Vulval Cancer Relative Survival:

Basic Information	
1. What is being measured?	The relative survival of vulval cancer, ICD-10 C51
2. Why is it being measured?	Surveillance of variation and trends
3. How is the indicator defined?	Defined as either the one-year, three-year or five-year relative survival rate of patients with vulval cancer in a given cohort Cancer site is coded according to the International Classification of Diseases, Edition 10 (ICD10) Survival data are provided via the regional Cancer Registries who collect data relating to each new diagnosis of cancer that occurs in their resident populations. This does not include secondary cancers or recurrences. Cancer Registries follow up each case to ascertain date of death Data are reported according to the calendar year in which the cancer was diagnosed and followed up for either 1, 3 or 5 years after diagnosis.
4. Who does it measure?	It measures the relative survival rate in women of all ages
5. When does it measure it?	Cancer Network level - One-year relative survival – 5 year cohorts – 2000-2004 to 2005-2009 - three-year - 5 year cohorts – 2000-2004 to 2003-2007 - five-year – 5 year cohorts – 2000-2004 to 2001-2005. Followed up to 2010.
6. Does it measure absolute numbers, proportions or rates?	Relative survival is defined as the observed survival rate divided by the expected survival rate of a similar cohort of people in the general population with respect to age, sex and year of observation.
7. Where does the data come from?	The data is taken from the UK Cancer Information Service (UKCIS) which contains all registration data from the English cancer registries as well as from the Scottish, Welsh and Northern Irish registries.
8. How accurate and complete are the data?	The eight National Cancer Registration Service regional offices collect, on a voluntary basis, data on cancers registered to residents of their areas. These data are loaded onto the database and validated. The extensive checks include the comparability of the cancer site and associated histology, consistency of dates, for example to check that the incidence date is not after the date of death. These checks are closely based on those promulgated by the International Agency for Research on Cancer (IARC). Once all the expected records for any one incidence year have been received and validated at Office of National Statistics (ONS), detailed tables are published on the numbers and rates of all types of cancer by age and sex, and by region of residence, as presented in the annual ONS publication MB1. Please visit http://www.ons.gov.uk to view

	MB1 reports for further details of the completion of registration each year. At the time of extraction of the data for use in the survival analysis, the vital status, whether alive, dead or not traced, should be known for almost 100% of the tumour records.
9. Are there any caveats/ problems/ weaknesses?	See link in note 8, above There are several different methods of calculating relative survival and not all cases are eligible for inclusion in the survival analyses. These differences may cause discrepancies with relative survival rates presented in other publications.
10. What methods are used to test the meaning of the data and variation?	**Lower and Upper Confidence Limits (LCL and UCL):** Confidence intervals are a way of expressing how certain we are about a figure, such as an estimated cancer survival rate. All CIs in this tool have been calculated at the 95% level of statistical significance and thus define a 95% chance that the interval contains the true value. When comparing the rates of different groups, the CIs can be compared to determine if the range of values overlap. If the CIs do not overlap then the difference between the rates is said to be statistically significant. Example of interpretation: Areas are said to have a statistically significantly higher or lower than expected relative survival rate. **Area Profile:** Spine Chart: The area profile presents a spine chart which allows a comparison of the local value (represented by a circle) against the national average (represented by a red line in the middle of the chart) and regional average (where available, represented by a diamond), but also where the local area lies in relation to the range of values for all the other local areas. The darker grey shading of the bar represents the 25th to 75th percentile of the range of values. Map: The map is coloured according to whether the rate is statistically significantly higher or lower than the England average, higher/lower than the national average but not significantly so and the same as the national average. The statistical significance tested by the CIs is different to the method described below for funnel plots and may present the same area differently in terms of statistical significance when compared to the national average. Example interpretation: The symbol in the spine chart is green (better) when survival from vulval cancer is statistically significantly higher than the England average; or red

