

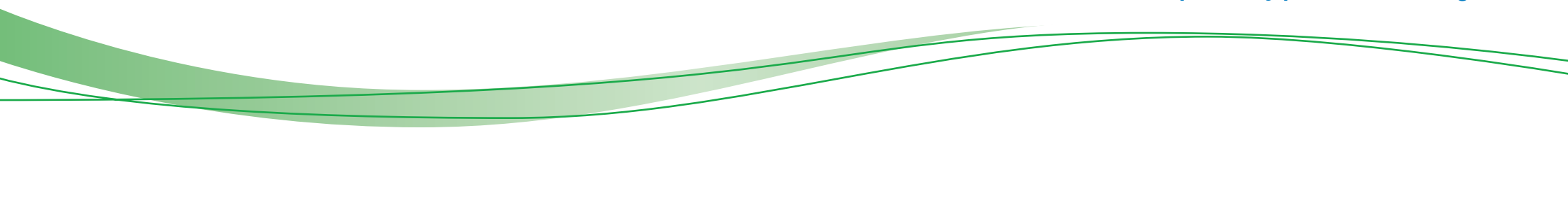
Cancer decision making:

turning data into intelligence

This guide has been developed collaboratively by Anglia Cancer Network, Cancer Research UK, Merseyside & Cheshire Cancer Network, Mount Vernon Cancer Network, North Trent Cancer Network, North East London Cancer Network and Roche Products Limited. Roche supported this joint working project by providing project management, facilitation and artwork resource.

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Introduction

This is an electronic guidance document to help assist users when using data (e.g. Cancer Commissioning Toolkit and Cancer Commissioning Guidance) to guide decisions and investigations.

Health service organisations are tasked with delivering health objectives and targets by prioritising resources according to need, both at the national and local level. Rational prioritisation should rely intrinsically on evaluation of data to identify areas for improvement.

Objectives

This guide is intended to provide a practical framework, incorporating key considerations, for the use of cancer data to inform health planning and decision making.

Who will use this guide?

Anyone or any team involved in supporting:

- commissioning
- service improvement
- Primary Care Trusts (PCTs) and Cancer Networks (CNs) in achieving cancer targets

The guide is divided into sections providing guidance on: understanding data, problem identification, action planning for change and working with stakeholders, embedding and sustaining change, and monitoring and evaluation. Case studies as practical examples of data use in decision making are also provided, along with a summary of Top 10 tactics for effective use of data to drive change.

Several factors are key to optimal data use in decision making

- A clear understanding of the value of different datasets and their limitations
- Translation of data into information and intelligence to make the data locally relevant and applicable
- Integration of data into strategic health improvement plans.

[Click here](#) to see how data can be used to make change happen.

The guide addresses several key questions: *What do we use the data for? How do we use the data? Who will use it? Who are the key influencers?*

Data can be used to inform all steps of the Health Service decision-making process, including

1. *prioritisation of areas for improvement*
2. *strategy development*
3. *commissioning services*
4. *monitoring of commissioned services*
5. *evaluation of providers / service model*
6. *change management*

Which stakeholders are actively involved depends on the step – the important thing is to involve all those from whom you need a behavioural change (e.g. clinicians), or who are key influencers.

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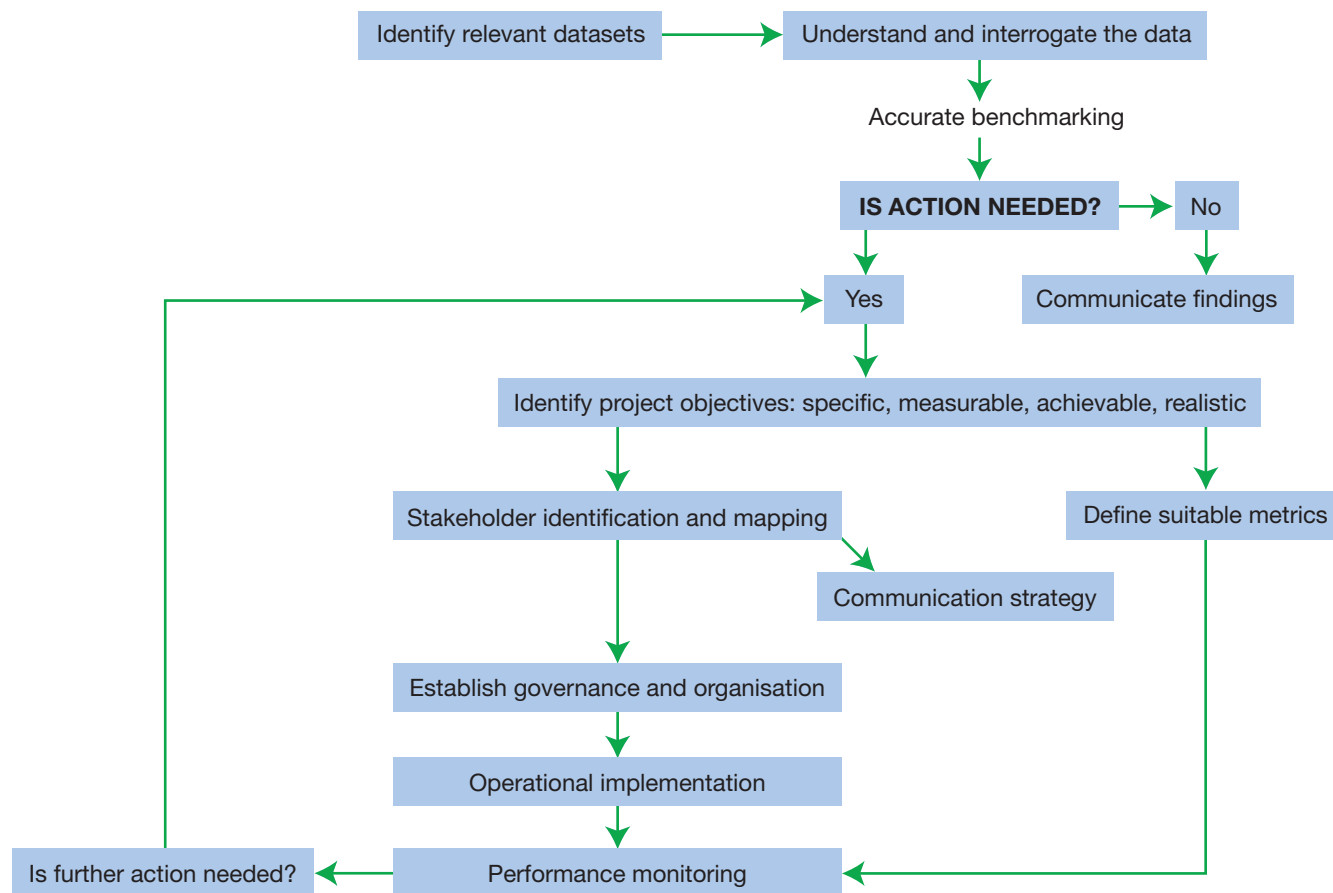
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Using data to make change happen

[Click here](#) to access a checklist for using data to diagnose focus areas



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Checklist for using data to diagnose focus areas

1. What is the local burden of disease?

- Undertake benchmarking against national, regional area and other cancer networks and Primary Care Trusts (PCTs).
- Look at **trends** (against targets) for **incidence**, **mortality** and **survival**. Looking at mortality rates in isolation can gloss over an underlying issue: question whether the mortality is as expected given the local incidence.

2. Are some groups more affected than others, i.e. are there health equity issues?

- Look at sub-groups of the local population, what is the survival by age, sex, ethnicity, deprivation?

3. Risk factors for cancer prevalence?

- What are the prevalence rates and trends for lifestyle and behavioural risk factors?

4. What is the current cost and PCT spend on cancer services?

- PCT and Cancer Network Programme Budgeting spend can be benchmarked against suitable comparator areas

5. Service provision against standards [NICE Improving Outcomes Guidance (IOG)]

- Consider both early diagnosis and treatment standards

6. Performance against standards

- For example waiting times (2-week wait, 31-day and 62-day waits), screening uptake, survival consensus targets

7. Patient satisfaction

- Data from national or local patient satisfaction surveys can be used to identify areas where change is needed

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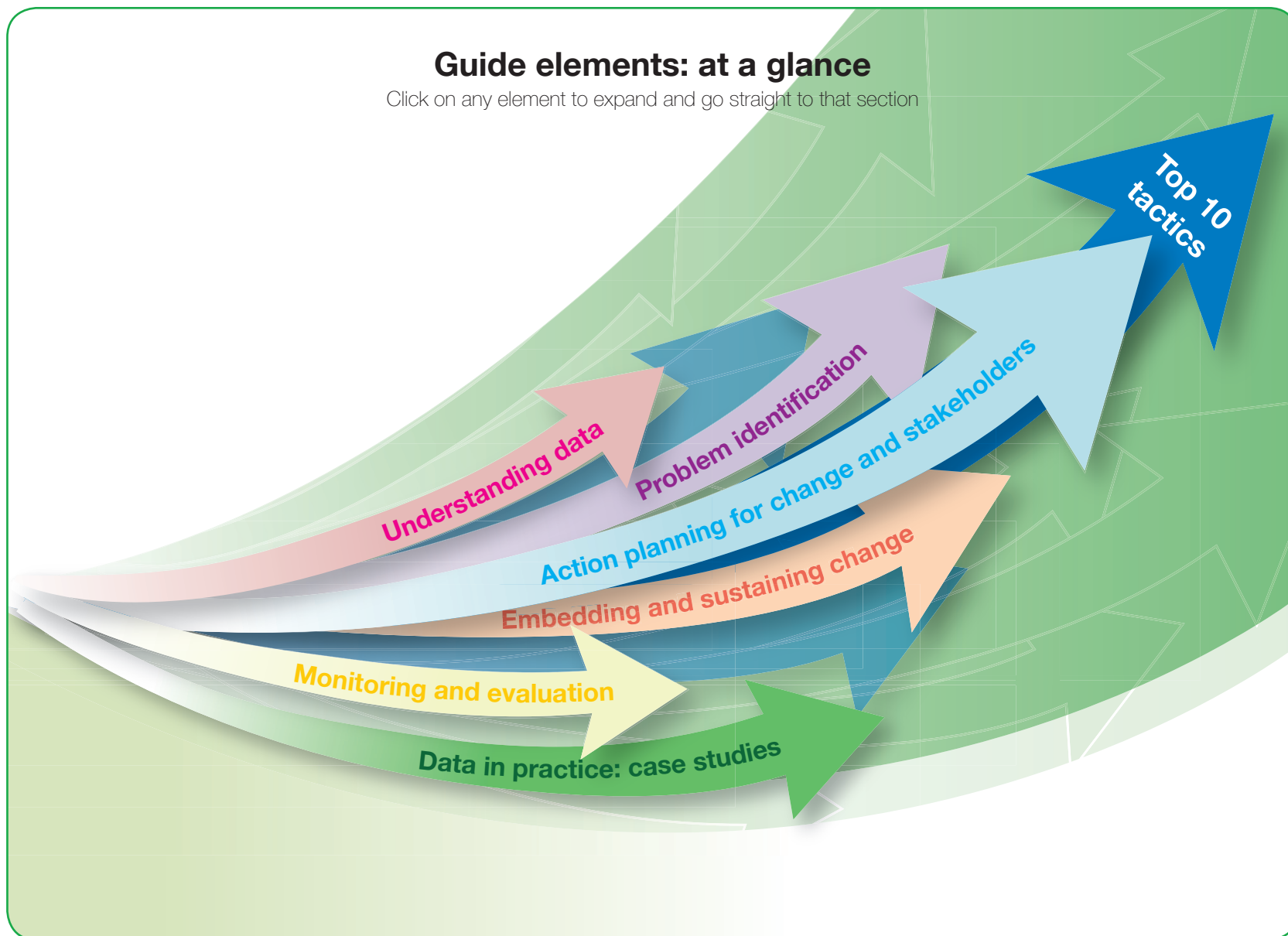
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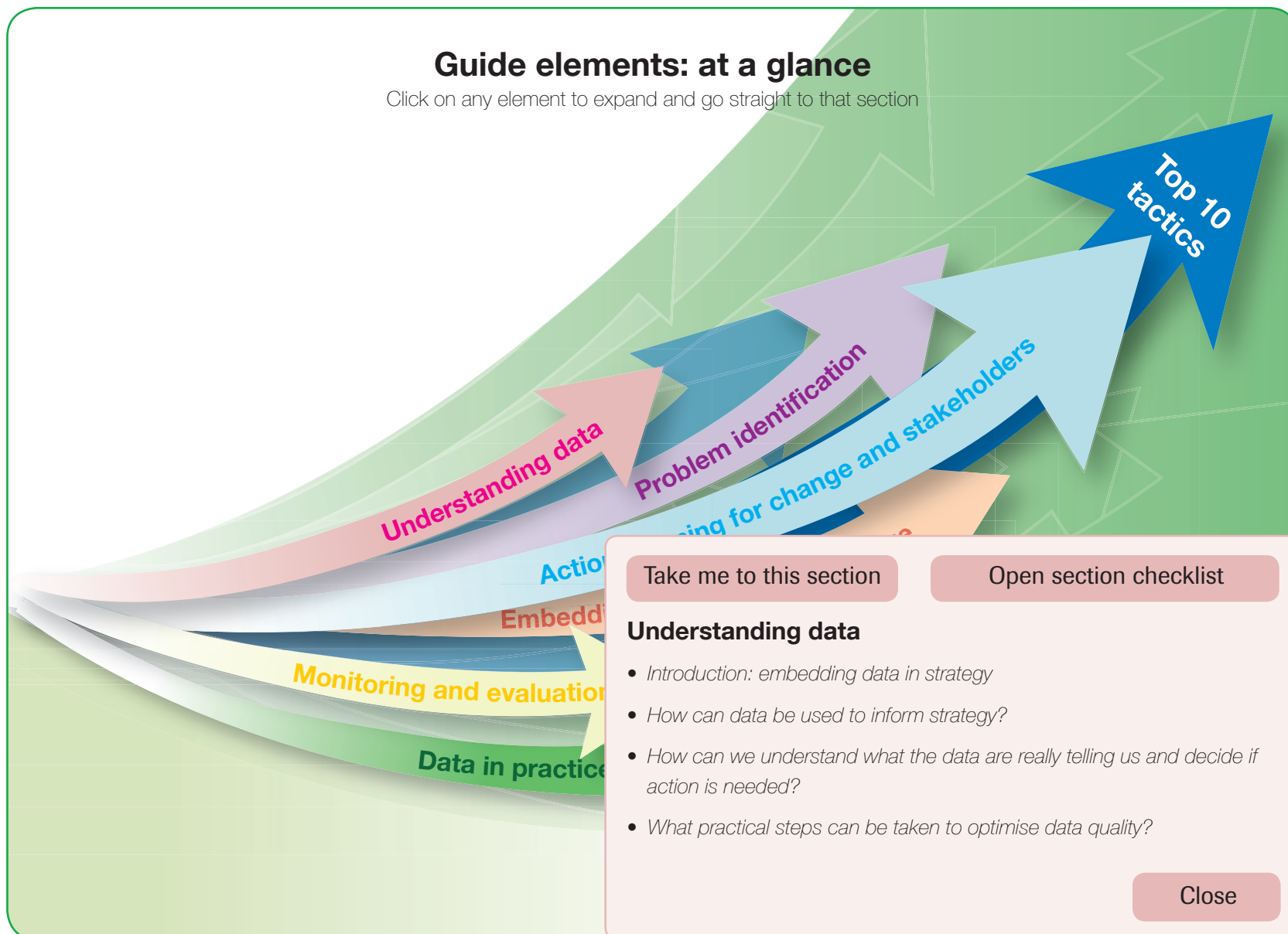
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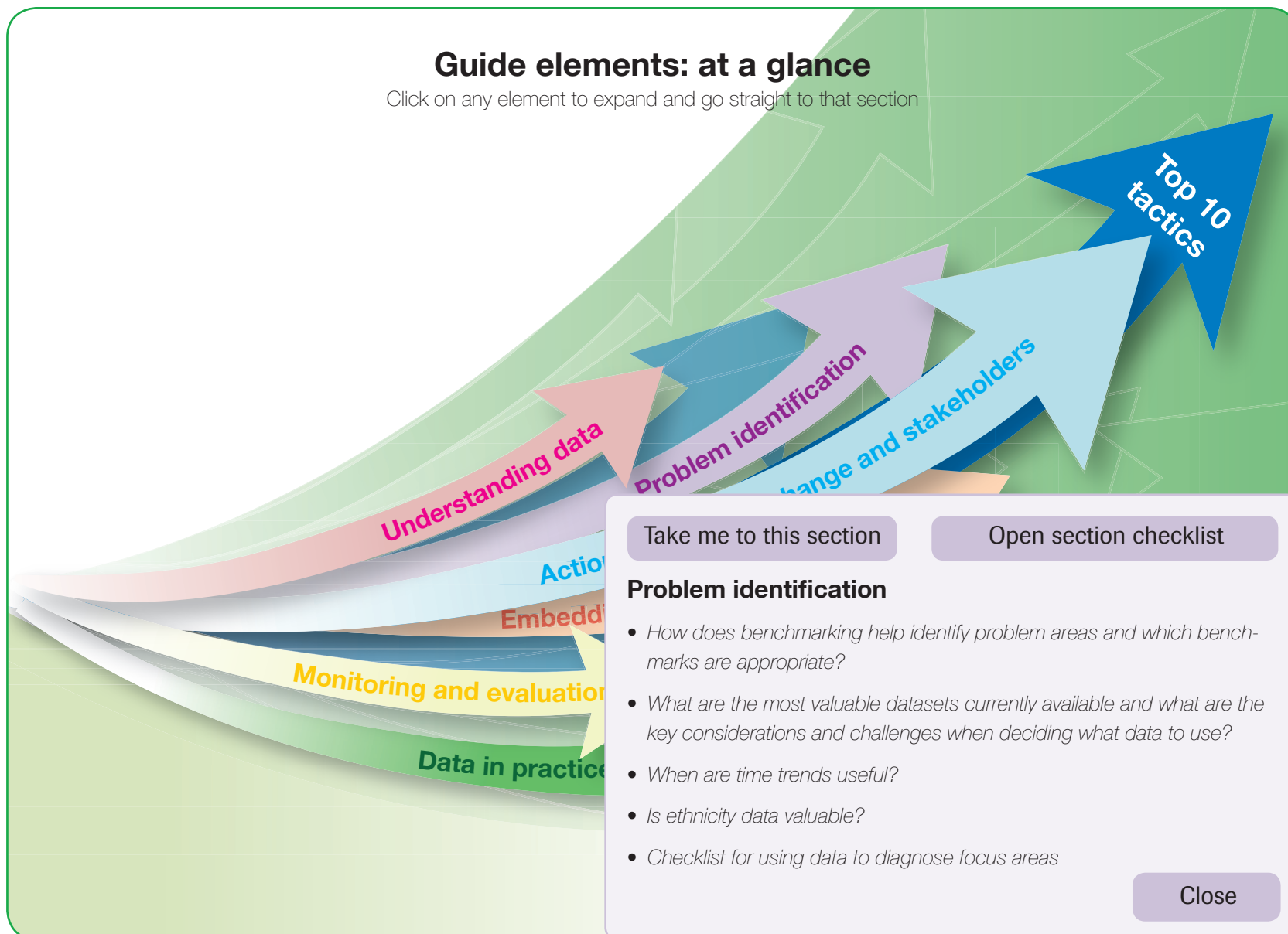
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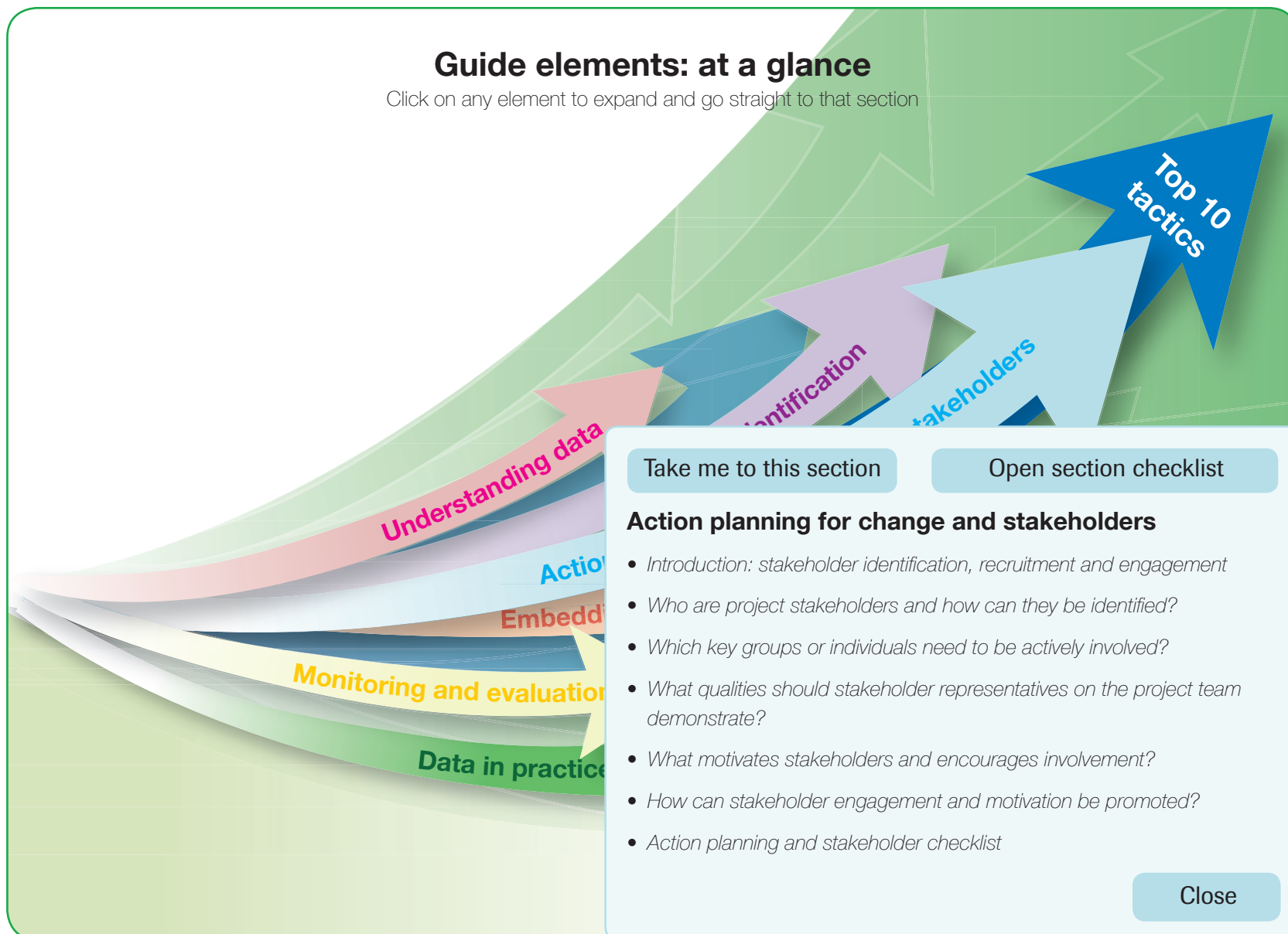
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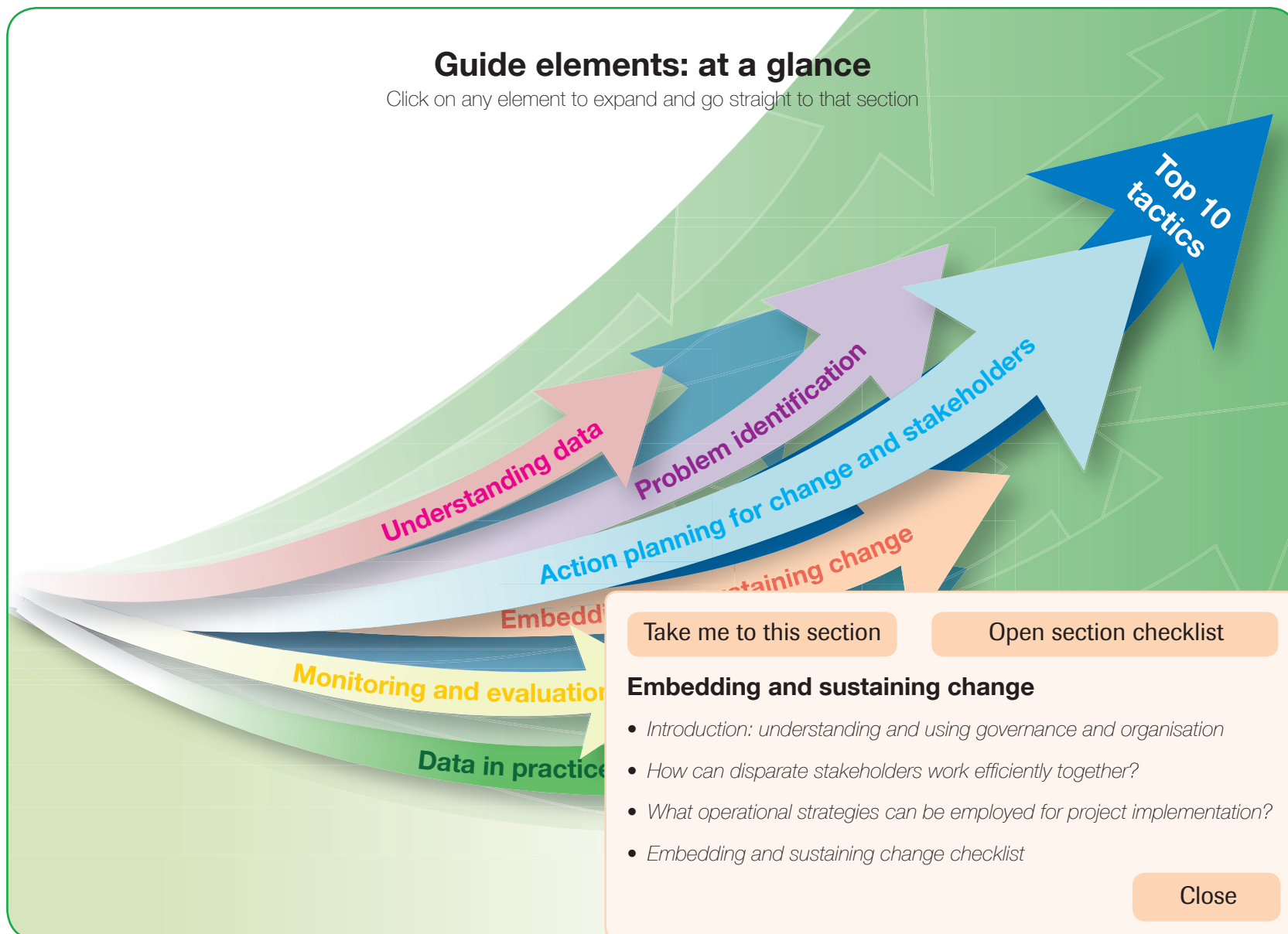
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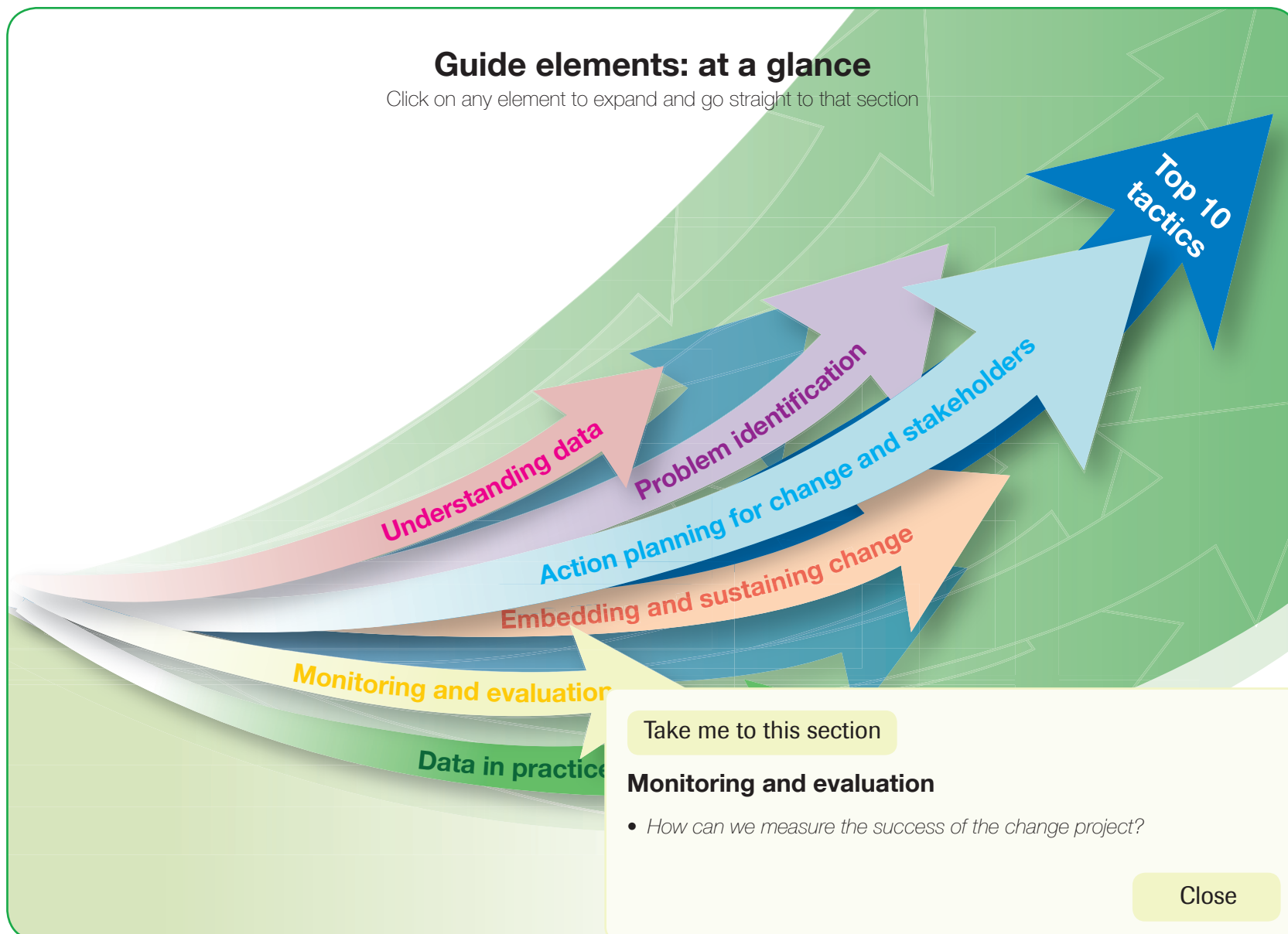
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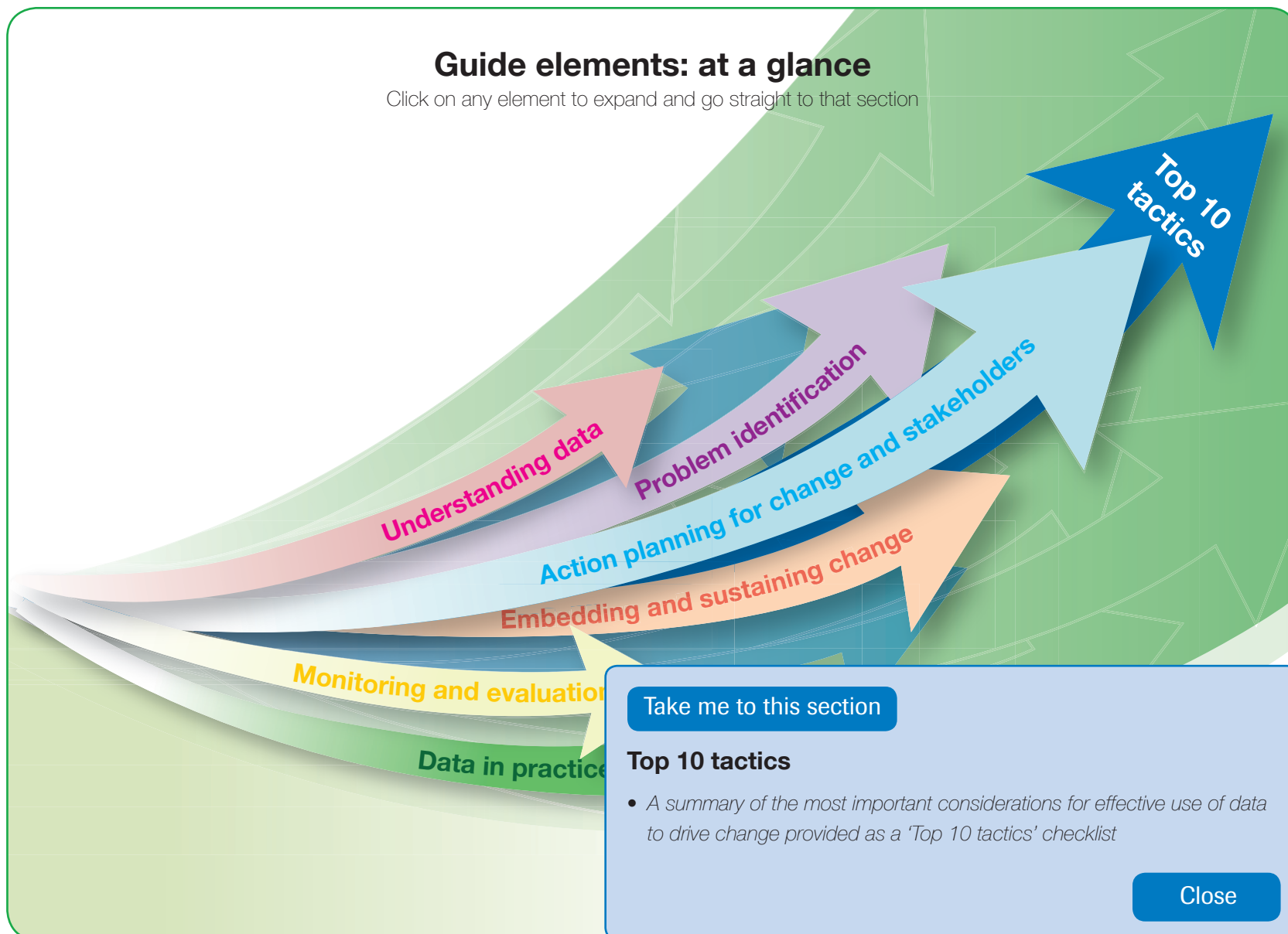
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- [Merseyside and Cheshire Cancer Network project: Development of an early detection strategy performance information framework](#)
- [North Trent Cancer Network project: Expected cancer incidence and expected radiotherapy fractions for local populations](#)
- [Thames Cancer Registry project: The usefulness of one-year survival data](#)
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Introduction: embedding data in strategy

