

# Journal of Adolescent and Young Adult Oncology

Journal Name: <http://mc.manuscriptcentral.com/jayao>

## Antineoplastic agents and (in)fertility: informing patients to improve decisions

Journal:	<i>Journal of Adolescent and Young Adult Oncology</i>
Manuscript ID	JAYAO-2017-0094.R2
Manuscript Type:	Original Article
Date Submitted by the Author:	n/a
Complete List of Authors:	Silva, Cristina; Universidade de Coimbra Faculdade de Farmacia, Pharmacology Department Santos, Teresa; Coimbra Hospital and University Centre (CHUC), EPE, Human Reproduction Department; Faculty of Medicine of the Univerisity of Coimbra Melo, Cláudia; Faculty of Psychology and Educational Sciences of the University of Coimbra; Unit for Psychological Intervention, Maternity Dr. Daniel de Matos, Coimbra Hospital and University Centre (CHUC), EPE Ribeiro Rama, Ana Cristina; Centre for 20th Century Interdisciplinary Studies CEIS20; Universidade de Coimbra Faculdade de Farmacia, Pharmacology Department
Keyword:	Infertility, Oncofertility, Supportive Care, Late Effects
Manuscript Keywords (Search Terms):	infertility, oncofertility, decision support, information resources, chemotherapy adverse effects, fertility preservation
Abstract:	<p>Purpose: Infertility is a potential adverse effect of cancer treatment, and future fertility is an important issue for cancer patients. In Portugal, the Centre for Fertility Preservation of CHUC, EPE, conducted a project to develop and disseminate oncofertility information resources. Here, we report the results of the specific component of this program, which intended to produce information resources that promote patients' awareness of the subject and to support decisions concerning fertility preservation.</p> <p>Methods: Guidance for writing health information for patients and criteria for developing decision aids were gathered. Information needs were assessed (literature review and locally applied questionnaire). Resources were pre-tested with a sample of patients and professionals. Their readability, presentation quality and ability to support decisions were evaluated.</p> <p>Results: General information handouts on infertility risk and decision aids about fertility preservation options were developed and positively evaluated. The resources are currently being distributed in collaboration with several national organizations.</p> <p>Conclusions: Through our multidisciplinary information program,</p>

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	reproductive-age cancer patients now have access to relevant information resources that will support timely, shared decision-making concerning fertility preservation.

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## Antineoplastic agents and (in)fertility: informing patients to improve decisions

### Running head

Oncofertility: Informing patients to improve decisions

### Authors

Cristina Silva<sup>1</sup>, Teresa Almeida Santos<sup>2,3</sup>, Cláudia Melo<sup>4</sup>, Ana Cristina Ribeiro Rama<sup>1,5</sup>

### Corresponding author

Cristina Silva<sup>1</sup>

[tina.silva@sapo.pt](mailto:tina.silva@sapo.pt)

Pólo das Ciências da Saúde

Azinhaga de Santa Comba

3000-548 Coimbra

Portugal

Mobile phone: +351 918842 294

Teresa Almeida Santos<sup>2,3</sup>

[anateresasantos.tas@gmail.com](mailto:anateresasantos.tas@gmail.com)

Edf. S. Jerónimo

Praceta Prof. Mota Pinto

3000-075 Coimbra

Portugal

Cláudia Melo<sup>4</sup>

[claudiasmelosilva@gmail.com](mailto:claudiasmelosilva@gmail.com)

Rua do Colégio Novo

3000-115 Coimbra

Portugal

Ana Cristina Ribeiro Rama<sup>1,5</sup>

[rama.acr@gmail.com](mailto:rama.acr@gmail.com)

Rua Filipe Simões n° 33

3000-186 Coimbra

Portugal

<sup>1</sup> Pharmacology Department, Faculty of Pharmacy of the University of Coimbra, Coimbra, Portugal.

<sup>2</sup> Centre for Fertility Preservation, Human Reproduction Department, Coimbra Hospital and University Centre (CHUC), EPE, Coimbra, Portugal.

<sup>3</sup> Faculty of Medicine of the University of Coimbra, Coimbra, Portugal.

<sup>4</sup> Faculty of Psychology and Educational Sciences of the University of Coimbra, Coimbra, Portugal.

<sup>5</sup> Centre for 20th Century Interdisciplinary Studies CEIS20. University of Coimbra, Coimbra, Portugal.

Keywords: infertility; fertility preservation; oncofertility; information resources, decision support

**Abstract**

Purpose: Infertility is a potential adverse effect of cancer treatment, and future fertility is an important issue for cancer patients. In Portugal, the Centre for Fertility Preservation of CHUC, EPE, conducted a project to develop and disseminate oncofertility information resources. Here, we report the results of the specific component of this program, which intended to produce information resources that promote patients' awareness of the subject and to support decisions concerning fertility preservation.

