

Workshop on co-morbidity data collection

22nd October 2009

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Executive summary

Information on co-morbidity is important for both clinical decision making and for adjusting outcomes data in retrospective analyses. The Cancer Reform Strategy highlighted the importance of these data and identified that this is currently poorly collected. Together with the NHS Information Centre and NHS Connecting for Health, the National Cancer Intelligence Network (NCIN) is engaged in a project to redevelop the National Cancer Dataset. This provides an ideal opportunity to have collection of co-morbidity data agreed as a national information standard and to embed it into routine practice.

However, collection of co-morbidity data poses serious challenges. It is necessary to define why the information is being collected, when and how this will be done and whether a generic or site specific tool should be used. To begin to address these and other issues, approximately fifty participants representing a range of clinical specialties, cancer registries and other interested groups took part in a workshop on 22nd October 2009.

Three speakers presented experiences from other countries where collection of co-morbidity has been tried. Dr Jay Piccirillo began the day by describing the background to the Adult Co-morbidity Evaluation-27 (ACE-27), a chart-based co-morbidity index for patients with cancer. Dr. Piccirillo presented a range of work on co-morbidities to demonstrate both their clear impact on survival and that there are limited differences between different instruments or between generic and site specific instruments. He was also able to share some lessons from the US experience of national data collection. The closing message from the presentation was 'just do it' and this was echoed throughout the day. Dr Maryska Janssen-Heijnen and Dr Robert Milroy presented experiences in co-morbidity collection from the Netherlands and Scotland respectively. Both showed the impact that co-morbidities can have on survival and, once again, the key message was that different instruments have similar value and any collection of data is better than none.

The next set of speakers discussed different aspects of calculating co-morbidities from routine data. Jayne Harding discussed the wider work being carried out within NHS Connecting for Health to prepare guidance on co-morbidity collections and how coders within the health service will be trained and supported. James Thomas presented some initial work to use the NCIN's linked national cancer data repository to calculate Charlson scores (a standard scoring system based on routine data) retrospectively. Once again, co-morbidities were shown to have a clear impact on survival and, although this information is imperfect and retrospective, it is available now. Dr Diane Stockton outlined a similar approach using routinely linked data from the NHS in Scotland. In this case she compared a calculated Charlson score with an even simpler 'bed-days' index. This showed that the number of days spent in hospital during a defined period prior to a diagnosis of cancer was still predictive of death after adjustment for age and sex.

The last presentation of the day was from Dr Mick Peake, who shared the results of a simple survey of the Chairs of NCIN's Site Specific Clinical Reference Groups (SSCRGs). This asked which co-morbidities were of particular importance for each site and where they had their impact. The results demonstrated the variation in the requirements of different sites, particularly for children, teenagers and young adults. Any national solution to data collection will need to balance these varying requirements with consistency across sites.

Having heard the background information, the delegates took part in two facilitated workshop sessions to discuss the methodologies presented and their views on what a generic co-morbidity tool might look like; what site-specific modifications might be required and how collection could be embedded within the NHS.

There was a strong feeling that collection should begin as soon as possible using the tools available, rather than waiting for a tool that meets every requirement to be developed. For retrospective data collection, Charlson scoring was a possibility as were more basic measurements such as bed-days. If possible, however, information should be collected prior to the MDT meeting and made available to inform the discussions. For this, both ACE-27 and the American Society of Anaesthesiologists (ASA) grade were considered as possible with the former having wider clinical relevance..

Most delegates felt that some form of site specific modification would be useful but that this should take the form of adjustments or additions to a common instrument, rather than using different indices altogether. The need for a specific focus on the requirements of children, teenagers and young adults was clear but the expectation was that this could also be a modification to an existing tool. NCIN's SSCRGs were expected to play a key role in this process. Throughout, the consensus was to use what we have now rather than wait to develop a perfect methodology.

As was outlined on the day, this workshop was not expected to solve the issue of collecting co-morbidity data. However, the discussions that took place and the clear consensus that data collection should begin as soon as possible allows NCIN to develop an action plan. This will be published separately for consultation and discussion with all of the relevant stakeholders.

1. Introduction: Why should we routinely collect co-morbidity information?

- 1.1 Clinical decision making in cancer is influenced by a range of individual and tumour factors. The appropriate course of treatment will depend on the site, stage and aggressiveness of the tumour, as well as the patient's preferences, age, performance status and any co-morbidity. The establishment of the National Cancer Intelligence Network (NCIN) was a key commitment of the Cancer Reform Strategy (CRS), which stated that *".....Better information on cancer services and outcomes will enhance patient choice, drive up service quality and underpin stronger commissioning"*. The CRS highlighted the importance of information on co-morbidity for adjusting outcomes data and that this is currently poorly collected. Although the CRS is an England specific strategy, the NCIN is a UK-wide organisation and will work in a similar fashion with the other UK nations.
- 1.2 Together with the NHS Information Centre (NHS IC) and NHS Connecting for Health (NHS CfH), NCIN is engaged in a project to redevelop the National Cancer Dataset for use as a full operational standard in England. This will involve a review of the current business needs for the different collections and ensure that the outputs are fit for purpose. Co-morbidity data were identified as a priority area for change in the review that initiated the project. This provides an ideal opportunity to have collection of co-morbidity data mandated by the Information Standards Board for Health and Social Care (ISB HaSC) and embed it into routine practice. The timescales for the project (show in Figure 1) give ample time for consultation and agreement on the appropriate definitions, with this workshop the forming the start of the process.

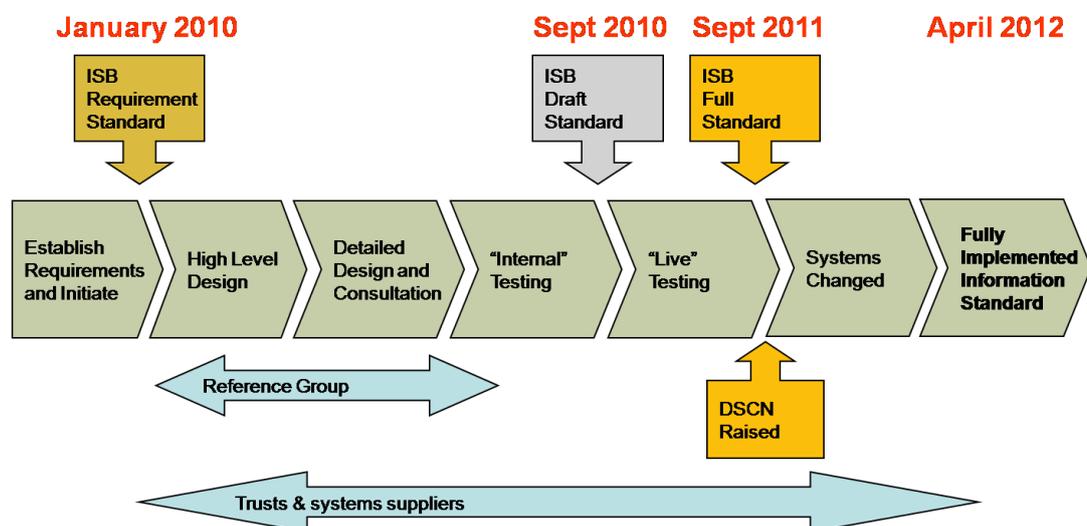


Figure 1. Outline plan for review of the National Cancer Dataset (Source: NHS IC)

- 1.3 One possible definition of co-morbidity is *"a disease or illness affecting a cancer patient in addition to but not as a result of their index (current) cancer"*. However, this immediately raises further questions about how co-morbidity should be assessed. What elements are important and should a metric of co-morbidity look only at whether a condition is present or also measure the severity of the condition? Should we examine individual conditions or the cumulative disease burden? Finally, is the focus on life history or current active disease and when should co-morbidities be assessed, at point of diagnosis only or also at recurrence?

