Scoping Tools

NHS

	Indicator	Where the indicator is available/how the indicator can be collected	Notes
OUTCOME MEASURES	Proportion of non-screen detected new cancers diagnosed through 2 week (urgent) referral	Available from the Cancer Waiting Times database, accessible by PCTs and registries (also published in the CRS 2nd annual report).	A useful measure which provides insight into the number of patients being diagnosed through the urgent referral pathway as opposed to other routes.
	Stage of disease at diagnosis	Cancer Registries hold staging information. This can also be collected from MDTs.	Easily accessible staging data can vary considerably according to site (for instance NYCRIS staging data completeness report: breast and cervix: 80 - 90%, uterus ~ 20%) and also according to registry. This will affect whether you can use stage as an outcome measure for your project.
	'Spread' or 'No spread' (in the absence of staging data)	This information must be collected manually from General Practice (by going through letters from consultants).	The Improvement Foundation Healthy Communities Collaborative programme had difficulty collecting this measure from secondary care, and also raised concerns about the correctness of spread info for lung cancer - information about spread is not always given as many cases are inoperable. No spread of disease was defined as: Duke's A or B for bowel cancer, nodes negative for breast cancer and tumour confined to the primary site for lung cancer. The information was collected from general practice using hospital letters and details from the management development teams which are sent to the general practitioner at the time of diagnosis. Spread is a difficult measure to collect and requires close cooperation with general practices. However, if collected reliably it represents a powerful outcome measure for an intervention.
	Uptake/coverage of breast, bowel or cervical screening	The screening programme holds uptake information, it is also available in the Cancer Commissioning Toolkit (CCT). This information can be accessed at greater frequency by accessing information directly from screening providers. Uptake is also available by GP practice from Breast Screening units.	The Office of National Statistics /the Information Centre publish annual bulletins on breast and cervical screening (bowel is in development), with coverage and uptake (for breast) broken down by PCT. When deciding on your source for screening data it may be important to consider the time you may have to wait for data.
	One year survival data	Published annually and in the CCT, but only at PCT level for 4 major cancers	A good proxy for late diagnosis, and readily available from cancer registries. However, there is a significant time-lag until this information is available (over a year after diagnosis). There are also difficulties with looking at this data at PCT level and below - even at PCT level this shows a lack of precission around estimates even when several years are aggregated - which makes this generally unsuitable for monitoring.
INTERMEDIATE MEASURES	Number of referrals under the 2 week wait system	Available from the Cancer Waiting Times database (also published in the CRS 2nd annual report)	A useful measure which provides insight into the number of patients presenting and referral practices of primary care.
	Interval from first visit to primary care and referral	Must be audited manually from General Practice The GP cancer audit also collects this data	GPs collected these data in the National Primary Care Audit of Cancer. However the accuracy and completeness of this data is not established and may require validation/cleaning before it can be reliably used to measure the effectiveness of an intervention. This measure is likely to be more accurate than the number of visits to primary care per patient (because it is easier to collect).
	Attendances in primary care within a target age group (e.g. men over 55 with potentially cancer-related symptoms)	Must be audited manually from GPs	This data may be unreliable - the effectiveness of an interventions can be better judged by counting the number of cancer cases diagnosed or looking at the proportion diagnosed through urgent referral. However, this measure is more immediate and may be easier to audit. In conjunction with the number of cancer cases diagnosed it can give useful information about the burden an intervention is causing and whether it is getting the message across to the right people or the 'worried well'. Example measures from Derby intervention focusing on colorectal cancer (to be extracted from practice databases): All GP consultations on the following symptoms - Abdominal Mass, Rectal Bleeding (Painful and Painless), Change of Bowel Habit Patient details required: Ethnicity, Age, Gender, Postcode.
	Number of visits to primary care before onward referral	Must be audited manually from General Practice The GP cancer audit also collects this data	GPs collect this data in the National Primary Care Audit of Cancer. However the accuracy and completeness of this data is not established and may require validation/cleaning before it can be reliably used to measure the effectiveness of an intervention.