Understanding and analysing data is the first step in identifying areas of concern where improvements in health outcomes are needed.

The goal is to develop an optimal strategy such that once patients enter the health intervention programme, outcomes should be comparable regardless of an area's social and economic circumstances.

This section of the guide identifies key datasets and explains how they can be used to underpin and drive change.

How can data be used to inform strategy?

There is a difference between data, information and intelligence. A strategy document should have data embedded rather than appended, providing a translation of data into intelligence to give relevance and perspective. It is important to be aware of the limitations of the data and to ensure that data are used appropriately.

How can we understand what the data are really telling us and decide if action is needed?

Overarching issues need to be broken down and further investigated. [Dissecting the data](#) to understand the deeper issues allows problem areas to be identified, with prioritisation and focused targeting of tailored interventions to specific groups to drive improvement.

When assessing data, it is important to understand if figures refer to Trusts, geographical areas, open cohorts (where there is a turnover of the population and entries or losses to the cohort), closed cohorts (where only losses to follow-up are allowed), pathways or other groups. It is only possible to compare data from similar groups.

What practical steps can be taken to optimise data quality?

It is important to optimise data quality where possible. In some cases data may be incomplete, however, in practical terms it may be necessary to use the data that are available, bearing in mind the limitations of specific datasets and considering the integrity of the data. Use of existing datasets can lead to improvement in quality as the data are interrogated, reviewed and amended as appropriate.

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There are four key dimensions to assessing and optimising data quality

Completeness: care should be taken when using and interpreting incomplete data. For example, where ethnicity data is only 80% complete the ethnic composition of the other 20% may confound any conclusions that can be drawn.

Consistency and accuracy: it is not appropriate to compare data that have different definitions. For example, data on skin cancer from one Trust may include data on all skin cancers whereas data from another Trust may only include malignant melanoma.

Robustness of sample size: [sample sizes](#) of subgroups need to be sufficiently large to enable robust comparisons to be made. Use of 95% [confidence intervals](#) will test the robustness of the comparisons and give confidence in the conclusions drawn.

Appropriate standardisation: it is generally inappropriate to compare [crude rates](#) (e.g. of incidence or survival) in populations with very different demographic structures. Direct or indirect standardisation should be used.

Data should be cross-validated against other datasets. Clinician knowledge should be utilised to help with data interpretation, to prevent misrepresentation or use of misleading or ambiguous data. In some cases the [relevance](#) of the evidence base at different stages of disease may also need to be assessed.

[Click here](#) for a data checklist and summary.

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Data checklist

- What data sources are available and relevant to this project?
- Are the data sources easy to access or is a degree of technical knowledge needed?
- How up to date are the data?
- Are the data sources of high quality and how complete are they?
- Can other appropriate bodies be approached to fill in the gaps?
- How accurate are the data sources?
- Is the sample size sufficient to provide robust data?
- Is a quality assurance process in place?
- Who can be approached to sense-check the data?

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Open section checklist

- How can we understand what the data are really telling us and decide if action is needed?
- What practical steps can be taken to optimise data quality?

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Consistency and accuracy: it is not appropriate to compare data that have different definitions. For example, one Trust may include data on a specific cancer type while another Trust may only include data on a specific stage of cancer.

Robustness of sample size: [sample sizes](#) of subgroups need to be sufficiently large to enable robust comparisons to be made. Use of 95% [confidence intervals](#) will test the robustness of the comparisons and give confidence in the conclusions drawn.

Appropriate standardisation: it is generally inappropriate to compare data (or survival) in populations with different characteristics. Direct or indirect standardisation may be appropriate.

Data should be cross-validated against other data sources. Data should be utilised to help with data interpretation and not used for use of misleading or ambiguous data. Data should be used to build an evidence base at different stages of cancer.

[Click here](#) for a data checklist and summary.

For example, in lung cancer the goal of radiotherapy for late stage disease may be palliative therefore less radiotherapy is given while for earlier stages the goal is active disease treatment and greater number of fractions are administered. Thus data, viewed as an average or as overall radiotherapy use may not wholly reflect the full picture and further interrogation of the data may be appropriate: caution should be exercised when using averages and assumptions avoided.

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How does benchmarking help identify problem areas and which benchmarks are appropriate?

Identification, establishment and validation of relevant benchmarks are essential in deciding whether intervention is needed. Accurate and relevant benchmarking ensures correct identification of 'real' issues that need to be addressed.

Accurate and relevant benchmarking ensures correct identification of 'real' issues that need to be addressed

Accurate benchmarking also delivers local intelligence rather than information so that end-users can use the data to develop localised and tailored solutions.

Which benchmarks are appropriate?

Data should first be benchmarked against national trends at a Cancer Network (CN) or Primary Care Trust (PCT) level, before subgroup comparisons (for example, by age) because as sample size decreases, the robustness of the data is reduced. [Click here](#) to view an illustrative example from North East London CN.

When benchmarking by CN or PCT it is useful to understand which CNs/ PCTs have similar demographics to benchmark against. [Click here](#) to view an illustrative example from Mount Vernon CN.

It may be possible to identify clusters with similar characteristics to allow for comparison with similar population groups.

Comparison with EU figures is valuable for planning and commissioning purposes. EU data provides a realistic target of what can be achieved. EU benchmarking should be against countries with a similar level of registration. For example, Scandinavian countries such as Sweden, Norway, Finland or Denmark, may be suitable comparators. The National Cancer Intelligence Network (NCIN) and National Cancer Action Team (NCAT) have developed 'consensus targets' for the four major tumours of 1-year [relative survival](#) rates informed by European comparisons (see *Local Awareness and Early Diagnosis Baseline Assessments: A Guide for Cancer Networks and Primary Care Trusts*. Available at:

www.ncin.org.uk/docs/LAEDI_Baseline_Guide_May_2009.pdf)

EU data provide a realistic target of what can be achieved

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Benchmarking outputs should be memorable, understandable and user-friendly. For example the RAG (red, amber green) system could be used as an initial starting point where 'R' identifies areas of potential concern for further investigation or intervention. See practical example from the [Anglia CN project](#).

	INCIDENCE (cancers diagnosed 2002–2006)	1-YEAR RELATIVE SURVIVAL (cancers diagnosed 2002–2006)	5-YEAR RELATIVE SURVIVAL (cancers diagnosed 1998–2002)	MORTALITY (deaths 2003–2007, persons aged 0–74)
ALL CANCERS	11	11	10	4
C00–C14: Lip, oral cavity and pharynx	8	3	6	4
C15: Oesophagus	2	18	24	8
C16: Stomach	16	12	21	7
C18–C20: Colorectum	23	10	5	9
C25: Pancreas	7	12	25	9
C33–C34: Trachea, bronchus and lung	8	8	20	6
C43: Malignant melanoma of skin	20	6	9	18
C50: Breast (f)	23	3	4	21
C53: Cervix uteri	5	19	10	3
C54–C55: Uterus	28	13	15	19
C56: Ovary	12	13	19	12
D61: Prostate	21	10	10	9
D62: Testis	19	7	5	14
D64: Kidney, except renal pelvis	23	22	20	25
D67: Bladder	5	23	23	7
D69–C72: Eye, brain, and other parts of the central nervous system	12	22	19	5
C81: Hodgkin's disease	27	27	7	6
C82–C85: Non-Hodgkin's lymphoma	16	20	22	18
C91–C95: Leukaemia	14	17	8	16

ACN Cancer landscape 'Tartan rug'. Source: NOIS data

The figure above shows how the RAG system forms a 'Tartan rug' output.

It is important to ensure that data have been appropriately standardised before benchmarking, note: use of unified weighted population, from programme budgeting spend allocation, to normalise data is typically inappropriate for cancer because the current unified weighted population formula is an indicator of total disease burden, whereas cancer is an age-related disease.

The use of age-standardised data is helpful for benchmarking of cancer-related service data.

Evidence suggests that 'unified weighted populations' are inappropriate denominators by which to measure inequalities in healthcare provision. When benchmarking, the use of alternative denominators can lead to a more pronounced and consistent pattern of care quality, for example age.

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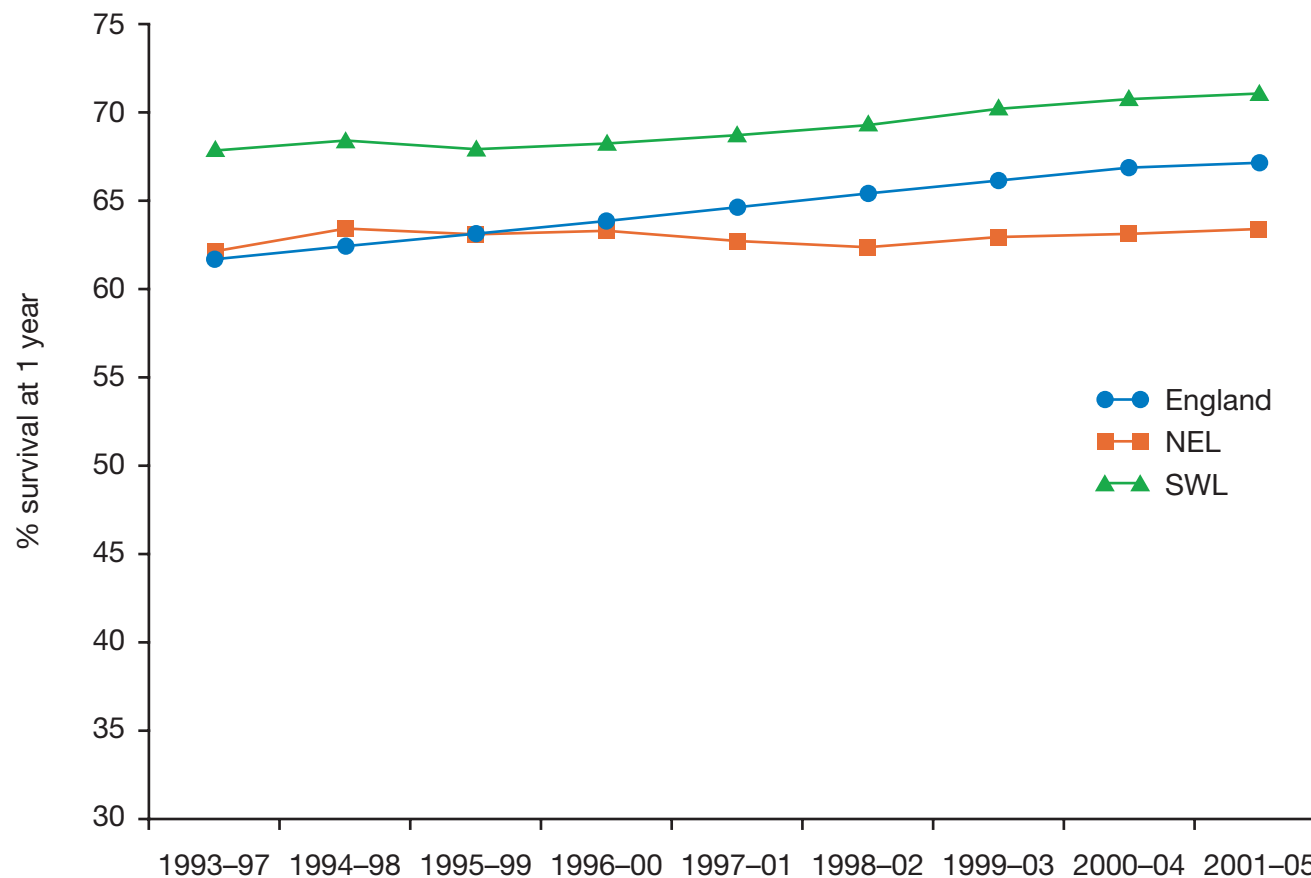
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Trends in 1-year survival from all cancers in North East London (NEL), England and South West London (SWL)



Data source: Cancer e-Atlas

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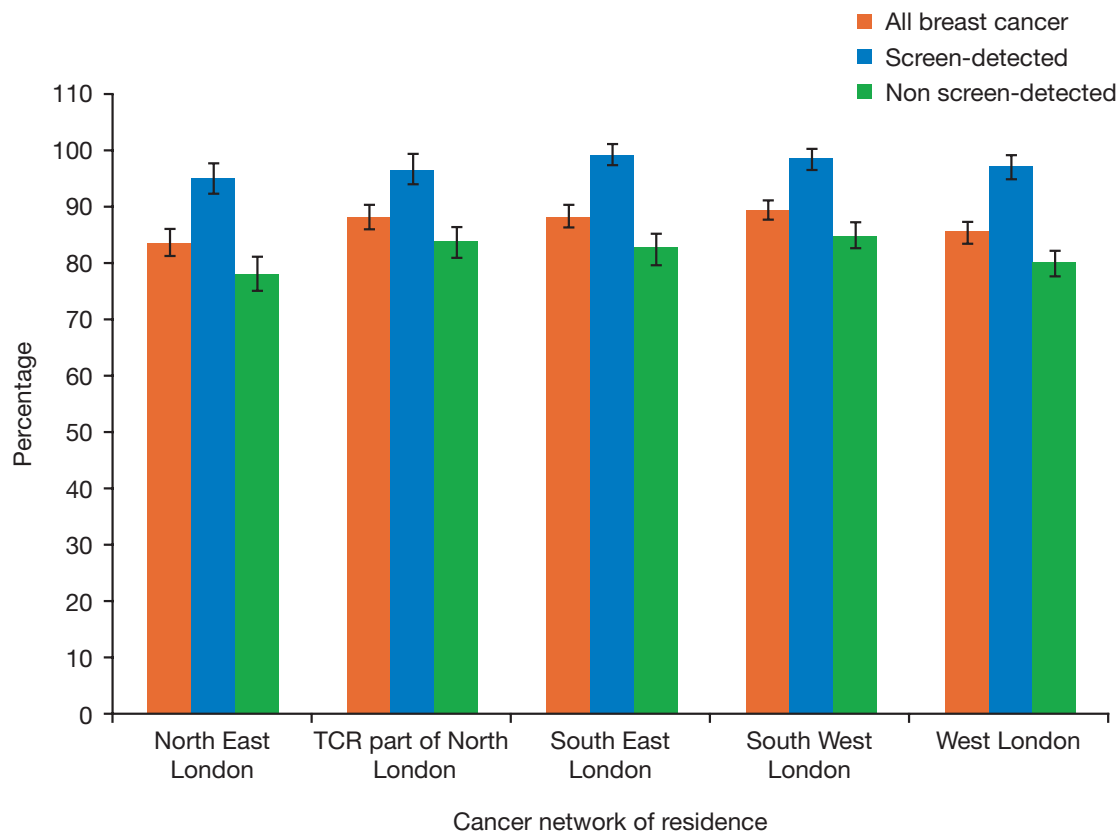
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Period analysis of relative survival for breast cancer in the 50–64 year age group by cancer network of residence, London 2001–2005



Relative survival of North East London Cancer Network patients of screening age is not statistically significantly different from the rest of London for either screen-detected or symptomatic disease

Data source: Thames Cancer Registry (TCR) and London Breast Screening QARC analysis

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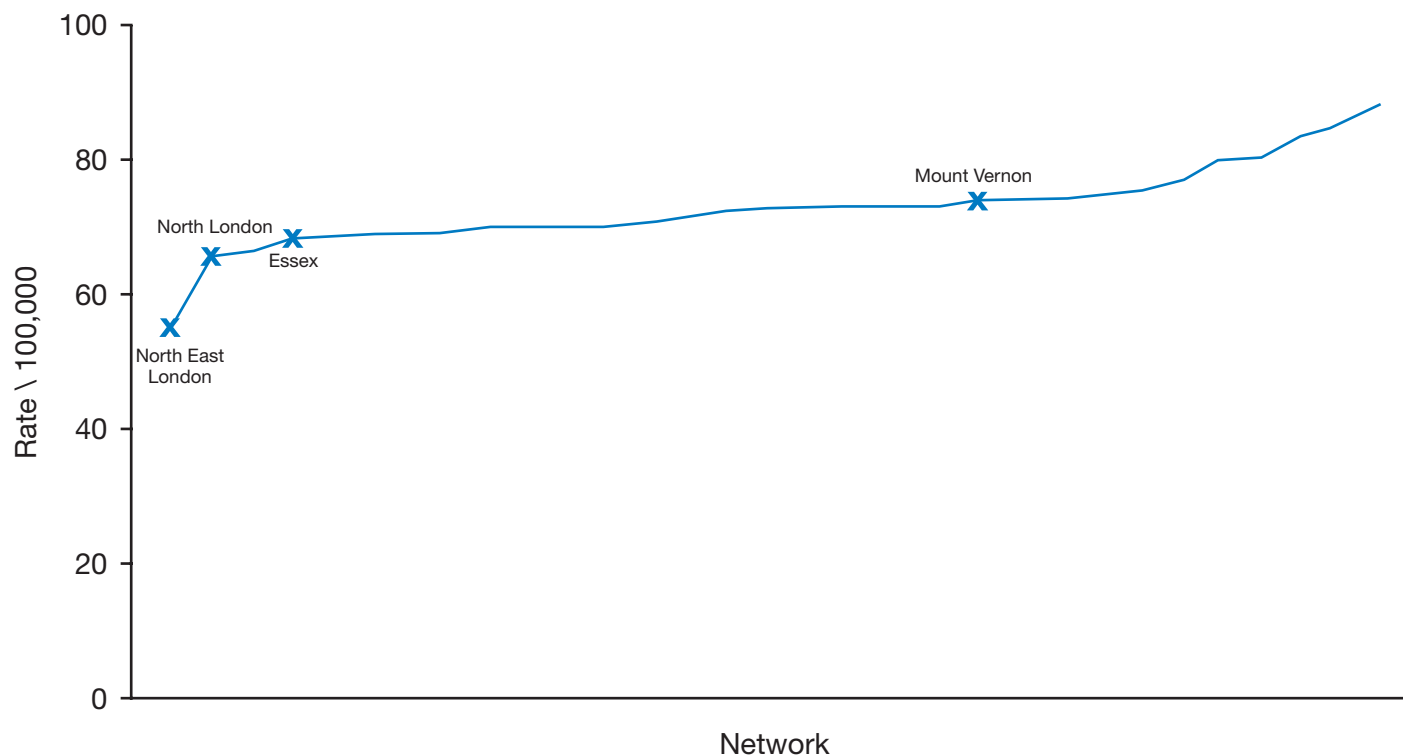
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An illustrative example of benchmarking against comparators with similar demographics – age-standardised incidence of breast cancer: ‘all’ age group (2005)



Data source: Cancer Commissioning Toolkit

The number of patients with a breast cancer diagnosis (incidence), per 100,000 population within North East London, North London, Essex and Mount Vernon Cancer Networks.

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What are the most valuable datasets currently available and what can they tell us?

Health intervention programmes aim to improve outcomes for patients, and relative survival is often a key tool for measuring outcomes.

1-year relative survival

- Surrogate for stage of presentation, and wider burden of disease in the local population

5-year relative survival

- Indicator of overall outcomes, including both stage of presentation and quality of care provided

Kaplan-Meier curves are valuable for identifying early deviation in survival ([Click here](#) to see examples from the North East London CN project).

Five- and 1-year survival can be useful indicators that outcomes need improvement. However, it should be noted that survival data may merely identify that there is a problem. Further work may be needed to understand the reasons for poor survival and inform decisions about possible interventions.

[Click here](#) to view a list of some of the most informative datasets. Note, the Cancer Commissioning Toolkit is a useful collated data source (www.cancertoolkit.co.uk). The Toolkit includes a range of high-level indicators and also links to more detailed information including data on prevention, screening, referral and treatment.

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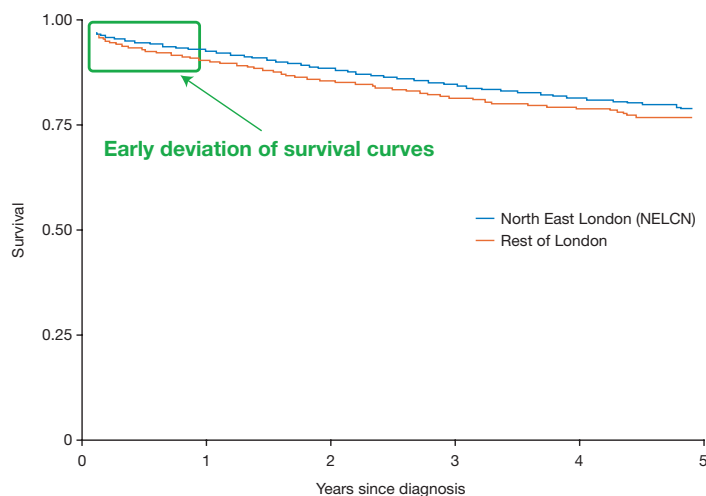
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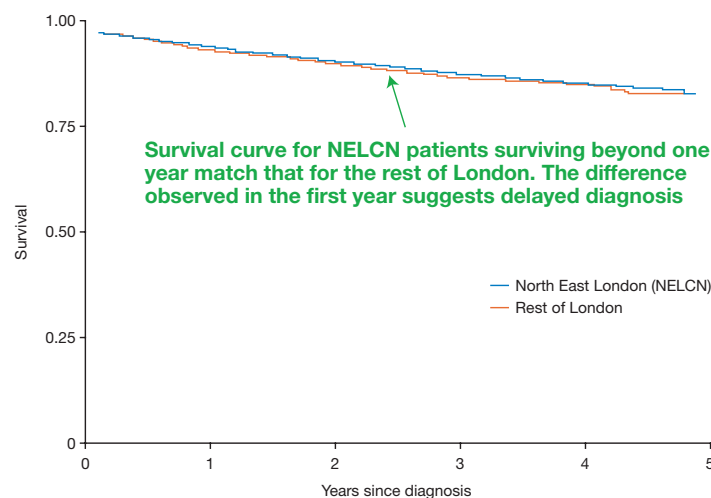
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Kaplan-Meier survival estimates for female breast cancer in NELCN and the rest of London, 2001–2005



Data source: Thames Cancer Registry

Kaplan-Meier survival estimates for female breast cancer in NELCN and the rest of London for patients surviving to one year, 2001–2005



Data source: Thames Cancer Registry

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Data type	Nation	Source	Link	Description	Notes
Incidence	England	NCHOD NCIS + Cancer e-atlas (NCIN) + Cancer Registries Reports and direct data requests	www.nchod.nhs.uk/ www.ncin.org.uk/analysis/ncis.shtml www.ncin.org.uk/analysis/eatlas.shtml	DSR (3-year average). Count (3-year average).	Data provided by regional cancer registries. Network populations derived using Lower Super Output area provided by ONS to UKACR.
Mortality	England			DSR (3-year average). Count (3-year average).	Data provided by ONS. Network populations derived using Lower Super Output area provided by ONS to UKACR.
Survival	England			1-, 3- and 5-year relative survival (5 year average).	Network populations derived using Lower Super Output area provided by ONS to UKACR.
Cancer spend	England	Programme Budgeting (DOH)	www.dh.gov.uk/en/Managingyourorganisation/Financeandplanning/Programmebudgeting/DH_075743	Spend per 100,000 population, by programme by financial year.	Continual refinements to data collection, coding and calculation of references costs affect the allocation of costs to programme categories from one year to the next. Caution is advised when using programme budgeting data to draw conclusions on changes in spending patterns between years.
Ethnicity	England	Office of National Statistics + Cancer Registry may also hold this information for cancer patients	www.statistics.gov.uk/StatBase/Product.asp?vlnk=14238	Resident population estimates by age, gender, ethnic group.	Experimental statistics are in testing phase and not fully developed. It is important that these statistics are clearly marked as experimental.
Deprivation	England	Communities and Local Government	www.communities.gov.uk/communities/neighbourhoodrenewal/deprivation/deprivation07/	Deprivation indices and rank by PCT.	The Index of Multiple Deprivation (IMD) 2007 combines indicators that cover a range of economic, social and housing issues, into a single deprivation score. The PCT index uses an 'Average score' which is the population weighted average of the combined IMD scores for the LSOAs in a district.
Breast screening	England	The Information Centre (NHS)	www.ic.nhs.uk/statistics-and-data-collections/screening/breast-cancer/breast-screening-programme-england-2007-08	Data reported include numbers invited, numbers screened, and the outcomes of screening (including diagnosis of cancer).	Eligibility: every 3 years for all women in the UK aged 50 years and over.
Cervical screening	England	The Information Centre (NHS)	www.ic.nhs.uk/statistics-and-data-collections/screening/cervical-screening	Data reported include numbers invited, numbers screened, and the outcomes of screening (including diagnosis of cancer).	Eligibility: every 3 to 5 years for all women in the UK aged 25–64 years.
Bowel screening	England	The Information Centre (NHS) Bowel Cancer Screening Programme (NHS)	www.cancerscreening.nhs.uk/bowel/index.html www.bcsp.nhs.uk	Data reported include numbers invited, numbers screened, and the outcomes of screening (including diagnosis of cancer).	Final screening centres are being rolled out. Expected to complete end of 2009. Unknown when first data will be published. Eligibility: every 2 years to all men and women aged 60 to 69 years. People over 70 can request a screening kit.
Treatment	England	National Audit information (e.g. LUCADA, DAHNO, NBOCAP, AUGIS, MBR)	www.ic.nhs.uk		National audit data is becoming more complete in terms of number of Trusts supplying data. Note, the information is useful for comparing treatment patterns across the country but may not adequately uncover local inequalities. Detailed treatment data is only currently available direct from MDTs or patient notes.
Hospital Episode Statistics	England	HES online NHS Information Centre Some agencies provide services to extract and manipulate data (e.g. Dr Fosters, Binley's).	www.hesonline.nhs.uk	Database containing records of admissions to NHS hospitals. Each record covers a period of care or episode. Records contain patient, clinical, administrative and geographical information.	HES are a rich and complex data source that can be used to answer a wide range of questions. There are approximately 60 different fields. Care must be taken with analysis as coding is incomplete for many fields (i.e. drug treatment). Outpatient and Accident and Emergency data are collected but not linked to PBR so coding is incomplete.
Disease staging data	UK	Cancer registries			Disease staging is not a mandatory data field for cancer registration. Staging data held by cancer registries is incomplete. Staging data, since April 2009, forms part of the national dataset being provided electronically from MDTs to Cancer Registries as required by acute contract.