- 1.4 Before looking at how co-morbidity information might be collected, it is necessary to consider its purpose. Collecting such data can help to predict outcomes, perhaps as part of a personal prognostogram, and to better understand peri-treatment morbidity/mortality and longer term complications. It can also contribute to care quality assessment, helping to compare treatment selection and contributing to case mix adjustment in comparative survival (and treatment) rates. When and how the information is collected will strongly influence its suitability for different purposes; these purposes need to be defined upfront. Even when the purpose of collection is clear, decisions are needed about whether a generic or site specific scale should be used, whether a different approach is needed for children and young adults and whether data should be collected directly or derived from other sources.
- 1.5 Collecting data on co-morbidities clearly poses serious challenges. It was considered during the definition of the current cancer dataset in 2001/2 and although there is an existing entry for co-morbidity in adults in the cancer registration dataset, this says only that *“Investigations into the possible use of the ACE-27 coding system are continuing”*. Recognising this, the objective of the workshop was not to reach the ultimate answer but rather to the progression of a co-morbidity journey and definition of a clear way forward.
- [DN: I haven't been able to find a copy or reference to Jenny Millman's report – Richard / Di do you have one?]**
- 1.6 The aims of the day were:
- To consider the need for routine co-morbidity data collection in all cancer patients
 - To evaluate current methodologies
 - To consider attributes of a generic tool
 - To consider any site specific elements
 - To consider feasibility of collection
- 1.7 Approximately 50 participants from NCIN's Site Specific Clinical Reference Groups (SSCRGs), representing a range of clinical specialties, cancer registries and other interested groups heard short lectures from a renowned international faculty and took part in two facilitated workshops to discuss the issues. This document summarises the information presented at the workshop and the discussions that took place.

2. Co-morbidity scales

The American Experience – Dr Jay Piccirillo

ACE-27

- 2.1 Dr Piccirillo began by describing the background to the Adult Co-morbidity Evaluation-27 (ACE-27). ACE-27 is a chart-based co-morbidity index for patients with cancer developed through modification of the Kaplan-Feinstein Co-morbidity Index (KFI). Ailments were included on the basis of evidence for their impact on treatment and prognosis, their prevalence (required to be 1% of patients or greater) and whether they were a significant predictor of outcome. In addition, the aim was to avoid additional costs for data capture. The system has been validated in a study of 19,268 cancer patients¹.

¹ JAMA 2004; 291:2441-2447

- 2.2 A web-based co-morbidity education program for cancer coders has been developed and an electronic version of the index is available². The web based training includes a pre-assessment, the training course itself, and a final exam. Coding competency has been reassessed after one- and six-months and validation of the scores assigned by registrars show that they are retaining the skills taught and that both intra- and inter-registrar reliability is good.
- 2.3 The overall prevalence of co-morbidity is high³ and it has a clear impact on survival (Figure 2). This relationship persists however the data are cut (by gender, age, ethnicity, tumour site, etc.), although co-morbidities have a greater impact in some tumour types than others.

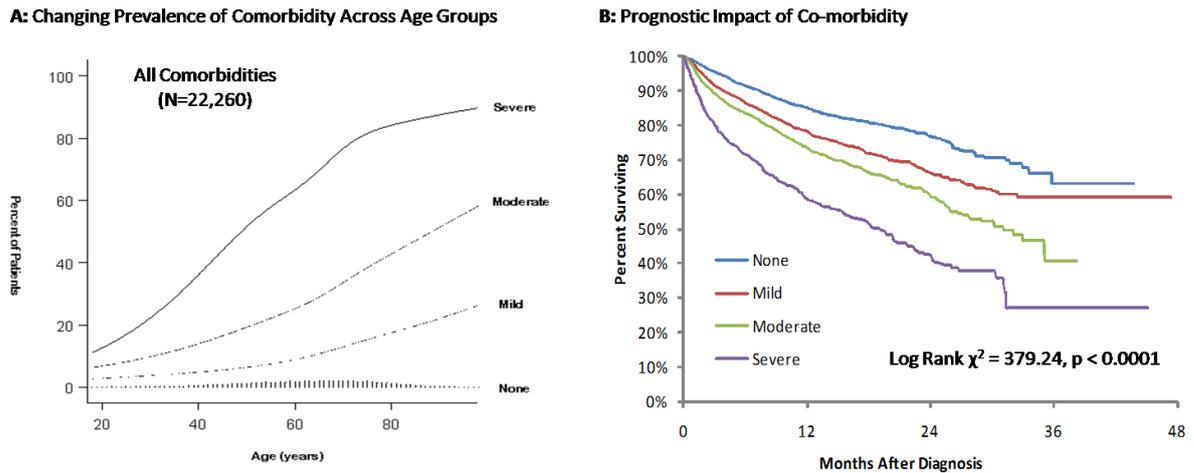


Figure 2. (A) Prevalence and (B) prognostic impact of co-morbidities

Comparison of co-morbidity indices and scoring systems

- 2.4 To compare general co-morbidity indices with site specific versions, the Surveillance, Epidemiology, and End Results (SEER) Medicare-linked database was used to identify 15,493 patients with incident squamous cell carcinomas of the oral cavity, pharynx, and larynx. Comorbid ailments were identified through the use of the ICD-9 edition codes in the Medicare inpatient and outpatient claims for 7131 patients. In the comparison of two general co-morbidity indices with two disease-specific indices, no instrument clearly performed better than the others and the general indices performed as well as the disease-specific indices⁴.
- 2.5 Although the various indices perform similarly, the use of claims based data does potentially overestimate the prevalence of co-morbidities. In a random sample of 588 newly diagnosed cancer patients during a one-year period a comparison of claims and chart-based methods showed important differences in both the number and agreement when identifying individual diseases. The two methods yield large differences in the distribution of patients among co-morbidity with, for example 71% of patients scored "No" co-morbidity in the chart-based approach compared with 26% in the claims-based approach⁵.

² <http://cancercomorbidity.wustl.edu/ElectronicACE27.aspx>

³ Critical Reviews Oncology-Hematology 2008;76(2):124-132

⁴ Medical Care. 2004; 42 (5):482-486

⁵ Journal of Registry Management 2006; 33(1):10-16

- 2.6 Within a single coding scheme, a variety of methods for scoring and combining ailments may be used. In a comparison of eight different scoring systems, the inclusion of any co-morbidity information added prognostic value to the baseline model and no scheme performed significantly better than the others. Adding complexity to the scoring scheme did not improve the prognostic estimates or clinical value.

National data collection – the US experience

- 2.7 Dr Piccirillo described the US Commission on Cancer (COC) Co-morbidity Initiative and some of the problems with this attempt at collection. In 2003 COC mandated the collection of comorbidity information as defined by the ICD-9-CM codes from the hospital discharge attestation sheet as a new element in Facility Oncology Registry Data Standards⁶.
- 2.8 However this attempt has several flaws. Only inpatients were to be recorded, leading to collection of information on only approximately 60% of patients and a high degree of bias. Conditions were recorded in the sequence in which they appeared on the patient's discharge notes, even though these are ordered to maximise reimbursement rather than by clinical relevance. Finally, any conditions identified by an ICD-9 code existing at the time of diagnosis were to be included, without guidance to the relevance of the 15,000 possible ICD-9 codes. The only exceptions were secondary diagnoses of cancer, which were excluded as co-morbidities despite their importance.