	Duration of symptoms amongst patients diagnosed with cancer	Must be audited manually from General Practice The GP cancer audit also collects this data	GPs collected these data in the National Primary Care Audit of Cancer. However the accuracy and completeness of this data is not established and may require validation/cleaning before it can be reliably used to measure the effectiveness of an intervention. The accuracy of this information will depend on patients' recollection.
AWARENESS MEASURES	Awareness levels (derived from the CR-UK Cancer Awareness Measure) *Interview*	Commissioned surveys required.	The Cancer Awareness Measure (CAM) is a validated set of questions designed to reliably assess cancer awareness. It was developed by Cancer Research UK, University College London, King's College London and University of Oxford in 2007-8. The CAM provides a good measure of people's awareness of signs, symptoms and risk factors for cancer. It also provides some information on their anticipated barriers to referral and delay - this information should be treated with caution as it does not represent actual behaviour, only intentions. It is worth noting that awareness on its own does not guarantee behaviour change, and so if possible a CAM survey should not be used in isolation to evaluate/monitor your intervention.
	Awareness levels (derived from the CR-UK Cancer Awareness Measure) *Self-complete*	Self complete surveys can be completed by post, at events or at services' locations. The updated CAM toolkit has self-complete versions of the generic, bowel, lung and breast CAMs.	Self-complete surveys should represent a good balance of cost effectiveness and efficacy.
	Awareness levels (derived from the CR-UK Cancer Awareness Measure) *Internet*	Commissioned surveys required	CAM data can be collected via the internet (see toolkit) offering a cost-effective way of collecting data on awareness. The effeicitiveness of this will depend on the internet use of the people whose cancer awareness you are trying to measure, and so will need to be carefully judged.
	Recall of the project/intervention (e.g. did completers of the CR-UK CAM or people in the target audience presenting to primary care remember the campaign?)	Commissioned surveys required, or see the NSMC general guidance around process evaluation	This does not provide any behavioural information or information on outcomes.

BACKGROUND

Baseline Assessments
All cancer networks have completed baseline assessments including much of this information (in 2009/10). Networks should also have plans to sustain and monitor this information, and so may be able to provide the data for your evaluation/monitoring.

Accessing the data
Evaluation often requires access to data that are collected or held by others, for example primary or secondary care or cancer registries. This can present huge challenges for a project. If possible, it is advisable to trial the data collection process, to ensure that the data can be collected in the time that is available. Ensuring that all key stakeholders are fully informed and engaged may help to ensure that data collection processes run as smoothly as possible.

Equalities Monitoring
Collecting data on your intervention by equalities group can be a useful way of understanding the effect you're having on different groups. Some of this information should be readily accessible, for instance gender and age. Postcode information is often accessible, and this can give an indication of deprivation. Ethnicity and sexual orientation amay be more difficult to access, but some general practices will have this information to hand.

Differing expectations – finance
It can become clear that stakeholders have differing expectations as to the importance of evaluation and the amount of budget that should be allocated to it. Funders or commissioners may be reluctant to provide funding for evaluation. However, evaluation is a vital component of any project and should not be viewed as a luxury. It is entirely worthy of resource allocation.

Differing expectations – timeliness
Evaluation can be a time-consuming process, depending on the objectives of the project, the chosen indicators and access to data, amongst other factors. There can be pressure to demonstrate the impact of a project within a short time frame. If evaluation is considered from the beginning of a project, it will be possible to see exactly which evaluation outcomes are expected and when. While it may not be possible to share the full evaluation with the interested party, there may be certain data that can be presented.

Linking Indicators to your behavioural goals
The indicators used in your intervention need to provide clear measurement of the behavioural goals you've set yourself - if your goal is to increase the number of early stage diagnoses then recall of a poster tells you nothing about progress towards it!

National Social Marketing Centre Toolbox