

Review of cancer incidence and survival statistics

Office for National Statistics

December 2012

We invite you to submit a response to this consultation by completing and returning this feedback form. Please submit responses to cancer.newport@ons.gov.uk or to:

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The closing date for receipt of responses is **Wednesday 20 February 2013**.

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Brief description of your (or your organisation's) area of interest:

Breast Cancer Campaign only funds research into breast cancer and will support research at any centre of excellence in the UK and the Republic of Ireland. The charity has a particular interest in supporting innovative research and will fund the best breast cancer research in the UK and Ireland, providing that it is of the highest quality.

Breast Cancer Care is here for anyone affected by breast cancer. We bring people together, provide information and support, and campaign for improved standards of care. We use our understanding of people's experience of breast cancer and our clinical expertise in everything we do. Visit www.breastcancercare.org.uk or call our free helpline on 0808 800 6000.

Proposal 1: The distribution of stage at diagnosis

1. How useful do you feel this item would be? Please indicate your answer using the scale below.

Very useful

Neither

Not at all useful

1

2

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2. Please provide reasons for your assessment of how useful the item would be.

There is currently no regularly published information regarding distribution of stage at diagnosis for breast cancer in the UK. Yet, it is acknowledged that understanding stage of diagnosis contributes to our knowledge of the success of both treatments and also effectiveness of early diagnosis measures. Therefore, Proposal 1 is a key indicator for measuring performance of both public health but also the effectiveness of cancer services.

An issue to consider for breast cancer is what marker of stage to collect, as two markers of stage are in use – one is the classical stage numbering system indicating how big the tumour is and whether it has spread, with stage 1 (early) through to stage 3 (advanced/metastatic). Another commonly used system for breast cancer is the Nottingham Prognostic Index (NPI), which takes into account both stage as above and 'grade', which is a measure of how different the cells in the tumour look from normal breast cells, from grade 1 (cells look similar to normal cells) to grade 4 (cells look the least like normal cells).

The Association of Breast Surgery (ABS) annual audits (e.g. <http://www.cancerscreening.nhs.uk/breastscreen/publications/ba10-11.html>) provide information about screen-detected breast cancer regarding tumour size, grade, lymph node status, and NPI.

3. Do you believe that this item will help inform policy?

Yes

No

4. Please provide reasons for your assessment of whether the item will help inform policy or not.

Information on stage at diagnosis supports the focus on improving outcomes that the Government is committed to. The Public Health Outcomes Framework has an indicator relating to cancers diagnosed at stage 1 and 2, so it is therefore vital that information on stage is collected in order to report on performance against this indicator- the data would have to be available at CCG and local authority level however to be of maximum benefit. Additionally, staging information is useful for understanding the impact public health measures have had.

5. Do you have any concerns about the proposed new item?

Yes

No

6. If so, please indicate what these concerns are.

No concerns but in addition to the issue of NPI, we also believe information should be available when women have subsequently been diagnosed with recurrent or secondary breast cancer and other cancers. The report from a pilot study in 2011 of data collection about people with recurrent or secondary breast cancer from NCIN and Breast Cancer Care showed that information about the vast majority of these patients is already being collected (<http://www.ncin.org.uk/view.aspx?rid=1043>). However, one of the concerns raised by the report was the incompleteness of the data available, even though all data should be collected through the National Cancer Waiting Times Monitoring Dataset (NCWTMDS) which has been a mandatory requirement since 2009.

As stage is not collected uniformly across the country, it will be important to take this into account when collecting the information and to ensure that information published is of sufficient comparability and quality and that it is available at CCG and local authority level.

Proposal 2: Incidence by demographic factors such as deprivation, ethnic group or occupation

1. How useful do you feel this item would be? Please indicate your answer using the scale below.

Very useful		Neither		Not at all useful
1	2	3	4	5

2. Please provide reasons for your assessment of how useful the item would be.

While demographic differences in breast cancer incidence/treatment/survival have previously been identified, including in the All Breast Cancer reports, regular publication by the ONS of incidence and demographic figures would support activity to address these differences and plan services appropriately.

