

# Women's experience and knowledge of adjuvant endocrine therapy for early breast cancer: A European survey

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## INTRODUCTION

Adjuvant endocrine therapy is used in the treatment of women with hormone responsive breast cancer to reduce the risk of recurrence. Women generally remain on adjuvant endocrine therapy for five years although there is emerging evidence that suggests the value of extending treatment duration. The GAEA (Gathering Information on Adjuvant Endocrine therapy) Initiative aims to delineate women's knowledge and experience of adjuvant endocrine therapy and develop programmes targeted at meeting their needs.

A survey was carried out as part of this initiative with the aim of determining breast cancer patients' knowledge about and attitudes towards adjuvant endocrine therapy, ascertaining their informational and support needs while taking adjuvant endocrine therapy and defining how best to meet these needs. The survey involved a qualitative and quantitative phase and was conducted in 9 countries (Austria, France, Germany, Hungary, Italy, Spain, Sweden, Switzerland, and UK) that represent different regions of Europe and different size countries. The research was carried out by Adelphi International Research.

## METHODOLOGY

A literature search was undertaken to define the issues to include in a qualitative discussion guide about women's experience of adjuvant endocrine therapy in early breast cancer. The discussion guide was piloted, translated into the survey languages (English, French, German, Hungarian, Italian, Spanish and Swedish) and face-to-face interviews were carried out with 32 patients currently taking adjuvant endocrine therapy for early breast cancer in 8 of the survey countries (Switzerland was not included). The aim of these interviews was to identify the correct parameters to explore, and language to use, in the quantitative survey.

A quantitative questionnaire was developed, pilot tested in the survey languages and then administered to a convenience sample of post-menopausal women that met the following criteria: diagnosis of early breast cancer and currently receiving adjuvant endocrine therapy for one year or more with any of the following drugs: anastrozole, exemestane, letrozole or tamoxifen.

Women were recruited via advertisements in the media, posters displayed in pharmacies and clinics, as well as through the GAEA collaborating organisations, other European patient advocacy groups and healthcare professionals. Participants were given the option of either self-completing the questionnaire or completing it by telephone or face-to-face interview. A total of 547 questionnaires were analysed.

	Sample Achieved
Total	547
Austria	34
France	92
Germany	82
Hungary	34
Italy	90
Spain	71
Sweden	36
Switzerland	12
UK	96

To obtain aggregated EU results each country's data was weighted according to its size relative to the incidence of breast cancer across the EU, using figures from Globocan 2002 (WHO).

## RESULTS

71% of those surveyed were between 51-70 years of age. 13% were 71 or over. Nearly half of respondents were retired (43%), 39% were educated to a higher level and 44% had Internet access. A similar proportion of women surveyed were taking one of the available aromatase inhibitors (49%) as were taking anti-oestrogen tamoxifen (51%). The participants had been taking treatment for an average of 2.6 years.

Figure 1: Survey Respondent Demographics

Age	50 or younger	51-60	61-70	71 or over	Not Stated	
	16%	36%	35%	13%	*	
Working Status	Employed**	Retired	Disabled/LT sick	Homemaker	Unemployed	Not stated
	31%	43%	4%	18%	3%	1%
	Internet Access					
	Yes	No				
	44%	56%				
	Highest Education Level					
Primary/Secondary	Higher Education***	Not stated				
60%	39%	1%				
Current AET	Aromatase inhibitor	Tamoxifen				
	49%	51%				