Prognostigram

- 2.9 Using real-time clinical outcomes data, Washington University have developed an interactive web-based computer program that generates patient-specific survival information⁷. The survival curve generated is based on information about the patient – age, gender, race, co-morbidity – and the tumour – tumour site, stage, and histologic grade. The tool is available to patients, families, health care professionals, administrators to improve decision-making and quality of care.

Conclusions

- 2.10 Dr Piccirillo's conclusions were that co-morbidity is important in the selection of treatment, estimates of prognosis and evaluation of quality of care. Valid instruments exist for time-efficient collection of comorbid information and investigators should choose instrument based on availability, comfort with the methodology, and outcomes of interest. The continued exclusion of co-morbidity impedes the scientific study of cancer and the humanistic care of patients. A valid co-morbidity assessment should be added as a required data element to hospital-based and central cancer registries.
- 2.11 *The ACE-27 instrument is included in Appendix C of this report and a patient questionnaire provided by Newcastle upon Tyne Hospitals NHS Trust is included in Appendix D.*

The Dutch Experience – Dr Maryska Janssen-Heijnen

- 2.12 Quality of life and independence are as important for the elderly as for younger people. However, the elderly are rarely included in clinical trials making it hard to assess the impact of cancer and cancer treatments on this patient group. Routine collection of information on co-morbidities can begin to answer these questions. Dr Janssen-Heijnen

⁶ Journal Registry Management. 2003;30:117-122.

⁷ <http://www.fourthtime.com/wustl/prognostigram>

highlighted that the recording of co-morbidities only takes a few minutes extra for a cancer registry that is extracting data from patient records. The number of diseases, their severity and the type of disease are the most important information; once these are held the choice of scoring system can depend on the research question.

- 2.13 The Eindhoven Cancer Registry (ECR) has recorded co-morbidity information since 1993, coding this from medical records using an adapted Charlson score (a standard scoring system based on routine data). Only co-morbidities present at the time of diagnosis are recorded; those developing during treatment are not included. Identification of co-morbidities for inclusion is based on a list of conditions. To improve the accuracy of scoring this list includes abbreviations and common alternative terms. A comparison of the ECR score with the ACE-27 system showed strong (88% - 97%) agreement for the most common conditions, although differences between the classification systems meant that the median number of conditions was lower for ECR than ACE-27.
- 2.14 Co-morbidity information can provide insights into tumour etiology. For example COPD is more prevalent in males with lung cancer, while diabetes is more prevalent in women with cancer of the pancreas and corpus uteri. In the first instance smoking is likely to be a common factor and while obesity may be common in the second. Co-morbidities may also explain the choice of treatment (for example, surgery vs none in lung cancer or surgery and chemotherapy vs surgery alone for colon cancer).

The Scottish lung cancer experience – Dr Robert Milroy

- 2.15 Dr Milroy, speaking on behalf of the Scottish Lung Cancer Forum, described early results from a prospective audit of lung cancer patients. The audit, conducted from 2005-2008 at four centres in Scotland, collected a 'Scottish Co-morbidity Index' (see Box 1) on almost 900 lung cancer patients. Performance status, both at present and six months previously was also collected. The co-morbidity information was collected on paper forms during clinics and data items were generally readily available. The exception to this was diabetes scoring where a simple score based on how the disease was controlled would have been more pragmatic.
- 2.16 The four centres showed variation in levels of co-morbidity, with more deprived areas experiencing more co-morbidity. Deprivation was also strongly associated with poor and deteriorating performance status, independent of co-morbidities, as well as lower levels of treatment. Survival and multivariate factors are now being analysed for these patients and should produce further insights.

Scoring of co-morbidity (Scottish Co-morbidity Index)	
<u>COPD</u> (BTS/GOLD guidelines)	<u>CVA</u> (NIH Stroke Scale)
0 No disease	
1 FEV1 > 60%	<u>Dementia</u> (Clinical Dementia Rating)
2 FEV1 40-60%	<u>Diabetes</u> (No disease, HbA1c)
3 FEV1 < 40%	
<u>IHD</u> (Canadian CV Society Classification)	<u>Renal Failure</u> (GFR)
0 No disease	<u>Previous malignancy</u>
1 Angina with strenuous/prolonged exertion	<u>Weight Loss</u> (0, <5%, 5-10%, >10%)
2 Angina after walking 200 hundred yards flat/flight stairs	<u>Peripheral Vascular Disease</u> (claudication)
3 Inability to carry on any level of exertion/angina at rest	
<u>CCF</u> (NYHA classification)	<u>Alcohol</u> (units/wk)
0 No disease	
1 Slight limitation of physical activity due to dyspnoea	
2 Comfortable at rest, less than ordinary activity causes dyspnoea	
3 Dyspnoea at rest	

Box 1. Scottish Co-morbidity Index

3. Deriving co-morbidity information from hospital data

DH and NHS CfH co-morbidity initiatives – Jayne Harding

- 3.1 The NHS in England currently uses OPCS-4 codes to record interventions and procedures and ICD-10 codes for disease classification. However, the ICD-10 codes currently in use are not the latest version released by the World Health Organisation. The codes in use in England were last updated in April 2004; an ongoing piece of work is assessing the cost and impact of implementing the latest changes. This forms part of the role of the Data Standards and Products team at NHS CfH.
- 3.2 The guidance for coding chronic conditions is “*Any condition that affects the management of the patient within the current episode of care should be coded*”. Common conditions included are:
 - Arthritis/ osteoarthritis
 - Diabetes
 - COPD/ Asthma, Bronchitis, Emphysema
 - IHD/ Angina/ hypertension
 - Epilepsy
- 3.3 The NHS Classifications Service are also developing guidance on co-morbidities and have produced a paper on this for coders. This will be reviewed with a clinical sub-group in October 2009 to ensure that the information recorded is clinically driven. CfH will also involve the NCIN in this process.

The value of HES for co-morbidity analysis – James Thomas

- 3.4 The National Cancer Data Repository (NCDR) has been prepared by the Northern and Yorkshire Cancer Registry and Information Service (NYCRIS) and Thames Cancer Registry (TCR) on behalf of NCIN. This repository currently includes the following linked datasets:
 - ONS Minimum Cancer Dataset (1971-2006 / 9.2 million tumours)
 - Merged English cancer registries dataset (1990-2006 / 5.3 million tumours) containing additional tumour and treatment information

- Inpatient Hospital Episode Statistics (HES) data (1997-2007 / 33 million episodes / 4.9 million patients)
- 3.5 NCIN intends the NCDR to be used to monitor processes and outcomes of care and, given its influence on care, information on co-morbidity levels is important for this purpose. Unfortunately only limited co-morbidity information is included in the NCDR. To address this, Charlson scores have been calculated based on the diagnosis information in HES.
- 3.6 Each HES record contains up to fourteen diagnosis fields. To calculate the Charlson score from the NCDR, these diagnoses were assessed for three time periods prior to diagnosis (1yr / 2yr / all episodes). ICD10 codes included in the Charlson index were looked up across all episodes in the time period, excluding the codes representing the tumour of interest. The matched ICD10 codes were grouped into Charlson Groups which were then further matched to avoid double counting. For example, severe diabetes complications counted over Diabetes Complications. Scores from each group were summed to give a final score.
- 3.7 Increasing the time period increased the number of tumour records with an associated Charlson score. Using all episodes prior to diagnosis, 19.6% of tumour records had associated co-morbidities with a mean score of 1.76. Increased co-morbidity resulted in lower survival for colorectal cancer patients (see Figure 3).