Methods: Guidance for writing health information for patients and criteria for developing decision aids were gathered. Information needs were assessed (literature review and locally applied questionnaire). Resources were pre-tested with a sample of patients and professionals. Their readability, presentation quality and ability to support decisions were evaluated.

Results: General information handouts on infertility risk and decision aids about fertility preservation options were developed and positively evaluated. The resources are currently being distributed in collaboration with several national organizations.

Conclusions: Through our multidisciplinary information program, reproductive-age cancer patients now have access to relevant information resources that will support timely, shared decision-making concerning fertility preservation.

## 1. Introduction

Infertility is a potential adverse effect of antineoplastic cancer therapy. The degree of gonadal toxicity from chemotherapy is influenced by several factors, such as patient age, total dose administered and the nature of antineoplastic agents.<sup>1,2</sup> The possibility of an early diagnosis and considerable advances in cancer treatment, along with a rising incidence of cancer in teenagers and young adults, has led to an increase in the number of cancer survivors of reproductive age. In addition to facing the consequences of the disease, these patients will have to address the consequences of cancer treatments for their fertility.<sup>3</sup> It is recognized that future fertility is an important issue for these patients;<sup>4</sup> therefore, shared decisions concerning fertility preservation (FP) must occur at the time of diagnosis.

In this context, oncofertility, a term coined in 2006 by Teresa Woodruff, has recently emerged as a multidisciplinary field with the purpose of fulfilling the needs of cancer patients regarding their reproductive potential.<sup>5</sup> Several professional organizations in the field of oncology have published recommendations regarding FP, advising health professionals to discuss infertility risks and FP options with all cancer patients of reproductive age.<sup>6,7</sup> However, a number of published studies indicate that not every oncologist is following these orientations and that a considerable proportion of cancer patients is still not informed about the risks and possibilities regarding FP.<sup>8-13</sup> Moreover, surveys of reproductive-age cancer patients and survivors disclose gaps in the information received about the opportunity of preserving fertility, the techniques available or the possibility of consultation with a reproductive medicine specialist.<sup>14-17</sup>

Decisions regarding FP, especially for female cancer patients, are complex and preference-sensitive, i.e., they need to consider patients' values for benefits and harms

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3 across options.<sup>18</sup> All options come with risks and success rates and decisions  
4 concerning FP often have to be made in a short time frame, along with other treatment  
5 decisions and in a period of a great emotional distress. Several patient-related factors  
6 contribute to a quality decision-making process, including patients' values and attitudes,  
7 support from family and friends and the acquisition of information.<sup>19,20</sup> Information  
8 resources conceived to support decisions in healthcare such as decision aids<sup>21,22</sup> or  
9 decision trees<sup>23</sup> provide a more clear understanding of the available options, facilitate  
10 discussions and increase patients' and professionals' involvement in the decision-  
11 making process.  
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22 In the specific setting of infertility risk in cancer patients, the access to specialized  
23 information concerning FP improved patients' knowledge of the available options<sup>24</sup> and  
24 reduced decisional conflicts.<sup>25</sup>  
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28 In Portugal, oncofertility is of increasing importance in the context of quality of life in  
29 cancer survival. Recently, several Portuguese scientific societies, including the  
30 *Sociedade Portuguesa de Medicina da Reprodução* (Portuguese Society for  
31 Reproductive Medicine, SPMR) and the *Sociedade Portuguesa de Oncologia*  
32 (Portuguese Oncology Society, SPO), in cooperation with the national hematology and  
33 andrology professional societies, published and endorsed the "Portuguese  
34 Recommendations for Preserving the Reproductive Potential of Cancer Patients".<sup>26</sup> This  
35 document was the final outcome of the 1<sup>st</sup> and 2<sup>nd</sup> Portuguese Oncofertility Meetings in  
36 2015 and 2016. The Portuguese *Centro de Preservação da Fertilidade* (Centre for  
37 Fertility Preservation, CFP) of Coimbra Hospital and University Centre (CHUC), EPE,  
38 was a leader in this process and has been working actively since 2012 to promote local  
39 and national awareness of oncofertility. In cooperation with the *Liga Portuguesa Contra*  
40 *o Cancro* (Portuguese League Against Cancer, LPCC), a Portuguese nonprofit cancer  
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3 patients organization, the CFP conducted a project to develop and disseminate  
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5 oncofertility information resources, directed both to health professionals and cancer  
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7 patients. Here, we report the results of the specific component of this information  
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9 program, which aimed to produce information resources for cancer patients to promote  
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11 their informed participation in decisions in the context of infertility risks and FP.  
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## 13 14 15 16 2. Methods