Abbreviations: ONS=Office for National Statistics; UKACR=United Kingdom Association of Cancer Registries; LSOA=Lower Layer Super Output Area; MDT=Multidisciplinary Team;

DSR=direct (age) standardised rate; NCHOD=National Centre for Health Outcomes Development.

Although staging data may not be routinely available, it can add value and accuracy to data analyses. Patient-specific treatment data and outcomes are also valuable.

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When are time trends useful?

The use of time trends can be highly valuable in showing 'direction of travel', and can be used effectively with incidence, mortality and relative survival data. Comparison of time trends with both national data and selected benchmark CNs can provide insight into whether rates of improvement are better or worse than average.

It is recommended that mortality time trends by CN/ PCT should be compared together with the incidence trends for the same CN/PCT to start to understand whether the local cancer services are having a positive impact on patient outcomes. Whilst a mortality time trend viewed on its own could be flat suggesting little progress is being made, when viewed with an increasing incidence trend this can show altogether a totally different and more positive picture. [Click here](#) to view an illustrative example from North London CN.

It is also useful to analyse the time trends for incidence, mortality and relative survival according to patient age (both ≤ 75 years and >75 years). Average length of stay (ALoS) data can also be useful to understand which tumours are driving in-patient costs but it may be necessary to [separate and analyse the data](#) according to procedure.

Other data that may be valuable as and when it becomes available includes:

- Staging data from multidisciplinary teams (MDT). Of note, MDT data including staging, forms part of the contracted minimum cancer dataset to be provided on a prospective basis to Cancer Registries from April 2009.

Is ethnicity data valuable?

Ethnicity data can provide valuable insight into variations in access to, or outcomes of healthcare between different groups, but is reliant on accurate coding. Unfortunately all current sources of ethnicity data are incomplete. Care needs to be taken to use the appropriate sub-grouping of ethnic categories, such that the sample size is large enough to draw conclusions without averaging differences between populations. For example use of 'Asian' category, covering Indian, Pakistani and Bangladeshi, may not provide sufficient granularity. In addition, recording of ethnicity may be problematic as it is self-defined. Ethnicity is not included on death certificates: only place of birth is recorded and this may not reflect ethnicity.

- Significant event audits (SEA) and primary care audit data including referrals and patient outcomes.
- Analysis of referrals data to show referral route, (e.g. the proportion of cancers that come through urgent referrals or standard referral) with further breakdown of data by PCT and GP practice.

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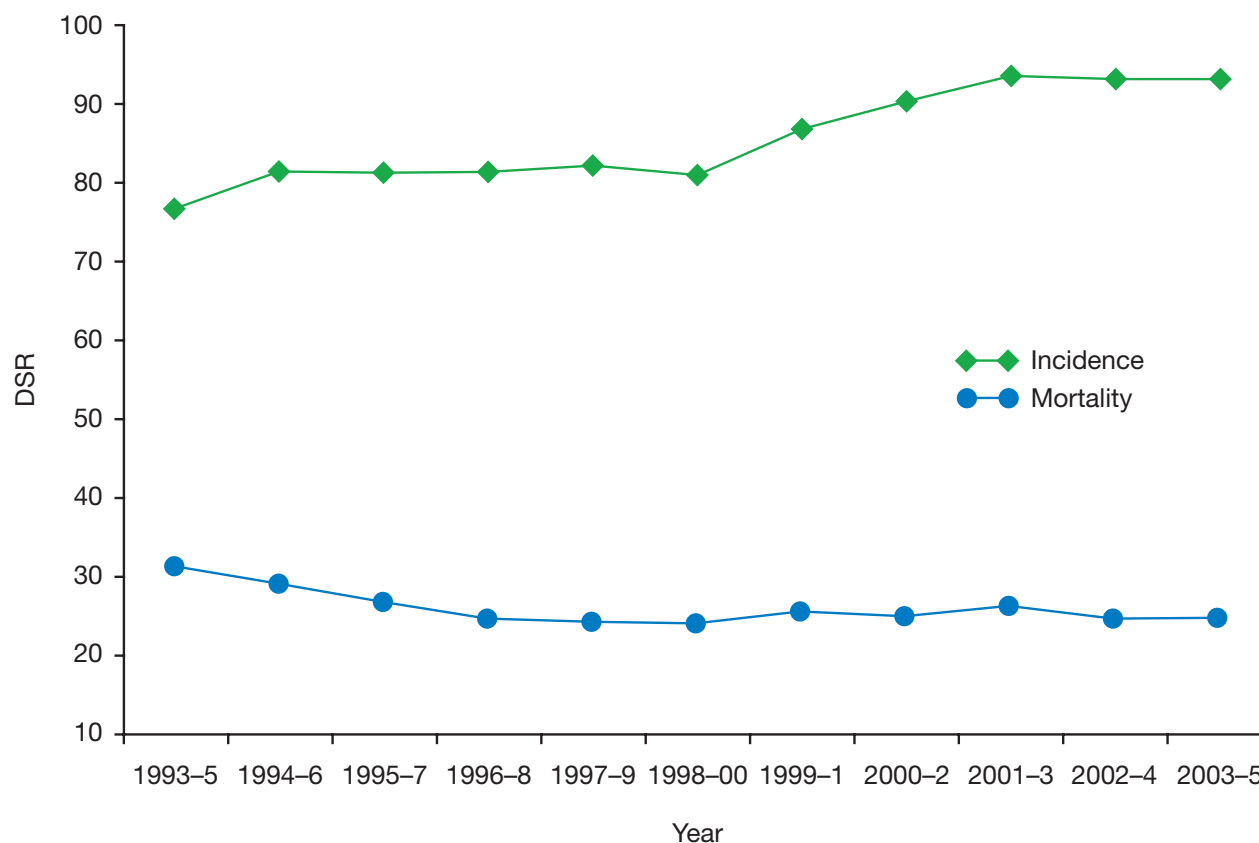
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Prostate cancer incidence vs mortality



North London Cancer Network

Date: October 2009

Data Source: Cancer e-Atlas. Last accessed October 09. www.apho.org.uk/addons/_4990/atlas.html

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It is also useful to analyse the time trends for relative survival according to patient characteristics. Average length of stay (ALoS) data can be used to identify which tumours are driving in-patient activity. [Separate and analyse the data](#) according to procedure.

Other data that may be valuable as and when it becomes available includes:

- Staging data from multidisciplinary teams (MDT). Of note, MDT data including staging, forms part of the contracted minimum cancer dataset to be provided on a prospective basis to Cancer Registries from April 2009.

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For example, patients undergoing palliative care may have longer ALoS than those undergoing active treatment and this will impact overall ALoS data. This example also illustrates the need to be cautious when using averages and to interrogate the data to reveal the 'real' picture.

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...erral route, (e.g. the proportion of cancers that come through urgent referrals of standard referral) with further breakdown of data by PCT and GP practice.

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Problem identification

What are key considerations when deciding what data to use and what are the challenges?

Availability of up-to-date data is essential from project start to ensure that findings are relevant. High quality and [completeness of data](#) are also important.

Data accuracy is essential; however, currently available datasets may differ in accuracy. Quality control and checks for accuracy of data are essential in order to ensure acceptance of the findings: even small inaccuracies can lead to stakeholder disengagement and loss of credibility. The size of the sample group from which the data are gathered impacts data accuracy. Precision of data (for example relative survival) may be low in smaller sample groups such as PCTs and therefore may be difficult to interpret or use as an indicator as it may lack the precision to track yearly relative survival improvements. The key is understanding the data robustness; data for common cancers in larger PCTs, pooled over sufficient number of years may provide useful insight. [Click here](#) to see an example of outlier or hotspot identification using a [funnel plot](#).

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Quality control and checks for accuracy of data are essential in order to ensure acceptance of the findings.

Once the problem has been identified using the data, issues that need to be addressed can be formulated and project objectives identified. It may also be necessary to determine whether additional data is needed then an action plan can be developed.

[Click here](#) for a checklist for using data to diagnose focus areas.

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Problem identification

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Data accuracy is essential; however, data from different sources may differ in accuracy. Quality control and checks for accuracy of data are essential in order to ensure findings are reliable. Even small inaccuracies can lead to misleading findings and loss of credibility. The size of the sample group and the number of data points gathered impacts data accuracy. Precision of data (for example relative survival) may be low in smaller sample groups such as PCTs and therefore may be difficult to interpret or use as an indicator as it may lack the precision to track yearly relative survival improvements. The key is understanding the data robustness; data for common cancers in larger PCTs, pooled over sufficient number of years may provide useful insight. [Click here](#) to see an example of outlier or hotspot identification using a [funnel plot](#).

For example, the lack of specific data such as disease stage can hamper analysis; however it may be possible to use contract agreements to obtain missing information.

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to diagnose focus areas.

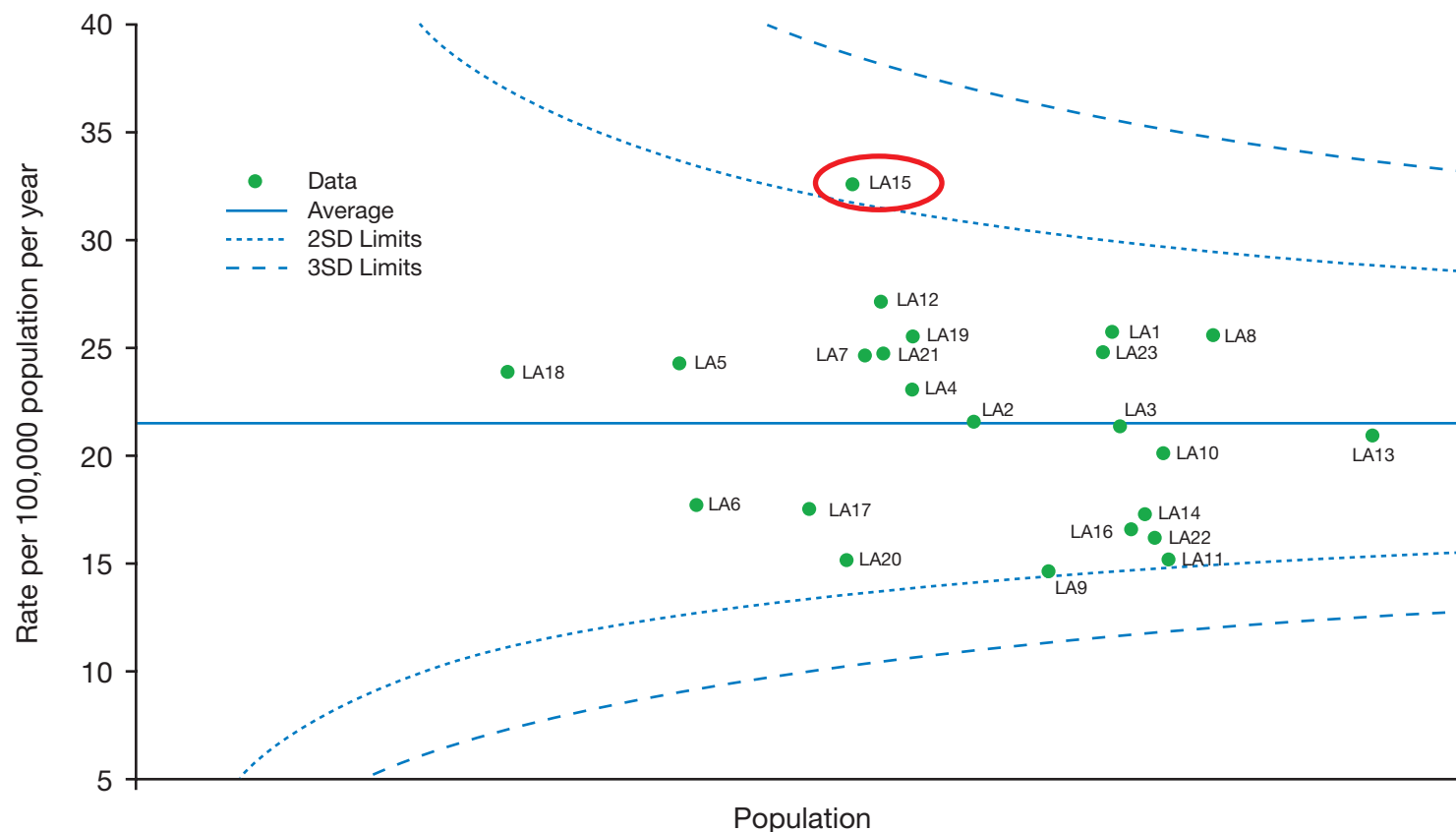
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Data source: National Cancer Information Service (NCIS). Chart by Anglia CN.

Note: Population is adjusted due to standardised calculations.

The funnel plot tool, provided by Eastern Region Public Health Observatory (ERPHO), can be used to identify outliers or hotspots which may not be immediately apparent using other methods. The plot is easy to use and provides a visual way of showing if a result is statistically significant, for example LA15 lung cancer mortality.

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Checklist for using data to diagnose focus areas

1. What is the local burden of disease?

- Undertake benchmarking against national, regional area and other cancer networks and Primary Care Trusts (PCTs).
- Look at **trends** (against targets) for **incidence**, **mortality** and **survival**. Looking at mortality rates in isolation can gloss over an underlying issue: question whether the mortality is as expected given the local incidence.

2. Are some groups more affected than others, i.e. are there health equity issues?

- Look at sub-groups of the local population, what is the survival by age, sex, ethnicity, deprivation?

3. Risk factors for cancer prevalence?

- What are the prevalence rates and trends for lifestyle and behavioural risk factors?

4. What is the current cost and PCT spend on cancer services?

- PCT and Cancer Network Programme Budgeting spend can be benchmarked against suitable comparator areas

5. Service provision against standards [NICE Improving Outcomes Guidance (IOG)]

- Consider both early diagnosis and treatment standards

6. Performance against standards

- For example waiting times (two-week wait, 31-day and 62-day waits), screening uptake, survival consensus targets

7. Patient satisfaction

- Data from national or local patient satisfaction surveys can be used to identify areas where change is needed

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and which bench-

and what are the data to use?

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Introduction: stakeholder identification, recruitment and engagement

Cancer is a multifaceted and complicated disease. The patient pathway is likely to involve a range of clinical and non-clinical personnel. Where existing processes or structures need to change it is important to ensure that the relevant stakeholders are engaged. This section of the guide deals with identification of key stakeholders and how to involve and motivate them throughout the project.

Who are project stakeholders and how can they be identified?

Key stakeholders are those individuals, groups or organisations who will be affected by the change programme or who are tasked with implementing the programme. Identification of key stakeholders and their effective engagement is a critical success factor for any change project. Early engagement with stakeholders promotes meaningful stakeholder ownership of the project.

Stakeholder identification and mapping should address several questions

- Who is going to be affected by the change?
- How will they be impacted – is this impact positive or negative?
- What are their interests in relation to the programme and how can this affect programme outcomes or success?
- How can we manage and communicate the programme so that the benefits of change are clear?
- Who is going to be tasked with implementing and monitoring change?

Stakeholders: Which key groups or individuals need to be actively involved?

There should be a clear rationale for involving stakeholders in the project. When assessing need for involvement several important points should be considered. As well as the stakeholders defined above, the project team should also include stakeholders with a deep knowledge of the issue to provide a relevant perspective. For example, clinicians, public health experts, academics, information experts who can form an expert reference group.

For a change project that affects a specific community or group, community champions should be identified and involved. They should be able to represent the target community (for example, target patient group), and ideally have some emotional attachment to the cause, maybe through personal experience or first-hand knowledge of the challenge to be addressed.

For a change project that affects a specific community or group, community champions should be identified and involved.

Any organisation or group who ultimately will be paying for the change programme is a stakeholder. Organisations affected by either increased costs or cost savings as a result of the programme are stakeholders and should be active participants.

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What qualities should stakeholder representatives on the project team demonstrate?

Stakeholders able to represent their group or organisation should be invited to participate early in the project. Although the choice of stakeholder groups is in many ways predetermined by the nature of the project, selection of individuals from the stakeholder organisations to be actively involved and form a core part of the project team is recommended. When selecting representatives from your stakeholder group it is important to define the [key qualities or characteristics](#) individual stakeholders should demonstrate.

Stakeholders: What motivates stakeholders and encourages involvement?

A variety of factors can be stakeholder incentives or motivators. These include

- Project objectives that are in line with existing targets and objectives, and an underlying compatibility of agendas and priorities
- Potential for cost savings or more efficient resource use

See practical example from the [Anglia CN project](#).

- Availability of project funding

See practical example from the [Cancer Research UK project](#).

- Personal drivers, such as recognition and esteem, academic interest, improving outcomes for their patients, and personal belief in the cause
- Acknowledgment of involvement, for example through publication activity
- Peer influence or pressure

How can stakeholder engagement and motivation be promoted?

Communication with and engagement of stakeholders is essential. It is also important to share relevant information and share it quickly. Each stakeholder or stakeholder group may represent a specific communication audience: a tailored communications programme will help to optimise engagement with each group.

At the very beginning engage your key stakeholders with the problem/challenge and ask for their ideas, both with regards to contributing factors and analysis required.

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What qualities should stakeholders project team demonstrate?

Stakeholders able to represent their interests should be invited to participate early in the project. The composition of stakeholder groups is in many ways critical to the project, selection of individuals from the project community to be actively involved and form a core partnership is highly recommended. When selecting representatives for the project group it is important to define the key characteristics that stakeholders should demonstrate.

Stakeholders: What motivates s involvement?

A variety of factors can be stakeholders include

- Project objectives that are in line with the company's strategy and an underlying compatibility of the project with the company's culture
- Potential for cost savings or more efficient use of resources

Identifying individual stakeholder representatives for the project team

- *Is the proposed stakeholder a champion of the cause, convinced of the need for change and enthusiastic or passionate about the issue? Are they dynamic?*
- *Are they an advocate in the relevant arena and within appropriate forums? Are they willing to be outspoken?*
- *Is the stakeholder credible and well respected, especially by their peers?*
- *Do they hold a level of authority (either formal or informal) that allows them to influence change?*
- *Does the stakeholder demonstrate leadership – are they able to drive change and motivate or influence others, both within their own and relevant external organisation?*
- *Is this stakeholder important for implementation of agreed actions or impacted by the proposed changes?*
- *Does the stakeholder have interorganisational roles with the ability to access groups within other stakeholder organisations?*
- *On a practical level, do they possess project management skills? Are they effective delegators, realistic and in possession of good time-management skills?*

Individuals covering all the different aspects of the list will make up your project steering group or project team.

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Understand the data and make it understandable

It is crucial to have a deep understanding of the data and its relevance in the clinical setting. In order to engage stakeholders, the need for action should be communicated in a way that is relevant and memorable to the specific audience. For example data such as survival curves and percentages could be translated into actual patient numbers for greater impact.

Data such as survival curves and percentages should be translated into actual patient numbers for greater impact.

Turn challenges into drivers for change

Being an outlier can be motivational by establishing a clear need for change or improvement. Comparison with peers, for example performance versus other CNs or PCTs, demonstrates that improvement is achievable.

Quick wins

'Quick wins' can demonstrate how a small change can have a large impact in a relatively short timescale. For example projects that improve patient pathway and achieve efficiencies or those that increase referrals. See practical examples from [Anglia CN](#), [Merseyside and Cheshire CN](#) and [Cancer Research UK projects](#).

[Click here](#) for an action planning for change and stakeholder checklist and summary.

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- *Have key stakeholders been identified and 'ideal' representatives selected for involvement?*
- *Has the position of the stakeholder relative to the change project, been assessed?*
- *Can these profiles be used to enable information presentation or reports to be tailored to key areas of interest through a targeted communications strategy?*
- *Has the data been translated into relevant and memorable information for each target audience?*
- *Would formal qualitative research through focus groups be valuable?*
- *Are there existing patient / community groups with whom formal links can be developed or are new groups needed?*
- *Is the project change targeted at a particular ethnic/cultural group? If so, can community engagement be promoted through outreach? Is there a need for ethnically- or culturally-matched outreach workers?*
- *Can peer comparisons of relative performance be leveraged to add a competitive motivator?*

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Introduction: understanding and using governance and organisation

Different organisations and stakeholder groups will have their own governance and organisational structures. This section of the guide deals with how these structures and processes may be best used to implement a change project.

How can disparate stakeholders work efficiently together?

- From project start, clarity, definition and agreement of specific roles and responsibilities and optimisation of system alignment for each organisation is critical. This ensures that all important issues are captured and addressed.
- Different organisations will have their own organisational structures: ensure you have locally-relevant definitions.
- Responsibility for initiative delivery may lie with the PCT. CNs are likely to have a role in monitoring progress and acting as mediators by highlighting to PCTs poor contract compliance, for example MDT data not being supplied within contracted timelines.
- Relevant CNs may cover more than one SHA and initiatives may be applicable to several PCTs: a clear understanding of what has to be delivered and by whom is essential. A Service Level Agreement (SLA) or Memorandum of Agreement should be developed.
- Terms of reference should link formally to the structure and into existing governance arrangements within the CN. Reporting lines into the appropriate body within existing structures should be formalised, typically the Project Steering Group will formally report to the CN Board and/or the relevant tumour board or service improvement board. See practical example from the [Mount Vernon CN project](#).

- Governance structures should ensure links with other groups involved in relevant projects that support or have an impact on the change project.

What operational strategies can be employed for project implementation?

- Develop links to commissioning and other funding sources, for example PCTs and local authorities, to maintain the project beyond pilot phase into general implementation.
- Harness the commissioning network by ensuring joint representation at key forums.
- Identify those groups who will also benefit from the initiative in terms of common objectives, targets and needs and present findings tailored according to their objectives.
- Assess whether the intervention is relevant or applicable to other subgroups (for example, other tumours or other patient groups). See practical example from the [Cancer Research UK project](#).
- Develop or use an existing action group to drive practical implementation, for example through establishment of a Public Health Action Board (PHAB). See practical example from the [North East London CN project](#).

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Embedding and sustaining change

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Embedding and sustaining change: What operational strategies can be employed for project implementation (cont'd)?

- Show the relevance of project outcomes and how it links to regional and national plans, for example SHA plans.
 - At the macro level, cancer should be highlighted as a priority area. At the micro level, key data should be embedded into cancer strategies.
- Develop relevant metrics to allow measurement of delivery against best practice. Be aware that metrics may evolve over time – evaluate metrics and targets as appropriate

- Ensure that relevant contracts are put into place and are enforceable through defining local specifications.
- Use contract review processes as a lever to ensure compliance with metrics.

[Click here](#) for an embedding and sustaining change checklist and summary.

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Embedding and sustaining change checklist

- *Have specific roles and responsibilities been clearly defined and agreed?*
- *Is a Service Level Agreement (SLA) or Memorandum of Agreement in place?*
- *Can contracts be used to define the type and quality of data required?
Can the contract review process be used to ensure compliance?*
- *Have reporting lines been formalised?*
- *Have links with relevant groups, commissioning and other funding sources been established?*
- *Can the project be adapted to benefit other subgroups of patients or tumour types?*
- *Is there an existing group that can drive practical implementation or does one need to be developed?*
- *Have relevant metrics been identified? Are indicators discriminating, meaningful and easily communicated?*

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Monitoring and evaluation

How can we measure the success of the change project?

Relevant metrics should be defined and are essential to monitor the achievement of the project strategy.

- Each project should have a defined overall goal, which it is useful to express in terms of patient outcomes. See practical example from the [North East London CN project](#).
- Each project should also have specific and measurable objectives, for example to increase patient referrals within a specified population and time frame by X%.

- Indicators should be identified at the start of the project. These can then be used to get a baseline for the current service and to demonstrate successful completion of the project. Indicators should be discriminating and meaningful.
- Where standard data are unavailable or unsuitable for measurement of the success of an intervention or change, suitable project-specific metrics should be generated.

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Top 10 tactics

This guide provides practical guidance and strategies to drive the successful use of data in cancer decision making and service improvement. The most important considerations are prioritised in the checklist table below.

Tactic / Critical Success Factor	Priority
Baseline assessment and accurate benchmarking to assess genuine need for intervention and magnitude of challenge	1
Agreement of focussed, clear and measurable objectives with identification and definition of target outcomes	2
Identification of stakeholders through rigorous stakeholder mapping to ensure early involvement, with continued relevant, meaningful and targeted communication throughout project to maintain engagement	3
Identification and implementation of relevant metrics – both for the project objectives and for the change to be implemented	4
Identification of similar evidence-based projects or initiatives, and development of links to share good practice, information and resources for mutual benefit	5
Ensure robustness of data through evaluation of data quality and accuracy	6
Awareness of data limitations, for example impact of sample size, use of averages	7
Motivational project leadership	8
Formalisation of governance framework and terms of reference with clearly defined roles and responsibilities for all project participants	9
Evaluation of the cost benefit of implementing the change and assessment of value for money	10

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This guide has been developed collaboratively by Anglia Cancer Network, Cancer Research UK, Merseyside & Cheshire Cancer Network, Mount Vernon Cancer Network, North Trent Cancer Network, North East London Cancer Network and Roche Products Limited. Roche supported this joint working project by providing project management, facilitation and artwork resource.



Fighting cancer with information

www.ecric.nhs.uk



Anglia Cancer Network

www.angliacancernetwork.nhs.uk

CANCER RESEARCH UK



www.cancerresearchuk.org



<http://www.northtrentcancernetwork.nhs.uk>

Merseyside and Cheshire
Cancer Network



www.mccn.nhs.uk



www.mountvernoncancernetwork.nhs.uk

North East London Cancer and Research Network



www.nelcn.nhs.uk



www.rocheuk.com

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Project examples and key learnings

North East London Cancer Network (NELCN)

Project objectives and direct outcomes

The NELCN project aimed to address breast cancer inequalities, specifically poor five-year relative survival compared with other similar CNs. Data analysis revealed that the driver for poor five-year relative survival was suboptimal one-year relative survival. As a result of this project NELCN has established a survival-specific target to improve one-year relative survival to within 95% confidence interval of London levels by 2012.

Datasets and methodology

Five-year relative survival was assessed by CN and by inner/outer NELCN, by age, by screen-detected disease and symptomatic disease. Incidence was assessed by CN and PCT, by stage, by deprivation quintile, and by treatment received. In addition, data on hospital episode statistics, HER2-positive treatment rates and drug usage were evaluated. Data analysis methods included Kaplan-Meier survival curves and Cox hazard proportional analysis.

Stakeholders, responsibility and communication

The project is a successful example of a joint working project between NELCN, Thames Cancer Registry and Roche. NELCN established a multi-professional project team, a clinical champion group and a formal project board. NELCN ensured that the board was chaired by a lead clinician who was key to decision making and driving change. A clinical lead, project lead and project manager were also appointed. Clinician involvement was sought through regular presentations to the Tumour Advisory Board (TAB) and a multidisciplinary team workshop is planned to improve clinical ownership of the project. Wider stakeholder buy-in to the project was achieved through an active communication programme providing timely project updates to all relevant PCT, Trust, CN and third party boards and committees. At each planned update, a formal agenda time and presentation ensured consistency of communication messages and an ordered cascade of information.

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North East London Cancer Network (NELCN)

Governance, structure and implementation

A formal governance structure was established with the project team reporting to the Project Board, TAB and CN Board, and a joint working agreement put in place to define clear roles and responsibilities. In addition a Public Health workshop was organised leading to the establishment of a Public Health Action Board (PHAB) to drive practical implementation of the project. Commissioning levers are being used to increase cancer funding in PCT plans.

Metrics and performance monitoring

NELCN are monitoring progress using breast pathway metrics, which are reviewed by the TAB every three months. They also plan to develop a 1-year relative survival metric with Joint Clinical Investigation (JCI) of all deaths within one year. Contract review processes are being used as a lever to encourage compliance with metrics.

Key learnings

- Limit univariate analyses of characteristics to CNs as PCT analysis can distract from the main question
- Use univariate analyses to develop Cox proportional hazards analysis
- Kaplan-Meier curves can be used to identify early deviation
- PCT 1-year relative survival data allows validation of interventions aimed at improving survival
- Avoid making assumptions about the cause of survival differences without analysis
- Take a forensic approach to analysis
- Beware of averages - other deprived populations may have similar outcomes to NELCN but these may be masked by satisfactory averages at a CN level

For more information on the NELCN project contact:

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Elizabeth Davies elizabeth.davies@kcl.ac.uk

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Project examples and key learnings

Mount Vernon Cancer Network (MVCN)

Project objectives and direct outcomes

The MVCN project aimed to prioritise CN spend through data analysis. As a result of the project, specific improvement projects will be developed and implemented based on identified priorities. In addition, initial project findings have been disseminated promoting wider stakeholder participation.