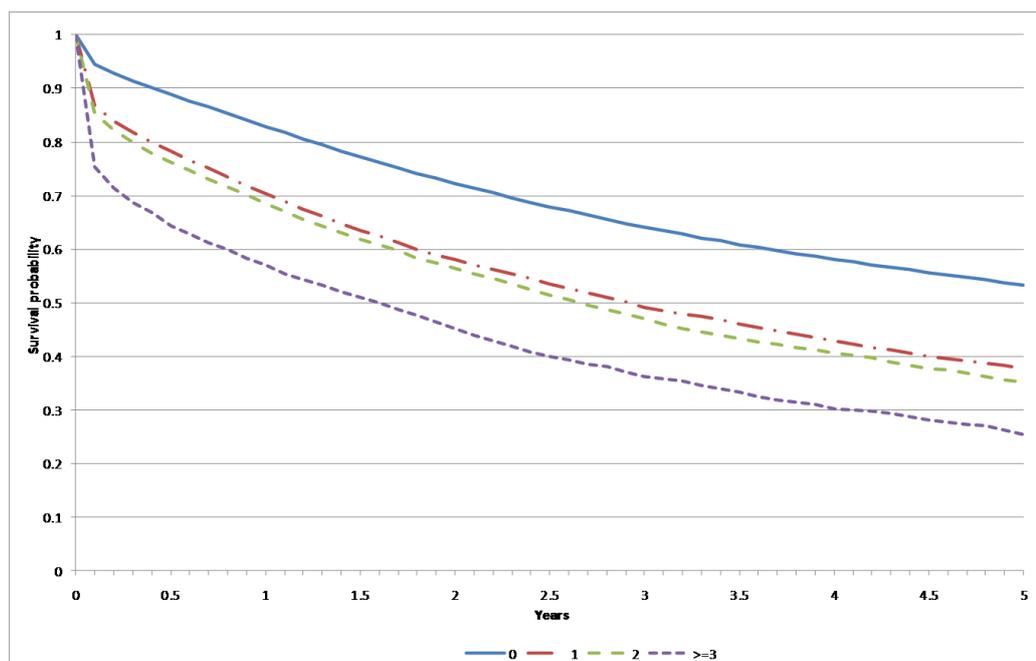


Figure 3. Colorectal survival by Charlson score

- 3.8 Although this method provides co-morbidity information there are a number of complications. The calculated score is very dependent on date of cancer diagnosis and this can vary due to differences in registration processes between registries. In many cases a cancer diagnosis is the first in-patient episode; only including episodes prior to diagnosis may miss co-morbidity codes that are present but have not been recorded. It is likely that the primary tumour or suspected tumours are sometimes being scored as co-morbidities, due respectively to differences in the coding of cancers between registries and HES and to coding of suspected cancer diagnoses in HES. Finally cancers and metastatic cancer make up a large proportion of the scores, raising the question of whether any cancer information should be used in the calculation of the score for cancer

purposes. Further work needs to be undertaken to assess the best approach to calculating co-morbidity from the available data.

Measuring co-morbidity when analysing cancer data – Dr Diane Stockton

- 3.9 The NHS in Scotland routinely collects episode-based records relating to all hospital discharges (or transfers). These SMR01 records form the basis of the Scottish linked dataset, which also includes cancer registrations (SMR06), death registrations and psychiatric records (SMR04). These data are routinely linked each month using probabilistic matching.
- 3.10 SMR01 data, which are similar to English HES information, include a principal diagnosis and up to five secondary diagnosis codes. These secondary diagnoses are either active problems related to the admission or a record of background co-morbidities from a defined list⁸. An audit of data collection from 2004-6 suggested that these fields are approximately 72% accurate, largely due to under-reporting.
- 3.11 Co-morbidity at the time of diagnosis has been measured in two ways using the Scottish linked dataset: the Charlson index to take account of impact of specific diseases and a 'bed-days' index to try to estimate the accumulated effects of ill health. The bed-days index is the number of days spent in hospital in a defined period prior to the cancer diagnosis.
- 3.12 For each group of patients, an increasing number bed days was predictive of death after adjustment for age and sex. Investigation of the optimal time period of follow-up showed that co-morbidity in the two years prior to date of interest was found to be as strongly predictive of death as longer follow-up intervals. Table 1 shows adjusted crude 2-year survival for five cancer sites for patients with varying bed days in the period 6-24 months prior to diagnosis and for patients with and without co-morbidities under the Charlson index.

Co-morbidity	Breast	Colon	Rectum	Kidney	Bladder
Bed-days					
None	83.4	54.3	59.6	48.9	65.2
1-10	86.0	51.7	62.7	60.8	63.3
11-29	69.0	44.1	34.5	45.8	60.0
30+	52.2	24.6	26.1	33.3	37.5
Charlson					
No	84.8	55.8	61.3	53.5	66.4
Yes	54.4	33.1	40.2	34.8	46.8

Table 1. Age and sex adjusted crude 2-year survival

- 3.13 This information is readily available from existing data and hospital co-morbidity is a strong predictor of cancer patient survival, independent of age, for all the cancers investigated. Even the bed-days index, although crude, appears robust and doesn't rely

⁸ See details at <http://www.isdscotland.org/isd/files/SMR01%20Other%20Conditions%20-%20coding%20guidance.doc>

on coding. However, both of these methods do rely on this existence of linked information and fail to account for the severity of disease.

- 3.14 The strongest marker of co-morbidity is bed-days in the six months preceding diagnosis, but this is not always easy to interpret. For diseases where clinical diagnosis may be difficult to achieve quickly, it may be important to exclude bed-days in the 6 months preceding the diagnosis; when this is done the impact of specific diseases gains importance. The “best” measure of co-morbidity differed by cancer type, so any comprehensive hospital-based co-morbidity index will have to take into account both the impact of specific diseases and the accumulated effects of ill health.

Discussion points

- 3.15 The discussion following these presentations raised a number of issues including:
- 3.16 The similarity between the co-morbidity data under discussion and the actuarial information regularly used by insurance companies. Could we learn from their experiences? Dr Piccirillo’s impression was that reinsurance groups have supported work in this area in the past but this is because they feel their methods could be improved and that they would like more clinical information. However, the fact that patients can routinely supply this information does highlight one way of gathering data.
- 3.17 The importance of understanding co-morbidities extends beyond cancer and the need to link this work with other NHS initiatives was highlighted. Ms Harding was able to explain that a Clinical Advisory Panel will make recommendations on general and site specific measures and that NCIN will be involved in this process.
- 3.18 Finally a problem was raised with using co-morbidity information to explain differences in treatment. Even very ill patients may still benefit from aggressive treatment, though by less than others – the assumption that the optimal treatment changes due to co-morbidities is not necessarily correct. Dr Piccirillo explained that his group have found exactly that effect in their own work.

4. Current experience of the NCIN Site Specific Clinical Reference Groups

- 4.1 To understand the current experience and requirements of the NCIN SSCRGs, the NCIN Clinical Lead, Dr Mick Peake, has carried out a simple survey of SSCRG Chairs. The results of this survey, shown in Table 2, summarise how co-morbidities impact treatment and outcomes, while Table 3 shows the sites of most relevance for various co-morbidities. Of particular interest is the wide variation in the importance of this information and how it may affect both treatment decisions and long term outcomes.

