SHORT COMMUNICATION

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Data managers: A survey of the European Society of Breast Cancer Specialists in certified multi-disciplinary breast centers

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Abstract

The European Society of Breast Cancer Specialists (EUSOMA) requires that the breast centers' core team includes a trained person responsible for data collection and analysis. We addressed a questionnaire to the data managers of the EUSOMA breast centers network in order to acquire information with regard to their education, training, role, activity, recognition, and satisfaction. Breast centers' data managers are highly educated individuals with a variety of backgrounds carrying out, more frequently part-time and as temporary employees, a job for which they received little specific training. These findings support the importance of defining a core curriculum and a training program.

KEYWORDS
audit, breast center, data base, data collection, data manager, multi-disciplinary core team, quality control

1 | INTRODUCTION

According to 2003 and 2006 European Parliament resolutions,[1,2] multi-disciplinary breast centers (BC), as defined in the first edition (year 2000) of the European Society of Breast Cancer Specialists (EUSOMA) document on "The requirements of a specialist breast center",[3] should have been established throughout Europe by 2016.

In the cited article,[3] EUSOMA describes how a breast center should be organized in terms of critical mass, services, health professionals, and equipments. The data manager (DM) is indicated in the document as a member of the interdisciplinary core team (Figure 1) being defined as a "trained and dedicated person responsible for breast data management," working "under the supervision of a designated core team clinician." The breast center DM is not a patient navigator, as he/she takes care of the BC data and generally has not direct contact with the patients and is not involved in the organization of the patient journey, but rather in its monitoring.

The EUSOMA document requires that "BC formally identify a DM who has responsibility for ensuring that all relevant and required data are collected, recorded, and analyzed" preferably contemporaneous to the patient management process. As a result of this, data management is now recognized essential by many health care providers in Europe and represents a mandatory requirement for the main BC certification schemes.

However, the characteristics of these emerging professionals and the actual role they play in the BC are little known. In order to acquire such information, we decided to conduct a survey among EUSOMA-certified BC.

2 | MATERIALS AND METHODS

European Society of Breast Cancer Specialists developed a 44-question web questionnaire which was submitted in September–December 2015 to the 28 DMs of all EUSOMA-certified multi-disciplinary BC (n = 28).
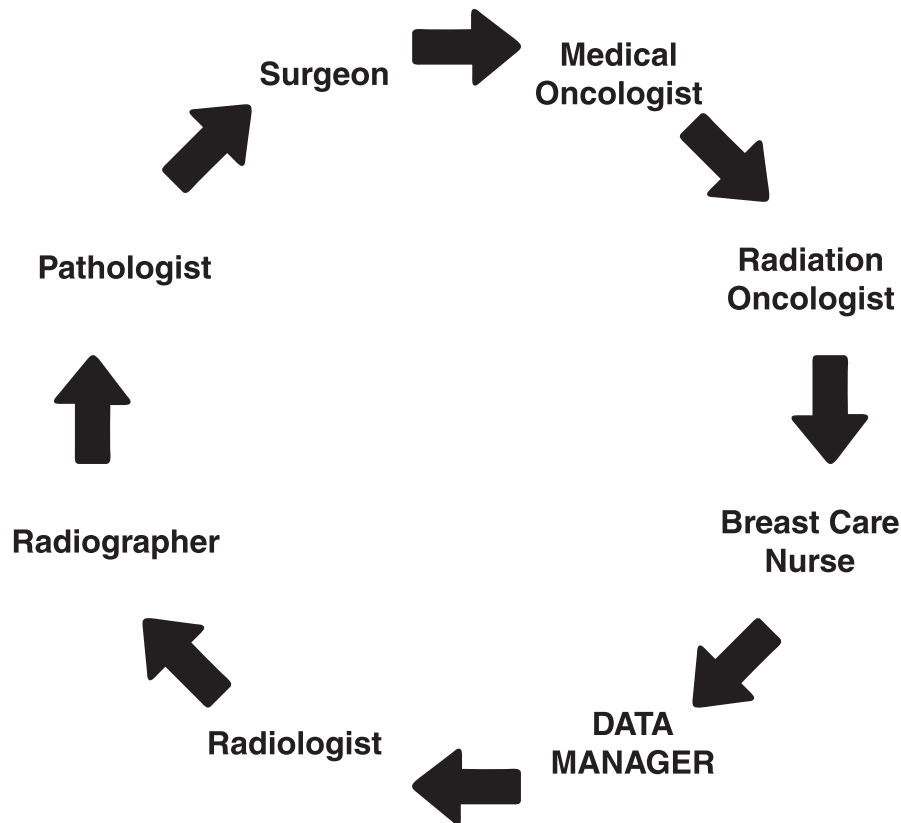

[†]See Appendix 1.