Deprivation
While there are various individual reports concerning breast cancer and deprivation (such as <http://www.ons.gov.uk/ons/rel/hsg/health-statistics-quarterly/no--36--winter-2007/trends-in-cancer-incidence-by-deprivation--england-and-wales--1990-2002.pdf> and <http://www.ncin.org.uk/view.aspx?rid=73>, and http://www.ncin.org.uk/publications/data_briefings/breast_cancer_deprivation.aspx), there is no regularly published information on this. Breast cancer is one of only a few cancers where the incidence *increases* with increasing affluence – usually the reverse is true.

Ethnicity
Statistics regarding breast cancer and ethnicity are not currently published regularly, although there are statistics available in both the ‘All Breast Cancer’ reports and via NCIN. The examples of differences in incidence that have previously been identified include:

“In patients of known White ethnicity, only 19% of breast cancers were diagnosed under the age of 50, compared with 49% in those of known to be Black and 31-35% in those of known to be Chinese or Asian. Conversely, 27% of cancers in patients known to be White were diagnosed in those aged over 70 compared with only 7-10% of those known to be Asian, Black, or Chinese” (first All Breast Cancer report)

Occupation
As far as we are aware, there is no regularly published information on cancer incidence by occupation, but there are a few individual academic papers published, e.g <http://www.ncbi.nlm.nih.gov/pubmed/19925375>

3. Do you believe that this item will help inform policy?

Yes	<input checked="" type="checkbox"/>
No	<input type="checkbox"/>

4. Please provide reasons for your assessment of whether the item will help inform policy or not.

Given the Government's commitment to addressing inequalities, ensuring information on demographic factors and incidence is regularly available is vital. This information should support CCGs to appropriately plan and commission services for their communities and so maximise the usefulness of the data, local geographic breakdowns should be provided too.

5. Do you have any concerns about the proposed new item?

Yes

No

6. If so, please indicate what these concerns are.

Proposal 4: The proportion of patients who receive different types of treatment

1. How useful do you feel this item would be? Please indicate your answer using the scale below.

Very useful

Neither

Not at all useful

1

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2. Please provide reasons for your assessment of how useful the item would be.

Information on treatments is extremely useful but it needs to be understood in the context of stage of diagnosis, If this information were available at a sub-national level and alongside demographic information it would also increase its usefulness.

Information on which treatments patients receive in England is currently available in the Hospital Episode Statistics (HES): <http://www.ic.nhs.uk/hes> and each procedure has a specific code, and the data available provides all the procedures performed for each code, regardless of which disease they were used to treat. Data can be obtained on procedures performed for a given primary diagnosis (e.g. breast cancer), but this involves a data request.

Some treatment information about screen-detected breast cancer in the UK is also provided by the Association of Breast Surgery (ABS) annual audits (for example: <http://www.cancerscreening.nhs.uk/breastscreen/publications/ba10-11.html>), which provides some information about the proportion of patients who receive different types of surgery (i.e. full or partial mastectomy) and subsequent reconstruction, as well as some information about neo-adjuvant therapy, and adjuvant therapy following surgery (radiotherapy, chemotherapy & endocrine therapy).

3. Do you believe that this item will help inform policy?

Yes

x

No

4. Please provide reasons for your assessment of whether the item will help inform policy or not.

Information on access to treatments should support improving performance and understanding variation.

5. Do you have any concerns about the proposed new item?

Yes

x

No

6. If so, please indicate what these concerns are.

We would be concerned if this information was produced without accompanying narrative and explanation. Information on treatments is extremely useful but it needs to be understood in the context of stage of diagnosis, If this information were available at a sub-national level and alongside demographic information it would also increase its usefulness.

Further detail on treatment types would also be required for breast cancer, for example, if one treatment was 'surgery', would further detail on whether this is a mastectomy or lumpectomy be available? The specifics of treatment subtype and the usefulness of this needs to be assessed more fully during development of this output,

Proposal 5: The distribution of treatment type by stage at diagnosis

1. How useful do you feel this item would be? Please indicate your answer using the scale below.

Very useful

Neither

Not at all useful

1

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2. Please provide reasons for your assessment of how useful the item would be.

At present there is limited, regular information available in this area. The Association of Breast Surgery (ABS) reports do provide some information in relation to screen detected breast cancers on surgery performed based on size of tumour, and whether it is invasive or non-invasive. The ABS reports also provide information about neo-adjuvant therapy based on grade and size, invasive/non-invasive, but not on stage. Adjuvant therapy is provided based on invasive/non-invasive.