	Breast	Colo-rectal	Gynae	Haem	H&N	Lung	Sarcoma	Skin	UGI	TYA
PS	±	+++	+	+++	+	+++	±	++	+++	±
C-M	++	+++	++	+	++	+++	+	+	+++	±
Surgery	+	+++	+	-	++	+++	+	±	+++	±
Chemo	++	++	++	++	++	++	+	+	++	±
RT	++	+	+	±	+	++	±	-	±	±

Peri-op mortality	+	++	+	-	+	+++	+	-	+++	±
Overall survival	+	++	+	+	++	+	±	±	+	±
Late effects	+++	++	+	+++	+	+	+	+	+	+++
Tools	ASA	ASA Possum	UK Gosoc	ACE27 ADL	ACE 27	No (lung function)	No	No	ASA	No

Table 2. Site-specific review of the importance of co-morbidity data

- 4.2 To take the first of three contrasting examples, the median survival for a lung cancer patient is approximately six months and their median age 71. Of these patients, approximately 85% are smokers or ex-smokers and there is a high incidence of cardio-respiratory illnesses. Major intrathoracic surgery is the best treatment option given the lung toxicity of radical radiotherapy and performance status is central to most treatment decisions. The issues of concern are selection for surgery, peri-operative mortality and post-operative quality of life.

Co-morbidity	Sites of most relevance	Key Measures
Cardiac	Lung, UGI, Colo-rectal, Head & Neck	Echo, Exercise ECG, MUGA scan, Angiography
Respiratory	Lung, UGI, Colo-rectal, Head & Neck	Lung Function (FEV ₁ , etc.) Exercise testing Quantitative perfusion scan
Cerebro-vascular	Lung, UGI, Colo-rectal, Head & Neck	
Dementia	All	
Renal	All	Creatinine & clearance
Hepatic	All	LFTs
Weight / nutrition	UGI, Head & Neck	BMI, Serum albumin, weight loss
Obesity	Gynae, UGI	BMI
Previous surgery/RT/Chemo	Gynae, Colo-rectal, urology, Head & Neck	
'Frailty'	?All (except children & TYAs)	Stair climb, 'Tray test' Subjective

Table 3. Sites most impacted by selected co-morbidities

- 4.3 For breast cancer, median survival is greater than 14 years, patients are generally younger and a more 'normal' range of co-morbidities is observed. The curative surgery is much less invasive and performance status is not often important in first line treatment. The major issues here are much more likely to be fitness for reconstructive surgery and

the long term effects of chemotherapy and radiotherapy treatments (for example cardiac toxicity and second cancers).

- 4.4 Finally, for children, teenagers and young adults, co-morbidities are a much smaller problem affecting no more than 5% of individuals (mostly congenital defects, immunodeficiency, genetic syndromes and diabetes). Performance status is rarely important in determining treatment and the major concern is possible late effects of cancer treatments.
- 4.5 Each of these and other sites has its own particular requirements. Any approach must address these as well as allowing for the differing ways in which co-morbidity information may be used: in selection for treatment; in risk adjusting outcomes; in predicting possible late effects of treatment and in contributing to our understanding of population-level survival / prognosis.

5. Considering a generic co-morbidity tool

- 5.1 During the day, delegates took part in two facilitated discussion sessions to consider a generic co-morbidity tool. The key themes from these discussions are outlined below.

Workshop session one

- 5.2 In this first session, groups were asked to discuss:
 - What are the weaknesses and strengths of the methodologies presented so far?
 - What other methodologies should be considered?
 - When and who should collect co-morbidity data?
- 5.3 A distinction was drawn between real time collection of information (e.g. to inform clinical decision making) and *post-hoc* analysis of existing data (for monitoring of care quality and outcomes). The purpose for which data are to be used will affect the relative suitability of different methodologies. For 'real time' data collection, ACE-27 was considered clinically relevant, although there was some debate about the length of time required to collect the information. For retrospective collection Charlson scoring was a possibility as were more basic measurements such as bed-days. Here, though, there was concern that simple inpatient bed-days might be inappropriate given the current focus on moving more treatment out of secondary care; a broader measure of care episodes might be necessary.
- 5.4 Information from primary care was considered a promising alternative source of co-morbidity information and several groups suggested ways in which these data might be obtained, including through the Quality and Outcomes Framework (QOF). Ideally, general practice data would be available electronically, both for use at Multi-Disciplinary Team (MDT) meetings and for inclusion in the NCDR⁹. Until this is achieved including standard information on co-morbidities in GP referral letters would avoid duplicate data collection and better inform treatment. Another suggested index was the American Society of Anesthesiologists (ASA) grade, which is regularly used in some surgical specialities. Finally, similar information might be obtained through a very simple set of lifestyle questions addressing weight loss, BMI, smoking and alcohol consumption.

⁹ Since this workshop it has been learned that the GP Extraction System currently under development by the NHS IC is likely to retrieve only anonymised data.

- 5.5 Patients might also contribute to data collection. In Newcastle, a short patient survey is used to streamline the collection of ACE-27 information¹⁰. Use of this survey reduces the clinician time taken to complete the ACE-27 assessment to five minutes and actively involves patients in the process. Whatever index or indices are finally adopted (there may be a case to use a combination of approaches) and however information is collected, there was consensus that the approach must be a standard nationally and, ideally, across all tumour types. There was a strong belief that collection should begin as soon as possible using the tools available, rather than waiting for a tool that meets every requirement to be developed.
- 5.6 When the information is collected depends on how it will be used. Time at MDT meetings is valuable and any data collection here would need to be quick, simple and ideally supported by electronic data entry tools. If possible, information should be collected prior to the MDT meeting and made available to inform the discussions. Whether co-morbidity data are collected prospectively or calculated based on routine management data, clinical input is vital to ensure accuracy. However, this requires that appropriate incentives are in place (i.e. commissioners will need to be engaged) and that the importance of these data is communicated to clinicians.

Workshop session two

- 5.7 In the second session, the groups were asked to address:
- What generic methodology would you pick based on the discussions so far?
 - What site specific modifications might be necessary (with a particular focus on the needs of children, teenagers and young adults)?
 - How would you communicate this work and the importance of co-morbidity information to the clinical community?
- 5.8 Almost all of the co-morbidity indices discussed previously were favoured by one or more groups but the consensus was that we should be pragmatic in using existing methodologies, accepting that these may not be perfect. Once again the belief was that there is benefit in collecting some information now rather than waiting. ASA grading and ACE-27 were both suggested as clinically relevant and widely used. It was suggested that if these were too complex to collect routinely then a question as simple as 'is any co-morbidity present?' or 'was standard treatment followed and, if not, why?' might provide valuable information (although defining 'standard' for the later question might be difficult). However, experience with the National Lung Cancer Audit suggests that such high level questions are too subjective to have real value.
- 5.9 GP data were again highlighted as a potentially valuable source. For retrospective analyses (which could be conducted immediately), Charlson scoring seemed favoured over the more basic methods such as bed-days. An underlying principle that information should only be recorded once was emphasised.
- 5.10 A common theme was the need to future proof collection against changes in clinical practice. One way to ensure this is to collect and record underlying data on co-morbid conditions which can then be used to calculate scores using an index of choice, rather than (or as well as) collecting the score from a particular index. To fit with NCIN's overall objectives, data should be collected once then shared.
- 5.11 Most groups felt that some form of site specific modification would be useful but that this should take the form of adjustments or additions to a common instrument, rather

¹⁰ This survey is included as Appendix D

than using different indices altogether. The need for a specific focus on the requirements of children, teenagers and young adults was clear but the expectation was that this could also be a modification to an existing tool. NCIN's SSCRGs were expected to play a key role in this process. Once again the consensus was to use what we have now rather than wait to develop a perfect methodology.