FIGURE 1 The breast core team according to the European Society of Breast Cancer Specialists document on "The requirements of a specialist breast center"[3]

The questionnaire included five sections. The first part of the survey addressed questions on age, gender, affiliation and prior and/or contemporaneous jobs. The second section was devoted to education and on the existence of a formal definition of a job title for data management in their country. A third part was dedicated to specific training received as compared to the training they would consider appropriate. The following section investigated working time dedicated to data management, working place, type of assignments with questions about their actual role in the multi-disciplinary breast care team and how this role was practically and formally recognized, the presence of the clinical supervisor, the involvement in audit planning, audit meetings, and data presentation. Access to and use of the eusomaDB—the EUSOMA BC Network Web data warehouse, employed for audit and clinical research[4–6]—has also been assessed. Finally, the last few questions were about satisfaction and whether respondents were in favor of formulating and publishing an EUSOMA recommendation on the core curriculum for BC data managers, similar to what has been done for other professionals.[7,8]

3 | RESULTS

Twenty-four DMs from 23 of 28 BC (82%) filled the questionnaire. Responders were from Belgium (5), Germany (1), Italy (12), the Netherlands (1), and Switzerland (5).

Most DMs (21 of 24) were females of a wide range of ages (25-64). The majority, but not all, were highly educated: 67% held a PhD or a Master degree, 12% completed education with a high school diploma, and the remaining 21% with college graduation. Some were nurses, a few physicians; others were software specialists or had been trained as clinical trials managers or for administrative positions. All stated to be proficient in at least one foreign language.

More than half of DMs held their post for more than 5 years, and for all except one, this was not their first job. The majority (71%) of 28 previous jobs were in the health sector, about evenly distributed in administrative or clinical positions. Data management was the only current job for two-thirds of DMs, while the remaining dedicated from 5 to more than 15 hours weekly to another contemporaneous working activity. Only eight of twenty-four worked full time in the BC as DM, and twenty-one percent worked less than 10 hours per week in the job (Table 1).

TABLE 1 Working hours per week as breast center data manager

Weekly working hours	Number of answers	%
>30	8	33.3
21-30	5	20.8
11-20	6	25.0
10 or less	5	20.8
Total	24	100

TABLE 2 Source of information on patients follow-up (21/24 DM responded; multiple answers allowed)

Source	Number of answers	% of 21 respondents
Breast center clinical follow-up records	19	90.4
External gynecologists	8	38.1
General practitioners	7	33.3
Database of discharge records from other hospitals	6	28.6
Direct calls to patients	6	28.6
Population cancer registries	5	23.8
Mortality registries	10	47.6
Other	3	14.3
Total	64	–

All DMs but one had a clinical supervisor. Half declared to have no direct contact with patients, but all felt to be part of the multidisciplinary team and all except one felt their role in the team was recognized by the other team members. However, only 17 of 24 (71%) participated in the weekly multi-disciplinary meetings. All BC had a clinical electronic data base, which was filled in 29% of cases contemporaneous to patients' management. One third of DMs declared to register all data personally, while more than half shared this task with other members of the BC in the different disciplines, meaning that the data base was installed in a hospital network and often linked with the hospital management system. All declared to be involved in data checks before analysis.

In four cases, the data base was custom-made, while the remaining 19 BC used 10 different commercial systems. Eighty-eight percent of DMs reported to be responsible for organizing the annual (38%) or sixmonthly (54%) performance and clinical audit meetings, including preparatory data analysis, mainly consisting in the monitoring of the EUSOMA quality indicators[9] and in the consequent review of relevant case histories. Forty percent declared to present personally the results to the team as well as to have the responsibility of monitoring the compliance and the effect of the corrective actions proposed at the audit meetings. According to EUSOMA, DMs are responsible for informing the other team members in time if any problem emerges from data monitoring and from results of quality indicators, in order to allow a timely response. As a DM, put it in his/her own words:

> I am responsible for the data analyses and I discuss the results with every discipline together with the head of the centre. Every 3 months we have an audit meeting with all the team members but I do the analyses much more often so that if anything is not according to agreement I discuss it with the involved specialists and possible problems are solved. I also have a small dataset I see every day (including waiting time to first appointment, imaging and pathology results, waiting time to surgery), so we are able to act directly and not have to wait for the three monthly audit meeting.

Information on patients follow-up is collected and recorded by 87,5% of respondents, using mostly data from clinical follow-up records and various other sources (Table 2). They have access to population cancer registries in 24% of cases.

All DMs except one know how to access the eusomaDB for checking the results of the quality indicators, calculated in an automated and standard way, and the accuracy of individual clinical histories, and for benchmarking. Sixty-two percent declare to use it approximately once a month or more.