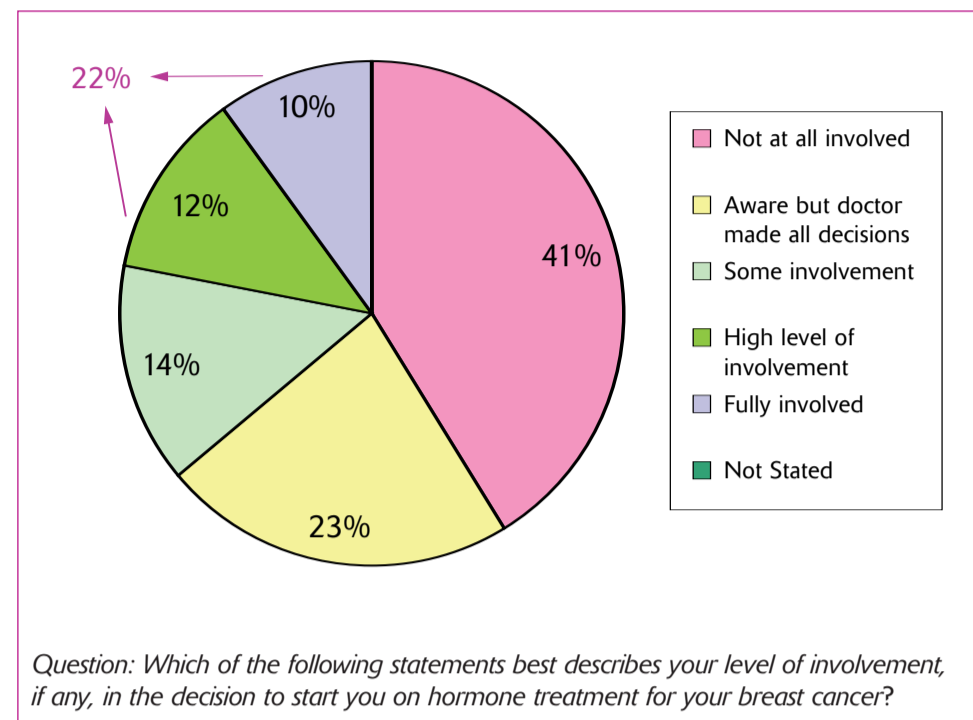
\* <0.5%  
\*\* Full-time, part-time, self-employed  
\*\*\* College + graduate + post graduate

## INVOLVEMENT IN TREATMENT DECISION MAKING

Just over 41% of women surveyed were not involved at all in the decision to start adjuvant endocrine therapy. Almost one in four women were made aware of different treatment options but they

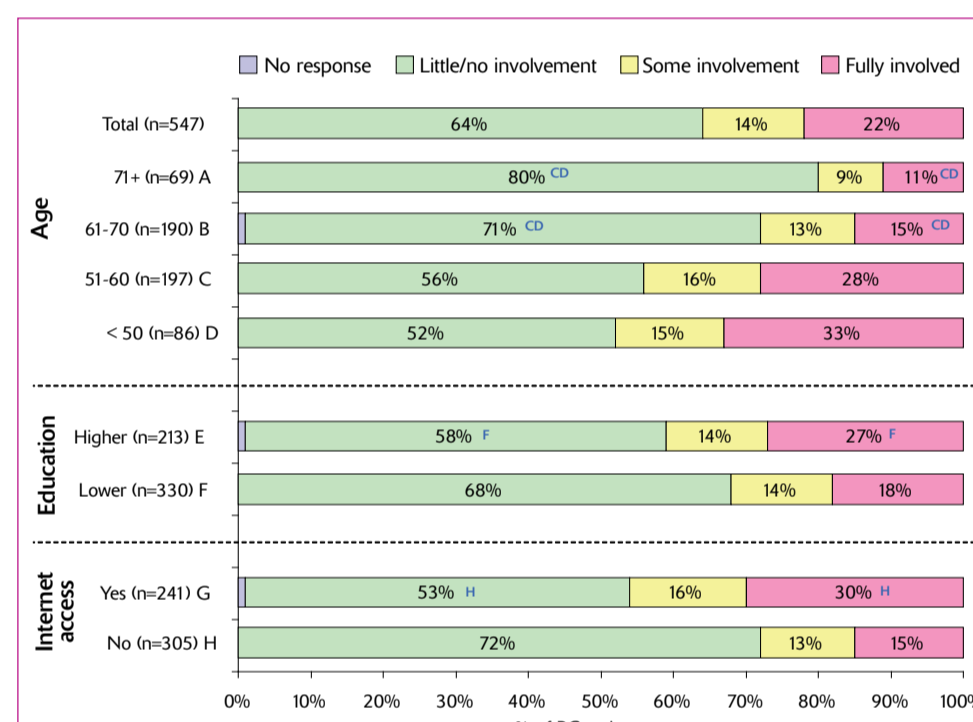
were not involved in the decision to start them on treatment. Only 22% of patients were fully or highly involved in the decision to start adjuvant endocrine therapy whereas another 14% had some level of involvement.