### 17 18 19 2.1. Assessment of information needs

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21 A literature search on Medline, through PubMed, was conducted to identify primary  
22  
23 quantitative studies evaluating cancer patients' information needs or gaps in knowledge  
24  
25 concerning infertility risks and FP options. The search equation was built using the  
26  
27 following MeSH terms: *Patient Education as Topic; Consumer Health*  
28  
29 *Information/methods; Health education; Antineoplastic Agents/adverse effects;*  
30  
31 *Infertility, Female; Infertility, Male; Sperm Banks; Cryopreservation; Reproductive*  
32  
33 *Techniques, Assisted; and Fertility Preservation.* The eligible articles were retrieved,  
34  
35 and their results were gathered and organized. Additionally, a questionnaire directed to  
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37 cancer survivors that had been diagnosed in reproductive age was applied locally\*.  
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39 These self-reported, anonymous questionnaires were distributed by clinicians in follow-  
40  
41 up consultations at several clinical departments of CHUC, EPE. Demographic,  
42  
43 reproductive and clinical information was requested. Participants were asked to rate, on  
44  
45 a 5-point Likert scale (ranging from *Not important* to *Extremely important*), their self-  
46  
47 perceived importance of discussing specific information topics regarding infertility risks  
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49 and FP before cancer treatment initiation. An additional question queried patients on the  
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55 \*This self-reported questionnaire was developed and administered in collaboration with Cláudia Melo, as the responsible researcher of a  
56 PhD project on Health Psychology about fertility preservation.

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3 usefulness of several information strategies (from *Not useful* to *Extremely useful*). The  
4  
5 study received approval from the local ethical committee, and the questionnaire was  
6  
7 previously tested in a small group of cancer survivors. Patients were informed of the  
8  
9 objectives and methods of the study, and all participants signed written consent.  
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## 11 12 13 2.2. Development of information resources

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15 The information resources were designed to target cancer patients of reproductive age  
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17 (18 to 40 years) with a recent cancer diagnosis (any type of cancer) before treatment  
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19 initiation. To include relevant, yet specific, information for each gender (for instance,  
20  
21 about fertility markers), distinct resources were developed for male and female patients.  
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23 Bearing in mind that the risk of infertility is not acknowledged by many cancer  
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25 patients<sup>27-31</sup> and the complexity of the decision-making process regarding FP,  
26  
27 particularly in women, two different types of written patient information resources were  
28  
29 planned: 1) general information handouts with the aim of raising awareness of the  
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31 effects of cancer and cancer treatments on fertility; 2) decision aids with the aim of  
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33 supporting decisions in the context of FP.  
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37 With the purpose of producing quality written health information materials, searches  
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39 were conducted in Medline, through PubMed, to find general guidance for writing  
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41 health information for patients. For the specific production of the decision aids, the  
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43 criteria included in the DISCERN instrument<sup>32</sup> (<http://www.discern.org.uk/index.php>)  
44  
45 were taken into account. DISCERN consists of 16 key questions intending to evaluate  
46  
47 the reliability of the publication, the information provided about treatment choices and  
48  
49 its overall quality. This tool was designed to help users of consumer health information  
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51 judge the quality of written information about treatment choices but can also be used as  
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53 a checklist for authors and producers of written consumer health information.  
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3 Published evidence on infertility risks and FP options in cancer patients was identified  
4 and the most current evidence-based knowledge on clinical indications, time requisites,  
5 success rates, risks and advantages/disadvantages of each FP technique was gathered.  
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### 10 11 2.3. Evaluation of information resources 12

#### 13 *Readability* 14

15 Readability is a measure of the facility with which a text is read, according to the length  
16 of words and sentences. Preliminary versions of the information resources were tested  
17 for readability using the *Fernandez-Huerta index*, a modified version of the *Flesch*  
18 *Reading Ease score* for the Spanish language.<sup>33</sup> In the *Flesch Reading Ease score*, the  
19 results range from 0 (the worst level, very difficult to read) to 100 (the best readability  
20 level). Usually, a reading ease of 60-70 is considered standard (Table 1).<sup>34</sup>  
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28 The number of words and syllables was estimated using the software *TextMeter*, an  
29 application of text statistics for the Portuguese language. After the first readability  
30 results, improvements were made by using alternative, shorter words and building less  
31 complex sentences.  
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#### 38 *Pre-test* 39

40 The first drafts of both the general information handouts and the decision aids were  
41 provided, along with an evaluation form, to reproductive-age cancer patients and  
42 survivors by oncologists and psychologists in fertility preservation and follow up  
43 consultations. They were also evaluated by a variety of healthcare professionals with  
44 direct or indirect involvement in the care of reproductive-age cancer patients (Table 2).  
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3 asking if the different options were presented in a balanced way; if the information on  
4 each option was sufficient; and if the information would increase the knowledge about  
5 the options, help patients to discuss the options with their oncologist and promote their  
6 participation in decisions.  
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### 10 11 12 13 *Quality*