Forty-two percent of DMs reported to have received less than 10 hours of specific training in the BC regarding their job, 29% from
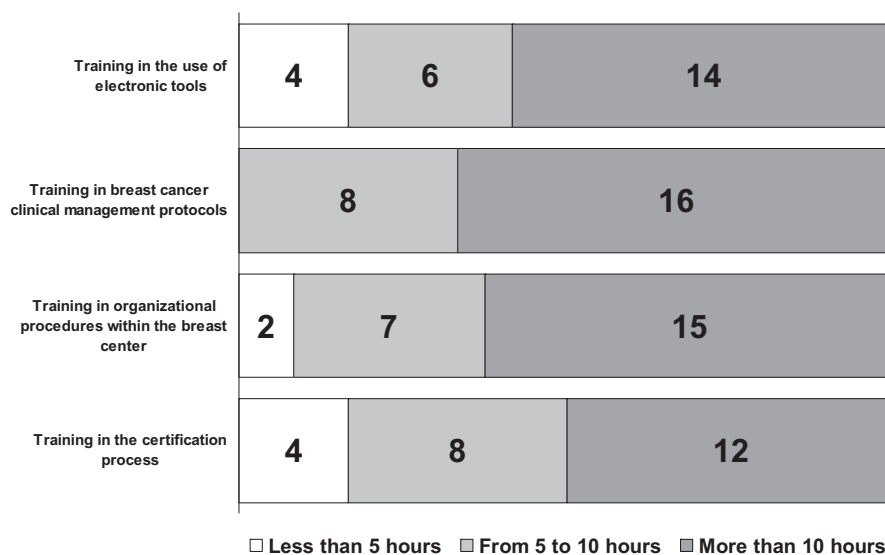
FIGURE 2 Answers to the question: "If you were asked to train a data manager with no prior experience at all who would cover a position similar to yours, how many hours of specific training would be required?"

Legend: □ Less than 5 hours ■ From 5 to 10 hours ■ More than 10 hours

Bars:
- Training in the use of electronic tools: 4 | 6 | 14
- Training in breast cancer clinical management protocols: 8 | 16
- Training in organizational procedures within the breast center: 2 | 7 | 15
- Training in the certification process: 4 | 8 | 12

11 to 25 hours, and the remaining more than 25. If asked to train a data manager with no prior experience at all, the majority declared that more than 10 hours training for each of four subjects (use of informatics tools, basic training in breast cancer clinical management, training in organizational procedures within the BC and training on the certification process) would be required (Figure 2), with the largest share of time devoted to clinical management protocols.

Only 30% stated that a formally defined job title for DM in the health sector, with job description, existed in their own country. Eighty percent declared that an European document proposing a core curriculum for breast centers' DM would be useful.

Despite the difficulties and the precariousness of their job situation, 20 (83%) of the interviewed DMs reported, in a five classes scale, to be satisfied or very satisfied with their job, and only one declared to be unsatisfied or very unsatisfied.

4 | DISCUSSION

In the EUSOMA document "The requirements of a specialist breast centre",[3] recommendations and standards for specialized health professionals are defined for the core team members but not specifically for DMs. No European guideline or recommendation has been issued so far as for the core curriculum and the training of breast centers DMs.

BC data managers are highly educated individuals with a variety of backgrounds carrying out, more frequently part-time and as temporary employees, a job for which they received little specific training. They represent an important added value in the specialist BC model and are instrumental for assuring and improving quality and as an aid to research.

Differently from data managers employed for the conduction of clinical trials, technical skills that DMs in BC should master include not as much advanced statistical expertise but rather the ability to coordinate data entry, monitor parameters relevant to quality of care, and feed back the good and the bad results to the multi-disciplinary team, putting data in the context of clinical and organizational pathways. Their job often requires, in addition to technical capability, a good amount of personal and social competences, such as decisional and innovative spirit, skills in moderation and mediation, and ability to communicate, which are of essential importance for the good functioning of the breast care team.

These functions are key to the EUSOMA certification process, where site visits are preceded by the acquisition of a report on the results of quality indicators and are often followed by further data reports aimed at showing the effect of the prescribed corrective actions.

5 | CONCLUSIONS

The role of DMs in the multi-disciplinary specialist BC would probably be more beneficial to quality of care if a core curriculum, a job title description, and the definition of specific training modules were agreed at European and Country levels. An EUSOMA recommendation spelling out a core curriculum for BC data managers is deemed it would be helpful by the majority of the DMs interviewed.

CONFLICT OF INTEREST

Authors have declared no conflict of interests.

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APPENDIX 1

EUSOMA Breast Centers Network Data Managers

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