Datasets and methodology

MVCN used data from E-Atlas and the Cancer Commissioning Toolkit as well as Cancer Registry data, PCT breast screening data and Department of Health programme budget data. Data was benchmarked against North East London, North London and Essex CNs and also against England averages. Age-standardised mortality, mortality crude rate and deaths per year were assessed along with age-standardised incidence by age. One-, three- and five-year survival (all age-standardised) were also analysed. Survival rate and PCT mortality time trends were analysed in order to assess 'direction of travel' and spend versus outcomes was evaluated.

Stakeholders, responsibility and communication

The project is a successful example of a joint working project and involved a wide variety of stakeholders including, CN Executives, representatives from public health, commissioning and primary care groups within PCTs, the Eastern Cancer Registry and Information Centre (ECRIC), which registers malignant tumours in the East of England, Roche and invited consultants.

Key decisions were made by the group as a whole, with involvement of Lead Clinicians throughout the data-finding process. The project findings were presented to the Tumour Site Specific Group (TSSG) and to the wider CN, PCT and clinicians. A summary report and poster of process and initial data findings was developed for wide distribution to encourage and maintain stakeholder interest in the project. A second summary will be produced to communicate improvement projects, explain the monitoring process and disseminate final project outcomes. MVCN is also organising a data-training day for TSSG leads to improve understanding of the data, its credibility and what it demonstrates.

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Mount Vernon Cancer Network (MVCN)

Governance, structure and implementation

Terms of reference were agreed and the working group was formally established into the governance structure of the MVCN.

Metrics and performance monitoring

The TSSG will be devising specific improvement projects and establishing relevant metrics as an integral project element.

Key learnings

- Use relevant and appropriate benchmarks to establish the cancer landscape
- Different datasets may vary in accuracy: accuracy is crucial for credibility of data and data findings
- Be aware that incidence, mortality and survival data represent averages which minimises variance but may also mask trend changes
- Methods of data collection for cancer spend have changed: be aware of anomalies when comparing time series
- Use the most up-to-date data available: older data may not reflect recent service changes
- Ensure that all parties are committed to and focused on the project
- Be realistic about project timescales

For more information on the MVCN project contact:
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Project examples and key learnings

Anglia Cancer Network (ACN)

Project objectives and direct outcomes

The ACN project aimed to define a landscape of cancer within the CN in order to inform the CN cancer strategy by identifying priority areas. As a result of the project, the CN's baseline was established and a memorable and understandable system to capture and represent key cancer data was developed which facilitated identification of the top five cancers to be addressed within the ACN cancer strategy.

Datasets and methodology

The ACN project used National Cancer Information Service (NCIS) data as a versatile dataset for CN comparisons. Data analysed for 19 cancers included cancer incidence (from 2002–6), 1-year relative survival (from 2002–6), 5-year relative survival (from 1998–2002) and mortality (deaths from 2003–7 for persons aged <75 years). The results of the analysis were presented in an intuitive '[Tartan rug](#)' format, using colour-coded categories for visual impact.

The Red, Amber, Green (RAG) system provides a memorable and user-friendly output of data analyses where red coding identifies areas of potential concern for further investigation. In addition, the system can capture and compare data from a range of tumour sites, providing information relevant to different TSSGs and in a format that can be repeated for different PCTs. The RAG system can provide a snapshot of cancer data but does not capture information on trends; however, it could be amended to provide a time dimension. [Click here](#) to see an example of a Tartan rug output.

The RAG system can provide a snapshot of cancer data but does not capture information on trends.

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Project objectives and direct outcomes

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The RAG system can provide a snapshot of cancer information on trends.

The Tartan rug output highlights the value of 'quick wins' and demonstrates how a moderately simple but effective product can have a significant impact on data use in informing cancer strategy in a relatively short timescale.

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	INCIDENCE (cancers diagnosed 2002–2006)	1-YEAR RELATIVE SURVIVAL (cancers diagnosed 2002–2006)	5-YEAR RELATIVE SURVIVAL (cancers diagnosed 1998–2002)	MORTALITY (deaths 2003–2007, persons aged 0–74)
ALL CANCERS	11	11	10	4
C00–C14–Lip, oral cavity and pharynx	8	3	6	4
C15: Oesophagus	2	18	24	8
C16: Stomach	16	12	21	7
C18–C20: Colorectum	23	10	5	9
C25: Pancreas	7	12	25	9
C33–C34: Trachea, bronchus and lung	8	8	20	6
C43: Malignant melanoma of skin	20	6	9	18
C50: Breast (f)	23	3	4	21
C53: Cervix uteri	5	19	10	3
C54–C55: Uterus	28	13	15	19
C56: Ovary	12	13	19	12
C61: Prostate	21	10	10	9
C62: Testis	19	7	5	14
C64: Kidney, except renal pelvis	21	22	20	26
C67: Bladder	5	23	23	7
C69:–C72: Eye, brain, and other parts of the central nervous system	12	22	19	5
C81: Hodgkin's disease	27	27	7	6
C82–C85: Non-Hodgkin's lymphoma	16	20	22	18
C91–C95: Leukaemia	14	17	8	16

ACN Cancer landscape 'Tartan rug'. Source NCIS data

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Anglia Cancer Network (ACN)

Stakeholders, responsibility and communication

Initial stakeholders included the public health groups of the six PCTs within the CN. In addition, ACN sought input and advice from the Eastern Region Public Health Observatory (ERPHO) and undertook selected on-line consultation through a Yahooogroup.

ACN: Transforming in-patient care

One finding from the project that encourages stakeholder motivation was that potential cost savings were identified. Comparison of ACN cancer bed day rates with that of other CNs revealed that reduction of ACN rates to that of the lowest CN could achieve a saving of around one-third of current spend. Data analysis also revealed that average length of stay for cancer in-patients differed according to cancer type and also by Trust within the CN. In terms of bed-days, colorectal cancer was identified as one of the three top cancers within ACN, a finding that could aid prioritisation of CN resources.

Governance, structure and implementation

As the project progressed, governance was established through the Strategy and Commissioning Group which includes lead clinicians from a range of different tumour types. Engagement of the Group provided a driving organisation for the project and allowed finalisation and agreement of the ACN strategy. By fostering dialogue with end-users, the project served to promote the use of data in improving services.

Metrics and performance monitoring

Though no formal metrics were put in place, the fact that other CNs have expressed an interest in developing similar systems for their use highlights the success of the project. In addition, the project has demonstrated longevity as the Strategy and Commissioning Group are now assessing future data needs in order to refine data outputs and usefulness.

Key learnings

- Clarify project ownership and responsibilities
- Assess availability of data including timelines
- Be selective when using metrics
- Embed key data into strategy documents rather than appending data
- Seek advice and input from organisations experienced in similar data-driven projects
- Identify and use 'quick wins' to raise the profile and demonstrate the benefit of data use in strategy decisions

For more information on the ACN project contact:
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Project examples and key learnings

Merseyside and Cheshire Cancer Network (MCCN)

Project objectives and direct outcomes

The MCCN project aimed to understand how PCT commissioning plans are engaged and aligned with the MCCN Early Detection and Prevention Strategy and to develop a product that would measure PCT commissioning plans against the ideals of the Early Detection and Prevention Strategy. The project deliverable was a performance product to enable customers to benchmark performance against local, national and international benchmarks across a variety of areas for a number of different stakeholders. The product also aimed to provide PCT's with the appropriate tools to monitor and address priorities for local cancer services.

Datasets and methodology

The MCCN team designed a performance framework which comprised a number of key categories: data on pre-treatment patient staging; screening information including variation compared with national rates; incidence, mortality and survival data; data on referral activity (for example, numbers of referrals and referral hit rates by stakeholders); data on emergency activity and varying length of stay. The approach taken by the MCCN team was to develop key indicators working closely with the Health Inequalities Manager.

Stakeholders, responsibility and communication

The project was initially piloted in one PCT with presentation of the project to the Locality Group and liaison with the PCT as well as screening and registry leads, allowing agreement of datasets to be used within the project. The benefit of the project was communicated to relevant groups and stakeholders including commissioners and clinicians during these presentations. A manual report was produced along with an in-house application which was tested prior to being rolled out to other localities.

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Merseyside and Cheshire Cancer Network (MCCN)

Governance, structure and implementation

The MCCN project is now being piloted with Liverpool PCT and Halton and St Helen's PCT and governance structures will be defined as part of this pilot programme. A manual report is being produced along with an in-house application which will be tested by the pilot PCTs prior to being rolled out to other PCTs within the CN.

Metrics and performance monitoring

The metrics used will reflect the key objectives of the performance framework.

- *Proportion of cancers staged at three months*
- *Number of cancer MDTs reaching a 90% registration status after a defined time period*
- *Number of urgent cancer referrals*
- *Total number of urgent referrals by tumour type*
- *Urgent cancer referral yield rate*
- *Median cancer waiting time*
- *Screening uptake*
- *Percentage of patients never screened*
- *Number of cancers detected via screening*
- *Variation in 1- and 5-year survival rates*
- *Variation in cancer incidence and cancer mortality compared with national and best EU figures*
- *Number of emergency admissions resulting in cancer diagnosis.*

Key learnings

- Ensure accuracy and relevance of benchmarks in order to deliver local intelligence
- Clearly identify end-users and their specific needs
- Define relevant metrics to validate the strategy
- Communicate and engage stakeholders and end-users, ensuring that benefits are clearly communicated

For more information on the MCCN project contact:
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North Trent Cancer Network (NTCN)

Project objectives and direct outcomes

The NTCN project aimed to understand the impact of the National Radiotherapy Advisory Group (NRAG) report recommendations on local services. The project has identified differences in radiotherapy provision from NRAG recommendations in a number of tumour sites. Initial data has also indicated geographical differences in provision. The data is to be interrogated further to inform commissioning and strategic planning.

Datasets and methodology

NTCN used fractionation data obtained directly from the Radiotherapy Centre as well as registrations data provided by the Trent Cancer Registry. Projected increases in incidence discussed within the NRAG report were also considered. Data analysis methods included: modelling of increases in incidence and fractionation required to meet that increase; identification

of gaps between current radiotherapy provision and recommended provision within the NRAG report; and mapping of radiotherapy provision to levels of deprivation.

Stakeholders, responsibility and communication

Stakeholder groups for the project included the Radiotherapy Centre, Trent Cancer Registry, neighbouring CNs and commissioners. Consultant oncologists were involved in data analysis and review, with clinician attendance at national and local events around NRAG. One objective is to establish an NRAG steering group and to ensure clinician representation and involvement in the group. Data was presented at the CN cancer board and the Health Inequalities group, and was also shared with Trent Cancer Registry. Wider dissemination of the data will be appropriate following further data analysis and refinement.

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North Trent Cancer Network (NTCN)

Governance, structure and implementation

Data was reviewed and approved by the Radiotherapy Centre before being provided to CN cancer boards and other groups.

Metrics and performance monitoring

Relevant metrics such as numbers of fractions delivered and waiting time impacts will be incorporated once the impact of the NRAG report is established and relevant strategies finalised.

Key learnings

- Use up to date data to ensure relevance of findings
- Develop and implement processes for quality control and checks for data accuracy in order to ensure credibility and acceptance of findings
- Leverage clinician knowledge to provide sanity checks of the data
- Cross-validate data against other datasets
- Evaluate the relevance of the evidence base, for example at different stages of disease
- Assess the level of technical knowledge needed and logistics of data access. This may be of particular relevance when taking data from technical hospital equipment.

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Project examples and key learnings

Thames Cancer Registry (TCR)

Project objectives and direct outcomes

The TCR project aimed to quantify the precision of one-year relative survival estimates, assessing how this affects their use as indicators for performance management. The project also aimed to identify 'outlier' PCTs and quantify the potential benefits of targeted interventions aimed at improving outlier status. A key driver for the project was the NAEDI recommendation that PCTs review their one-year survival data despite previous recommendations that they should not be used as a performance indicator at PCT level [Rachet B, Eayres D, Coleman MP. *Cancer survival indicators for primary care organisations in England – feasibility study. Report to the Department of Health. National Centre for Health Outcomes Development, October 2004*]. The project showed that the precision and usefulness of survival data varied considerably across PCTs due to large differences in the factors that drive precision (i.e. number of cases and deaths, and the size of PCT populations).

Datasets and methodology

TCR used one-year survival data for London and the South East Coast SHAs for patients diagnosed between 2001 and 2005, with follow up completed between 2002 and 2006. These data were extracted from the National Cancer Information Service (NCIS) for trachea, bronchus and lung cancer, breast cancer, colorectal cancer and prostate cancer. 95% confidence intervals around PCT estimates were also examined. The survival data were also compared to "best in Europe" consensus targets as proposed by Ellis-Brookes and Elliott (2009).

Stakeholders, responsibility and communication

The TCR project will have implications for a range of stakeholders at local and national level. The project findings have been shared through the local Public Health Forum for Cancer Networks and PCTs and the UK Association of Cancer Registries Conference. They will be communicated more widely through journal publication.

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Project examples and key learnings

Thames Cancer Registry (TCR)

Governance, structure and implementation

The project quantifies the imprecision of one-year relative survival data at the PCT level which even for the most common cancers can be considerable. Governance structures should reflect the availability of useful intelligence data. For example, decision-making for rare cancers would be more appropriate at the regional level rather than the local PCT level as local data lacks robustness and precision. For more common cancers, it may sometimes be appropriate to use local data to inform decisions at a local or PCT level.

Metrics and performance monitoring

The project findings highlight the need to choose suitable indicators that reflect the accuracy and precision of the data for metrics and performance monitoring. The suitability of one-year relative survival as an indicator varies significantly between cancer types and also varies between PCTs. Apparent differences in performance require careful local investigation.

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Key learnings

- Be aware that precision and usefulness of one-year relative survival data can vary considerably across different PCTs and cancer types
- Uncertainty of survival estimates need to be considered in the light of trend data and of population factors affecting survival e.g. the age structure and socioeconomic deprivation of a PCT
- Ensure that governance structures are appropriate and allow decision-making at a level which reflects the robustness and limitations of the data and the precision of the estimates
- Consideration of the gap between local performance and best in SHA or "best in Europe" consensus targets may inform local service planning and commissioning.

For more information on the TCR project contact:
Jeffery Lake jeffrey.lake@southwarkpct.nhs.uk

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Project examples and key learnings

Cancer Research UK (CRUK)

Project objectives and direct outcomes

The CRUK pilot project aimed to increase awareness, early detection and referrals for oral cancer in ethnic minority groups. As a result of the project, there was a six-fold increase in the number of patients referred with suspected oral cancer every year compared with diagnosed cases prior to the project.

Datasets and methodology

Qualitative data was obtained from focus group discussions and quantitative data from a modified Humphris Oral Cancer Awareness Scale to assess changes in awareness of symptoms and risk factors for oral cancer, attitudes and knowledge about early diagnosis, and awareness of the project, with data collection by bilingual English-Bengali field workers. Screening data from the project, data on cancer risk factors (from the Health Survey for England 2004: The Health of Ethnic Minorities), data on cancer incidence in ethnic minority groups, primarily from small-scale studies in local areas, but also from the National Cancer Intelligence Network (Ethnicity and Cancer Report 2009) was also assessed. Consideration of sample size for quantitative data was used to ensure data robustness and suitability: 400 residents were evaluated and pre- and post-samples matched in terms of age and gender.

Stakeholders, responsibility and communication

The pilot was run by CRUK, and led by the Health Information Manager, with assistance from the rest of the Health Information team, statistical information team, and the press office. The project was a partnership between CRUK and Tower Hamlets PCT, who provided the mobile dental unit for oral cancer screening, the dentist, and dental nurses. Other stakeholders included Queen Mary University of London and the Bangladeshi Stop Tobacco project, which provided community outreach workers for screening elements of the project. A Community Advisory Group (CAG) including representatives from these bodies, other health professionals, patients and community groups was established. A major benefit of CAG was the ease of communication: having defined members as points of contact facilitated timely dissemination of information and cascade to the most relevant audiences. Early engagement with stakeholders was critical to the success of the project and the availability of funding to improve awareness of oral cancer amongst a deprived high-risk group was a strong motivator of stakeholder participation.

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Cancer Research UK (CRUK)

Governance, structure and implementation

Clarity of roles, responsibilities and expectations was established through a Service Level Agreement which was developed with Queen Mary University of London for delivering on year of activity. Clinicians (oral maxillofacial surgeons, practice nurses, GPs, dentists) and CAG members provided expert guidance on the development of printed materials and screening sessions, as well as translations and provision of contacts. The pilot project was implemented by dentists and assisting dental nurses who conducted oral cancer screening. The use of bilingual, ethnically-matched outreach workers helped to encourage community compliance with referral for suspected oral cancer.

Metrics and performance monitoring

Metrics included number of patients screened and referred, compliance with referral, predictors of referral, and clinical outcomes. From the quantitative research, Chi-squared analysis of changes in awareness and logistic regression analysis was evaluated.

Key learnings

- Involve stakeholders as early as possible
- Generate suitable project-specific metrics if standard data are unavailable or unsuitable for performance assessment
- Take into account end-user profiles and assess the need for culturally matched outreach workers
- Attract or generate funding for the project as this can be a strong stakeholder motivator that demonstrates commitment

For more information on the CRUK project contact:

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Project examples and key learnings

East Midlands Cancer Network (EMCN)

Project objectives and direct outcomes

The cancer network aimed to supply quality assured clinical information to clinicians empowering them to radically change patient care.

The project utilised information from the Clinical Information Analysis (CIA) Programme which enabled the Network Pharmacists to benchmark service provision.

This information which was initially used in the south of the EMCN (former LNR) helped to drive better evidence-based treatment, development of standardised care protocols across the cancer centres, supported the robust investigation of apparently divergent practice and helped minimise inequality through postcode prescribing and access to treatment issues.

The project culminated in an oncology clinical governance meeting:

- To raise awareness amongst the Oncologists of the differences in clinical practice
- To benchmark practice
- To have an evidence based discussion in order to understand rationale for the regimens in use by reviewing current protocols
- To develop resource informed network wide guidelines.

The engagement with the clinicians, Acute Trusts and the Primary care Trusts has been strengthened by this project and, as a result, has increased compliance with NICE guidance and other key national standards. The project is now being rolled out across the EMCN as a whole.

Datasets and methodology

The data in the CIA Programme are linked data collated from existing sources held in many disparate unrelated systems. The data were centralised and translated into consistent content. Multiple data sources were used including the Cancer Register and Hospital Episode Statistics (HES), oncology databases and chemotherapy prescribing systems. The data were quality assured, validated with data providers and reported using a standard format, using defined groupings of Healthcare Resource Groups (HRGs) for surgical procedures and developed rules for classifying radiotherapy and chemotherapy regimens. Established nine years ago, the programme delivers continuous information collection and analysis of major surgery and all radiotherapy and all chemotherapy regimens by cancer site, provider and PCT and showing variations between providers and temporal trends.

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Project examples and key learnings

East Midlands Cancer Network (EMCN)

Stakeholders, responsibility and communication

The project was a successful example of a joint working project support by Trust Clinical Leads, Oncology Departments, Site Specific Teams, PCT commissioners, representatives from the CIA project, the Trent Cancer Registry and OCIOU.

The Cancer Network team worked together to ensure a positive outcome from this project. Strong clinical leadership was provided by the Network Director and Oncology NSSG chair. The pre-work undertaken by the Network Pharmacists demonstrating the inconsistencies in care from a cost perspective ensured that the commissioners were engaged and prepared to support the decisions made by the clinicians.

The information provided on the day empowered the clinicians to make informed decisions on patient care.

Governance Structure and implementation

The initial LNR project outcomes were supported by the PCTs. As the rollout takes place in the new EMCN the strong collaboration with the EM SCG who holds responsibility for commissioning drugs across NHS East Midlands will enable this project to expand. The recommendations will now be confirmed by the EM SCG and continue to result in increased adoption of clinically effective resource informed treatment protocols.

Metrics and performance monitoring

The SCG and EMCN are developing monitoring metrics in relation to adherence to agreed funded protocols.

Key learnings

- The Cancer Network team worked together to ensure a positive outcome from this project.
- Strong clinical champion is essential.
- The pre-work undertaken by the Network Pharmacist demonstrating the inconsistencies in care from a cost perspective ensured that the commissioners were engaged and prepared to support the decisions made by the clinicians
- The information provided empowered the clinicians to make informed decisions on patient care
- Clinicians' confidence in data is essential to understanding the issues
- Benchmarking with similar organisations is extremely useful when assessing care currently provided.
- Data are available to assess cancer care in a way that the NHS has to date, not used widely to support governance and commissioning.
- Discussions on contentious issues may require several iterations

For more information on the EMCN project contact:

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Cancer decision making:

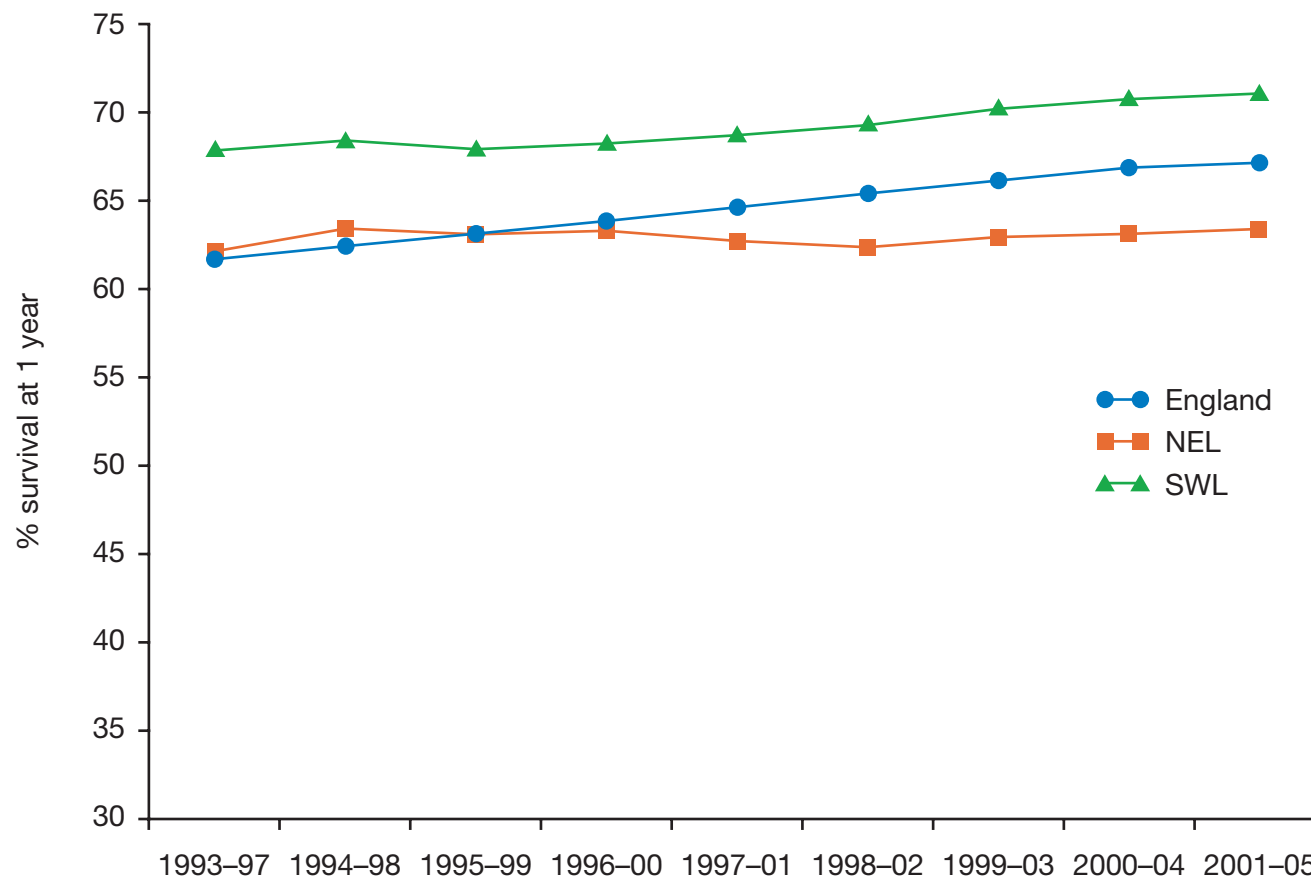
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Trends in 1 year survival from all cancers in North East London (NEL), England and South West London (SWL)



Data source: Cancer e-Atlas

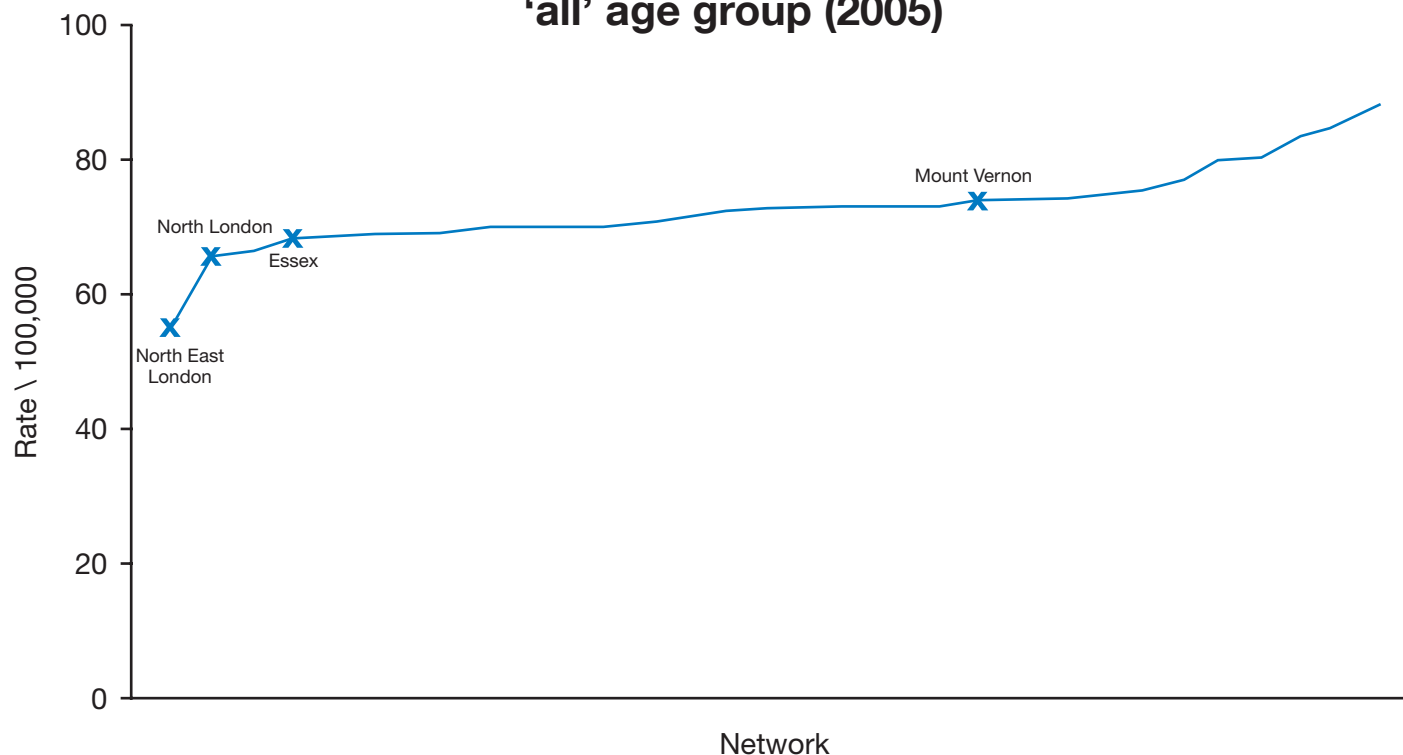
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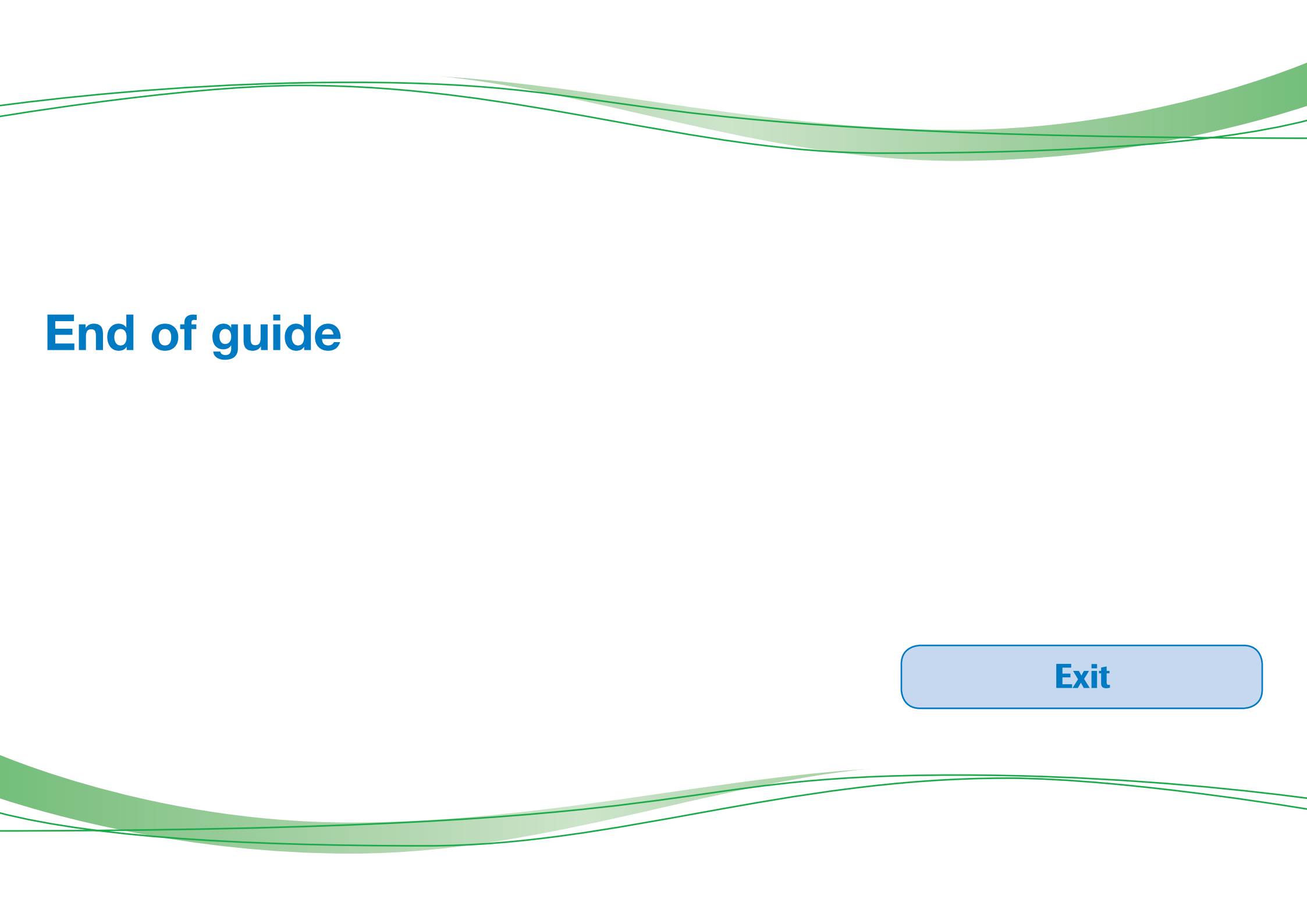
An illustrative example of benchmarking against comparators with similar demographics – age-standardised incidence of breast cancer: ‘all’ age group (2005)



Data source: Cancer Commissioning Toolkit

The number of patients with a breast cancer diagnosis (incidence), per 100,000 population within North East London, North London, Essex and Mount Vernon Cancer Networks.