Figure 2: Level of patient involvement in the decision to start adjuvant endocrine treatment



33% of women aged 71 years or over were made aware of treatment options whereas 55% of women 60 years or younger were made aware of their options. 57% of women aged 71 years or over were not at all involved in the decision to start on adjuvant endocrine therapy (average of 41%). In contrast only 22% of women aged 50 years or younger were not at all involved in decision making. Overall younger women, women with a higher level of education and those with Internet access were more likely to have been more actively involved in decision making.

Figure 3: Level of involvement with treatment decisions by patient demographic

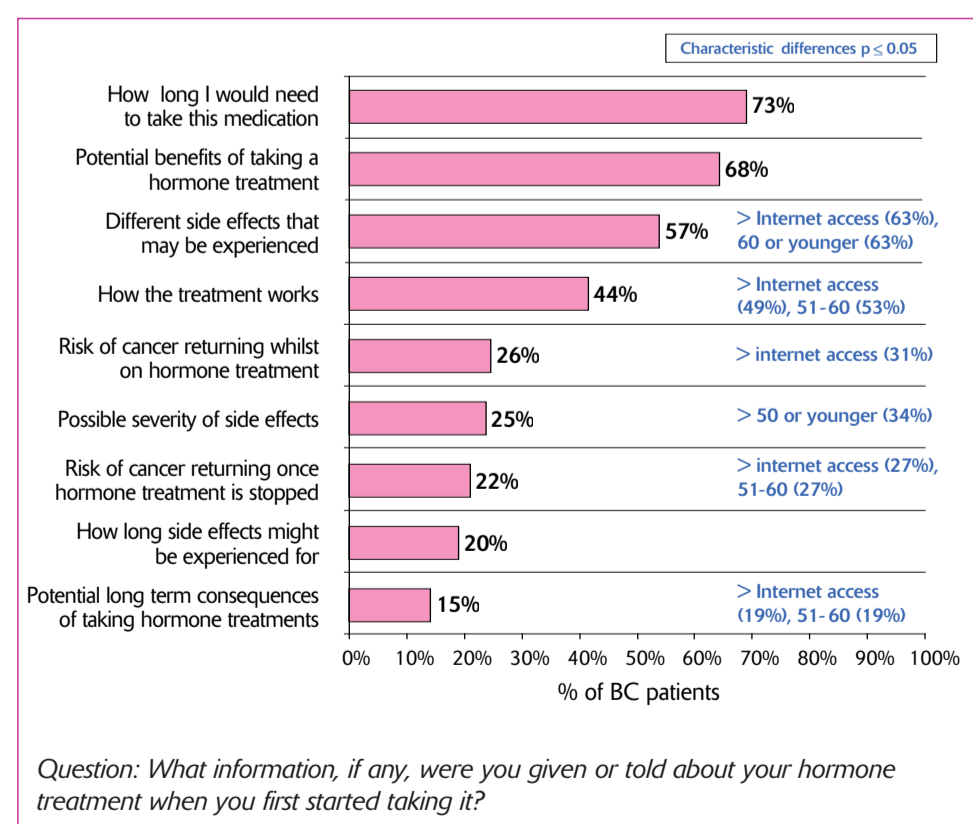


Those who were not involved in decision making were much less likely to be satisfied with their level of involvement.