	(worse) when survival is statistically significantly lower than the England average. Statistical significance is to the 95% confidence level. The symbol is orange when the relative survival rate for vulval cancer is not statistically significantly different to the national average. **Funnel Plot:** Funnel plots have become a preferred method of presenting comparisons between geographical areas or institutions in public health. This is opposed to the more conventional use of 'caterpillar' plots which visually imply a ranking of areas based on good or bad performance. In any process or system, variation is to be expected; the funnel plot approach makes it easier to identify which data points indicate areas that may be worthy of further investigation. Simple statistical methods are used to define limits of expected variation known as control limits. The group average is used as the estimate of expected 'performance' and the best estimate of expected variation around this average is both/either ± 2 standard deviations (SDs), equivalent to 95% confidence intervals, and/or ± 3 SDs, equivalent to 99.8% confidence intervals. Those areas that fall outside of these control limits are deemed to be statistically significantly different from the group average. More information on funnel plot methodology can be found in the following references: Spiegelhalter DJ, 2005. Funnel plots for comparing institutional performance. Statistics in Medicine, 24: 1185-1202. Association of Public Health Observatories (APHO), 2009. Statistical Process Control Methods in Public Health Intelligence, Technical Briefing no. 2, Available at http://www.apho.org.uk/resource/item.aspx?RID=39445 Map: The map is coloured according to where the areas fall relative to the 2 and 3 standard deviation funnels. Example of interpretation: Areas where vulval cancer survival rates are statistically significantly higher (better) than the England average fall below the horizontal green line (national average) and outside of the funnels. Those areas where survival is statistically significantly lower (worse) than the national average fall outside of the funnels above the horizontal line. Areas where the survival rate is not statistically significant fall inside the inner funnel around the horizontal line. Those areas that fall outside of the funnels in the funnel plots may require further investigation into the reasons for the statistically significantly low or high survival rates. Particular attention should be paid to those areas falling outside both funnels.

	Double map: Scatter Plot: The double map option displays a scatter plot of the association between the two chosen rates e.g. vulval cancer survival and deprivation. The correlation coefficient (r) statistic displayed at the top of the scatter plot is Pearson's correlation coefficient, often called the correlation. It measures the degree of 'straight-line' association between the two indicators and can take any value between -1 (perfect negative correlation) and 1 (perfect positive correlation). A value of zero indicates no correlation. Map: In the map, the range of values for survival is split into five groups (quintiles), and not according to statistical significance. Interpretation: The double map option displays a scatter plot of the association between the two chosen rates e.g. vulval cancer survival and deprivation. The correlation coefficient (r) statistic displayed at the top of the scatter plot is Pearson's correlation coefficient, often called the correlation. It measures the degree of 'straight-line' association between the two indicators and can take any value between -1 (perfect negative correlation) and 1 (perfect positive correlation). A value of zero indicates no correlation. If all the points lie very close to the straight line on a slope indicating, that as one variable increases (or decreases) the other increases (or decreases), then it can be said that there is a strong association between the two indicators. If the points are more scattered, but still in a straight line, would indicate that there is a weaker relationship. Interpretation of the relationship between two indicators should be made carefully; it does not mean there is a 'causal' relationship between the two indicators. **Single map:** Map: The map is coloured according to whether the rate is statistically significantly higher or lower than the England average, higher/lower than the national average but not significantly so and the same as the national average as based on comparison of confidence intervals. Time Series: The time series animation allows the user to view how the map changes for each indicator that has time series data, according to whether the rates are statistically significantly different or not.

