, its timing and the possible personal and familial consequences. If women need support with their decision making, they are referred to the psychologist of the team.

The surgical oncologists counsel patients in their choice of risk reducing strategies. Regarding breast cancer, they can opt for screening or for a preventive mastectomy with or without reconstructive surgery [7,8]. The latter service is provided by the plastic surgeons. All women opting for preventive mastectomy are referred to the psychologist to discuss this option and the consequences.

Regarding ovarian cancer, women with a positive family history or a *BRCA1/2* mutation are counselled by a gynecological oncologist on risk reducing strategies for ovarian cancer. Women are counselled on lifestyle, family planning and on the optimal timing of risk-reducing salpingo-oophorectomy (RRSO) and the short- and long-term sequellae [9–11]. Since ovarian cancer screening is not effective, from 2009 this option is not offered anymore. After RRSO, women visit the family cancer clinic for advice regarding prevention or treatment of hot flushes, psychosexual functioning and osteoporosis [12–14].

By offering the care for these women in such an integrated way, the university hospital can take the lead as initiating participant in a managed clinical network of the catchment area [15,16]. In a managed clinical network, one of the major challenges is to develop better access to relevant generic information for women and clinicians (sharing knowledge) – from general practitioner’s data, to hospital units including surgeons and gynecologists, to cancer centre registries and back.

From 1994, all newly referred women are entered into the BrOCa registration. Included are women with a *BRCA1* or *BRCA2* mutation, not tested women with a first degree relative with a *BRCA1* or *BRCA2* mutation and women with a life time risk of more than 30% to develop breast cancer or a risk of more than 10% to develop ovarian cancer.

For all registered patients, there is a linkage connection with the municipal registry to check whether a person is alive and still living in the catchment area in the North of the Netherlands, a linkage with diagnoses and care data of the general practitioner and with pharmacy prescriptions is planned. In 1994, when our family cancer clinic started, patient data were entered in lists guaranteeing a prospective registration of a consecutive cohort of all women attending. Nowadays, all information concerning a contact is put into the database during the consultation. For these registrations we have developed a prospective system with an entry interface in which most of the collected information is predefined. The physician can just click and upon finishing the consultation, the database is filled with the entered information and a letter to the referring physician is produced automatically as well. Information not entered during the consult (among others results of mammography or serum level of CA125) is retrieved from the hospital information system by using the unique identifiers on a regular basis.

For each research project relevant data are retrieved from the registration and linked by the use of a unique identifier. These new datasets are anonymized. In all research projects, the involved care providers participate as well as one of the epidemiologists. All new patients are asked for informed consent. Every research project based on the BrOCa registration and tissue/serum bank has to be approved by the Medical Ethical Committee.

Our prospective system guarantees that no patient contacts are missed and that information exchange with the referring doctor is much faster and more accurate than before. Due to the interface with a predefined format, the data reliability is enhanced. The time between the hospital consultation and the written report to the referring doctor has come down to 5 days at a maximum.

The evaluation of the effectiveness and cost-effectiveness of the provided care has been performed on the following topics: the penetrance of *BRCA1* and *BRCA2* mutations and variants [17–23], the effectiveness of surveillance [24–29], psychological and familial...
aspects [7,13,30,31] and on the safety and effects of RRSO [11,14]. Because there is increasing evidence that ovarian cancer screening is not effective in detecting early ovarian cancer, since 2009 ovarian cancer screening has been abandoned and women are counselled on lifestyle, family planning and on the optimal timing of risk-reducing salpingo-oophorectomy (RRSO) and the short- and long-term sequellae [9–11].

The strength of this prospective cohort registration is that it improves the quality of care for this patient group. As a consequence of this systematic evaluation of care we nowadays include not only the doctors’ perspective on the trade off between surveillance and preventive surgery (preventive surgery to prevent dying from cancer) but also patients perspective (preventive surgery to diminish cancer worries and prevent getting cancer). This database allows us to pool data with other (inter)national centres. The main weakness is that the amount of items on which data is collected is as yet limited. This can also be considered as an advantage because it makes this registry complete and up to date but, when research is planned, for most research questions additional information form the patient files is needed.

Women with an inherited increased risk of breast and ovarian cancer should be seen in a multidisciplinary setting to deliver up to date and optimal care and evaluate the short term and long term consequences of the given care.

Contributors
JdV, HH, JPJ, PMW, JCO, MJM contributed to the multidisciplinary care for these women. All authors contributed to the data registration and to this manuscript. All authors have read and approved this manuscript and agree with publication of their names.

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The authors have no financial of any other kind of personal conflicts with this manuscript.

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References

Geertruida H. De Bock* Department of Epidemiology, University Medical Center Groningen, University of Groningen, PO Box 30.001, 9700 RB Groningen, The Netherlands

Jan Willem Hesselink Department of Surgery, University Medical Center Groningen, University of Groningen, Groningen, The Netherlands

Carriene Roorda Department of Epidemiology, University Medical Center Groningen, University of Groningen, Groningen, The Netherlands

Jaap De Vries Department of Surgery, University Medical Center Groningen, University of Groningen, Groningen, The Netherlands
Harry Hollema  
Department of Pathology, University Medical Center Groningen, University of Groningen, Groningen, The Netherlands

Jan P.C. Jaspers  
Department of Psychology, University Medical Center Groningen, University of Groningen, Groningen, The Netherlands

Theo Kok  
Department of Radiology, University Medical Center Groningen, University of Groningen, Groningen, The Netherlands

Paul M.N. Werker  
Department of Plastic Surgery, University Medical Center Groningen, University of Groningen, Groningen, The Netherlands

Jan C. Oosterwijk  
Department of Genetics, University Medical Center Groningen, University of Groningen, Groningen, The Netherlands

Marian J.E. Mourits  
Department of Gynaecology, University Medical Center Groningen, University of Groningen, Groningen, The Netherlands

* Corresponding author. Tel.: +31 13610739. E-mail address: G.H.de.Bock@umcg.nl (G.H. De Bock)

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