## PROVISION OF INFORMATION ABOUT ADJUVANT ENDOCRINE THERAPY

Despite the fact that the women surveyed were generally satisfied with the information they received from healthcare professionals, less than half (44%) received information on how the treatment works. Only 25% of patients were informed of the possible severity of side effects, 20% of the duration of side-effects and 22% of the risk of their cancer recurring at the end of adjuvant endocrine therapy. Younger women and women with Internet access were found to receive more information at the start of treatment than older or less educated patients.

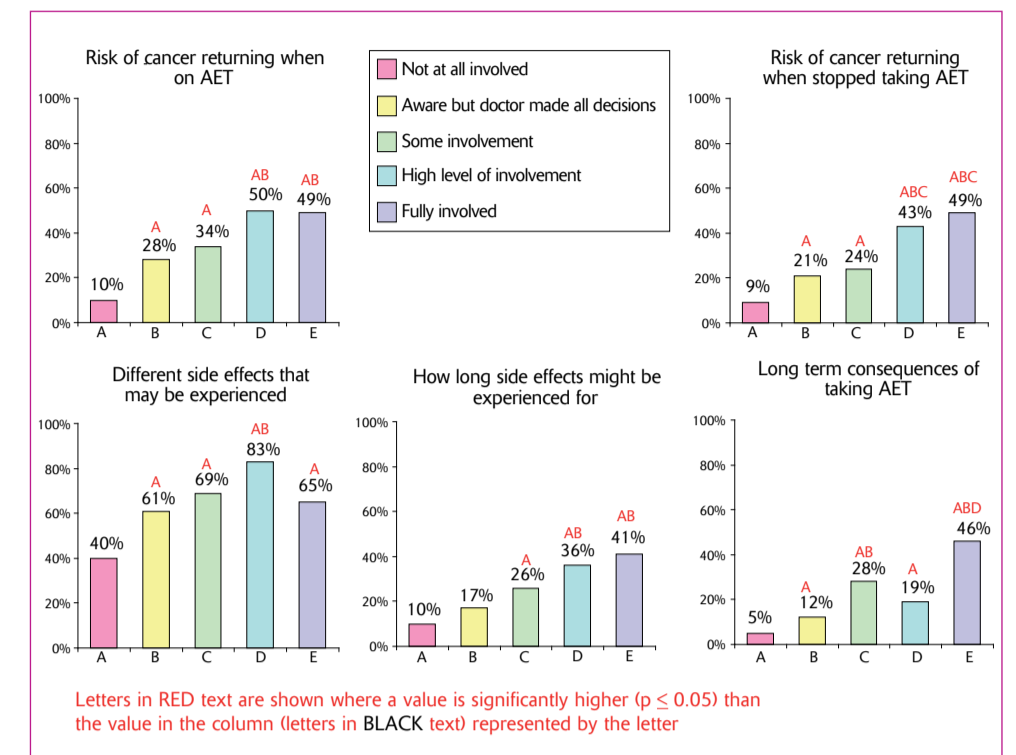
Figure 4: Information provided to patients at the outset of adjuvant endocrine therapy



Question: What information, if any, were you given or told about your hormone treatment when you first started taking it?

Women who were more actively involved in treatment decision making were significantly more likely to be told about treatment-related side effects, long term consequences of treatment and risk of their cancer recurring compared to those who had little or no involvement ( $p \leq 0.05$ ).

Figure 5: Awareness of side effects and risk of recurrence by involvement in treatment decision