Understanding treatments offered alongside stage of diagnosis would be more useful than treatments alone. However, to maximise the value of this, information should be provided alongside other factors such as geography and demographics

3. Do you believe that this item will help inform policy?

Yes

No

4. Please provide reasons for your assessment of whether the item will help inform policy or not.

Regularly published and clearly available information in this area would increase transparency on activity and services across the country. However, to maximise the value of this, information should be provided alongside other factors such as geography and demographics, e.g. information on age alongside this data would provide further knowledge and understanding of age inequality issues that exist.

5. Do you have any concerns about the proposed new item?

Yes

No

6. If so, please indicate what these concerns are.



Proposal 6: The distribution of treatment type by demographic factors such as age, sex, deprivation, ethnic group and occupation

1. How useful do you feel this item would be? Please indicate your answer using the scale below.

Very useful		Neither		Not at all useful
1	2	3	4	5

2. Please provide reasons for your assessment of how useful the item would be.

Information available in this area could provide insights into potential inequalities that exist, however, knowing stage of diagnosis alongside this information would provide a much more accurate impression of why certain treatments are offered and where there may be concerns.

3. Do you believe that this item will help inform policy?

Yes	<input checked="" type="checkbox"/>
No	<input type="checkbox"/>

4. Please provide reasons for your assessment of whether the item will help inform policy or not.

Addressing inequalities in treatments for older people has been recognised as a vital issue and the All Party Parliamentary Group on Breast Cancer is currently undertaking an inquiry on this issue. Considerable research has shown there are issues relating to different treatments, e.g. access to surgery and age, for some time. The Breast Cancer Quality Standard includes the following statement “People with early invasive breast cancer, irrespective of age, are offered surgery, radiotherapy and appropriate systemic therapy, unless significant comorbidity precludes it”, therefore, tracking the proportion of treatments by age group would provide information to monitor this.

5. Do you have any concerns about the proposed new item?

Yes	<input type="checkbox"/>
No	<input type="checkbox"/>

6. If so, please indicate what these concerns are.

To fully understand reasons behind variations in treatment the data should be standardised in some way to allow comparisons. Alongside the data should be an interpretive discussion that explores the reasons for variations, ideally additional analysis which takes into account clinically relevant differences in treatment practice should be complete for this output.

Proposal 7: Survival by stage at diagnosis

1. How useful do you feel this item would be? Please indicate your answer using the scale below.

Very useful

Neither

Not at all useful

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2. Please provide reasons for your assessment of how useful the item would be.

This will highlight potential inequalities in survival. This item will be more useful if it is understood in the context of other factors to make it of more practical value.

3. Do you believe that this item will help inform policy?

Yes

No

4. Please provide reasons for your assessment of whether the item will help inform policy or not.

This will add to the proxy evidence to support the importance of early diagnosis in relation to survival and highlight the cancer types where early diagnosis makes the biggest impact on survival. This output will inform the government agenda to save 5,000 lives per year by 2014/15 by improving cancer survival. This output will also feed in to national strategy emerging from Domain 1 of the NHS Commissioning Board.

5. Do you have any concerns about the proposed new item?

Yes

No

6. If so, please indicate what these concerns are.

Proposal 8: Survival by type of treatment

1. How useful do you feel this item would be? Please indicate your answer using the scale below.

Very useful

Neither

Not at all useful

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2. Please provide reasons for your assessment of how useful the item would be.

While understanding survival by type of treatment is important, there are a number of issues to consider alongside this to ensure that this does not create confusion, including:

- What was the stage at diagnosis?
- What is the range of treatments people received?
- Is someone being treated for recurrent or metastatic breast cancer?

Clinical relevance of the outcomes may be lost without more detailed analyses.

3. Do you believe that this item will help inform policy?

Yes

No

4. Please provide reasons for your assessment of whether the item will help inform policy or not.

5. Do you have any concerns about the proposed new item?

Yes

No

6. If so, please indicate what these concerns are.

Proposal 9: Survival by stage at diagnosis and type of treatment

1. How useful do you feel this item would be? Please indicate your answer using the scale below.

Very useful

Neither

Not at all useful

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2. Please provide reasons for your assessment of how useful the item would be.