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15 The quality of the information resources was assessed using EQIP (Ensuring Quality  
16 Information for Patients), a tool designed to measure the presentation quality of all  
17 types of written health care information,<sup>35</sup> and the above-mentioned DISCERN  
18 instrument.<sup>32</sup>  
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26 A flow diagram showing the sequence of steps in the development process can be seen  
27 in Figure 1.  
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## 30 31 32 33 3. Results

### 34 35 3.1. Information needs

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37 In accordance with the defined eligibility criteria, ten published articles were selected  
38 and analyzed.<sup>27-31; 36-40</sup> Data on methods and results on reported patient information  
39 needs or gaps in knowledge were collected from each individual article and are  
40 presented in Table 3.  
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45 In relation to the identification of local information needs, a sample of 31 cancer  
46 survivors answered and returned the questionnaire. It was not possible to calculate the  
47 response rate, as the total number of questionnaires distributed to patients by clinicians  
48 is not known. The mean age ( $\pm$  SD) of the participants was of 34.4 years ( $\pm$  6.5),  
49 corresponding to a mean age of 26.6 years ( $\pm$  7.5) at diagnosis. Most participants were  
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3 females (n=27), and the most frequent cancer diagnoses were lymphoma (n=9), breast  
4 cancer (n=8) and osteosarcoma (n=8). The majority of survivors (n=23) had been  
5 treated with systemic chemotherapy. Almost one third (n=10) reported effects of cancer  
6 treatments on fertility, and 15 answered that they did not know or were unsure of those  
7 effects. Two patients used a fertility preservation technique before treatment initiation,  
8 and three patients had children after cancer treatment. Table 4 presents the information  
9 topics included in the questionnaire. All topics were rated as *Extremely important to be*  
10 *discussed* or *Very important to be discussed* by a significant majority of participants.  
11 Concerning the strategies that are useful to inform cancer patients on these topics,  
12 consultation with a reproductive medicine specialist and the supply of information  
13 through written information resources or the Internet were the most valued.  
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### 29 3.2. Information resources

30 The contents of the information resources were developed with our previously  
31 mentioned purposes in mind (section 2.2) and the information needs most frequently  
32 identified in the international literature and/or reported by the local sample of survivors.  
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34 General criteria for writing health information for patients were collected from several  
35 published guidance documents<sup>41-42</sup> and organized according to the following themes:  
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37 content (e.g., clearly defined aim), language (e.g., avoid paternalism and value  
38 judgements, use active voice, avoid technical terms), organization (e.g., use bullets and  
39 write short, single idea paragraphs), layout and graphics (e.g., avoid uppercase and  
40 italic, align text to the left), illustrations (e.g., use only to improve understanding) and  
41 learning and motivation (include interactive materials). These criteria supported the  
42 process of writing and organizing the information content.  
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3 In the general handouts, the information was organized in the format of *Questions &*  
4 *Answers* as a form of dividing text and making it more attractive to read.<sup>42</sup> In the  
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6 decision aids, after a brief introduction discussing the relevance of shared decision-  
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8 making regarding FP, contents were structured according to the two main decision  
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10 points: 1) the decision to use or not use a FP technique; 2) when applicable, the decision  
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12 of which FP technique to choose. In each decision point, the positive and negative  
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14 aspects of each option were presented. Moreover, in the second decision point, detailed  
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16 information on the procedures and target populations for each FP technique was  
17  
18 included. A third section was designed with a set of three *questions & answers*  
19  
20 regarding general issues such as costs, maximum length of cryopreservation and fate of  
21  
22 the non-used cryopreserved cells/tissues. Interactive components to increase learning  
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24 and motivation (i.e., a box that patients can use to write questions and a small  
25  
26 knowledge quiz at the end) were developed for all information resources. In the final  
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28 section, other relevant sources of information were presented, including the address of  
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30 the CFP's website and contact numbers of national telephone helplines on cancer and  
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32 oncofertility.  
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37 Table 5 and Table 6 display images of the front page and briefly outline the contents  
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39 included in the handouts and decision aids, respectively. As the local sample of  
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41 survivors reported that provision of information through the Internet would also be a  
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43 useful strategy, the information contents were also adapted to be digitally displayed on  
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45 the CFP's website.  
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### 50 3.2.1. Evaluation of the information resources

#### 51 *Readability*

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3 The final versions of the handouts informing of the possible effects of cancer (and  
4 cancer treatments) on male and female fertility were rated by the Fernandez-Huerta  
5 readability index as *fairly difficult* (score of 51). Readability of the decision aids to  
6 support FP decisions was classified as *difficult*, with scores of 46 for the male and 49 for  
7 the female decision aids.  
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#### 10 11 12 13 *Pre-test*