11. Geography provided in this toolkit	Since April 2013 the NHS health boundaries for Primary Care Trusts, Cancer Networks and Strategic Health Authorities have been become non-operational and have been replaced by other organisational structures responsible for the commissioning and performance management of cancer services, namely Clinical Commissioning Groups, Local Area Teams and Strategic Clinical Networks. However, in the absence of established boundaries and available data for these new organisations we have only been able to present sub-national data for the old organisations. The old organisations still retain some currency and relevance to the commissioning and public health structures as redefined and this is explained below: PCTs Many PCTs are coterminous with the Clinical Commissioning Groups and therefore statistics at PCT level for these CCGs will still be largely relevant. Cancer Networks Cancer Networks were formed in order to oversee and organise the local implementation of the Cancer Plan and Cancer Reform Strategy for the areas within their jurisdiction. There were 28 Cancer Networks in England which have now been replaced by 12 Strategic Clinical Networks which will provide support to cancer networks 'nesting' within their boundary. In consultation with the Gynaecological Site Specific Reference Group (SSCRG) it was decided that cancer network levels figures would be carried forward in the absence of any other relevant boundary, particularly as this will provide data for on-going peer review and whether improvements are being made over time. NHS Strategic Health Authorities (SHA) Strategic Health Authority data is available for the incidence, mortality and survival data. However, these organisation no longer exist and the figures serve to provide a regional comparison in the absence of any other available data at present. The values for the SHAs can be seen by toggling the map and comparison button on each map. In the health profile, the regional value is shown as a grey diamond. Some cancer networks cross over more than one SHA boundary, the regional average is used for each cancer network and PCT where the majority of the area resides. However, when filtering in the, single, double and health profile map, the cancer networks that have a significant area falling within the boundary of the SHA are shown. The SHAs can be highlighted on the map by ticking the box in the legend. The borders will then be highlight in red.
12. Further data availability	The UKCIS holds a more extensive dataset and can be accessed via NHSnet only. If you wish to request a login for the UKCIS please visit your regional cancer registry website. • Northern and Yorkshire Cancer Registry and Information Service (www.nycris.nhs.uk)

	• North West Cancer Intelligence Service (www.nwcis.nhs.uk) • Trent Cancer Registry (http://www.empho.org.uk/tcr/aboutUs.aspx) • West Midlands Cancer Intelligence Unit (www.wmpho.org.uk/wmciu) • Eastern Cancer Registration and Information Centre (www.ecric.nhs.uk) • Oxford Cancer Intelligence Unit (www.ociu.nhs.uk) • Thames Cancer Registry (www.tcr.org.uk) • South West Cancer Intelligence Service (www.swpho.nhs.uk)
13. Frequency/ timeliness of data updates	At present the latest survival year is earlier than the current year. Registries are working to reduce this delay to ensure the improved timeliness of publications.
14. Disclosure control	Rates are suppressed when they are based on fewer than 10 deaths in a cohort.
15. Rationale for inclusion	Surveillance of variation and trends in the survival from vulval cancer allows health care professionals to identify areas where survival is poorer and may be improved. One-year survival is generally taken as a proxy for stage of disease at diagnosis whilst longer term survival may be taken as an indication of the success of treatment. Measuring relative survival may be useful in informing policy or new interventions to help improve the survival chances of cancer patients.
16. Technical details	Methods of calculating relative survival: In the UKCIS, the actuarial method of calculating relative survival is used (D.M. Parkin and T. Hakulinen, pp159-176, Chapter 12 Analysis of Survival in Cancer Registration: Principles and Methods, IARC Scientific Publications No. 95, Lyon, 1991). This method is also used by the International Agency for Research on Cancer in the EUROCARE and EUROCARE-2 studies (IARC Scientific Publications No. 132, Lyon, 1995 and No. 151, Lyon, 1999, respectively). An alternative method of calculating relative survival is to use a non-proportional hazards model, such as that used by the Office for National Statistics (Cancer Survival Trends in England and Wales 1971-1995, Series SMPS No. 61, The Stationery Office: London, 1999). Warning: Differences in relative survival methods or exclusion criteria may cause discrepancies with relative survival rates presented in other publications. For these reasons, relative survival rates should not be

	compared across different publications (for example, survival rates presented in the UKCIS should not be compared with survival rates published by the Office for National Statistics). Eligibility for inclusion in the relative survival analyses: The following cases have been excluded from the relative survival analyses in the UKCIS: - Cases where the date of diagnosis is the same as the date of death (mainly Death Certificate Only cases) - Cases with incomplete dates (such as unknown month of diagnosis or death) - Cases aged over 99 at diagnosis