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What are key considerations when deciding what data to use and what are the challenges?

Availability of up-to-date data is essential from project start to ensure that findings are relevant. High quality and [completeness of data](#) are also important.

Data accuracy is essential; however, data may differ in accuracy. Quality control checks on data are essential in order to ensure that even small inaccuracies can lead to misleading findings and loss of credibility. The size of the data set and the way data are gathered impacts data accuracy (for example relative survival) may be different for PCTs and therefore may be different as an indicator as it may lack the precision for improvements. The key is understanding the data for common cancers in larger PCTs. Data of years may provide useful insights for outlier or hotspot identification using the data, issues that need to be identified. It may be that additional data is needed then a summary.

Quality control and checks for accuracy of data are essential in order to ensure acceptance of the findings.

Data checklist

- What data sources are available and relevant to this project?
- Are the data sources easy to access or is a degree of technical knowledge needed?
- How up to date are the data?
- Are the data sources of high quality and how complete are they?
- Can other appropriate bodies be approached to fill in the gaps?
- How accurate are the data sources?
- Is the sample size sufficient to provide robust data?
- Is a quality assurance process in place?
- Who can be approached to sense-check the data?

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Introduction: embedding data in strategy

Understanding and analysing data is the first step in identifying areas of concern where improvements in health outcomes are needed.

The goal is to develop an optimal strategy such that once patients enter the health intervention programme, outcomes should be comparable regardless of an area's social and economic circumstances.

This section of the guide identifies how data can be used to underpin and drive change.

How can data be used to inform strategy?

There is a difference between data, information and intelligence. A good document should have data embedded in it. The translation of data into intelligence to inform strategy is important to be aware of the limitations of data and how they are used appropriately.

How can we understand what the data are really telling us and decide if action is needed?

Overarching issues need to be broken down and further investigated.

[Dissecting the data](#) to understand the deeper issues allows problem areas to be identified, with prioritisation and focused targeting of tailored interventions to specific groups to drive improvement.

When assessing data, it is important to understand if figures refer to

For example, it may be appropriate to interrogate data on patient demographics to assess whether a particular issue is related to factors such as age or ethnic group. Separate and detailed analysis of these data subgroups can provide a clearer picture, where practical and where data are available. For comparison/benchmarking purposes data should be age standardised. These are readily available from National Cancer Information Service (NCIS) or National Centre for Health Outcomes Development (NCHOD), and allow quick comparisons of areas to be made. However, comparisons of age-specific rates, for example to see if cancer incidence is higher in younger age groups in some populations, may also be of interest.

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cohorts (where there is a turnover of the cohort), closed cohorts (where the cohort is fixed at the start of the study), pathways or other groups. It is only when data are analysed in these groups.

How can we optimise data quality?

Where possible. In some cases data quality may be an issue. In some terms it may be necessary to consider the limitations of specific data. Use of existing datasets and how the data are interrogated, reviewed

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Action planning for change and stakeholders

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Understand the data and make it understandable

It is crucial to have a deep understanding of the data and its relevance in the clinical setting. In order to engage stakeholders, the need for action should be common and memorable to the specific audience. Survival curves and percentages of patient numbers for greater impact.

Data such as survival curves and percentages should be translated into a format that is easy to understand for greater impact.

Turn challenges into drivers for change

Being an outlier can be motivational by establishing a clear need for change or improvement. Comparison with peers, for example performance versus other CNs or PCTs, demonstrates that improvement

Small change can have a large impact. For example projects that improve referral rates or those that increase referrals. See [Merseyside and Cheshire CN](#) for more information.

Use the action planning and stakeholder checklist and

Action planning and stakeholder checklist

- Have key stakeholders been identified and 'ideal' representatives selected for involvement?
- Has the position of the stakeholder relative to the change project, been assessed?
- Can these profiles be used to enable information presentation or reports to be tailored to key areas of interest through a targeted communications strategy?
- Has the data been translated into relevant and memorable information for each target audience?
- Would formal qualitative research through focus groups be valuable?
- Are there existing patient / community groups with whom formal links can be developed or are new groups needed?
- Is the project change targeted at a particular ethnic/cultural group? If so, can community engagement be promoted through outreach? Is there a need for ethnically- or culturally-matched outreach workers?
- Can peer comparisons of relative performance be leveraged to add a competitive motivator?

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Embedding and sustaining change

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Embedding and sustaining change: What operational strategies can be employed for project implementation (cont'd)?

- Show the relevance of project outcomes and how it links to regional and national plans, for example SHA plans.
 - At the macro level, cancer should be linked to regional and national plans. At the micro level, key data should be linked to local plans.
- Develop relevant metrics to allow for monitoring and evaluation in practice. Be aware that metrics need to be relevant to the project and targets as appropriate.

- Ensure that relevant contracts are put into place and are enforceable through defining local specifications.
- Use contract review processes as a lever to ensure compliance with metrics.

Embedding and sustaining change checklist

- *Have specific roles and responsibilities been clearly defined and agreed?*
- *Is a Service Level Agreement (SLA) or Memorandum of Agreement in place?*
- *Can contracts be used to define the type and quality of data required? Can the contract review process be used to ensure compliance?*
- *Have reporting lines been formalised?*
- *Have links with relevant groups, commissioning and other funding sources been established?*
- *Can the project be adapted to benefit other subgroups of patients or tumour types?*
- *Is there an existing group that can drive practical implementation or does one need to be developed?*
- *Have relevant metrics been identified? Are indicators discriminating, meaningful and easily communicated?*

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Checklist for using data to diagnose focus areas

1. What is the local burden of disease?

- Undertake benchmarking against national, regional area and other cancer networks and Primary Care Trusts (PCTs).
- Look at **trends** (against targets) for **incidence**, **mortality** and **survival**. Looking at mortality rates in isolation can gloss over an underlying issue: question whether the mortality is as expected given the local incidence.

2. Are some groups more affected than others, i.e. are there health equity issues?

- Look at sub-groups of the local population, what is the survival by age, sex, ethnicity, deprivation?

3. Risk factors for cancer prevalence?

- What are the prevalence rates and trends for lifestyle and behavioural risk factors?

4. What is the current cost and PCT spend on cancer services?

- PCT and Cancer Network Programme Budgeting spend can be benchmarked against suitable comparator areas

5. Service provision against standards [NICE Improving Outcomes Guidance (IOG)]

- Consider both early diagnosis and treatment standards

6. Performance against standards

- For example waiting times (2-week wait, 31-day and 62-day waits), screening uptake, survival consensus targets

7. Patient satisfaction

- Data from national or local patient satisfaction surveys can be used to identify areas where change is needed

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Understanding data

There are four key dimensions to assessing and optimising data quality

Completeness: care should be taken when using and interpreting incomplete data. For example, where ethnicity data is only 80% complete the ethnic composition conclusions that can be drawn.

Consistency and accuracy: if different Trusts use definitions that have different definitions. For example, one Trust may include data on all cases, while another Trust may only include new diagnoses.

Robustness of sample size: sample sizes of subgroups need to be sufficiently large to enable robust comparisons to be made. Use of small sample sizes may lead to a lack of robustness of the comparisons drawn.

Direct or indirect standardisation is generally inappropriate to use for comparisons of (incidence or survival) in populations with different ethnic compositions.

Data should be cross-validated against other sources of data. Data should be utilised to help with data interpretation and not used for the purpose of use of misleading or ambiguous data. Data should be used to build an evidence base at different stages of care.

[Click here](#) for a data checklist and summary

Data checklist

- What data sources are available and relevant to this project?
- Are the data sources easy to access or is a degree of technical knowledge needed?
- How up to date are the data?
- Are the data sources of high quality and how complete are they?
- Can other appropriate bodies be approached to fill in the gaps?
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Problem identification

What are key considerations and what are the challenges?

Availability of up-to-date findings are relevant and important.

Data accuracy is essential. Data may differ in accuracy and data are essential for even small inaccuracies and loss of credibility. Data are gathered from a range of sources, for example relative to PCTs and there are many indicators as it may be used for improvements. The data for common cancers over a number of years may provide an outlier or hotspot.

Checklist for using data to diagnose focus areas

1. What is the local burden of disease?

- Undertake benchmarking against national, regional area and other cancer networks and Primary Care Trusts (PCTs).
- Look at **trends** (against targets) for **incidence**, **mortality** and **survival**. Looking at mortality rates in isolation can gloss over an underlying issue: question whether the mortality is as expected given the local incidence.

2. Are some groups more affected than others, i.e. are there health equity issues?

- Look at sub-groups of the local population, what is the survival by age, sex, ethnicity, deprivation?

3. Risk factors for cancer prevalence?

- What are the prevalence rates and trends for lifestyle and behavioural risk factors?

4. What is the current cost and PCT spend on cancer services?

- PCT and Cancer Network Programme Budgeting spend can be benchmarked against suitable comparator areas

5. Service provision against standards [NICE Improving Outcomes Guidance (IOG)]

- Consider both early diagnosis and treatment standards

6. Performance against standards

- For example waiting times (two-week wait, 31-day and 62-day waits), screening uptake, survival consensus targets

7. Patient satisfaction

- Data from national or local patient satisfaction surveys can be used to identify areas where change is needed

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There are four key dimensions to assessing and optimising data quality

Completeness: care should be taken when using and interpreting incomplete data. For example, where ethnicity data is only 80% complete the ethnic composition of the other 20% may confound any conclusions that can be drawn.

Consistency and accuracy: it is not appropriate to compare data that have different definitions. For example, data on skin cancer from one Trust may include data on all skin cancers whereas data from another Trust may only include melanoma.

Robustness of sample size: [sample sizes](#) of subgroups need to be sufficiently large to enable robust comparisons to be made. Use of 95% [confidence intervals](#) will test the robustness of the comparisons and give confidence in the conclusions drawn.

Appropriate standardisation: it is generally inappropriate to compare crude rates (e.g. of incidence or survival) in populations with very different demographic structures. Direct or indirect standardisation

Data should be cross-validated against other sources of data. Data should be utilised to help with data interpretation and not used for use of misleading or ambiguous data. Data should be used to build an evidence base at different stages of care.

[Click here](#) for a data checklist and summary.

Most data are based on a sample of a population rather than an entire population. The larger the sample size the more likely it is that the data are an accurate representation of the entire population, conversely, the smaller the sample size the more prone to data error or misrepresentation.

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There are four key dimensions to assessing and optimising data quality

Completeness: care should be taken when using and interpreting incomplete data. For example, where ethnicity data is only 80% complete the ethnic composition of the other 20% may confound any conclusions that can be drawn.

Consistency and accuracy: it is not appropriate to compare data that have different definitions. For example, one Trust may include data on all patients, while another Trust may only include new patients.

Robustness of sample size: [sample sizes](#) of subgroups need to be sufficiently large to enable robust comparisons to be made. Use of 95% [confidence intervals](#) will test the robustness of the comparisons and give confidence in the conclusions drawn.

Appropriate standardisation: it is generally inappropriate to compare rates (incidence or survival) in populations with different characteristics. Direct or indirect standardisation

Data should be cross-validated against other sources. Data should be utilised to help with data interpretation and not used for use of misleading or ambiguous data. Data should be used to build an evidence base at different stages of care.

[Click here](#) for a data checklist and summary

A confidence interval (CI) indicates the likely range of values (X–Y) for an unknown parameter. CIs are often expressed at the 95% level which means that 95% of the time, the unknown parameter will be a value between the lower confidence limit (X) and the upper confidence limit (Y). The difference between X and Y (i.e. the confidence interval) indicates the degree of certainty or uncertainty regarding the unknown parameter: the wider the confidence interval the less certain the parameter. The 95% CI correlates to a 5% (or 0.05) probability of the unknown parameter not being within confidence limits, hence a 'p value' of less than 0.05 being statistically significant.

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There are four key dimensions to assessing and optimising data quality

Completeness: care should be taken when using and interpreting incomplete data. For example, where ethnicity data is only 80% complete the ethnic composition of the other 20% may confound any conclusions that can be drawn.

Consistency and accuracy: it is not appropriate to compare data that have different definitions. For example, data on skin cancer from one Trust may include data on all skin cancers whereas data from another Trust may only include melanoma.

Robustness of sample size: [sample sizes](#) of subgroups need to be sufficiently large to enable robust comparisons to be made. Use of 95% [confidence intervals](#) will test the robustness of the comparisons and give confidence in the conclusions drawn.

Appropriate standardisation: it is generally inappropriate to compare [crude rates](#) (e.g. of incidence or survival) in populations with very different demographic structures. Direct or indirect standardisation

Data should be cross-validated against other sources. Data should be utilised to help with data interpretation and not use of misleading or ambiguous data. Data should be used to build an evidence base at different stages of change.

[Click here](#) for a data checklist and summary.

Counts and crude rates represent real figures from a given area, whereas age-standardised rates represent comparable figures if a study population matched the chosen standard population (and does not necessarily indicate true caseload). Standardised rates are useful for comparison between areas and not for analysis of patient numbers in a given area.

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How does benchmarking help identify problem areas and which benchmarks are appropriate?

Identification, establishment and validation of relevant benchmarks are essential in deciding whether intervention is needed. Accurate and relevant benchmarking ensures correct identification of 'real' issues that need to be addressed.

Accurate and relevant benchmarking ensures correct identification of 'real' issues

Accurate benchmarking also delivers information so that end-users can use tailored solutions.

Which benchmarks are appropriate?

Data should first be benchmarked against national trends at a Cancer Network (CN) or Primary Care Trust (PCT) level, before subgroup comparisons (for example, by age) because as sample size decreases, the robustness of the data is reduced. [Click here](#) to view an illustrative example from North East London CN.

When benchmarking by CN or PCT it is useful to understand which CNs/ PCTs have similar demographics to benchmark against. [Click here](#) to view an illustrative example from Mount Vernon CN.

It may be possible to identify clusters with similar characteristics to allow for comparison with similar population groups.

Relative survival is a survival measure that compares against the background mortality in a population. Therefore 100% relative survival represents no additional deaths than would be expected in the normal population, and does not represent a zero mortality rate.

[Close](#)

Comparison with EU figures is valuable for planning and commissioning. For example, a realistic target of what can be achieved by benchmarking against countries with a high survival rate, such as Scandinavian countries or Denmark, may be suitable for the National Cancer Intelligence Network (NCIN) and other networks. The NCIN have developed 'consensus' 1-year [relative survival](#) rates informed by European comparisons (see *Local Awareness and Early Diagnosis Baseline Assessments: A Guide for Cancer Networks and Primary Care Trusts*. Available at: www.ncin.org.uk/docs/LAEDI_Baseline_Guide_May_2009.pdf)

EU data provide a realistic target of what can be achieved

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What are key considerations when deciding what data to use and what are the challenges?

Availability of up-to-date data is essential from project start to ensure that findings are relevant. High quality and [completeness of data](#) are also important.

Data accuracy is essential; however, data may differ in accuracy. Quality control data are essential in order to ensure that even small inaccuracies can lead to loss of credibility. The size of data gathered impacts data accuracy (for example relative survival) may be different as PCTs and therefore may be difficult to use as an indicator as it may lack the precision to track yearly relative survival improvements. The key is understanding the data robustness; data for common cancers in larger PCTs, pooled over sufficient number of years may provide useful insight. [Click here](#) to see an example of outlier or hotspot identification using a [funnel plot](#).

Funnel plots are scatter plots which take into account confidence limits and are useful for comparing observations or data from different areas (such as different Trusts) with varying sample sizes. The funnel plot incorporates a line drawn at the average or mean as well as upper and lower control limits: as sample sizes decrease, an observation must be further from the average to be considered significantly different. Thus outliers can be identified based on their distance from the average, any data point outside of the control limits is significantly different.

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Quality control and checks for accuracy of data are essential in order to ensure acceptance of the findings.

Once the problem has been identified using the data, issues that need to be addressed can be identified. If project objectives identified. It may be that additional data is needed then to diagnose focus areas.

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Confidence interval:

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Crude rates:

Counts and crude rates represent real figures from a given area, whereas age-standardised rates represent comparable figures if a study population matched the chosen standard population (and does not necessarily indicate true caseload). Standardised rates are useful for comparison between areas and not for analysis of patient numbers in a given area.

Funnel plot:

Funnel plots are scatter plots which take into account confidence limits and are useful for comparing observations or data from different areas (such as different Trusts) with varying sample sizes. The funnel plot incorporates a line drawn at the average or mean as well as upper and lower control limits: as sample sizes decrease, an observation must be further from the average to be considered significantly different. Thus outliers can be identified based on their distance from the average, any data point outside of the control limits is significantly different.

Relative survival:

Relative survival is a survival measure that compares against the background mortality in a population. Therefore 100% relative survival represents no additional deaths than would be expected in the normal population, and does not represent a zero mortality rate.

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Understanding data

- What data sources are available and relevant to this project?
- Are the data sources easy to access or is a degree of technical knowledge needed?
- How up to date are the data?
- Are the data sources of high quality and how complete are they?
- Can other appropriate bodies be approached to fill in the gaps?
- How accurate are the data sources?
- Is the sample size sufficient to provide robust data?
- Is a quality assurance process in place?
- Who can be approached to sense-check the data?

Problem Identification

1. What is the local burden of disease?

- Undertake benchmarking against national, regional area and other cancer networks and Primary Care Trusts (PCTs).
- Look at **trends** (against targets) for **incidence, mortality** and **survival**. Looking at mortality rates in isolation can gloss over an underlying issue: question whether the mortality is as expected given the local incidence.

2. Are some groups more affected than others, i.e. are there health equity issues?

- Look at sub-groups of the local population, what is the survival by age, sex, ethnicity, deprivation?

3. Risk factors for cancer prevalence?

- What are the prevalence rates and trends for lifestyle and behavioural risk factors?

4. What is the current cost and PCT spend on cancer services?

- PCT and Cancer Network Programme Budgeting spend can be benchmarked against suitable comparator areas

5. Service provision against standards [NICE Improving Outcomes Guidance (IOG)]

- Consider both early diagnosis and treatment standards

6. Performance against standards

- For example waiting times (two-week wait, 31-day and 62-day waits), screening uptake, survival consensus targets

7. Patient satisfaction

- Data from national or local patient satisfaction surveys can be used to identify areas where change is needed

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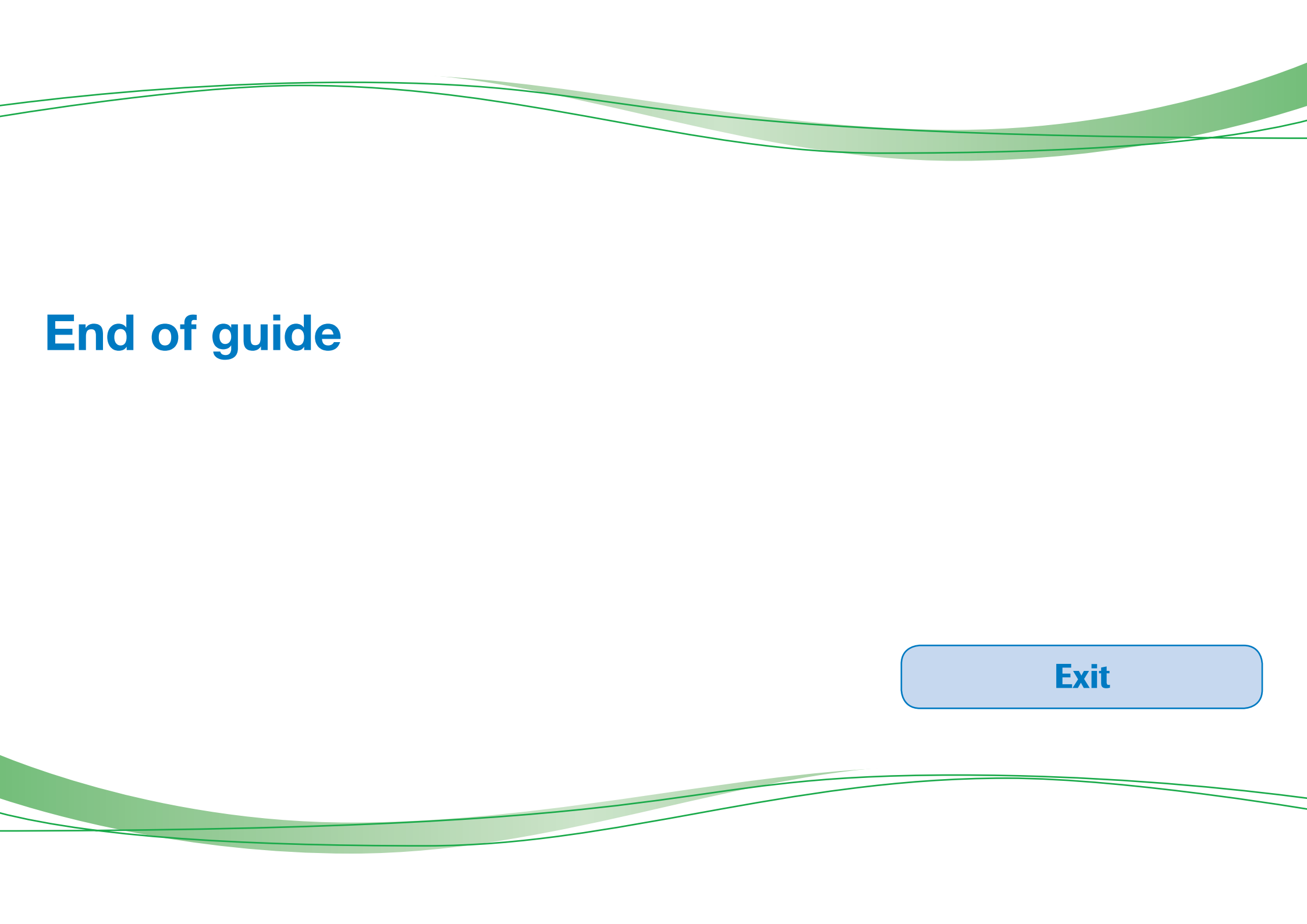
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Action planning for change and stakeholders

- Have key stakeholders been identified and 'ideal' representatives selected for involvement?
- Has the position of the stakeholder relative to the change project, been assessed?
- Can these profiles be used to enable information presentation or reports to be tailored to key areas of interest through a targeted communications strategy?
- Has the data been translated into relevant and memorable information for each target audience?
- Would formal qualitative research through focus groups be valuable?
- Are there existing patient / community groups with whom formal links can be developed or are new groups needed?
- Is the project change targeted at a particular ethnic/cultural group? If so, can community engagement be promoted through outreach? Is there a need for ethnically- or culturally-matched outreach workers?
- Can peer comparisons of relative performance be leveraged to add a competitive motivator?

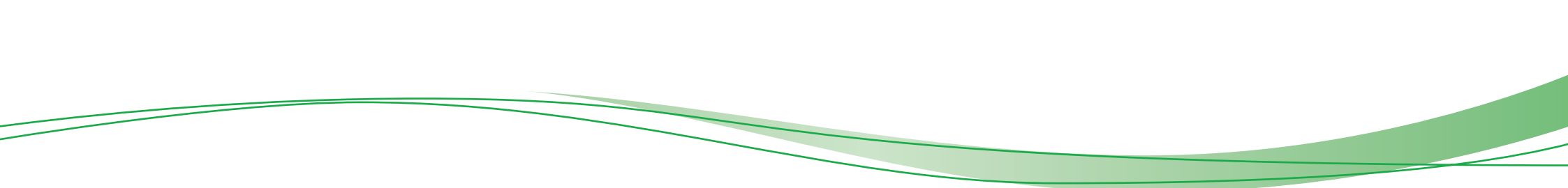
Embedding and sustaining change checklist

- Have specific roles and responsibilities been clearly defined and agreed?
- Is a Service Level Agreement (SLA) or Memorandum of Agreement in place?
- Can contracts be used to define the type and quality of data required? Can the contract review process be used to ensure compliance?
- Have reporting lines been formalised?
- Have links with relevant groups, commissioning and other funding sources been established?
- Can the project be adapted to benefit other subgroups of patients or tumour types?
- Is there an existing group that can drive practical implementation or does one need to be developed?
- Have relevant metrics been identified? Are indicators discriminating, meaningful and easily communicated?



End of guide

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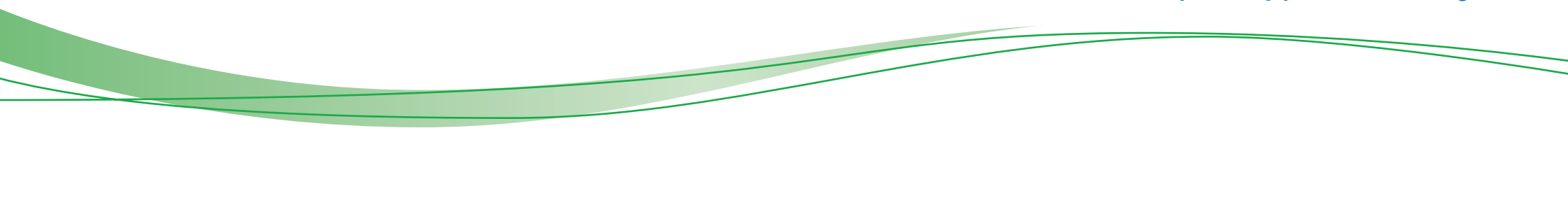
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This guide has been developed collaboratively by Anglia Cancer Network, Cancer Research UK, Merseyside & Cheshire Cancer Network, Mount Vernon Cancer Network, North Trent Cancer Network, North East London Cancer Network and Roche Products Limited. Roche supported this joint working project by providing project management, facilitation and artwork resource.

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Introduction

This is an electronic guidance document to help assist users when using data (e.g. Cancer Commissioning Toolkit and Cancer Commissioning Guidance) to guide decisions and investigations.

Health service organisations are tasked with delivering health objectives and targets by prioritising resources according to need, both at the national and local level. Rational prioritisation should rely intrinsically on evaluation of data to identify areas for improvement.

Objectives

This guide is intended to provide a practical framework, incorporating key considerations, for the use of cancer data to inform health planning and decision making.

Who will use this guide?

Anyone or any team involved in supporting:

- commissioning
- service improvement
- Primary Care Trusts (PCTs) and Cancer Networks (CNs) in achieving cancer targets

The guide is divided into sections providing guidance on: understanding data, problem identification, action planning for change and working with stakeholders, embedding and sustaining change, and monitoring and evaluation. Case studies as practical examples of data use in decision making are also provided, along with a summary of Top 10 tactics for effective use of data to drive change.

Several factors are key to optimal data use in decision making

- A clear understanding of the value of different datasets and their limitations
- Translation of data into information and intelligence to make the data locally relevant and applicable
- Integration of data into strategic health improvement plans.

[Click here](#) to see how data can be used to make change happen.

The guide addresses several key questions: *What do we use the data for? How do we use the data? Who will use it? Who are the key influencers?*

Data can be used to inform all steps of the Health Service decision-making process, including

1. *prioritisation of areas for improvement*
2. *strategy development*
3. *commissioning services*
4. *monitoring of commissioned services*
5. *evaluation of providers / service model*
6. *change management*

Which stakeholders are actively involved depends on the step – the important thing is to involve all those from whom you need a behavioural change (e.g. clinicians), or who are key influencers.