- 5.12 A number of levers were suggested to communicate this work and embed it into routine practice. Key themes were: making data collection simple and easy as a part of standard clinical practice; demonstrating and then educating clinicians in the benefits of doing this; publishing and using data to drive up standards; and mandating collection then using commissioning levers to withhold payment if this isn't done. An example of how change was achieved in the collection of staging data through education about its benefits was mentioned, as was the possibility of building an evidence base from the work of cardiologists and the experience of other countries.

6. Next steps

- 6.1 Di Riley closed the workshop by thanking all of the participants and making some brief comments on the next steps. The need to do something now, not wait for a perfect solution seems clear. Although there is value in analyses based on routine data such as HES, it also seems clear that we should try to embed collection of co-morbidity data into routine practice at the time of diagnosis.
- 6.2 This information is relevant to clinical care and must be a part of everyday processes. There will not be lots of extra coders to implement this; therefore any solution will need to be simple, quick, easy and relevant. The focus on a generic tool with site specific additions is interesting although clearly further discussions will be required with some SSCRGs, in particular that covering children, teenagers and young adults.
- 6.3 We now need to consider the results of the day, discuss this with various interested groups (the Cancer Programme Board, the UK Association of Cancer Registries Executive, the NCIN Clinical Chairs Forum and others) and develop an action plan. We will need to consider what we can pilot and where, what training will be required and where NCIN money will make the most difference. This will not be an instant change but this workshop is the first step to making the change happen.

Appendix A. List of participants

The following individuals took part in the workshop:

Name	Representing	Name	Representing
Alex Smith	Haematology SSCRG	Linda Dutton	NCIN
Alison Roe	NHS IC	Martin Lee	Breast SSCRG
Alison Stone	NCIN	Maryska Janssen-Heijnen	Speaker
Anna Gavin	NICR	Matthew Francis	Sarcoma SSCRG / WMCIU
Bill Allum	UGI	Michael Chapman	NCIN
Catherine Lagord	WMCIU	Mick Peake	Speaker / NCIN
Charlotte Lambourn	Brain& CNS SSCRG	Mike Mendall	UGI SSCRG
Chris Carrigan	NCIN	Mike Swart	Anaesthetist
Ciaran Towens	Macmillan	Neil Hanchett	Thames Cancer Registry
Claire Beattie	ECRIC	Nicky Coombes	NCIN
David Forman	NCIN	Nicola Bell	Lung SSCRG
Di Riley	NCIN	Paul Finan	Colorectal SSCRG
Diane Stockton	ISD	Paul Silcocks	Trent Cancer Registry
Dorina Kallogjeri	Washington University	Peter Collins	Brain & CNS SSCRG
Elizabeth Davies	TCR	Richard Wight	Chair
Elsbeth MacDonald	Commissioning	Rob Milroy	Speaker
Eva Morris	NYCRIS	Rob Turner	Sarcoma SSCRG
Hamish Ross	Haematology SSCRG	Robin Crawford	Gynae SSCRG
Henrik Moller	TCR	Roz Stanley	NHS IC
James Salt	NHS IC	Ru Mcdonagh	Urology SSCRG
James Thomas	NYCRIS	Sean McPhail	Urology SSCRG / SWPHO
Jane Maher	Macmillan	Sion Barnard	Lung SSCRG
Jane Whittome	Jane Whittome	Steve Dean	NHS IC
Jason Smith	Colorectal SSCRG	Steven Oliver	NYCRIS
Jay Piccirillo	Washington University	Sue Forsey	Chemotherapy
Jayne Harding	Connecting for Health	Tony Moran	CTYA SSCRG / NWCIS
Jill Birch	CTYA SSCRG	Tracey Parker	DH / NHS CfH
Julia Verne	Urology / Skin SSCRGs	Vinidh Paleri	Head & Neck SSCRG
Julie Lees	Brain & CNS SSCRG		
Julie Michalowski	NHS IC		
Kellie Peters	OCIU		

Appendix B. List of abbreviations

ACE-27	Adult Co-morbidity Evaluation-27
ASA	American Society of Anesthesiologists
NHS CfH	NHS Connecting for Health
COC	Commission on Cancer
CRS	Cancer Reform Strategy
ECR	Eindhoven Cancer Registry
HES	Hospital Episode Statistics
NHS IC	NHS Information Centre
ISB	Information Standards Board
KFI	Kaplan-Feinstein Co-morbidity Index
MDT	Multi-Disciplinary Team
NCIN	National Cancer Intelligence Network
NYCRIS	Northern and Yorkshire Cancer Registry and Information Service
SEER	Surveillance, Epidemiology, and End Results
SSCRG	Site Specific Clinical Reference Group
TCR	Thames Cancer Registry

Appendix C. Adult Comorbidity Evaluation-27

Adult Comorbidity Evaluation-27

Identify the important medical comorbidities and grade severity using the index.
Overall Comorbidity Score is defined according to the highest ranked single ailment, except in the case where two or more Grade 2 ailments occur in different organ systems. In this situation, the overall comorbidity score should be designated Grade 3.