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15 In general, both cancer patients and healthcare professionals rated the information  
16 resources as easy to read, with contents that are relevant, complete and well organized.  
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18 Only a few minor changes were necessary, mainly of language and sentence structure.  
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20 Additionally, decision aids were considered by all participants as useful for shared  
21 decision-making and clinical practice.  
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#### 24 25 26 *Quality assessment*

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28 All information resources scored high on presentation quality, with EQUIP scores  
29 varying between 77 and 89%. Consistent with the recommendations from this tool, the  
30 resources produced are “ready for distribution and should be reviewed in two to three  
31 years”. According to the criteria from the DISCERN instrument, the overall quality of  
32 the two decision aids developed was high (4 or 5 scores in all questions). This rating  
33 means that the information materials “are useful and appropriate sources of information  
34 about treatment choices and have the ability to support the patient’s decisions”.  
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#### 45 46 3.2.2. Publication and dissemination

47 The handouts informing of cancer and cancer treatment effects on male and female  
48 fertility were published in 2015 by the LPCC, which is also circulating these resources  
49 through its campaigns and website. With the collaboration of the *Ordem dos*  
50 *Farmacêuticos – Secção Regional de Coimbra* (Portuguese Pharmaceutical Society –  
51 Center Regional Section; SRC-OF), the handouts were also distributed to pharmacies all  
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3 over the country, in order to reach the population in a larger scale. More recently, the  
4 LPCC has also published the decision aids that are being distributed to oncologists and  
5 other cancer care clinicians, reproductive medicine specialists and fertility preservation  
6 centers, with the cooperation of SPMR and SPO.  
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10 Furthermore, all the produced information content is available, in Portuguese, on the  
11 website of the *Centre for Fertility Preservation of CHUC, EPE*

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14 ([www.centropreservacaofertilidade.pt](http://www.centropreservacaofertilidade.pt)).  
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#### 16 17 18 19 4. Discussion

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21 We believe that our systematic method for the provision of patient information—  
22 assessing information needs, providing information to meet those needs, pre-testing the  
23 information resources with the target population and assessing their quality with  
24 validated instruments—is a sound approach to facilitate decision-making among cancer  
25 patients in the context of infertility risks and FP options. Moreover, the use of quality  
26 decision aids that describe the path of patient decision-making and the consequences of  
27 each separate decision will lead patients to more informed clinical judgments.<sup>43-44</sup>  
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31 Our results indicate that the developed resources are relevant, reliable, and useful and  
32 have the ability to support shared decisions in the context of FP. They were positively  
33 evaluated by cancer patients, cancer survivors and health professionals working in the  
34 cancer and reproduction settings and achieved high quality scores according to the  
35 instruments EQIP and DISCERN. Concerning readability, the general handouts and the  
36 decision aids were scored as *fairly difficult* and *difficult* to read, respectively, which  
37 means they are suitable for readers with at least high-school grade levels. These low  
38 levels of readability are potential barriers for their ability to inform patients and support  
39 shared decisions so it is important to further assess the resources in real contexts of  
40 decision. Nevertheless, readability scores must always be interpreted with caution. They  
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3 assume that longer words and sentences are harder to read and do not measure  
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5 comprehension or indicate if the words are familiar to the reader. For example, some  
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7 recurrently used Portuguese words in the setting of reproduction and fertility  
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9 preservation, such as “espermatozoide”, “fertilidade” and “congelação”, are common  
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11 and easily understandable words, yet they negatively influence the readability scores  
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13 because of their many syllables. In the specific case of decision aids (scored as *difficult*  
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15 *to read*), it will be important to use direct measures of comprehension, such as their  
16  
17 ability to promote shared decision-making and to reduce decisional conflict.

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19 The developed resources were designed to target adult patients in reproductive age  
20  
21 faced with a diagnosis of any type of cancer. Accordingly, no cancer-specific  
22  
23 information about infertility risks or fertility preservation options was included.  
24  
25 Furthermore, they may not be suitable for children or adolescents with cancer, since  
26  
27 younger patients may have distinct needs and preferences regarding the provision of  
28  
29 information.<sup>45-46</sup> It is also a fact that some of the identified information needs remained  
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31 unmet. Some topics were beyond the scope of our resources (for instance, the effects of  
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33 cancer in sexual function, contraception in cancer patients or information about  
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35 infertility treatments), while for others, the information would be influenced by the  
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37 specific type of cancer (such as the risk of genetic transmission of cancer to offspring  
38  
39 and the risk of cancer recurrence due to pregnancy). Clearly, these are subjects to  
40  
41 include in upcoming information resources. Other limitations of our study are related to  
42  
43 the methods for the assessment of information needs. Due to time constraints,  
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45 qualitative studies were not included in the literature search, and the locally applied  
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47 questionnaire had a small number of participants.