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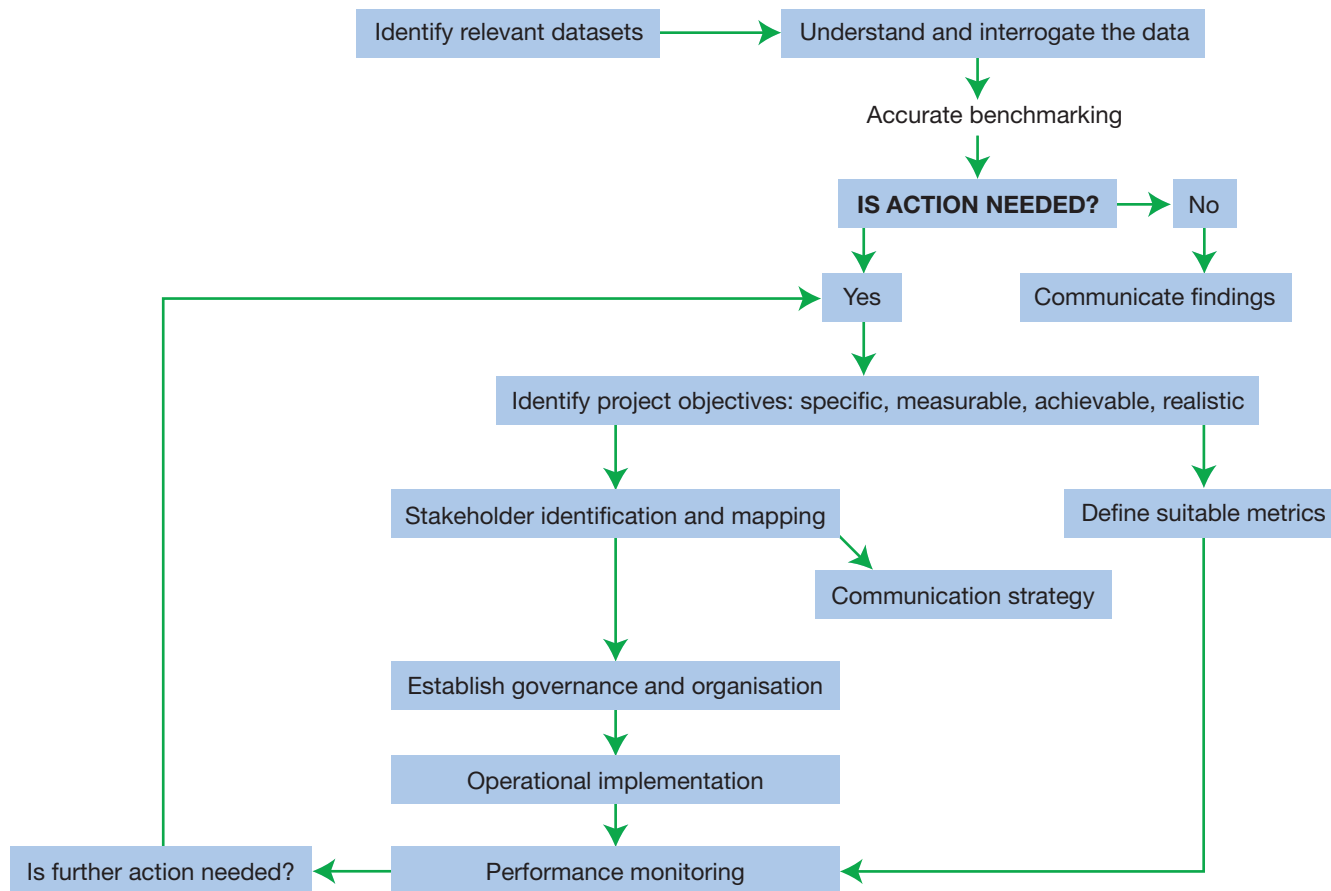
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Using data to make change happen

[Click here](#) to access a checklist for using data to diagnose focus areas



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Checklist for using data to diagnose focus areas

1. What is the local burden of disease?

- Undertake benchmarking against national, regional area and other cancer networks and Primary Care Trusts (PCTs).
- Look at **trends** (against targets) for **incidence**, **mortality** and **survival**. Looking at mortality rates in isolation can gloss over an underlying issue: question whether the mortality is as expected given the local incidence.

2. Are some groups more affected than others, i.e. are there health equity issues?

- Look at sub-groups of the local population, what is the survival by age, sex, ethnicity, deprivation?

3. Risk factors for cancer prevalence?

- What are the prevalence rates and trends for lifestyle and behavioural risk factors?

4. What is the current cost and PCT spend on cancer services?

- PCT and Cancer Network Programme Budgeting spend can be benchmarked against suitable comparator areas

5. Service provision against standards [NICE Improving Outcomes Guidance (IOG)]

- Consider both early diagnosis and treatment standards

6. Performance against standards

- For example waiting times (2-week wait, 31-day and 62-day waits), screening uptake, survival consensus targets

7. Patient satisfaction

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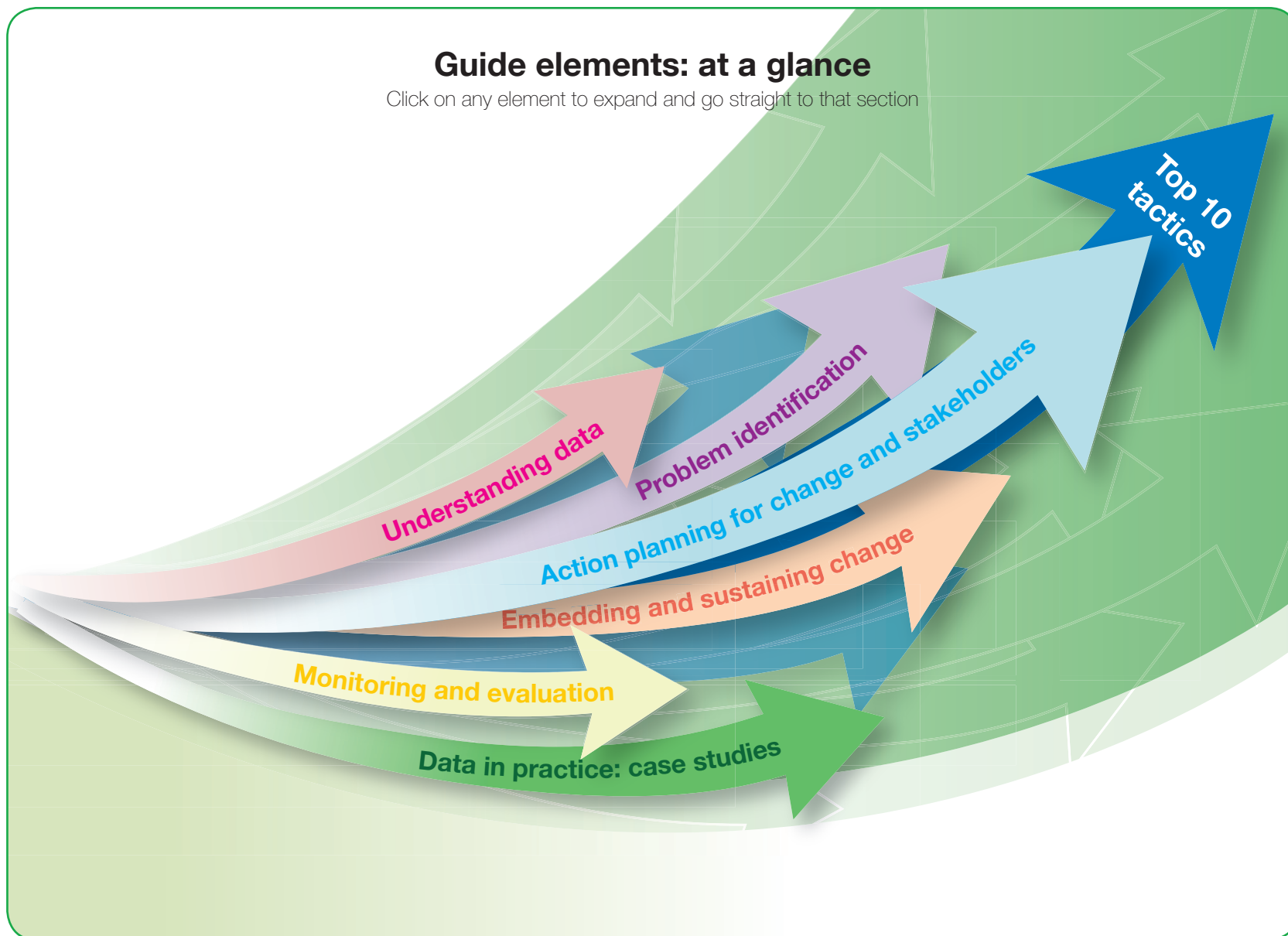
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Problem identification

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How does benchmarking help identify problem areas and which benchmarks are appropriate?

Identification, establishment and validation of relevant benchmarks are essential in deciding whether intervention is needed. Accurate and relevant benchmarking ensures correct identification of 'real' issues that need to be addressed.

Accurate and relevant benchmarking ensures correct identification of 'real' issues that need to be addressed

Accurate benchmarking also delivers local intelligence rather than information so that end-users can use the data to develop localised and tailored solutions.

Which benchmarks are appropriate?

Data should first be benchmarked against national trends at a Cancer Network (CN) or Primary Care Trust (PCT) level, before subgroup comparisons (for example, by age) because as sample size decreases, the robustness of the data is reduced. [Click here](#) to view an illustrative example from North East London CN.

When benchmarking by CN or PCT it is useful to understand which CNs/ PCTs have similar demographics to benchmark against. [Click here](#) to view an illustrative example from Mount Vernon CN.

It may be possible to identify clusters with similar characteristics to allow for comparison with similar population groups.

Comparison with EU figures is valuable for planning and commissioning purposes. EU data provides a realistic target of what can be achieved. EU benchmarking should be against countries with a similar level of registration. For example, Scandinavian countries such as Sweden, Norway, Finland or Denmark, may be suitable comparators. The National Cancer Intelligence Network (NCIN) and National Cancer Action Team (NCAT) have developed 'consensus targets' for the four major tumours of 1-year [relative survival](#) rates informed by European comparisons (see *Local Awareness and Early Diagnosis Baseline Assessments: A Guide for Cancer Networks and Primary Care Trusts*. Available at:

www.ncin.org.uk/docs/LAEDI_Baseline_Guide_May_2009.pdf)

EU data provide a realistic target of what can be achieved

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Benchmarking outputs should be memorable, understandable and user-friendly. For example the RAG (red, amber green) system could be used as an initial starting point where 'R' identifies areas of potential concern for further investigation or intervention. See practical example from the [Anglia CN project](#).

	INCIDENCE (cancers diagnosed 2002–2006)	1-YEAR RELATIVE SURVIVAL (cancers diagnosed 2002–2006)	5-YEAR RELATIVE SURVIVAL (cancers diagnosed 1998–2002)	MORTALITY (deaths 2003–2007, persons aged 0–74)
ALL CANCERS	11	11	10	4
C00–C14: Lip, oral cavity and pharynx	8	3	6	4
C15: Oesophagus	2	18	24	8
C16: Stomach	16	12	21	7
C18–C20: Colorectum	23	10	5	9
C25: Pancreas	7	12	26	9
C33–C34: Trachea, bronchus and lung	8	8	20	6
C43: Malignant melanoma of skin	20	6	9	18
C50: Breast (f)	23	3	4	21
C53: Cervix uteri	5	19	10	3
C54–C55: Uterus	28	13	15	19
C56: Ovary	12	13	19	12
D61: Prostate	21	10	10	9
D62: Testis	19	7	5	14
D64: Kidney, except renal pelvis	23	22	20	26
D67: Bladder	5	23	23	7
D69–C72: Eye, brain, and other parts of the central nervous system	12	22	19	5
C81: Hodgkin's disease	27	27	7	6
C82–C85: Non-Hodgkin's lymphoma	16	20	22	18
C91–C95: Leukaemia	14	17	8	16

ACN Cancer landscape 'Tartan rug'. Source: NOIS data

The figure above shows how the RAG system forms a 'Tartan rug' output.

It is important to ensure that data have been appropriately standardised before benchmarking, note: use of unified weighted population, from programme budgeting spend allocation, to normalise data is typically inappropriate for cancer because the current unified weighted population formula is an indicator of total disease burden, whereas cancer is an age-related disease.

The use of age-standardised data is helpful for benchmarking of cancer-related service data.

Evidence suggests that 'unified weighted populations' are inappropriate denominators by which to measure inequalities in healthcare provision. When benchmarking, the use of alternative denominators can lead to a more pronounced and consistent pattern of care quality, for example age.

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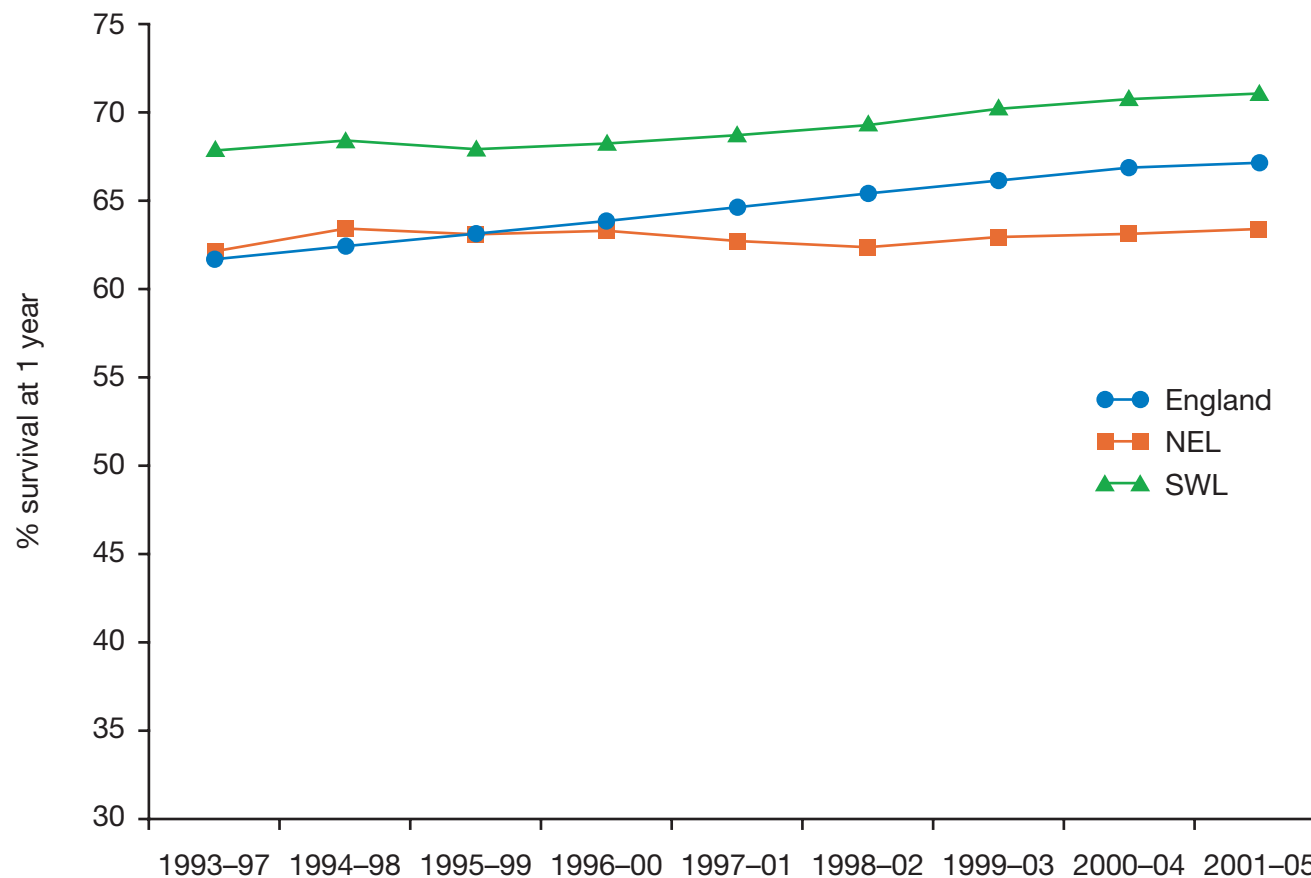
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Trends in 1-year survival from all cancers in North East London (NEL), England and South West London (SWL)



Data source: Cancer e-Atlas

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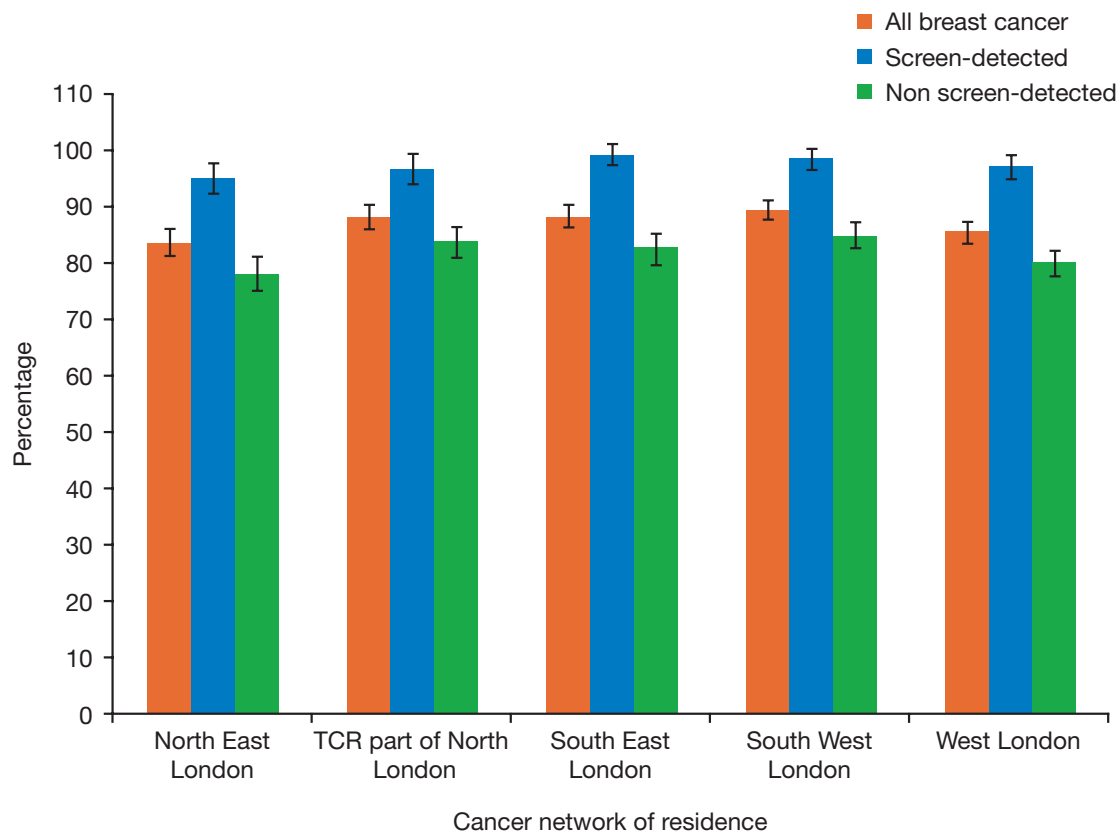
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Period analysis of relative survival for breast cancer in the 50–64 year age group by cancer network of residence, London 2001–2005



Relative survival of North East London Cancer Network patients of screening age is not statistically significantly different from the rest of London for either screen-detected or symptomatic disease

Data source: Thames Cancer Registry (TCR) and London Breast Screening QARC analysis

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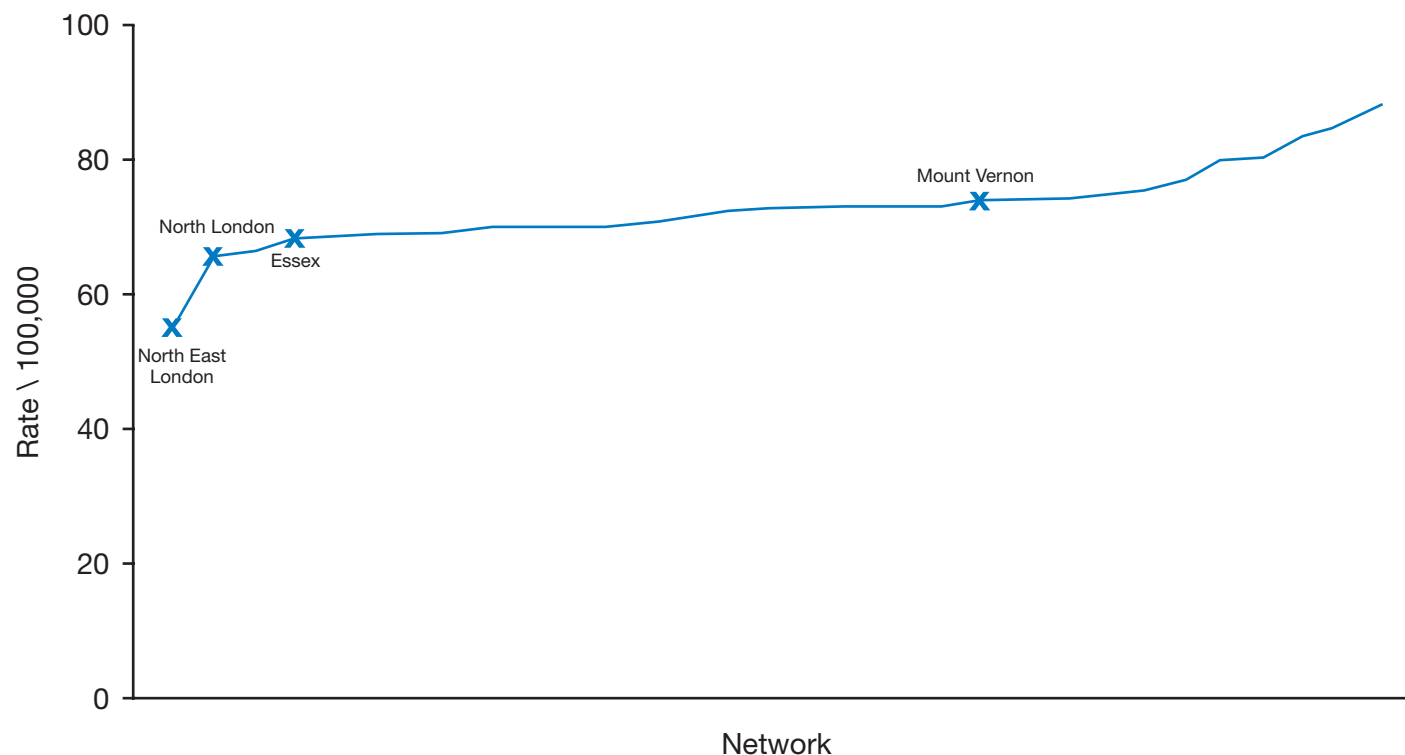
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An illustrative example of benchmarking against comparators with similar demographics – age-standardised incidence of breast cancer: ‘all’ age group (2005)



Data source: Cancer Commissioning Toolkit

The number of patients with a breast cancer diagnosis (incidence), per 100,000 population within North East London, North London, Essex and Mount Vernon Cancer Networks.

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What are the most valuable datasets currently available and what can they tell us?

Health intervention programmes aim to improve outcomes for patients, and relative survival is often a key tool for measuring outcomes.

1-year relative survival

- Surrogate for stage of presentation, and wider burden of disease in the local population

5-year relative survival

- Indicator of overall outcomes, including both stage of presentation and quality of care provided

Kaplan-Meier curves are valuable for identifying early deviation in survival ([Click here](#) to see examples from the North East London CN project).

Five- and 1-year survival can be useful indicators that outcomes need improvement. However, it should be noted that survival data may merely identify that there is a problem. Further work may be needed to understand the reasons for poor survival and inform decisions about possible interventions.

[Click here](#) to view a list of some of the most informative datasets. Note, the Cancer Commissioning Toolkit is a useful collated data source (www.cancertoolkit.co.uk). The Toolkit includes a range of high-level indicators and also links to more detailed information including data on prevention, screening, referral and treatment.

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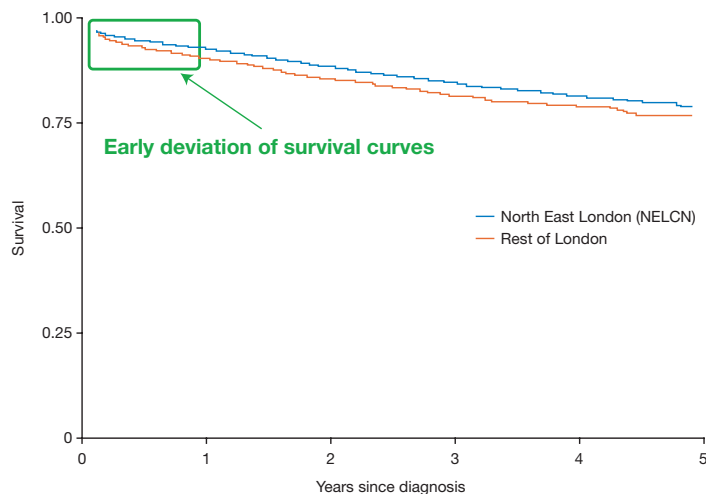
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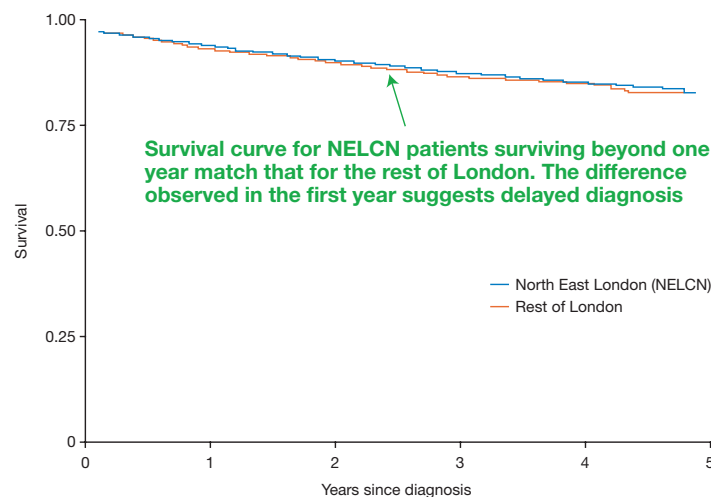
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Kaplan-Meier survival estimates for female breast cancer in NELCN and the rest of London, 2001–2005



Data source: Thames Cancer Registry

Kaplan-Meier survival estimates for female breast cancer in NELCN and the rest of London for patients surviving to one year, 2001–2005



Data source: Thames Cancer Registry

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Data type	Nation	Source	Link	Description	Notes
Incidence	England	NCHOD NCIS + Cancer e-atlas (NCIN) + Cancer Registries Reports and direct data requests	www.nchod.nhs.uk/ www.ncin.org.uk/analysis/ncis.shtml www.ncin.org.uk/analysis/eatlas.shtml	DSR (3-year average). Count (3-year average).	Data provided by regional cancer registries. Network populations derived using Lower Super Output area provided by ONS to UKACR.
Mortality	England			DSR (3-year average). Count (3-year average).	Data provided by ONS. Network populations derived using Lower Super Output area provided by ONS to UKACR.
Survival	England			1-, 3- and 5-year relative survival (5 year average).	Network populations derived using Lower Super Output area provided by ONS to UKACR.
Cancer spend	England	Programme Budgeting (DOH)	www.dh.gov.uk/en/Managingyourorganisation/Financeandplanning/Programmebudgeting/DH_075743	Spend per 100,000 population, by programme by financial year.	Continual refinements to data collection, coding and calculation of references costs affect the allocation of costs to programme categories from one year to the next. Caution is advised when using programme budgeting data to draw conclusions on changes in spending patterns between years.
Ethnicity	England	Office of National Statistics + Cancer Registry may also hold this information for cancer patients	www.statistics.gov.uk/StatBase/Product.asp?vlnk=14238	Resident population estimates by age, gender, ethnic group.	Experimental statistics are in testing phase and not fully developed. It is important that these statistics are clearly marked as experimental.
Deprivation	England	Communities and Local Government	www.communities.gov.uk/communities/neighbourhoodrenewal/deprivation/deprivation07/	Deprivation indices and rank by PCT.	The Index of Multiple Deprivation (IMD) 2007 combines indicators that cover a range of economic, social and housing issues, into a single deprivation score. The PCT index uses an 'Average score' which is the population weighted average of the combined IMD scores for the LSOAs in a district.
Breast screening	England	The Information Centre (NHS)	www.ic.nhs.uk/statistics-and-data-collections/screening/breast-cancer/breast-screening-programme-england-2007-08	Data reported include numbers invited, numbers screened, and the outcomes of screening (including diagnosis of cancer).	Eligibility: every 3 years for all women in the UK aged 50 years and over.
Cervical screening	England	The Information Centre (NHS)	www.ic.nhs.uk/statistics-and-data-collections/screening/cervical-screening	Data reported include numbers invited, numbers screened, and the outcomes of screening (including diagnosis of cancer).	Eligibility: every 3 to 5 years for all women in the UK aged 25–64 years.
Bowel screening	England	The Information Centre (NHS) Bowel Cancer Screening Programme (NHS)	www.cancerscreening.nhs.uk/bowel/index.html www.bcsp.nhs.uk	Data reported include numbers invited, numbers screened, and the outcomes of screening (including diagnosis of cancer).	Final screening centres are being rolled out. Expected to complete end of 2009. Unknown when first data will be published. Eligibility: every 2 years to all men and women aged 60 to 69 years. People over 70 can request a screening kit.
Treatment	England	National Audit information (e.g. LUCADA, DAHNO, NBOCAP, AUGIS, MBR)	www.ic.nhs.uk		National audit data is becoming more complete in terms of number of Trusts supplying data. Note, the information is useful for comparing treatment patterns across the country but may not adequately uncover local inequalities. Detailed treatment data is only currently available direct from MDTs or patient notes.
Hospital Episode Statistics	England	HES online NHS Information Centre Some agencies provide services to extract and manipulate data (e.g. Dr Fosters, Binley's).	www.hesonline.nhs.uk	Database containing records of admissions to NHS hospitals. Each record covers a period of care or episode. Records contain patient, clinical, administrative and geographical information.	HES are a rich and complex data source that can be used to answer a wide range of questions. There are approximately 60 different fields. Care must be taken with analysis as coding is incomplete for many fields (i.e. drug treatment). Outpatient and Accident and Emergency data are collected but not linked to PBR so coding is incomplete.
Disease staging data	UK	Cancer registries			Disease staging is not a mandatory data field for cancer registration. Staging data held by cancer registries is incomplete. Staging data, since April 2009, forms part of the national dataset being provided electronically from MDTs to Cancer Registries as required by acute contract.

Abbreviations: ONS=Office for National Statistics; UKACR=United Kingdom Association of Cancer Registries; LSOA=Lower Layer Super Output Area; MDT=Multidisciplinary Team;

DSR=direct (age) standardised rate; NCHOD=National Centre for Health Outcomes Development.

