

Multimedia Appendix 1:

Screenshots illustrating the search page and the list of retrieved stories for each of the 4 search conditions (i.e., control, story topics, writer profile, and combination condition).

Appendix to:

Overberg R, Otten W, De Man A, Toussaint P, Westenbrink J, Zwetsloot-Schonk B. How breast cancer patients want to search for and retrieve information from stories of other patients on the Internet: an online randomised controlled experiment.

Screenshot 1a: The search page of the control group.

The Amazones - Windows Internet Explorer

http://www.msbi.nl/verhalen/

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The Amazones

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The Amazones

Jonge vrouwen met borstkanker

Steun de Stichting

The folders below contain the stories sorted alphabetically by writer name.

A	B	C	D	E	F	G	H	I
J	K	L	M	N	O	P	Q	R
S	T	U	V	W	X	Y	Z	#

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Screenshot 1b: A list of stories retrieved in the control group.

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DE AMAZONES Jonge vrouwen met borstkanker

Stort een donatie op giro:

Home | Wie zijn wij | Ervaringsverhalen

<-Back | Afro | Amazone | Angel | Angel70 | Anita-U2 | Anja | Annie | Anto | Ar | Asmas

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Ervaringsverhalen

Select one of the names listed above to read a story.

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Screenshot 2a: The search page of the story topics group.

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The Amazones

Use the form below to search for stories.

Story topics:

Diagnosis

- feelings about diagnosis

Treatment

- Decision-making about treatment
 - having no choice
 - breast conserving surgery or mastectomy?
 - adjuvant treatment or not?
 - reconstruction or not?
 - prophylactic mastectomy other breast
 - ovary removal
 - other
- coping with treatment
- treatment side effects
 - arm lymphedema
 - hair loss
 - fatigue
 - nerve pain
 - hot flashes
 - skin problems
 - other

Health care system

- delay in/errors at diagnosis
- waiting for test results
- contact with medical staff
 - support
 - lack of understanding
- how treatment was performed
 - satisfied
 - dissatisfied
- second opinion

Living with it

- work & insurance

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Screenshot 2b: A list of stories retrieved in the story topics group.

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DE AMAZONES Jonge vrouwen met borstkanker

Stort een donatie op giro: **4340044**

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The Amazones

16 stories were found:

The number of pink ribbons (0–5) indicates to what extent a story matches with your search.

Pimmie
Topics found: coping with treatment, hair loss, breast conserving surgery or mastectomy?

The stories below do not completely match with your search:

Jose3
Topics found: coping with treatment, breast conserving surgery or mastectomy?

Chica
Topics found: hair loss, breast conserving surgery or mastectomy?

Lia
Topics found: coping with treatment, breast conserving surgery or mastectomy?

Monique 4
Topics found: coping with treatment, hair loss

Maddy
Topics found: coping with treatment, breast conserving surgery or mastectomy?

Roma
Topics found: coping with treatment, breast conserving surgery or mastectomy?

Spiderdon99
Topics found: hair loss, breast conserving surgery or mastectomy?

Leonie
Topics found: hair loss, breast conserving surgery or mastectomy?

Hariette
Topics found: hair loss, breast conserving surgery or mastectomy?

Katje
Topics found: coping with treatment, hair loss

Lxxn
Topics found: coping with treatment, breast conserving surgery or mastectomy?

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Screenshot 3a: The search page of the author profile group.

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http://www.msbi.nl/verhalen/

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The Amazones

DE AMAZONES Jonge vrouwen met borstkanker

Steun de Stichting **AMAZONES**

Home | Wie zijn wij | Ervaringsverhalen

The Amazones

The Amazones

Use the form below to search for stories.

Writer profile:

age at diagnosis 20-30 years

time since diagnosis less than 1/2 a year ago

children no

partner yes

treatment received

- breast conserving therapy
- mastectomy
- radiation therapy
- chemotherapy
- hormonal therapy
- immuno therapy (herceptin)
- breast reconstruction
- lymph node dissection

phase in the course of disease in first treatment period

search Reset

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Screenshot 3b: A list of stories retrieved in the author profile group.

The Amazonas - Windows Internet Explorer

http://www.msbi.nl/verhalen/

File Edit View Favorites Tools Help

The Amazonas

DE AMAZONES Jonge vrouwen met borstkanker

Steun de Stichting AMAZONES

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The Amazonas

10 stories were found but none of the stories completely matches your search.

The number of pink ribbons (0–5) indicates to what extent a story matches with your search.

Naia 
 age at diagnosis: 31 Children: No Partner: Living together
 Treatment received: Sept 2004: breast conserving surgery left breast * Oct-Dec 2004 four AC chemo regimens * Jan-Feb 2005: radiation therapy * Jan 2005-? hormonal therapy
 Time since diagnosis: 6 months Phase in the course of disease: in first treatment period

Queensryche 
 Age at diagnosis: 36 Children: No Partner: Living together
 Treatment received: Breast conserving surgery, at this moment radiation therapy (35x) after that chemo regimens (4x AC)
 Time since diagnosis: 3 months Phase in the course of disease: in first treatment period

Jolanda 
 Age at diagnosis: 24 Children: Unknown Partner: Unknown
 Treatment received: ...underwent breast conservingsurgery...but also had many glands removed...radiation therapy...chemo regimen, six times...five years of hormonal therapy, I think...
 Time since diagnosis: 5 months Phase in the course of disease: in first treatment period