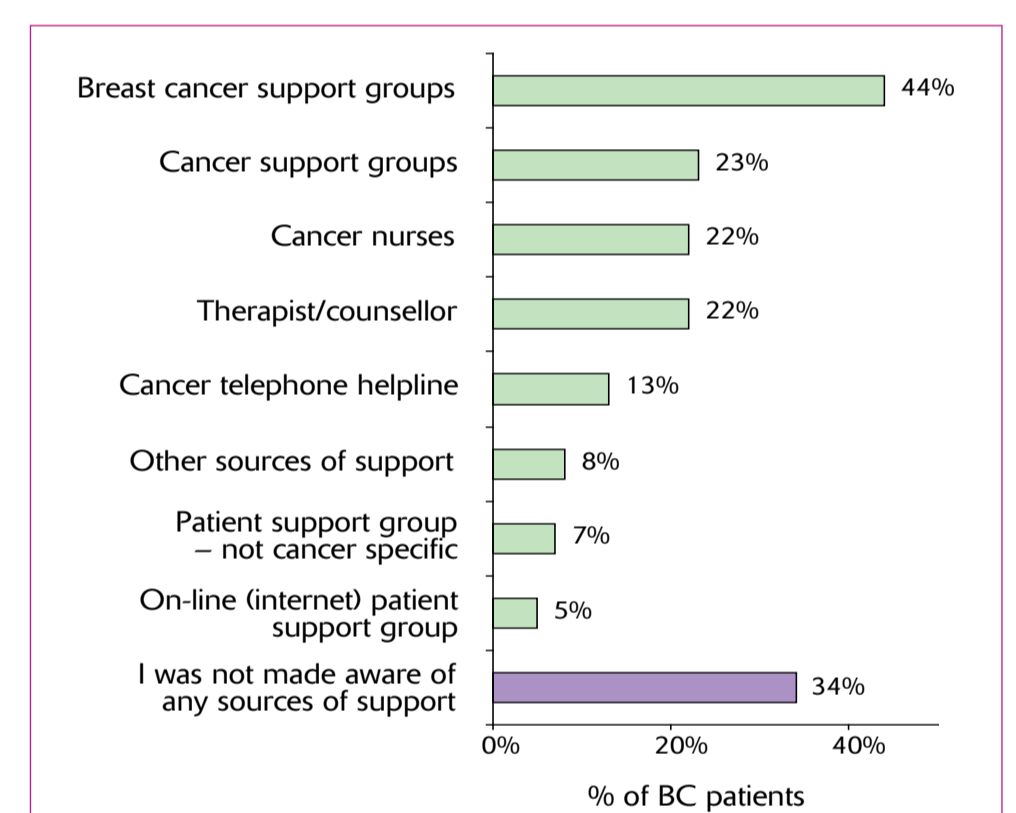


## SOURCES OF INFORMATION AND SUPPORT

Doctors were the most important and useful source of information and support for the women who took part in the survey. Written materials (e.g. information accompanying the medicine, brochures etc.) were shown to be a key source of information, yet less than a third of women indicated that these informational resources were of real value to them.

34% of those surveyed stated that they were not made aware of any support services at the time of diagnosis. Even though breast cancer support groups were shown to be a valuable source of information and support for women in the study, only 44% were made aware about the existence of such groups when they were diagnosed.

Figure 6: Awareness of sources of support at breast cancer diagnosis



Question: Which, if any, of the following sources of support were you made aware of when you were first diagnosed with breast cancer?

## CONCLUSION:

This survey has highlighted gaps in meeting patients' informational needs and in the degree to which they are involved in treatment decision making. Most of the women surveyed were not involved in the decision to start adjuvant endocrine therapy; nor were they made aware of different treatment options. The provision of information at the initiation of breast cancer treatment was shown to be sub-optimal. Older patients, those who are less well educated and those without Internet access were much less likely to be involved in decision making or to receive the information they need to make informed decisions.

All patients, regardless of age or educational level, should be helped to understand how adjuvant endocrine therapy works, the different treatments available, the possible side effects and their risk of recurrence so that they can make informed decisions about their treatment. Better communication between patients and professionals will facilitate this process, as will the development of high quality patient educational materials on adjuvant endocrine therapy. Special efforts are required to address the significant gaps in meeting the needs of older women, less well educated women and those who do not have Internet access.

These findings provide an initial insight into the needs of women taking adjuvant endocrine therapy and further research is required to develop greater understanding of and identify useful strategies for meeting these needs.

Note: A manuscript on the survey findings is currently being prepared and will be submitted to an international oncology publication.