Although staging data may not be routinely available, it can add value and accuracy to data analyses. Patient-specific treatment data and outcomes are also valuable.

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When are time trends useful?

The use of time trends can be highly valuable in showing 'direction of travel', and can be used effectively with incidence, mortality and relative survival data. Comparison of time trends with both national data and selected benchmark CNs can provide insight into whether rates of improvement are better or worse than average.

It is recommended that mortality time trends by CN/ PCT should be compared together with the incidence trends for the same CN/PCT to start to understand whether the local cancer services are having a positive impact on patient outcomes. Whilst a mortality time trend viewed on its own could be flat suggesting little progress is being made, when viewed with an increasing incidence trend this can show altogether a totally different and more positive picture. [Click here](#) to view an illustrative example from North London CN.

It is also useful to analyse the time trends for incidence, mortality and relative survival according to patient age (both ≤ 75 years and >75 years). Average length of stay (ALoS) data can also be useful to understand which tumours are driving in-patient costs but it may be necessary to [separate and analyse the data](#) according to procedure.

Other data that may be valuable as and when it becomes available includes:

- Staging data from multidisciplinary teams (MDT). Of note, MDT data including staging, forms part of the contracted minimum cancer dataset to be provided on a prospective basis to Cancer Registries from April 2009.

Is ethnicity data valuable?

Ethnicity data can provide valuable insight into variations in access to, or outcomes of healthcare between different groups, but is reliant on accurate coding. Unfortunately all current sources of ethnicity data are incomplete. Care needs to be taken to use the appropriate sub-grouping of ethnic categories, such that the sample size is large enough to draw conclusions without averaging differences between populations. For example use of 'Asian' category, covering Indian, Pakistani and Bangladeshi, may not provide sufficient granularity. In addition, recording of ethnicity may be problematic as it is self-defined. Ethnicity is not included on death certificates: only place of birth is recorded and this may not reflect ethnicity.

- Significant event audits (SEA) and primary care audit data including referrals and patient outcomes.
- Analysis of referrals data to show referral route, (e.g. the proportion of cancers that come through urgent referrals or standard referral) with further breakdown of data by PCT and GP practice.

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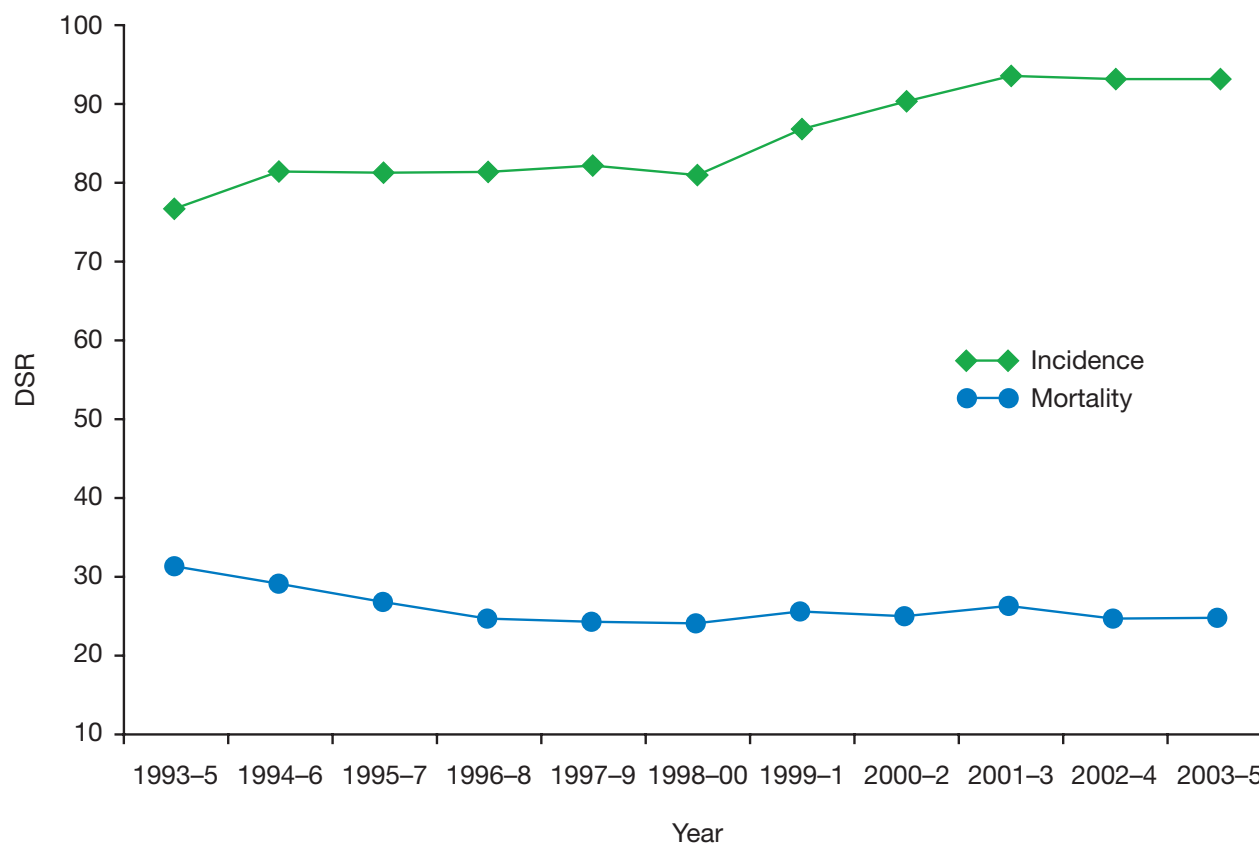
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Prostate cancer incidence vs mortality



North London Cancer Network

Date: October 2009

Data Source: Cancer e-Atlas. Last accessed October 09. www.apho.org.uk/addons/_4990/atlas.html

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What are key considerations when deciding what data to use and what are the challenges?

Availability of up-to-date data is essential from project start to ensure that findings are relevant. High quality and [completeness of data](#) are also important.

Data accuracy is essential; however, currently available datasets may differ in accuracy. Quality control and checks for accuracy of data are essential in order to ensure acceptance of the findings: even small inaccuracies can lead to stakeholder disengagement and loss of credibility. The size of the sample group from which the data are gathered impacts data accuracy. Precision of data (for example relative survival) may be low in smaller sample groups such as PCTs and therefore may be difficult to interpret or use as an indicator as it may lack the precision to track yearly relative survival improvements. The key is understanding the data robustness; data for common cancers in larger PCTs, pooled over sufficient number of years may provide useful insight. [Click here](#) to see an example of outlier or hotspot identification using a [funnel plot](#).

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Quality control and checks for accuracy of data are essential in order to ensure acceptance of the findings.

Once the problem has been identified using the data, issues that need to be addressed can be formulated and project objectives identified. It may also be necessary to determine whether additional data is needed then an action plan can be developed.

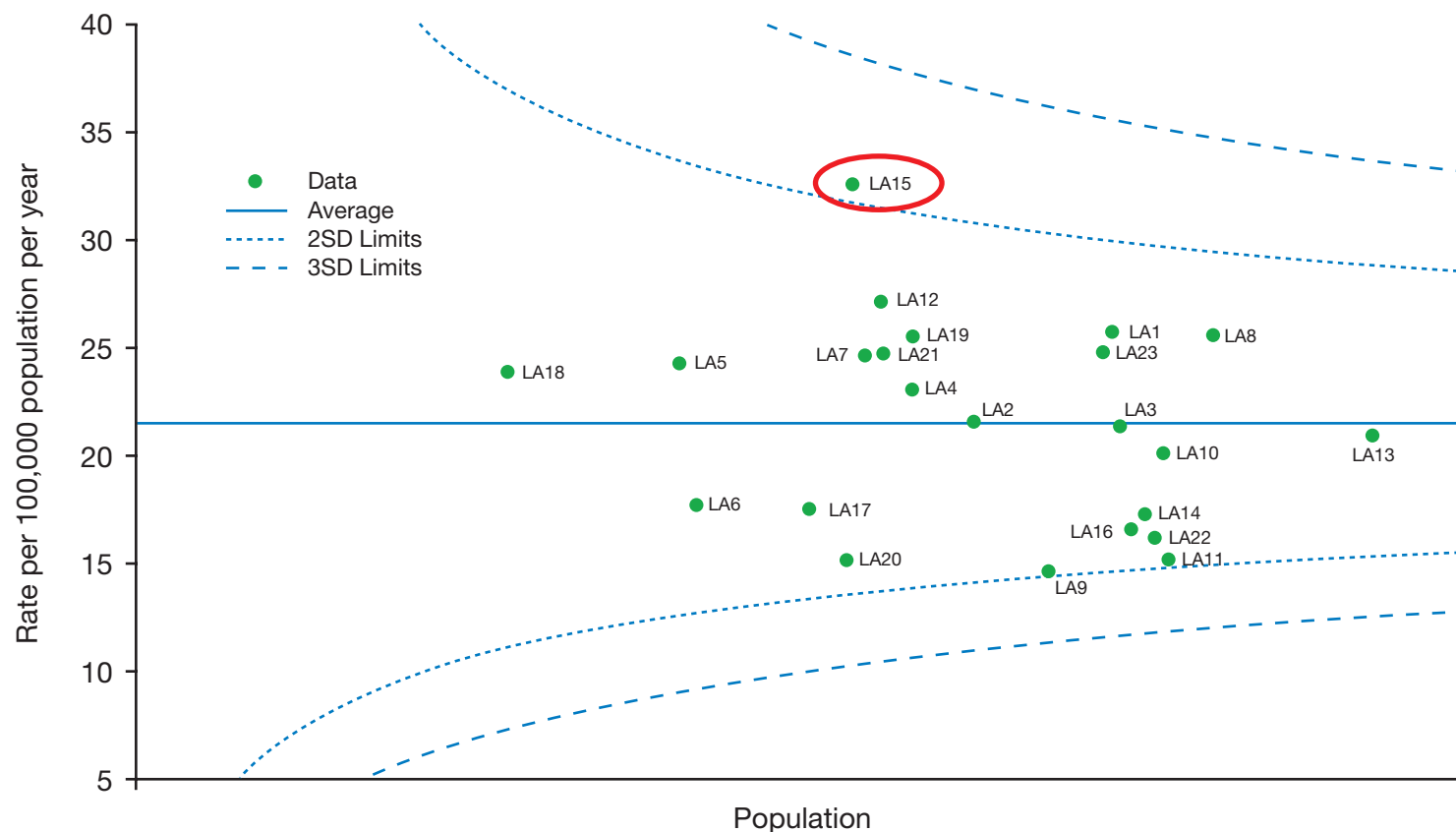
[Click here](#) for a checklist for using data to diagnose focus areas.

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Data source: National Cancer Information Service (NCIS). Chart by Anglia CN.

Note: Population is adjusted due to standardised calculations.

The funnel plot tool, provided by Eastern Region Public Health Observatory (ERPHO), can be used to identify outliers or hotspots which may not be immediately apparent using other methods. The plot is easy to use and provides a visual way of showing if a result is statistically significant, for example LA15 lung cancer mortality.

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Checklist for using data to diagnose focus areas

1. What is the local burden of disease?

- Undertake benchmarking against national, regional area and other cancer networks and Primary Care Trusts (PCTs).
- Look at **trends** (against targets) for **incidence**, **mortality** and **survival**. Looking at mortality rates in isolation can gloss over an underlying issue: question whether the mortality is as expected given the local incidence.

2. Are some groups more affected than others, i.e. are there health equity issues?

- Look at sub-groups of the local population, what is the survival by age, sex, ethnicity, deprivation?

3. Risk factors for cancer prevalence?

- What are the prevalence rates and trends for lifestyle and behavioural risk factors?

4. What is the current cost and PCT spend on cancer services?

- PCT and Cancer Network Programme Budgeting spend can be benchmarked against suitable comparator areas

5. Service provision against standards [NICE Improving Outcomes Guidance (IOG)]

- Consider both early diagnosis and treatment standards

6. Performance against standards

- For example waiting times (two-week wait, 31-day and 62-day waits), screening uptake, survival consensus targets

7. Patient satisfaction

- Data from national or local patient satisfaction surveys can be used to identify areas where change is needed

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Introduction: stakeholder identification, recruitment and engagement

Cancer is a multifaceted and complicated disease. The patient pathway is likely to involve a range of clinical and non-clinical personnel. Where existing processes or structures need to change it is important to ensure that the relevant stakeholders are engaged. This section of the guide deals with identification of key stakeholders and how to involve and motivate them throughout the project.

Who are project stakeholders and how can they be identified?

Key stakeholders are those individuals, groups or organisations who will be affected by the change programme or who are tasked with implementing the programme. Identification of key stakeholders and their effective engagement is a critical success factor for any change project. Early engagement with stakeholders promotes meaningful stakeholder ownership of the project.

Stakeholder identification and mapping should address several questions

- Who is going to be affected by the change?
- How will they be impacted – is this impact positive or negative?
- What are their interests in relation to the programme and how can this affect programme outcomes or success?
- How can we manage and communicate the programme so that the benefits of change are clear?
- Who is going to be tasked with implementing and monitoring change?

Stakeholders: Which key groups or individuals need to be actively involved?

There should be a clear rationale for involving stakeholders in the project. When assessing need for involvement several important points should be considered. As well as the stakeholders defined above, the project team should also include stakeholders with a deep knowledge of the issue to provide a relevant perspective. For example, clinicians, public health experts, academics, information experts who can form an expert reference group.

For a change project that affects a specific community or group, community champions should be identified and involved. They should be able to represent the target community (for example, target patient group), and ideally have some emotional attachment to the cause, maybe through personal experience or first-hand knowledge of the challenge to be addressed.

For a change project that affects a specific community or group, community champions should be identified and involved.

Any organisation or group who ultimately will be paying for the change programme is a stakeholder. Organisations affected by either increased costs or cost savings as a result of the programme are stakeholders and should be active participants.

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What qualities should stakeholder representatives on the project team demonstrate?

Stakeholders able to represent their group or organisation should be invited to participate early in the project. Although the choice of stakeholder groups is in many ways predetermined by the nature of the project, selection of individuals from the stakeholder organisations to be actively involved and form a core part of the project team is recommended. When selecting representatives from your stakeholder group it is important to define the [key qualities or characteristics](#) individual stakeholders should demonstrate.

Stakeholders: What motivates stakeholders and encourages involvement?

A variety of factors can be stakeholder incentives or motivators. These include

- Project objectives that are in line with existing targets and objectives, and an underlying compatibility of agendas and priorities
- Potential for cost savings or more efficient resource use

See practical example from the [Anglia CN project](#).

- Availability of project funding

See practical example from the [Cancer Research UK project](#).

- Personal drivers, such as recognition and esteem, academic interest, improving outcomes for their patients, and personal belief in the cause
- Acknowledgment of involvement, for example through publication activity
- Peer influence or pressure

How can stakeholder engagement and motivation be promoted?

Communication with and engagement of stakeholders is essential. It is also important to share relevant information and share it quickly. Each stakeholder or stakeholder group may represent a specific communication audience: a tailored communications programme will help to optimise engagement with each group.

At the very beginning engage your key stakeholders with the problem/challenge and ask for their ideas, both with regards to contributing factors and analysis required.

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Understand the data and make it understandable

It is crucial to have a deep understanding of the data and its relevance in the clinical setting. In order to engage stakeholders, the need for action should be communicated in a way that is relevant and memorable to the specific audience. For example data such as survival curves and percentages could be translated into actual patient numbers for greater impact.

Data such as survival curves and percentages should be translated into actual patient numbers for greater impact.

Turn challenges into drivers for change

Being an outlier can be motivational by establishing a clear need for change or improvement. Comparison with peers, for example performance versus other CNs or PCTs, demonstrates that improvement is achievable.

Quick wins

'Quick wins' can demonstrate how a small change can have a large impact in a relatively short timescale. For example projects that improve patient pathway and achieve efficiencies or those that increase referrals. See practical examples from [Anglia CN](#), [Merseyside and Cheshire CN](#) and [Cancer Research UK projects](#).

[Click here](#) for an action planning for change and stakeholder checklist and summary.

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Action planning and stakeholder checklist

- *Have key stakeholders been identified and 'ideal' representatives selected for involvement?*
- *Has the position of the stakeholder relative to the change project, been assessed?*
- *Can these profiles be used to enable information presentation or reports to be tailored to key areas of interest through a targeted communications strategy?*
- *Has the data been translated into relevant and memorable information for each target audience?*
- *Would formal qualitative research through focus groups be valuable?*
- *Are there existing patient / community groups with whom formal links can be developed or are new groups needed?*
- *Is the project change targeted at a particular ethnic/cultural group? If so, can community engagement be promoted through outreach? Is there a need for ethnically- or culturally-matched outreach workers?*
- *Can peer comparisons of relative performance be leveraged to add a competitive motivator?*

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Embedding and sustaining change

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Introduction: understanding and using governance and organisation

Different organisations and stakeholder groups will have their own governance and organisational structures. This section of the guide deals with how these structures and processes may be best used to implement a change project.

How can disparate stakeholders work efficiently together?

- From project start, clarity, definition and agreement of specific roles and responsibilities and optimisation of system alignment for each organisation is critical. This ensures that all important issues are captured and addressed.
- Different organisations will have their own organisational structures: ensure you have locally-relevant definitions.
- Responsibility for initiative delivery may lie with the PCT. CNs are likely to have a role in monitoring progress and acting as mediators by highlighting to PCTs poor contract compliance, for example MDT data not being supplied within contracted timelines.
- Relevant CNs may cover more than one SHA and initiatives may be applicable to several PCTs: a clear understanding of what has to be delivered and by whom is essential. A Service Level Agreement (SLA) or Memorandum of Agreement should be developed.
- Terms of reference should link formally to the structure and into existing governance arrangements within the CN. Reporting lines into the appropriate body within existing structures should be formalised, typically the Project Steering Group will formally report to the CN Board and/or the relevant tumour board or service improvement board. See practical example from the [Mount Vernon CN project](#).

- Governance structures should ensure links with other groups involved in relevant projects that support or have an impact on the change project.

What operational strategies can be employed for project implementation?

- Develop links to commissioning and other funding sources, for example PCTs and local authorities, to maintain the project beyond pilot phase into general implementation.
- Harness the commissioning network by ensuring joint representation at key forums.
- Identify those groups who will also benefit from the initiative in terms of common objectives, targets and needs and present findings tailored according to their objectives.
- Assess whether the intervention is relevant or applicable to other subgroups (for example, other tumours or other patient groups). See practical example from the [Cancer Research UK project](#).
- Develop or use an existing action group to drive practical implementation, for example through establishment of a Public Health Action Board (PHAB). See practical example from the [North East London CN project](#).

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Embedding and sustaining change: What operational strategies can be employed for project implementation (cont'd)?

- Show the relevance of project outcomes and how it links to regional and national plans, for example SHA plans.
 - At the macro level, cancer should be highlighted as a priority area. At the micro level, key data should be embedded into cancer strategies.
- Develop relevant metrics to allow measurement of delivery against best practice. Be aware that metrics may evolve over time – evaluate metrics and targets as appropriate

- Ensure that relevant contracts are put into place and are enforceable through defining local specifications.
- Use contract review processes as a lever to ensure compliance with metrics.

[Click here](#) for an embedding and sustaining change checklist and summary.

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Monitoring and evaluation

How can we measure the success of the change project?

Relevant metrics should be defined and are essential to monitor the achievement of the project strategy.

- Each project should have a defined overall goal, which it is useful to express in terms of patient outcomes. See practical example from the [North East London CN project](#).
- Each project should also have specific and measurable objectives, for example to increase patient referrals within a specified population and time frame by X%.

- Indicators should be identified at the start of the project. These can then be used to get a baseline for the current service and to demonstrate successful completion of the project. Indicators should be discriminating and meaningful.
- Where standard data are unavailable or unsuitable for measurement of the success of an intervention or change, suitable project-specific metrics should be generated.

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Top 10 tactics

This guide provides practical guidance and strategies to drive the successful use of data in cancer decision making and service improvement. The most important considerations are prioritised in the checklist table below.

Tactic / Critical Success Factor	Priority
Baseline assessment and accurate benchmarking to assess genuine need for intervention and magnitude of challenge	1
Agreement of focussed, clear and measurable objectives with identification and definition of target outcomes	2
Identification of stakeholders through rigorous stakeholder mapping to ensure early involvement, with continued relevant, meaningful and targeted communication throughout project to maintain engagement	3
Identification and implementation of relevant metrics – both for the project objectives and for the change to be implemented	4
Identification of similar evidence-based projects or initiatives, and development of links to share good practice, information and resources for mutual benefit	5
Ensure robustness of data through evaluation of data quality and accuracy	6
Awareness of data limitations, for example impact of sample size, use of averages	7
Motivational project leadership	8
Formalisation of governance framework and terms of reference with clearly defined roles and responsibilities for all project participants	9
Evaluation of the cost benefit of implementing the change and assessment of value for money	10

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Fighting cancer with information

www.ecric.nhs.uk



Anglia Cancer Network

www.angliacancernetwork.nhs.uk

CANCER RESEARCH UK



www.cancerresearchuk.org



<http://www.northtrentcancernetwork.nhs.uk>

Merseyside and Cheshire
Cancer Network



www.mccn.nhs.uk



www.mountvernoncancernetwork.nhs.uk

North East London Cancer and Research Network



www.nelcn.nhs.uk



www.rocheuk.com

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Project examples and key learnings

North East London Cancer Network (NELCN)

Project objectives and direct outcomes

The NELCN project aimed to address breast cancer inequalities, specifically poor five-year relative survival compared with other similar CNs. Data analysis revealed that the driver for poor five-year relative survival was suboptimal one-year relative survival. As a result of this project NELCN has established a survival-specific target to improve one-year relative survival to within 95% confidence interval of London levels by 2012.

Datasets and methodology

Five-year relative survival was assessed by CN and by inner/outer NELCN, by age, by screen-detected disease and symptomatic disease. Incidence was assessed by CN and PCT, by stage, by deprivation quintile, and by treatment received. In addition, data on hospital episode statistics, HER2-positive treatment rates and drug usage were evaluated. Data analysis methods included Kaplan-Meier survival curves and Cox hazard proportional analysis.

Stakeholders, responsibility and communication

The project is a successful example of a joint working project between NELCN, Thames Cancer Registry and Roche. NELCN established a multi-professional project team, a clinical champion group and a formal project board. NELCN ensured that the board was chaired by a lead clinician who was key to decision making and driving change. A clinical lead, project lead and project manager were also appointed. Clinician involvement was sought through regular presentations to the Tumour Advisory Board (TAB) and a multidisciplinary team workshop is planned to improve clinical ownership of the project. Wider stakeholder buy-in to the project was achieved through an active communication programme providing timely project updates to all relevant PCT, Trust, CN and third party boards and committees. At each planned update, a formal agenda time and presentation ensured consistency of communication messages and an ordered cascade of information.

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Project examples and key learnings

North East London Cancer Network (NELCN)

Governance, structure and implementation

A formal governance structure was established with the project team reporting to the Project Board, TAB and CN Board, and a joint working agreement put in place to define clear roles and responsibilities. In addition a Public Health workshop was organised leading to the establishment of a Public Health Action Board (PHAB) to drive practical implementation of the project. Commissioning levers are being used to increase cancer funding in PCT plans.

Metrics and performance monitoring

NELCN are monitoring progress using breast pathway metrics, which are reviewed by the TAB every three months. They also plan to develop a 1-year relative survival metric with Joint Clinical Investigation (JCI) of all deaths within one year. Contract review processes are being used as a lever to encourage compliance with metrics.

Key learnings

- Limit univariate analyses of characteristics to CNs as PCT analysis can distract from the main question
- Use univariate analyses to develop Cox proportional hazards analysis
- Kaplan-Meier curves can be used to identify early deviation
- PCT 1-year relative survival data allows validation of interventions aimed at improving survival
- Avoid making assumptions about the cause of survival differences without analysis
- Take a forensic approach to analysis
- Beware of averages - other deprived populations may have similar outcomes to NELCN but these may be masked by satisfactory averages at a CN level

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Mount Vernon Cancer Network (MVCN)

Project objectives and direct outcomes

The MVCN project aimed to prioritise CN spend through data analysis. As a result of the project, specific improvement projects will be developed and implemented based on identified priorities. In addition, initial project findings have been disseminated promoting wider stakeholder participation.

Datasets and methodology

MVCN used data from E-Atlas and the Cancer Commissioning Toolkit as well as Cancer Registry data, PCT breast screening data and Department of Health programme budget data. Data was benchmarked against North East London, North London and Essex CNs and also against England averages. Age-standardised mortality, mortality crude rate and deaths per year were assessed along with age-standardised incidence by age. One-, three- and five-year survival (all age-standardised) were also analysed. Survival rate and PCT mortality time trends were analysed in order to assess 'direction of travel' and spend versus outcomes was evaluated.

Stakeholders, responsibility and communication

The project is a successful example of a joint working project and involved a wide variety of stakeholders including, CN Executives, representatives from public health, commissioning and primary care groups within PCTs, the Eastern Cancer Registry and Information Centre (ECRIC), which registers malignant tumours in the East of England, Roche and invited consultants.

Key decisions were made by the group as a whole, with involvement of Lead Clinicians throughout the data-finding process. The project findings were presented to the Tumour Site Specific Group (TSSG) and to the wider CN, PCT and clinicians. A summary report and poster of process and initial data findings was developed for wide distribution to encourage and maintain stakeholder interest in the project. A second summary will be produced to communicate improvement projects, explain the monitoring process and disseminate final project outcomes. MVCN is also organising a data-training day for TSSG leads to improve understanding of the data, its credibility and what it demonstrates.

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Mount Vernon Cancer Network (MVCN)

Governance, structure and implementation

Terms of reference were agreed and the working group was formally established into the governance structure of the MVCN.

Metrics and performance monitoring

The TSSG will be devising specific improvement projects and establishing relevant metrics as an integral project element.

Key learnings

- Use relevant and appropriate benchmarks to establish the cancer landscape
- Different datasets may vary in accuracy: accuracy is crucial for credibility of data and data findings
- Be aware that incidence, mortality and survival data represent averages which minimises variance but may also mask trend changes
- Methods of data collection for cancer spend have changed: be aware of anomalies when comparing time series
- Use the most up-to-date data available: older data may not reflect recent service changes
- Ensure that all parties are committed to and focused on the project
- Be realistic about project timescales

For more information on the MVCN project contact:

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Anglia Cancer Network (ACN)

Project objectives and direct outcomes

The ACN project aimed to define a landscape of cancer within the CN in order to inform the CN cancer strategy by identifying priority areas. As a result of the project, the CN's baseline was established and a memorable and understandable system to capture and represent key cancer data was developed which facilitated identification of the top five cancers to be addressed within the ACN cancer strategy.

Datasets and methodology

The ACN project used National Cancer Information Service (NCIS) data as a versatile dataset for CN comparisons. Data analysed for 19 cancers included cancer incidence (from 2002–6), 1-year relative survival (from 2002–6), 5-year relative survival (from 1998–2002) and mortality (deaths from 2003–7 for persons aged <75 years). The results of the analysis were presented in an intuitive '[Tartan rug](#)' format, using colour-coded categories for visual impact.

The Red, Amber, Green (RAG) system provides a memorable and user-friendly output of data analyses where red coding identifies areas of potential concern for further investigation. In addition, the system can capture and compare data from a range of tumour sites, providing information relevant to different TSSGs and in a format that can be repeated for different PCTs. The RAG system can provide a snapshot of cancer data but does not capture information on trends; however, it could be amended to provide a time dimension. [Click here](#) to see an example of a Tartan rug output.

The RAG system can provide a snapshot of cancer data but does not capture information on trends.

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turning data into intelligence

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	INCIDENCE (cancers diagnosed 2002–2006)	1-YEAR RELATIVE SURVIVAL (cancers diagnosed 2002–2006)	5-YEAR RELATIVE SURVIVAL (cancers diagnosed 1998–2002)	MORTALITY (deaths 2003–2007, persons aged 0–74)
ALL CANCERS	11	11	10	4
C00–C14–Lip, oral cavity and pharynx	8	3	6	4
C15: Oesophagus	2	18	24	8
C16: Stomach	16	12	21	7
C18–C20: Colorectum	23	10	5	9
C25: Pancreas	7	12	25	9
C33–C34: Trachea, bronchus and lung	8	8	20	6
C43: Malignant melanoma of skin	20	6	9	18
C50: Breast (f)	23	3	4	21
C53: Cervix uteri	5	19	10	3
C54–C55: Uterus	28	13	15	19
C56: Ovary	12	13	19	12
C61: Prostate	21	10	10	9
C62: Testis	19	7	5	14
C64: Kidney, except renal pelvis	21	22	20	26
C67: Bladder	5	23	23	7
C69:–C72: Eye, brain, and other parts of the central nervous system	12	22	19	5
C81: Hodgkin's disease	27	27	7	6
C82–C85: Non-Hodgkin's lymphoma	16	20	22	18
C91–C95: Leukaemia	14	17	8	16

ACN Cancer landscape 'Tartan rug'. Source NCIS data

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Anglia Cancer Network (ACN)

Stakeholders, responsibility and communication

Initial stakeholders included the public health groups of the six PCTs within the CN. In addition, ACN sought input and advice from the Eastern Region Public Health Observatory (ERPHO) and undertook selected on-line consultation through a Yahooogroup.

ACN: Transforming in-patient care

One finding from the project that encourages stakeholder motivation was that potential cost savings were identified. Comparison of ACN cancer bed day rates with that of other CNs revealed that reduction of ACN rates to that of the lowest CN could achieve a saving of around one-third of current spend. Data analysis also revealed that average length of stay for cancer in-patients differed according to cancer type and also by Trust within the CN. In terms of bed-days, colorectal cancer was identified as one of the three top cancers within ACN, a finding that could aid prioritisation of CN resources.