Cogent comorbid ailment	Grade 3	Grade 2	Grade 1
	Severe Decompensation	Moderate Decompensation	Mild Decompensation
Cardiovascular System			
Myocardial Infarct	<input type="checkbox"/> MI ≤ 6 months	<input type="checkbox"/> MI > 6 months ago	<input type="checkbox"/> MI by ECG only, age undetermined
Angina / Coronary Artery Disease	<input type="checkbox"/> Unstable angina	<input type="checkbox"/> Chronic exertional angina <input type="checkbox"/> Recent (≤ 6 months) Coronary Artery Bypass Graft (CABG) or Percutaneous Transluminal Coronary Angioplasty (PTCA) <input type="checkbox"/> Recent (≤ 6 months) coronary stent	<input type="checkbox"/> ECG or stress test evidence or catheterization evidence of coronary disease without symptoms <input type="checkbox"/> Angina pectoris not requiring hospitalization <input type="checkbox"/> CABG or PTCA (>6 mos.) <input type="checkbox"/> Coronary stent (>6 mos.)
Congestive Heart Failure (CHF)	<input type="checkbox"/> Hospitalized for CHF within past 6 months <input type="checkbox"/> Ejection fraction < 20%	<input type="checkbox"/> Hospitalized for CHF >6 months prior <input type="checkbox"/> CHF with dyspnea which limits activities	<input type="checkbox"/> CHF with dyspnea which has responded to treatment <input type="checkbox"/> Exertional dyspnea <input type="checkbox"/> Paroxysmal Nocturnal Dyspnea (PND)
Arrhythmias	<input type="checkbox"/> Ventricular arrhythmia ≤ 6 months	<input type="checkbox"/> Ventricular arrhythmia > 6 months <input type="checkbox"/> Chronic atrial fibrillation or flutter <input type="checkbox"/> Pacemaker	<input type="checkbox"/> Sick Sinus Syndrome <input type="checkbox"/> Supraventricular tachycardia
Hypertension	<input type="checkbox"/> DBP ≥ 130 mm Hg <input type="checkbox"/> Severe malignant papilledema or other eye changes <input type="checkbox"/> Encephalopathy	<input type="checkbox"/> DBP 115-129 mm Hg <input type="checkbox"/> DBP 90-114 mm Hg while taking antihypertensive medications <input type="checkbox"/> Secondary cardiovascular symptoms: vertigo, epistaxis, headaches	<input type="checkbox"/> DBP 90-114 mm Hg while <u>not</u> taking antihypertensive medications <input type="checkbox"/> DBP < 90 mm Hg while taking antihypertensive medications <input type="checkbox"/> Hypertension, not otherwise specified
Venous Disease	<input type="checkbox"/> Recent PE (≤ 6 mos.) <input type="checkbox"/> Use of venous filter for PE's	<input type="checkbox"/> DVT controlled with Coumadin or heparin <input type="checkbox"/> Old PE > 6 months	<input type="checkbox"/> Old DVT no longer treated with Coumadin or Heparin
Peripheral Arterial Disease	<input type="checkbox"/> Bypass or amputation for gangrene or arterial insufficiency < 6 months ago <input type="checkbox"/> Untreated thoracic or abdominal aneurysm (≥ 6 cm)	<input type="checkbox"/> Bypass or amputation for gangrene or arterial insufficiency > 6 months ago <input type="checkbox"/> Chronic insufficiency	<input type="checkbox"/> Intermittent claudication <input type="checkbox"/> Untreated thoracic or abdominal aneurysm (< 6 cm) <input type="checkbox"/> s/p abdominal or thoracic aortic aneurysm repair
Respiratory System			
	<input type="checkbox"/> Marked pulmonary insufficiency <input type="checkbox"/> Restrictive Lung Disease or COPD with dyspnea at rest despite treatment <input type="checkbox"/> Chronic supplemental O ₂ <input type="checkbox"/> CO ₂ retention (pCO ₂ > 50 torr) <input type="checkbox"/> Baseline pO ₂ < 50 torr <input type="checkbox"/> FEV1 (< 50%)	<input type="checkbox"/> Restrictive Lung Disease or COPD (chronic bronchitis, emphysema, or asthma) with dyspnea which limits activities <input type="checkbox"/> FEV1 (51%-65%)	<input type="checkbox"/> Restrictive Lung Disease or COPD (chronic bronchitis, emphysema, or asthma) with dyspnea which has responded to treatment <input type="checkbox"/> FEV1 (66%-80%)
Gastrointestinal System			
Hepatic	<input type="checkbox"/> Portal hypertension and/or esophageal bleeding ≤ 6 mos. (Encephalopathy, Ascites, Jaundice with Total Bilirubin > 2)	<input type="checkbox"/> Chronic hepatitis, cirrhosis, portal hypertension with moderate symptoms "compensated hepatic failure"	<input type="checkbox"/> Chronic hepatitis or cirrhosis without portal hypertension <input type="checkbox"/> Acute hepatitis without cirrhosis <input type="checkbox"/> Chronic liver disease manifested on biopsy or persistently elevated bilirubin (>3 mg/dl)
Stomach / Intestine	<input type="checkbox"/> Recent ulcers(≤ 6 months ago) requiring blood transfusion	<input type="checkbox"/> Ulcers requiring surgery or transfusion > 6 months ago	<input type="checkbox"/> Diagnosis of ulcers treated with meds <input type="checkbox"/> Chronic malabsorption syndrome <input type="checkbox"/> Inflammatory bowel disease (IBD) on meds or h/o with complications and/or surgery
Pancreas	<input type="checkbox"/> Acute or chronic pancreatitis with major complications (phlegmon, abscess, or pseudocyst)	<input type="checkbox"/> Uncomplicated acute pancreatitis <input type="checkbox"/> Chronic pancreatitis with minor complications (malabsorption, impaired glucose tolerance, or GI bleeding)	<input type="checkbox"/> Chronic pancreatitis w/o complications

Cogent comorbid ailment	Grade 3 Severe Decompensation	Grade 2 Moderate Decompensation	Grade 1 Mild Decompensation
Renal System			
End-stage renal disease	<input type="checkbox"/> Creatinine > 3 mg% with multi-organ failure, shock, or sepsis <input type="checkbox"/> Acute dialysis	<input type="checkbox"/> Chronic Renal Insufficiency with creatinine >3 mg% <input type="checkbox"/> Chronic dialysis	<input type="checkbox"/> Chronic Renal Insufficiency with creatinine 2-3 mg%.
Endocrine System (Code the comorbid ailments with the (*) in both the Endocrine system and other organ systems if applicable)			
Diabetes Mellitus	<input type="checkbox"/> Hospitalization ≤ 6 months for DKA <input type="checkbox"/> Diabetes causing end-organ failure <input type="checkbox"/> retinopathy <input type="checkbox"/> neuropathy <input type="checkbox"/> nephropathy* <input type="checkbox"/> coronary disease* <input type="checkbox"/> peripheral arterial disease*	<input type="checkbox"/> IDDM without complications <input type="checkbox"/> Poorly controlled AODM with oral agents	<input type="checkbox"/> AODM controlled by oral agents only
Neurological System			
Stroke	<input type="checkbox"/> Acute stroke with significant neurologic deficit	<input type="checkbox"/> Old stroke with neurologic residual	<input type="checkbox"/> Stroke with no residual <input type="checkbox"/> Past or recent TIA
Dementia	<input type="checkbox"/> Severe dementia requiring full support for activities of daily living	<input type="checkbox"/> Moderate dementia (not completely self-sufficient, needs supervising)	<input type="checkbox"/> Mild dementia (can take care of self)
Paralysis	<input type="checkbox"/> Paraplegia or hemiplegia requiring full support for activities of daily living	<input type="checkbox"/> Paraplegia or hemiplegia requiring wheelchair, able to do some self care	<input type="checkbox"/> Paraplegia or hemiplegia, ambulatory and providing most of self care
Neuromuscular	<input type="checkbox"/> MS, Parkinson's, Myasthenia Gravis, or other chronic neuromuscular disorder and requiring full support for activities of daily living	<input type="checkbox"/> MS, Parkinson's, Myasthenia Gravis, or other chronic neuromuscular disorder, but able to do some self care	<input type="checkbox"/> MS, Parkinson's, Myasthenia Gravis, or other chronic neuromuscular disorder, but ambulatory and providing most of self care
Psychiatric			
	<input type="checkbox"/> Recent suicidal attempt <input type="checkbox"/> Active schizophrenia	<input type="checkbox"/> Depression or bipolar disorder uncontrolled <input type="checkbox"/> Schizophrenia controlled w/ meds	<input type="checkbox"/> Depression or bipolar disorder controlled w/ medication
Rheumatologic (Incl. Rheumatoid Arthritis, Systemic Lupus, Mixed Connective Tissue Disorder, Polymyositis, Rheumatic Polymyositis)			
	<input type="checkbox"/> Connective Tissue Disorder with secondary end-organ failure (renal, cardiac, CNS)	<input type="checkbox"/> Connective Tissue Disorder on steroids or immunosuppressant medications	<input type="checkbox"/> Connective Tissue Disorder on NSAIDS or no treatment
Immunological System (AIDS should not be considered a comorbidity for Kaposi's Sarcoma or Non-Hodgkin's Lymphoma)			
AIDS	<input type="checkbox"/> Fulminant AIDS w/KS, MAI, PCP (AIDS defining illness)	<input type="checkbox"/> HIV+ with h/o defining illness. CD4+ < 200/μL	<input type="checkbox"/> Asymptomatic HIV+ patient. <input type="checkbox"/> HIV+ w/o h/o AIDS defining illness. CD4+ > 200/μL
Malignancy (Excluding Cutaneous Basal Cell Ca., Cutaneous SCCA, Carcinoma in-situ, and Intraepithelial Neoplasm)			
Solid Tumor including melanoma	<input type="checkbox"/> Uncontrolled cancer <input type="checkbox"/> Newly diagnosed but not yet treated <input type="checkbox"/> Metastatic solid tumor	<input type="checkbox"/> Any controlled solid tumor without documented metastases, but initially diagnosed and treated within the last 5 years	<input type="checkbox"/> Any controlled solid tumor without documented metastases, but initially diagnosed and treated > 5 years ago
Leukemia and Myeloma	<input type="checkbox"/> Relapse <input type="checkbox"/> Disease out of control	<input type="checkbox"/> 1 st remission or new dx <1yr <input type="checkbox"/> Chronic suppressive therapy	<input type="checkbox"/> H/o leukemia or myeloma with last Rx > 1 yr prior
Lymphoma	<input type="checkbox"/> Relapse	<input type="checkbox"/> 1 st remission or new dx <1yr <input type="checkbox"/> Chronic suppressive therapy	<input type="checkbox"/> H/o lymphoma w/ last Rx >1 yr prior
Substance Abuse (Must be accompanied by social, behavioral, or medical complications)			
Alcohol	<input type="checkbox"/> Delirium tremens	<input type="checkbox"/> Active alcohol abuse with social, behavioral, or medical complications	<input type="checkbox"/> H/o alcohol abuse but not presently drinking
Illicit Drugs	<input type="checkbox"/> Acute Withdrawal Syndrome	<input type="checkbox"/> Active substance abuse with social, behavioral, or medical complications	<input type="checkbox"/> H/o substance abuse but not presently using
Body Weight			
Obesity		<input type="checkbox"/> Morbid (i.e., BMI ≥ 38)	