Miranda 
 Age at diagnosis: 26 Children: No Children Partner: Living together
 Treatment received: Mastectomy of left breast, lymph node dissection (5 tested positive), chemo regimen will start in January (5 cycles of FEC), Radiation and hormonal therapy will follow.
 Time since diagnosis: 2 months Phase in the course of disease: in first treatment period

Dio 
 Age at diagnosis: 34 Children: Yes - 3 Partner: Living together
 Treatment received: Breast conserving surgery, lymph node dissection and after that radiation therapy, chemotherapy, hormonal therapy.
 Time since diagnosis: 3 months Phase in the course of disease: in first treatment period

Mary 
 Age at diagnosis: 37 Children: No Partner: Married
 Treatment received: Breast conserving surgery, radiation therapy, 5 cycles of FEC, hormonal therapy. Now genetic testing.
 Time since diagnosis: 5 months Phase in the course of disease: in first treatment period

Ellen
 Age at diagnosis: 38 Children: 1 little son Partner: Gehuwd

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Screenshot 4a: The search page of the combination group.

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DE AMAZONES Jonge vrouwen met borstkanker  Stort een donatie op giro: **4340044** 

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The Amazones

The Amazones

Use the form below to search for stories.

Story topics:

Diagnosis

- feelings about diagnosis

Treatment

- decision-making about treatment
 - having no choice
 - breast conserving surgery or mastectomy?
 - adjuvant treatment or not?
 - reconstruction or not?
 - prophylactic mastectomy other breast
 - ovary removal
 - other
- coping with treatment
- treatment side effects
 - arm lymphedema
 - hair loss
 - fatigue
 - nerve pain
 - hot flashes
 - skin problems
 - other

Health care system

- delay in/errors at diagnosis
- waiting for test results
- contact with medical staff
 - support
 - lack of understanding
- how treatment was performed

Writer profile:

age at diagnosis

time since diagnosis

children

partner

treatment received

- breast conserving therapy
- mastectomy
- radiation therapy
- chemotherapy
- hormonal therapy
- immuno therapy (herceptin)
- breast reconstruction
- lymph node dissection

phase in the course of disease

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Screenshot 4b: A list of stories retrieved in the combination group.

The screenshot shows a Windows Internet Explorer browser window displaying the website 'The Amazones'. The address bar shows the URL 'http://www.msbi.nl/verhalen/'. The website header includes the logo 'DE AMAZONES' and the text 'Jonge vrouwen met borstkanker'. A donation box on the right says 'Stort een donatie op giro: 4340044'. The main content area shows search results for '10 stories were found:'. The first story is for 'Maddy', with 5 pink ribbons indicating a high match. The second story is for 'Pimmie', with 4 pink ribbons. The third is for 'Miranda', with 2 pink ribbons. The fourth is for 'Christa', with 2 pink ribbons. The fifth is for 'Genara', with 2 pink ribbons. The sixth is for 'Moise75', with 2 pink ribbons. A 'New search' button is visible in the top right of the search results area. The browser's status bar at the bottom shows 'Done', 'Local intranet', and '100%' zoom.

The Amazones - Windows Internet Explorer
http://www.msbi.nl/verhalen/

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The Amazones

DE AMAZONES Jonge vrouwen met borstkanker

Stort een donatie op giro: 4340044

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The Amazones

10 stories were found: New search

The number of pink ribbons (0–5) indicates to what extent a story matches with your search.

Maddy

Age: 30 Children: ...no kids of my own... Partner: ...my boyfriend...
Treatment received: ...sentinel node treatment was no option...breast conserving surgery...had to undergo chemotherapy... have stopped taking zoladex and tamoxifen...
Time since diagnosis: 2 years Phase in the course of disease: free of cancer
Topics found: coping with treatment , breast conserving surgery or mastectomy?

The stories below do not completely match with your search:

Pimmie

Age: 32 Children: ...my daughter... Partner: ...my boyfriend...
Treatment received: ...a breast conserving surgery...tumour was capricious and was not completely removed, mastectomy... chemo regimen...
Time since diagnosis: a few months Phase in the course of disease: in first treatment period
Topics found: coping with treatment , breast conserving surgery or mastectomy?

Miranda

Age: 26 Children: No Children Partner: Living together
Treatment received: Mastectomy of left breast, lymph node dissection (5 tested positive), chemo regimen will start in January (5 cycles of FEC), Radiation and hormonal therapy will follow.
Time since diagnosis: 2 months Phase in the course of disease: in first treatment period
Topics found: coping with treatment

Christa

Age: 28 Children: ...1 daughter... Partner: ...married...
Treatment received: ...to have a mastectomy of my whole breast...for a chemo regimen...
Time since diagnosis: 1 year Phase in the course of disease: free of cancer
Topics found: breast conserving surgery or mastectomy?

Genara

Age: 26 Children: Daughter (8) en 2 sons (2 en 1) Partner: Living together
Treatment received: Mastectomy of left breast(11/12/04) Waiting for results for adjuvant treatment.
Time since diagnosis: 1 month Phase in the course of disease: in first treatment period
Topics found: breast conserving surgery or mastectomy?

Moise75

Age: 30 Children: Nee Partner: Samenwonend

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