Governance, structure and implementation

As the project progressed, governance was established through the Strategy and Commissioning Group which includes lead clinicians from a range of different tumour types. Engagement of the Group provided a driving organisation for the project and allowed finalisation and agreement of the ACN strategy. By fostering dialogue with end-users, the project served to promote the use of data in improving services.

Metrics and performance monitoring

Though no formal metrics were put in place, the fact that other CNs have expressed an interest in developing similar systems for their use highlights the success of the project. In addition, the project has demonstrated longevity as the Strategy and Commissioning Group are now assessing future data needs in order to refine data outputs and usefulness.

Key learnings

- Clarify project ownership and responsibilities
- Assess availability of data including timelines
- Be selective when using metrics
- Embed key data into strategy documents rather than appending data
- Seek advice and input from organisations experienced in similar data-driven projects
- Identify and use 'quick wins' to raise the profile and demonstrate the benefit of data use in strategy decisions

For more information on the ACN project contact:
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Merseyside and Cheshire Cancer Network (MCCN)

Project objectives and direct outcomes

The MCCN project aimed to understand how PCT commissioning plans are engaged and aligned with the MCCN Early Detection and Prevention Strategy and to develop a product that would measure PCT commissioning plans against the ideals of the Early Detection and Prevention Strategy. The project deliverable was a performance product to enable customers to benchmark performance against local, national and international benchmarks across a variety of areas for a number of different stakeholders. The product also aimed to provide PCT's with the appropriate tools to monitor and address priorities for local cancer services.

Datasets and methodology

The MCCN team designed a performance framework which comprised a number of key categories: data on pre-treatment patient staging; screening information including variation compared with national rates; incidence, mortality and survival data; data on referral activity (for example, numbers of referrals and referral hit rates by stakeholders); data on emergency activity and varying length of stay. The approach taken by the MCCN team was to develop key indicators working closely with the Health Inequalities Manager.

Stakeholders, responsibility and communication

The project was initially piloted in one PCT with presentation of the project to the Locality Group and liaison with the PCT as well as screening and registry leads, allowing agreement of datasets to be used within the project. The benefit of the project was communicated to relevant groups and stakeholders including commissioners and clinicians during these presentations. A manual report was produced along with an in-house application which was tested prior to being rolled out to other localities.

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Merseyside and Cheshire Cancer Network (MCCN)

Governance, structure and implementation

The MCCN project is now being piloted with Liverpool PCT and Halton and St Helen's PCT and governance structures will be defined as part of this pilot programme. A manual report is being produced along with an in-house application which will be tested by the pilot PCTs prior to being rolled out to other PCTs within the CN.

Metrics and performance monitoring

The metrics used will reflect the key objectives of the performance framework.

- *Proportion of cancers staged at three months*
- *Number of cancer MDTs reaching a 90% registration status after a defined time period*
- *Number of urgent cancer referrals*
- *Total number of urgent referrals by tumour type*
- *Urgent cancer referral yield rate*
- *Median cancer waiting time*
- *Screening uptake*
- *Percentage of patients never screened*
- *Number of cancers detected via screening*
- *Variation in 1- and 5-year survival rates*
- *Variation in cancer incidence and cancer mortality compared with national and best EU figures*
- *Number of emergency admissions resulting in cancer diagnosis.*

Key learnings

- Ensure accuracy and relevance of benchmarks in order to deliver local intelligence
- Clearly identify end-users and their specific needs
- Define relevant metrics to validate the strategy
- Communicate and engage stakeholders and end-users, ensuring that benefits are clearly communicated

For more information on the MCCN project contact:
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North Trent Cancer Network (NTCN)

Project objectives and direct outcomes

The NTCN project aimed to understand the impact of the National Radiotherapy Advisory Group (NRAG) report recommendations on local services. The project has identified differences in radiotherapy provision from NRAG recommendations in a number of tumour sites. Initial data has also indicated geographical differences in provision. The data is to be interrogated further to inform commissioning and strategic planning.

Datasets and methodology

NTCN used fractionation data obtained directly from the Radiotherapy Centre as well as registrations data provided by the Trent Cancer Registry. Projected increases in incidence discussed within the NRAG report were also considered. Data analysis methods included: modelling of increases in incidence and fractionation required to meet that increase; identification

of gaps between current radiotherapy provision and recommended provision within the NRAG report; and mapping of radiotherapy provision to levels of deprivation.

Stakeholders, responsibility and communication

Stakeholder groups for the project included the Radiotherapy Centre, Trent Cancer Registry, neighbouring CNs and commissioners. Consultant oncologists were involved in data analysis and review, with clinician attendance at national and local events around NRAG. One objective is to establish an NRAG steering group and to ensure clinician representation and involvement in the group. Data was presented at the CN cancer board and the Health Inequalities group, and was also shared with Trent Cancer Registry. Wider dissemination of the data will be appropriate following further data analysis and refinement.

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North Trent Cancer Network (NTCN)

Governance, structure and implementation

Data was reviewed and approved by the Radiotherapy Centre before being provided to CN cancer boards and other groups.

Metrics and performance monitoring

Relevant metrics such as numbers of fractions delivered and waiting time impacts will be incorporated once the impact of the NRAG report is established and relevant strategies finalised.

Key learnings

- Use up to date data to ensure relevance of findings
- Develop and implement processes for quality control and checks for data accuracy in order to ensure credibility and acceptance of findings
- Leverage clinician knowledge to provide sanity checks of the data
- Cross-validate data against other datasets
- Evaluate the relevance of the evidence base, for example at different stages of disease
- Assess the level of technical knowledge needed and logistics of data access. This may be of particular relevance when taking data from technical hospital equipment.

For more information on the NTCN project contact:
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Thames Cancer Registry (TCR)

Project objectives and direct outcomes

The TCR project aimed to quantify the precision of one-year relative survival estimates, assessing how this affects their use as indicators for performance management. The project also aimed to identify 'outlier' PCTs and quantify the potential benefits of targeted interventions aimed at improving outlier status. A key driver for the project was the NAEDI recommendation that PCTs review their one-year survival data despite previous recommendations that they should not be used as a performance indicator at PCT level [Rachet B, Eayres D, Coleman MP. *Cancer survival indicators for primary care organisations in England – feasibility study. Report to the Department of Health. National Centre for Health Outcomes Development, October 2004*]. The project showed that the precision and usefulness of survival data varied considerably across PCTs due to large differences in the factors that drive precision (i.e. number of cases and deaths, and the size of PCT populations).

Datasets and methodology

TCR used one-year survival data for London and the South East Coast SHAs for patients diagnosed between 2001 and 2005, with follow up completed between 2002 and 2006. These data were extracted from the National Cancer Information Service (NCIS) for trachea, bronchus and lung cancer, breast cancer, colorectal cancer and prostate cancer. 95% confidence intervals around PCT estimates were also examined. The survival data were also compared to "best in Europe" consensus targets as proposed by Ellis-Brookes and Elliott (2009).

Stakeholders, responsibility and communication

The TCR project will have implications for a range of stakeholders at local and national level. The project findings have been shared through the local Public Health Forum for Cancer Networks and PCTs and the UK Association of Cancer Registries Conference. They will be communicated more widely through journal publication.

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Thames Cancer Registry (TCR)

Governance, structure and implementation

The project quantifies the imprecision of one-year relative survival data at the PCT level which even for the most common cancers can be considerable. Governance structures should reflect the availability of useful intelligence data. For example, decision-making for rare cancers would be more appropriate at the regional level rather than the local PCT level as local data lacks robustness and precision. For more common cancers, it may sometimes be appropriate to use local data to inform decisions at a local or PCT level.

Metrics and performance monitoring

The project findings highlight the need to choose suitable indicators that reflect the accuracy and precision of the data for metrics and performance monitoring. The suitability of one-year relative survival as an indicator varies significantly between cancer types and also varies between PCTs. Apparent differences in performance require careful local investigation.

Key learnings

- Be aware that precision and usefulness of one-year relative survival data can vary considerably across different PCTs and cancer types
- Uncertainty of survival estimates need to be considered in the light of trend data and of population factors affecting survival e.g. the age structure and socioeconomic deprivation of a PCT
- Ensure that governance structures are appropriate and allow decision-making at a level which reflects the robustness and limitations of the data and the precision of the estimates
- Consideration of the gap between local performance and best in SHA or "best in Europe" consensus targets may inform local service planning and commissioning.

For more information on the TCR project contact:
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Cancer Research UK (CRUK)

Project objectives and direct outcomes

The CRUK pilot project aimed to increase awareness, early detection and referrals for oral cancer in ethnic minority groups. As a result of the project, there was a six-fold increase in the number of patients referred with suspected oral cancer every year compared with diagnosed cases prior to the project.

Datasets and methodology

Qualitative data was obtained from focus group discussions and quantitative data from a modified Humphris Oral Cancer Awareness Scale to assess changes in awareness of symptoms and risk factors for oral cancer, attitudes and knowledge about early diagnosis, and awareness of the project, with data collection by bilingual English-Bengali field workers. Screening data from the project, data on cancer risk factors (from the Health Survey for England 2004: The Health of Ethnic Minorities), data on cancer incidence in ethnic minority groups, primarily from small-scale studies in local areas, but also from the National Cancer Intelligence Network (Ethnicity and Cancer Report 2009) was also assessed. Consideration of sample size for quantitative data was used to ensure data robustness and suitability: 400 residents were evaluated and pre- and post-samples matched in terms of age and gender.

Stakeholders, responsibility and communication

The pilot was run by CRUK, and led by the Health Information Manager, with assistance from the rest of the Health Information team, statistical information team, and the press office. The project was a partnership between CRUK and Tower Hamlets PCT, who provided the mobile dental unit for oral cancer screening, the dentist, and dental nurses. Other stakeholders included Queen Mary University of London and the Bangladeshi Stop Tobacco project, which provided community outreach workers for screening elements of the project. A Community Advisory Group (CAG) including representatives from these bodies, other health professionals, patients and community groups was established. A major benefit of CAG was the ease of communication: having defined members as points of contact facilitated timely dissemination of information and cascade to the most relevant audiences. Early engagement with stakeholders was critical to the success of the project and the availability of funding to improve awareness of oral cancer amongst a deprived high-risk group was a strong motivator of stakeholder participation.

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Cancer Research UK (CRUK)

Governance, structure and implementation

Clarity of roles, responsibilities and expectations was established through a Service Level Agreement which was developed with Queen Mary University of London for delivering on year of activity. Clinicians (oral maxillofacial surgeons, practice nurses, GPs, dentists) and CAG members provided expert guidance on the development of printed materials and screening sessions, as well as translations and provision of contacts. The pilot project was implemented by dentists and assisting dental nurses who conducted oral cancer screening. The use of bilingual, ethnically-matched outreach workers helped to encourage community compliance with referral for suspected oral cancer.

Metrics and performance monitoring

Metrics included number of patients screened and referred, compliance with referral, predictors of referral, and clinical outcomes. From the quantitative research, Chi-squared analysis of changes in awareness and logistic regression analysis was evaluated.

Key learnings

- Involve stakeholders as early as possible
- Generate suitable project-specific metrics if standard data are unavailable or unsuitable for performance assessment
- Take into account end-user profiles and assess the need for culturally matched outreach workers
- Attract or generate funding for the project as this can be a strong stakeholder motivator that demonstrates commitment

For more information on the CRUK project contact:

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Project examples and key learnings

East Midlands Cancer Network (EMCN)

Project objectives and direct outcomes

The cancer network aimed to supply quality assured clinical information to clinicians empowering them to radically change patient care.

The project utilised information from the Clinical Information Analysis (CIA) Programme which enabled the Network Pharmacists to benchmark service provision.

This information which was initially used in the south of the EMCN (former LNR) helped to drive better evidence-based treatment, development of standardised care protocols across the cancer centres, supported the robust investigation of apparently divergent practice and helped minimise inequality through postcode prescribing and access to treatment issues.

The project culminated in an oncology clinical governance meeting:

- To raise awareness amongst the Oncologists of the differences in clinical practice
- To benchmark practice
- To have an evidence based discussion in order to understand rationale for the regimens in use by reviewing current protocols
- To develop resource informed network wide guidelines.

The engagement with the clinicians, Acute Trusts and the Primary care Trusts has been strengthened by this project and, as a result, has increased compliance with NICE guidance and other key national standards. The project is now being rolled out across the EMCN as a whole.

Datasets and methodology

The data in the CIA Programme are linked data collated from existing sources held in many disparate unrelated systems. The data were centralised and translated into consistent content. Multiple data sources were used including the Cancer Register and Hospital Episode Statistics (HES), oncology databases and chemotherapy prescribing systems. The data were quality assured, validated with data providers and reported using a standard format, using defined groupings of Healthcare Resource Groups (HRGs) for surgical procedures and developed rules for classifying radiotherapy and chemotherapy regimens. Established nine years ago, the programme delivers continuous information collection and analysis of major surgery and all radiotherapy and all chemotherapy regimens by cancer site, provider and PCT and showing variations between providers and temporal trends.

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East Midlands Cancer Network (EMCN)

Stakeholders, responsibility and communication

The project was a successful example of a joint working project support by Trust Clinical Leads, Oncology Departments, Site Specific Teams, PCT commissioners, representatives from the CIA project, the Trent Cancer Registry and OCIOU.

The Cancer Network team worked together to ensure a positive outcome from this project. Strong clinical leadership was provided by the Network Director and Oncology NSSG chair. The pre-work undertaken by the Network Pharmacists demonstrating the inconsistencies in care from a cost perspective ensured that the commissioners were engaged and prepared to support the decisions made by the clinicians.

The information provided on the day empowered the clinicians to make informed decisions on patient care.

Governance Structure and implementation

The initial LNR project outcomes were supported by the PCTs. As the rollout takes place in the new EMCN the strong collaboration with the EM SCG who holds responsibility for commissioning drugs across NHS East Midlands will enable this project to expand. The recommendations will now be confirmed by the EM SCG and continue to result in increased adoption of clinically effective resource informed treatment protocols.

Metrics and performance monitoring

The SCG and EMCN are developing monitoring metrics in relation to adherence to agreed funded protocols.

Key learnings

- The Cancer Network team worked together to ensure a positive outcome from this project.
- Strong clinical champion is essential.
- The pre-work undertaken by the Network Pharmacist demonstrating the inconsistencies in care from a cost perspective ensured that the commissioners were engaged and prepared to support the decisions made by the clinicians
- The information provided empowered the clinicians to make informed decisions on patient care
- Clinicians' confidence in data is essential to understanding the issues
- Benchmarking with similar organisations is extremely useful when assessing care currently provided.
- Data are available to assess cancer care in a way that the NHS has to date, not used widely to support governance and commissioning.
- Discussions on contentious issues may require several iterations

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Cancer decision making:

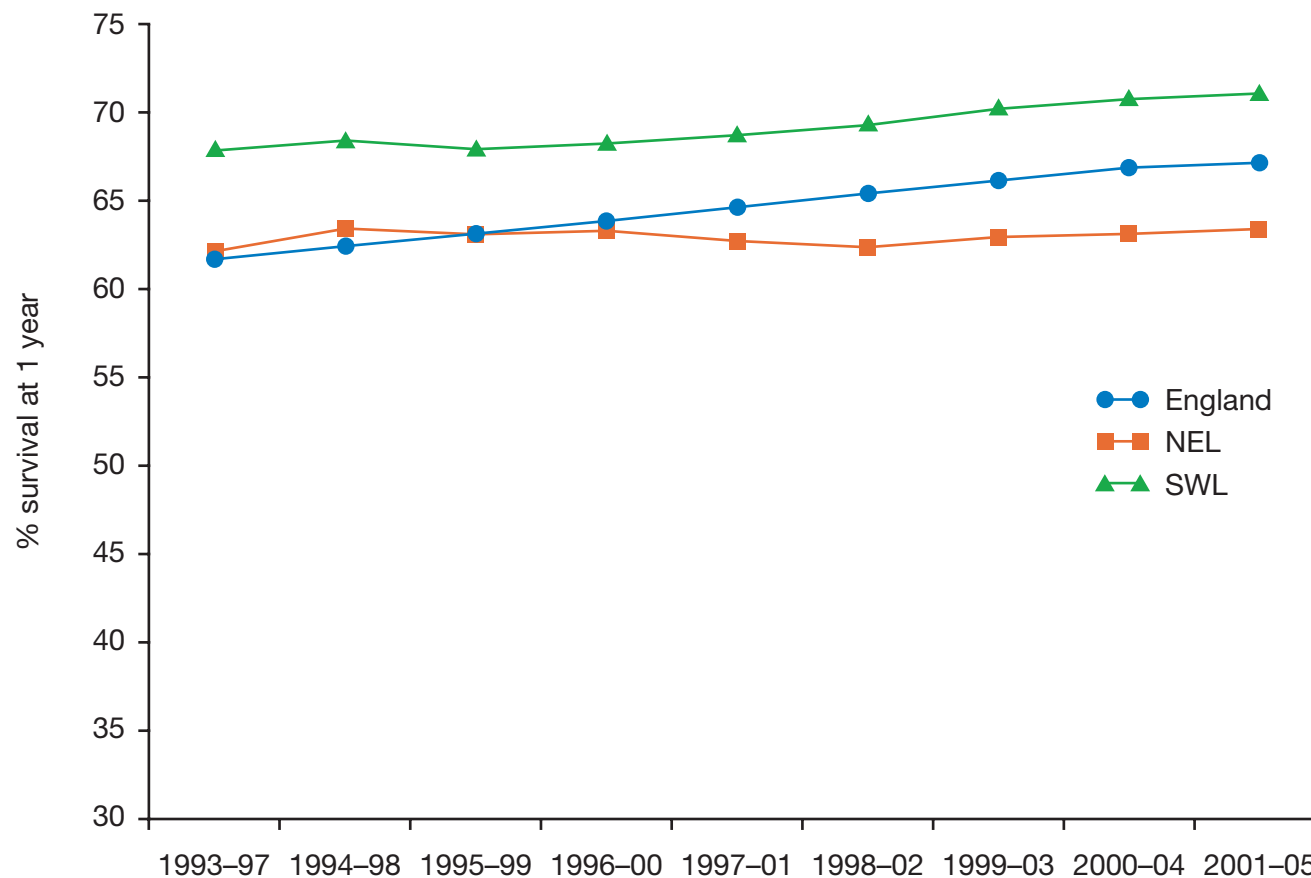
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Trends in 1 year survival from all cancers in North East London (NEL), England and South West London (SWL)



Data source: Cancer e-Atlas

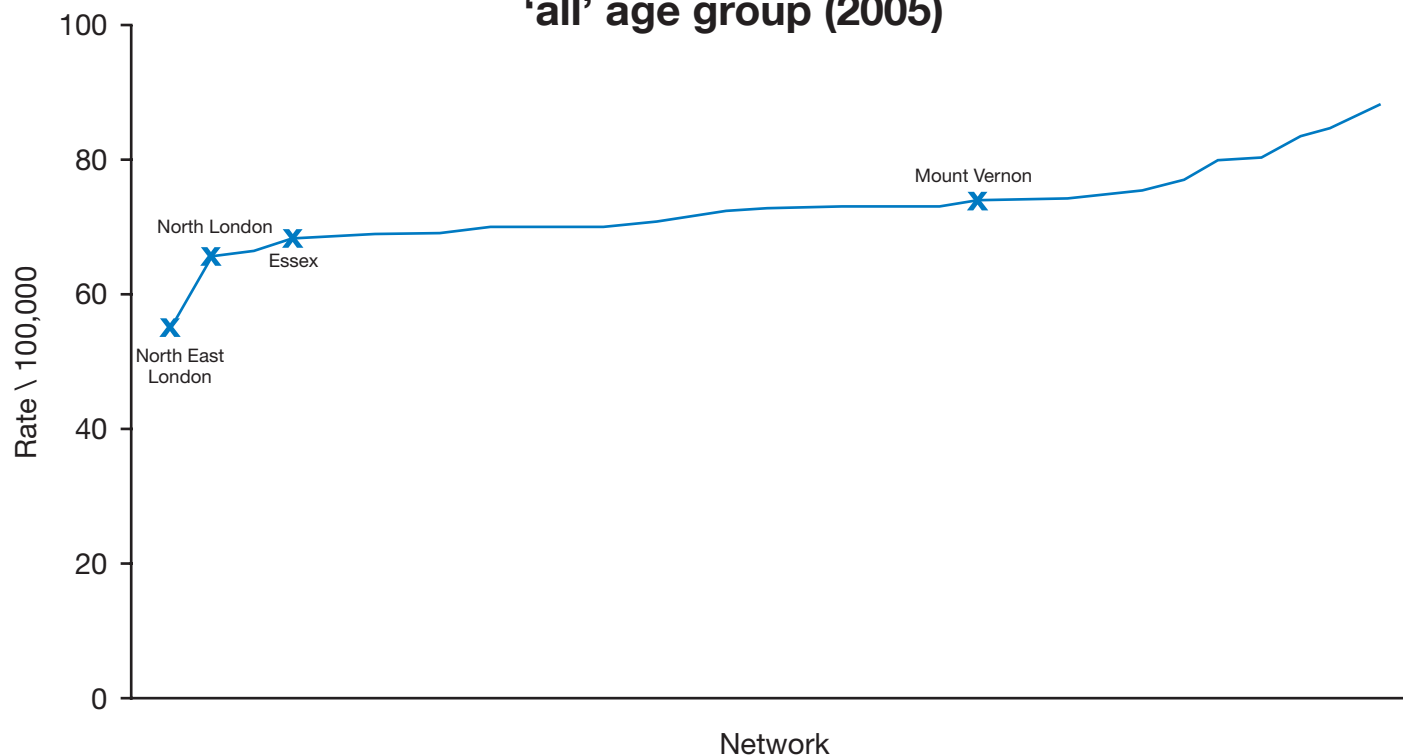
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An illustrative example of benchmarking against comparators with similar demographics – age-standardised incidence of breast cancer: ‘all’ age group (2005)



Data source: Cancer Commissioning Toolkit

The number of patients with a breast cancer diagnosis (incidence), per 100,000 population within North East London, North London, Essex and Mount Vernon Cancer Networks.

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Definitions

Confidence interval:

A confidence interval (CI) indicates the likely range of values (X–Y) for an unknown parameter. CIs are often expressed at the 95% level which means that 95% of the time, the unknown parameter will be a value between the lower confidence limit (X) and the upper confidence limit (Y). The difference between X and Y (i.e. the confidence interval) indicates the degree of certainty or uncertainty regarding the unknown parameter: the wider the confidence interval the less certain the parameter. The 95% CI correlates to a 5% (or 0.05) probability of the unknown parameter not being within confidence limits, hence a 'p value' of less than 0.05 being statistically significant.

Crude rates:

Counts and crude rates represent real figures from a given area, whereas age-standardised rates represent comparable figures if a study population matched the chosen standard population (and does not necessarily indicate true caseload). Standardised rates are useful for comparison between areas and not for analysis of patient numbers in a given area.

Funnel plot:

Funnel plots are scatter plots which take into account confidence limits and are useful for comparing observations or data from different areas (such as different Trusts) with varying sample sizes. The funnel plot incorporates a line drawn at the average or mean as well as upper and lower control limits: as sample sizes decrease, an observation must be further from the average to be considered significantly different. Thus outliers can be identified based on their distance from the average, any data point outside of the control limits is significantly different

Relative survival:

Relative survival is a survival measure that compares against the background mortality in a population. Therefore 100% relative survival represents no additional deaths than would be expected in the normal population, and does not represent a zero mortality rate.

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Section checklist

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Understanding data

- What data sources are available and relevant to this project?
- Are the data sources easy to access or is a degree of technical knowledge needed?
- How up to date are the data?
- Are the data sources of high quality and how complete are they?
- Can other appropriate bodies be approached to fill in the gaps?
- How accurate are the data sources?
- Is the sample size sufficient to provide robust data?
- Is a quality assurance process in place?
- Who can be approached to sense-check the data?

Problem Identification

1. What is the local burden of disease?

- Undertake benchmarking against national, regional area and other cancer networks and Primary Care Trusts (PCTs).
- Look at **trends** (against targets) for **incidence, mortality** and **survival**. Looking at mortality rates in isolation can gloss over an underlying issue: question whether the mortality is as expected given the local incidence.

2. Are some groups more affected than others, i.e. are there health equity issues?

- Look at sub-groups of the local population, what is the survival by age, sex, ethnicity, deprivation?

3. Risk factors for cancer prevalence?

- What are the prevalence rates and trends for lifestyle and behavioural risk factors?

4. What is the current cost and PCT spend on cancer services?

- PCT and Cancer Network Programme Budgeting spend can be benchmarked against suitable comparator areas

5. Service provision against standards [NICE Improving Outcomes Guidance (IOG)]

- Consider both early diagnosis and treatment standards

6. Performance against standards

- For example waiting times (two-week wait, 31-day and 62-day waits), screening uptake, survival consensus targets

7. Patient satisfaction

- Data from national or local patient satisfaction surveys can be used to identify areas where change is needed

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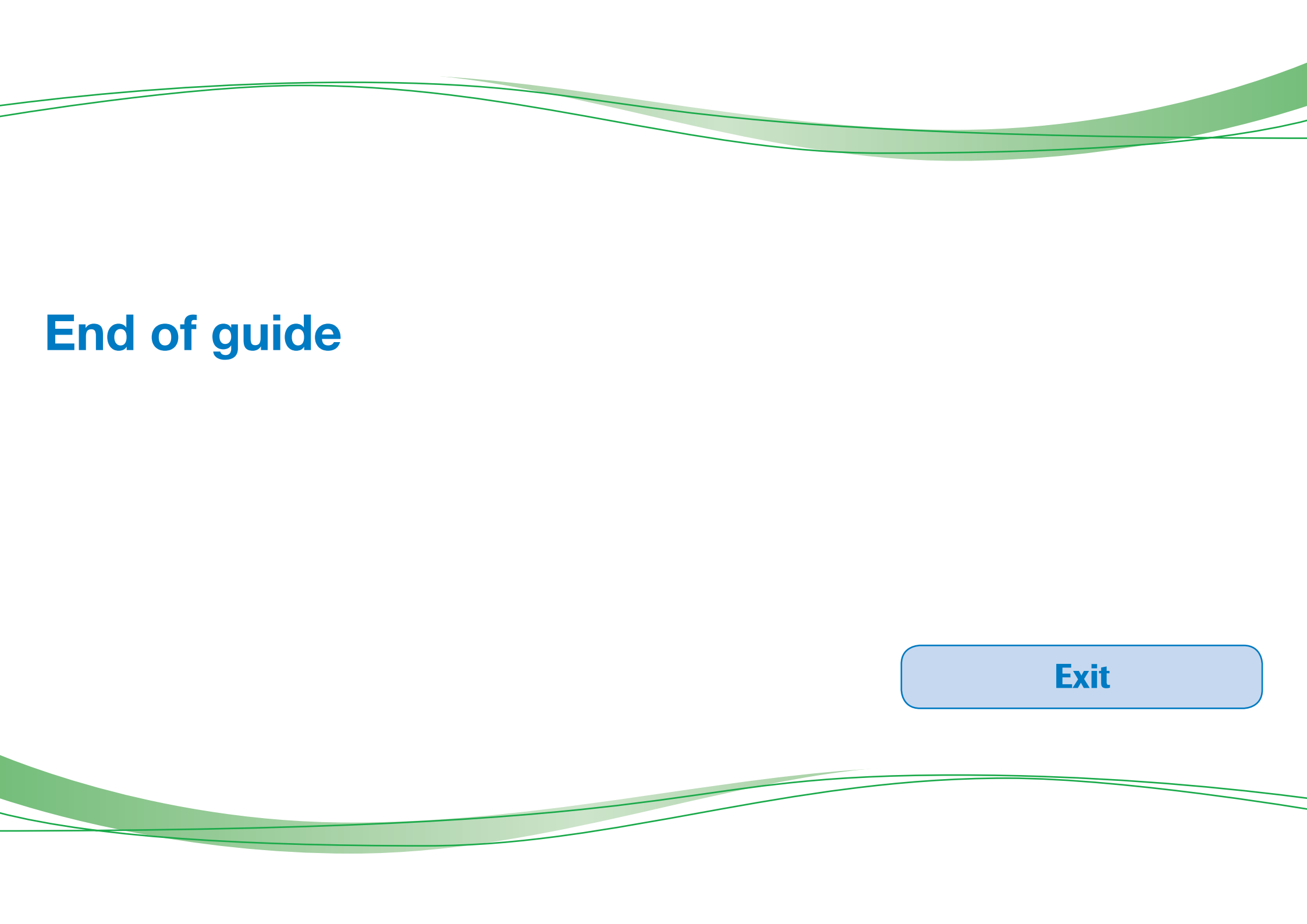
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Action planning for change and stakeholders

- Have key stakeholders been identified and 'ideal' representatives selected for involvement?
- Has the position of the stakeholder relative to the change project, been assessed?
- Can these profiles be used to enable information presentation or reports to be tailored to key areas of interest through a targeted communications strategy?
- Has the data been translated into relevant and memorable information for each target audience?
- Would formal qualitative research through focus groups be valuable?
- Are there existing patient / community groups with whom formal links can be developed or are new groups needed?
- Is the project change targeted at a particular ethnic/cultural group? If so, can community engagement be promoted through outreach? Is there a need for ethnically- or culturally-matched outreach workers?
- Can peer comparisons of relative performance be leveraged to add a competitive motivator?

Embedding and sustaining change checklist

- Have specific roles and responsibilities been clearly defined and agreed?
- Is a Service Level Agreement (SLA) or Memorandum of Agreement in place?
- Can contracts be used to define the type and quality of data required? Can the contract review process be used to ensure compliance?
- Have reporting lines been formalised?
- Have links with relevant groups, commissioning and other funding sources been established?
- Can the project be adapted to benefit other subgroups of patients or tumour types?
- Is there an existing group that can drive practical implementation or does one need to be developed?
- Have relevant metrics been identified? Are indicators discriminating, meaningful and easily communicated?



End of guide

Exit