OVERALL COMORBIDITY SCORE (Circle one.) **0** **1** **2** **3** **9**
 None **Mild** **Moderate** **Severe** **Unknown**

Appendix D. Example patent co-morbidity questionnaire

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ADULT CO-MORBIDITY EVALUATION

Please circle your answer as appropriate

Section 1 (heart and blood vessels)

- | | |
|---|-----------------|
| 1. Have you had a heart attack in the past?
If yes, please state the date. | YES/NO
..... |
| 2. Do you suffer from chest pain relating to your heart (angina)?
<i>If NO, please go to question 6</i> | YES/NO |
| 3. Is your angina (chest pain) present only on exertion or do
you have it at rest? | |
| 4. If yes, have you been hospitalised for the same? | YES/NO |
| 5. Have you had any surgical procedures done for chest pain (angina)?
If yes, please state the date. | YES/NO
..... |
| 6. Do you suffer from heart failure? <i>If NO, please go to question 11</i> | YES/NO |
| 7. Do you feel breathless on exertion/or do you wake up at night out of breath? | YES/NO |
| 8. If you have breathlessness, does it limit your activities? | YES/NO |
| 9. Has your breathlessness due to heart failure responded well to treatment? | YES/NO |
| 10. Have you been hospitalised for your heart failure?
If yes, please state the date. | YES/NO
..... |
| 11. Do you suffer from problems with irregular heartbeats?
<i>If NO, please go to question 13</i> | YES/NO |
| 12. Have you had a pacemaker inserted for this problem? | YES/NO |
| 13. Do you suffer from high blood pressure (hypertension)?
<i>If NO, please go to question 18</i> | YES/NO |
| 14. If yes, do you take medication for treatment of hypertension? | YES/NO |
| 15. Do you suffer from symptoms of dizziness, nose bleeds or headaches caused
by your high blood pressure? | YES/NO |
| 16. Have you had any eye or nervous problems due to the high blood pressure? | YES/NO |
| 17. Have you been admitted to the hospital for control of high blood pressure? | YES/NO |
| 18. Have you had blood clotting in your veins in the leg at any time in the past?
<i>If NO, please go to question 21</i>
If yes, please state the date. | YES/NO
..... |
| 19. Are you on medication to thin your blood after the blood-clotting episode? | YES/NO |

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20. Have you had any surgical procedure relating to the blood-clotting episode?
If yes, please mention the procedure. YES/NO
.....
21. Have you had blood clots in the blood vessels to the lungs?
If yes, please state the date. YES/NO
.....
22. Do you suffer from pain in your calf muscles when walking?
If NO, please go to question 25 YES/NO
23. If yes, have you had surgical treatment for this? YES/NO
24. Have you had had any limb amputation for blood vessel disease?
If yes, please state the date YES/NO
.....
25. Do you suffer from an aneurysm (enlarged blood vessels) in your chest or
abdomen? *If NO, please go to question 27* YES/NO
26. If yes, have you had treatment for the same? YES/NO

Section 2 (lungs)

27. Do you suffer from chronic bronchitis, emphysema or asthma?
If NO, please go to question 32 YES/NO
28. If yes, has your breathlessness responded to treatment? YES/NO
29. Does your breathlessness limit your activities? YES/NO
30. Is your breathlessness present at rest? YES/NO
31. Do you need supplemental oxygen on a regular basis? YES/NO

Section 3 (liver, stomach and pancreas)

32. Do you suffer from chronic liver problems such as hepatitis or cirrhosis?
If NO, please go to question 35 YES/NO
33. Have you been in hospital for bleeding problems in the gut?
If yes, please state the date. YES/NO
.....
34. Have you had a liver transplant? YES/NO
35. Have you been diagnosed to have ulcers in the stomach?
If NO, please go to question 38 YES/NO
36. Do you need medication for the same? YES/NO
37. Have you had surgery for ulcers? YES/NO
38. Do you suffer from mild absorption or inflammatory bowel disease? YES/NO

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39. Have you had problems with your pancreas and/or been in hospital for the same? YES/NO

Section 4 (kidney)

40. Do you suffer from any problem in your kidney? YES/NO
If NO, please go to question 43

41. Have you had a renal transplant? YES/NO
If yes, when?

42. Are you on dialysis? YES/NO
If yes, how long have you been on it?

Section 5 (diabetes)

43. Are you a diabetic? *If NO, please go to question 46* YES/NO
If yes, is it well controlled? YES/NO

44. Is it controlled on oral medication or by insulin?

45. Have you been in hospital for diabetes associated complications? YES/NO

46. Do you have problems in other organs caused by diabetes ie. for the eye, the nerves, the kidneys or the heart? YES/NO

Section 6 (brain and nerves)

47. Have you had any stroke in the past? *If NO, please go to question 49* YES/NO
If yes, please state when?

48. Has it left you with some disability? YES/NO

49. Do you need full support for self care? YES/NO

50. Do you suffer from multiple sclerosis, Parkinson's disease or myasthenia gravis? YES/NO

51. Do you suffer from depression or other psychiatric disorders? YES/NO
If NO, please go to question 53

52. If yes, are you on medication for the same? YES/NO

Section 7 (joints and muscles)

53. Do you suffer from rheumatoid arthritis or other joint or muscle disorders? YES/NO
If NO, please go to question 56

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54. If yes, please list the drugs that you currently take for this problem.

.....
.....
.....

55. Have you had kidney, lung or heart problems caused by the same diseases? YES/NO

Section 8

(Please note the questions below exclude the current condition for which you are being treated)

56. Have you been diagnosed as having any other cancer, leukaemia or lymphoma in the past? ***If NO, please go to question 59*** YES/NO
If yes, please state the date.

57. Are you currently on treatment for the same? YES/NO

58. Is it well controlled? YES/NO

Section 9

59. How much alcohol were you taking at the time you were diagnosed with the current cancer?units per week

60. Do you suffer from any illnesses relating to excess alcohol consumption? YES/NO
If NO, please END

61. Was your social life affected by excess alcohol consumption YES/NO

62. Did stopping alcohol at that time cause any withdrawal symptoms? YES/NO

Thank you for taking the time to answer this questionnaire.