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49 We wish to highlight the multidisciplinary context in which this project has been carried  
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51 out, involving cancer patients and survivors, a cancer patients' organization (LPCC),  
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3 oncologists and other cancer care professionals and professional and scientific societies  
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5 in the fields of oncology and reproductive medicine. We hope this intense cooperation  
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7 will contribute to a wider dissemination of the developed information materials to the  
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9 various stakeholders in the process of cancer care and to a more effective clinical  
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11 implementation. Additionally, it is important to note that information resources directed  
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13 to oncologists were also developed in the context of this program, including a main  
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15 booklet with comprehensive contents, tailored to the needs of clinicians working with  
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17 cancer patients, and a brochure with summarized contents intended for other cancer care  
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19 professionals and primary care professionals.<sup>47</sup>

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22 The developed resources are already available to the Portuguese population and to  
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24 cancer patients in several institutions all over the country. Our next step will be to  
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26 evaluate the resources with cancer patients using relevant measures such as  
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28 acceptability, knowledge, decision conflict or self-efficacy.

## 31 32 33 5. Conclusion

34  
35 The need to inform cancer patients in an effective and timely manner of their infertility  
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37 risks and the possibility and options of FP is a recognized relevant issue in the context  
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39 of quality of life in cancer survival. Through a systematic approach and establishing a  
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41 multidisciplinary collaboration, information resources directed to cancer patients' needs  
42  
43 were successfully developed and disseminated and will contribute to timely, shared and  
44  
45 informed clinical decisions in the context of FP.

## 46 47 48 49 50 **Acknowledgements**

51  
52 This work was supported by a research grant from the *Liga Portuguesa contra o Cancro*  
53  
54 (Grant LPCC/Celgene 2012).  
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3 The authors wish to thank to Professor Paula Fresco, PharmD, PhD, for her important  
4 contributions to revising the article's spelling and grammar.  
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10 **Author Disclosure Statement**

11 No competing financial interests exist.  
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Table 1. Flesch Reading Ease scores and corresponding readability and school levels.

<b>Flesch Reading Ease score</b>	<b>Readability level</b>	<b>School level (Easy to read for...)</b>
0-30	Very difficult	College graduate (University degree)
30-50	Difficult	College (University student)
50-60	Fairly difficult	10 <sup>th</sup> -12 <sup>th</sup> grade High school graduate
60-70	Standard	8 <sup>th</sup> -9 <sup>th</sup> grade
70-80	Fairly easy	7 <sup>th</sup> grade
80-90	Easy	6 <sup>th</sup> grade
90-100	Very easy	5 <sup>th</sup> grade

Table 2. Evaluation criteria and evaluation groups used to pre-test the information resources.

	<b>Evaluation criteria</b>	<b>Evaluation groups</b>
<b>General information handouts</b>	<ul style="list-style-type: none"> <li>• Content (usefulness, completeness, organization)</li> <li>• Language</li> <li>• Layout (colors, titles, highlights, fonts)</li> </ul>	<p><b>Patients</b></p> <ul style="list-style-type: none"> <li>• Female cancer patients (n=3)</li> <li>• Female cancer survivors (n=6)</li> <li>• Male cancer survivors (n=3)</li> </ul> <p><b>Cancer care professionals</b></p> <ul style="list-style-type: none"> <li>• Psychologists (n=1)</li> <li>• Hospital pharmacists (n=2)</li> <li>• Oncologists (n=2)</li> <li>• Hematologists (n=1)</li> <li>• Gynecologists (n=2)</li> </ul> <p><b>Human reproduction professionals</b></p> <ul style="list-style-type: none"> <li>• Reproductive medicine specialists (n=2)</li> <li>• Nurses (n=2)</li> </ul> <p><b>Other healthcare professionals</b></p> <ul style="list-style-type: none"> <li>• Community pharmacists (n=2)</li> </ul>
<b>Decision aids</b>	<ul style="list-style-type: none"> <li>• Content (usefulness, completeness, organization)</li> <li>• Language</li> <li>• Layout (colors, titles, highlights, fonts)</li> <li>• Ability to support decisions</li> <li>• Usefulness for clinical practice (health professionals)</li> </ul>	<p><b>Patients</b></p> <ul style="list-style-type: none"> <li>• Female cancer patients (n=3)</li> <li>• Female cancer survivors (n=6)</li> <li>• Male cancer survivors (n=3)</li> </ul> <p><b>Cancer care professionals</b></p> <ul style="list-style-type: none"> <li>• Psychologists (n=1)</li> <li>• Hospital pharmacists (n=2)</li> <li>• Oncologists (n=2)</li> <li>• Hematologists (n=1)</li> <li>• Gynecologists (n=2)</li> </ul> <p><b>Reproductive health professionals</b></p> <ul style="list-style-type: none"> <li>• Reproductive medicine specialists (n=2)</li> <li>• Embryologist (n=1)</li> <li>• Nurses (n=2)</li> </ul>



Table 3. Data on studies identifying cancer patients' information needs or gaps in knowledge concerning infertility risks and FP options.