This will highlight potential inequalities in survival. This item will be more useful if it is understood in the context of other factors to make it of more practical value.

3. Do you believe that this item will help inform policy?

Yes

No

4. Please provide reasons for your assessment of whether the item will help inform policy or not.

This will add to the proxy evidence to support the importance of early diagnosis in relation to survival and highlight the cancer types that early diagnosis makes the biggest impact on survival. This output will inform the government agenda to save 5,000 lives per year by 2014/15 by improving cancer survival. This output will also feed in to national strategy emerging from Domain 1 of the NHS Commissioning Board.

Gathering stage and treatment in combination should contribute to an understanding of whether differences are clinically appropriate or not but will not give a complete picture of the complexity of factors contributing to different outcomes.

5. Do you have any concerns about the proposed new item?

Yes

No

6. If so, please indicate what these concerns are.

Proposal 10: Survival by demographic factors such as deprivation, ethnic group and occupation

1. How useful do you feel this item would be? Please indicate your answer using the scale below.

Very useful

Neither

Not at all useful

1

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2. Please provide reasons for your assessment of how useful the item would be.

This will highlight potential inequalities in survival. This item will be more useful if it is understood in a geographical context too.

3. Do you believe that this item will help inform policy?

Yes

No

4. Please provide reasons for your assessment of whether the item will help inform policy or not.

5. Do you have any concerns about the proposed new item?

Yes

No

6. If so, please indicate what these concerns are.

General questions

1. Please rate the proposed new incidence and treatment related items in order of importance, where one equals most important and six equals least important.

Distribution of stage at diagnosis	<input type="text" value="1"/>
Incidence by demographic factors such as deprivation, ethnic group or occupation	<input type="text"/>
The proportion of patients who receive different types of treatment	<input type="text"/>
The distribution of treatment type by stage at diagnosis	<input type="text" value="3"/>
The distribution of treatment type by demographic factors such as age, sex, deprivation, ethnicity and occupation	<input type="text"/>
Incidence at a sub-national level, for example by local authority or clinical commissioning group	<input type="text" value="2"/>

2. Please rate the proposed new survival related items in order of importance, where one equals most important and four equals least important.

Survival by stage at diagnosis	<input type="text" value="3"/>
Survival by type of treatment	<input type="text" value="4"/>
Survival by stage at diagnosis and type of treatment	<input type="text" value="2"/>
Survival by demographic factors such as deprivation, ethnicity and occupation	<input type="text" value="1"/>

3. Please indicate if there are any other items that you have a requirement for in addition to those identified in the consultation document.

- Numbers of women with recurrent or secondary breast cancer and where appropriate, information provided on this. As well as wider consideration to the production of outputs for recurrence and secondary cancers
- Survival information is currently provided on a regular basis for one and five years for breast cancer but consideration should now be given to looking at 10 year survival figures.
- Should further consideration to cancer variation within certain cancers be considered, e.g. breast cancer? This could be particularly relevant for some indicators such as treatment.
- Distribution of treatment type at a sub-national level, e.g. LA or CCG level

4. Please indicate why you have a requirement for these items, and what you would use them for.

- While information is starting to be collected on the numbers of women with secondary breast cancer, understanding more on the number of women living with secondary breast cancer is essential for planning services and support.

5. Please provide any additional comments that are relevant to this consultation.

We support the development of national statistics and highly value the national statistics badge and

the independence, robustness and regularity of national statistics products.

We believe that some of the statistics proposed are complex and that it is important that quality of data is always robust and credible. Additionally, we believe that consideration should be given to what narrative is provided in relation to the data to ensure that variations highlighted are real, reasons for variations are explored, and to minimise the impact of confounding factors. This is particularly relevant for outputs where treatment type is a variable.

The NCIN also provides considerable information on cancer statistics and ensuring consistency between information provided by ONS and NCIN is important. Ensuring that the split and consistency between what the NCIN provides and what the ONS provides will be key. We have responded to this consultation by commenting on where information could usefully be provided on a national, regular basis and have not attempted to consider the issues that might arise as a result of a division of responsibilities.

Thank you for taking the time to respond to this consultation.