Reference	Title	Methods (sample)	Information needs / gaps in knowledge identified
Armuaud GM. J Clin Oncol 2012; 30:2147-53 <sup>27</sup>	Sex differences in fertility-related information received by young adult cancer survivors	Postal questionnaire sent to cancer survivors identified in population-based registers in Sweden (n=484)	<ul style="list-style-type: none"> <li>• Effects of cancer treatments on fertility</li> <li>• Effects of cancer treatments on future children</li> </ul>
Balthazar U. Fertil Steril 2011; 95:1913-6 <sup>36</sup>	Fertility preservation: a pilot study to assess previsit patient knowledge quantitatively	Consecutive new FP patients seen at the University of North Carolina completed a pre-consultation questionnaire (n=41)	<ul style="list-style-type: none"> <li>• Success rates of FP techniques</li> <li>• Effect of FP in cancer recurrence</li> <li>• Effects of cancer treatments on future children</li> <li>• Costs of FP</li> <li>• FP options before and after cancer treatment</li> <li>• Established <i>versus</i> experimental FP options</li> </ul>
Balthazar U. Hum Rep 2012; 27:2413-19 <sup>37</sup>	The current fertility preservation consultation model: are we adequately informing cancer patients of their options?	Web-based survey at academic IVF centers, including women aged 18-43 years seen for comprehensive FP consultation	<ul style="list-style-type: none"> <li>• Time requirements for FP</li> <li>• Pregnancy rates after FP</li> <li>• Effect of FP on cancer recurrence</li> <li>• Age as a very important factor for FP success</li> <li>• Maximum time of embryo/oocyte cryopreservation</li> <li>• Effects of oophorectomy in future fertility</li> </ul>
Jukkala AM, Fertil Steril 2010; 94:2396-8 <sup>28</sup>	Self-assessed knowledge of treatment and fertility preservation in young women with breast cancer	Online assessment of knowledge in women (18 to 50 years) with history of breast cancer (n=106)	<ul style="list-style-type: none"> <li>• Effects of cancer and cancer treatments on fertility</li> <li>• Infertility treatments</li> <li>• FP options</li> </ul>
Karen M. Oncol Nurs Forum 2010; 37:191-7 <sup>38</sup>	Development of the Fertility and Cancer Project: An Internet Approach to Help Young Cancer Survivors	Internet survey to assess fertility knowledge of young survivors of breast cancer from eight countries (n=106)	<ul style="list-style-type: none"> <li>• Infertility treatments</li> <li>• FP options</li> </ul>
Peate M. J Clin Oncol 2011; 29:1670-7 <sup>39</sup>	It's Now or Never: Fertility-Related Knowledge, Decision-Making Preferences, and Treatment Intentions in Young Women with Breast Cancer—An Australian Fertility Decision Aid Collaborative Group Study	Survey of women diagnosed with early breast cancer and reporting incomplete families (n=111)	<ul style="list-style-type: none"> <li>• Effects of hormonal therapy on fertility</li> <li>• Established <i>versus</i> experimental FP options</li> <li>• Effect of pregnancy on cancer recurrence</li> <li>• Success rates of FP techniques</li> <li>• Time requirements for FP</li> </ul>

1 2 3 4 5 6 7 8 9 10 11	Scanlon M. J Cancer 2012; 3: 217-25 <sup>29</sup>	Patient Satisfaction with Physician Discussions of Treatment Impact on Fertility, Menopause and Sexual Health among Pre- menopausal Women with Cancer	Questionnaire applied to pre- menopausal women with cancer diagnosis in 2 time points (at enrollment and at 1- year follow-up) (n=104)	<ul style="list-style-type: none"> <li>• Effects of cancer and cancer treatments on fertility</li> <li>• Effects of cancer and cancer treatments on sexual function</li> </ul>
12 13 14 15 16 17 18 19	Schover LR. J Clin Oncol 2002;20:1880- 9 <sup>30</sup>	Knowledge and Experience Regarding Cancer, Infertility, and Sperm Banking in Younger Male Survivors	Postal survey sent to men with a new diagnosis of cancer at 14-40 years of age (n=201)	<ul style="list-style-type: none"> <li>• Effects of cancer and cancer treatments on sperm quality</li> <li>• Infertility risk in boys <i>versus</i> girls</li> <li>• Amount of sperm needed for infertility treatments</li> <li>• Risk of cancer in future children</li> </ul>
20 21 22 23 24 25 26 27 28 29 30	Thewes B. J Clin Oncol 2005; 23:5155-65 <sup>40</sup>	Fertility- and Menopause-Related Information Needs of Younger Women with a Diagnosis of Early Breast Cancer	Mail questionnaire sent to women with a diagnosis of early- stage breast cancer aged $\leq 40$ years at diagnosis (n=228)	<ul style="list-style-type: none"> <li>• Contraception</li> <li>• Possibility of pregnancy after cancer treatment</li> <li>• Effects of pregnancy on cancer recurrence</li> <li>• Risks/benefits of having children after cancer</li> <li>• Effects of cancer treatments on future children</li> <li>• Statistics on infertility risks</li> <li>• Onset of infertility after cancer treatments</li> </ul>
31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47 48 49 50 51 52 53 54 55 56 57 58 59 60	Zebrack B. Supp Care Cancer 2008;16:1353- 60 <sup>31</sup>	Information and service needs for young adult cancer patients	Online survey of young adults aged 18-40 years and diagnosed with cancer between the ages of 15-35 (n=217)	<ul style="list-style-type: none"> <li>• Infertility risks</li> <li>• Infertility treatments/services</li> </ul>

Table 4. List of information topics ordered according to the number of cancer survivors rating them as *Extremely important* or *Very important* to discuss before treatment initiation (n=31).

<b>Information topics</b>	<b>Extremely important to discuss (n)</b>	<b>Very important to discuss (n)</b>	<b>Total (n)</b>
Risks of effects of cancer treatments for future reproductive function/fertility	17	11	28
Risk of malformation in the offspring due to cancer treatments	23	5	28
Possibility of having children after cancer	18	10	28
Type of effects of cancer treatments on reproductive function/fertility	20	8	28
In women, risk of cancer recurrence due to pregnancy	21	6	27
Risk of genetic transmission of cancer to the offspring	19	8	27
FP options before and during treatments	15	12	27
Available FP techniques	13	14	27
Advantages of FP techniques	14	13	27
Disadvantages of FP techniques	16	11	27
Interference of FP in cancer treatment	16	11	27
Duration of effects of cancer treatments on reproductive function/fertility	18	8	26
Success rates	14	12	26
Availability of FP specialists	14	12	26
In women, risk of early menopause due to cancer treatments	17	7	24
Costs	15	9	24
How long the gametes can stay cryopreserved	15	9	24

Table 5. Front pages, titles and information contents of the handouts informing of the possible effects of cancer (and cancer treatments) on male and female fertility.




Front-page image	Title	Questions & Answers
	<p><b>Fertility in Men/Women with Cancer: Know the Risks</b></p>	<ul style="list-style-type: none"> <li>▪ How to know if a woman/man is fertile?</li> <li>▪ Is it possible to have children after cancer?</li> <li>▪ When should the discussion with the doctor about the possible effects of cancer in fertility occur?</li> <li>▪ How to know if fertility can be affected?</li> <li>▪ How do cancer treatments affect fertility? Surgery, Radiotherapy, Chemotherapy...</li> </ul>

Table 6. Front pages, titles and information contents of the decision aids for male and female cancer patients to support shared decision-making about FP.

Front-page image	Title	Information contents
	<p><b>Fertility in Men with Cancer: Know the Fertility Preservation Options</b></p>	<ul style="list-style-type: none"> <li>▪ What is “fertility preservation”?</li> <li>▪ What are the available options? <ul style="list-style-type: none"> <li>▪ Comprehensive information on procedures, indications, success rates and risks of each FP technique;</li> </ul> </li> <li>▪ Answers to frequent questions regarding costs, conservation and disposal of the cryopreserved material;</li> <li>▪ Other sources of information: websites, telephone helplines;</li> <li>▪ Interactive components: box to write questions; knowledge quiz.</li> </ul>
	<p><b>Fertility in Women with Cancer: Know the Fertility Preservation Options</b></p>	<ul style="list-style-type: none"> <li>▪ What is “fertility preservation”?</li> <li>▪ What are the available options? <ul style="list-style-type: none"> <li>▪ 1<sup>st</sup> decision – to preserve or not fertility – positive and negative aspects of each option</li> <li>▪ 2<sup>nd</sup> decision – which FP technique to choose - comprehensive information on procedures, indications, success rates and risks of each FP technique;</li> </ul> </li> <li>▪ Answers to general questions regarding costs, maintenance and disposal of non-used cryopreserved material;</li> <li>▪ Other sources of information: websites, telephone helplines;</li> <li>▪ Interactive components: box to write questions; knowledge quiz.</li> </ul>

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Figure 1. Flow diagram showing the sequential steps in the development of information resources.



Figure 1. Flow diagram showing the sequential steps in the development of information resources.

368x250mm (96 x 96 DPI)

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