Recording and Evaluation of Co-Morbidity - An Update

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Introduction

- Co-morbidity included in “Adult” cancer datasets from outset
- Measures to be used uncertain
- Uncertainty about applicability of single system to all cancer “sites”
- Co-morbidities in children and TYAs seen as fundamentally different

Current Data Collection in CTYA Patients

CCLG / NRCT registration form:

- Congenital abnormalities, genetic disorders & chronic diseases in patient
- Family diseases & disorders

TYAC / NWCIS registration form:

- Other conditions in patient (instructions on what and how to record provided)
- Family history not separately recorded

Dilemmas

- What is most relevant to record in terms of patient outcome? (this condition or that?)
- Same information across all cancers or site-specific information?
- How should information be collected? (existing records or special data collection?)
- How should information be coded and classified (an existing system or specially created system?)

NCIN Co-Morbidity Workshop 22nd October

- Workshop held in London to address these dilemmas and other issues
- Wide representation of clinical specialties, cancer registries, interested groups (c.50 attendees)
- Series of presentations on international experience of collecting, analysing and applicability of co-morbidity data in cancer patients
- Several systems compared

NCIN Co-Morbidity Workshop 22nd October

- 2 workshop sessions to discuss methodologies
- Generic co-morbidity tool considered
- Need for site-specific modifications discussed
- Mechanisms of data collection and how this could be embedded within NHS

NCIN Action Plan

Based on the discussions at the workshop, NCIN have identified the following requirements:

- Collection of co-morbidity data must begin as soon as possible, with incremental improvements to follow, rather than waiting to deliver a perfect solution
- These data should be collected routinely as part of clinical care and made available for discussion at MDT meetings
- Site specific modifications may be necessary (and CTYAs will require special consideration) but these should be adjustments or additions to a common instrument

Actions

- Recommend that collection of an ACE-27 co-morbidity score is mandated for all adult cancer patients
- Identify where supplementary indices or information may be required
- Ensure that appropriate training is delivered to clinical teams, MDT co-ordinators and coders

Actions

- Exploit the opportunities that mandated collection of co-morbidity data across the NHS will provide to research improved collection methodologies
- Continue to investigate the use of existing data sources (e.g. HES) to calculate co-morbidity scores retrospectively
- Put in place appropriate governance arrangements to oversee and co-ordinate work

Adult Co-Morbidity Evaluation – 27 (ACE-27)

- 27–item co-morbidity index for patients with cancer developed and validated in USA (NCI sponsored)
- Defined list of diseases affecting 1% or more of patients
- Information abstracted from medical records through cancer registry system
- Co-morbidity coding added approximately 3% additional work effort

Adult Co-Morbidity Evaluation-27

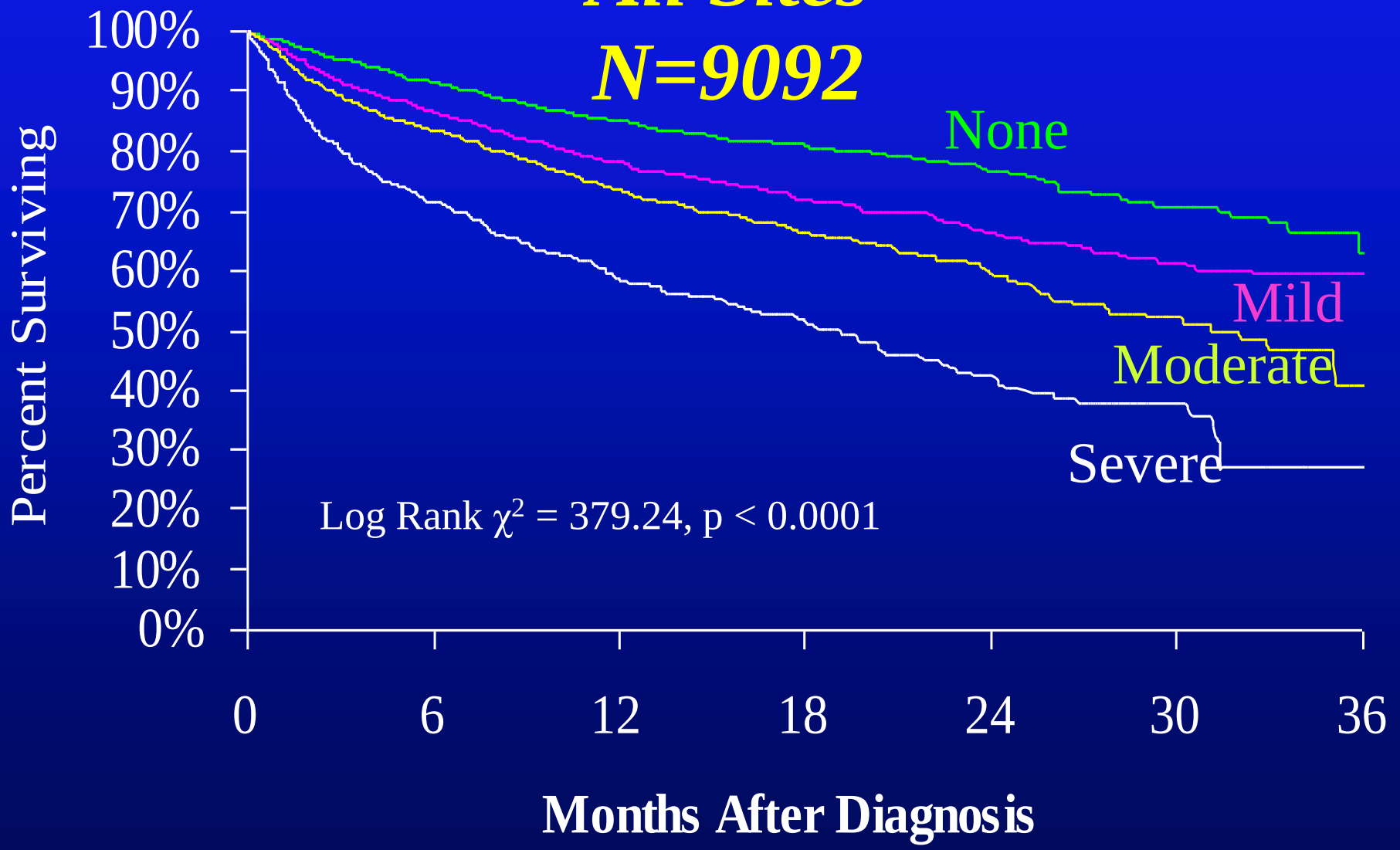
Cogent comorbid ailment	Grade 3 Severe Decompensation	Grade 2 Moderate Decompensation	Grade 1 Mild Decompensation
Cardiovascular System			
Myocardial Infarct	▪ MI≤ 6 months	▪ MI > 6 months ago	▪ Old MI by ECG only, age undetermined
Angina / Coronary Artery Disease	▪ Unstable angina	▪ Chronic exertional angina ▪ Recent (≤ 6 months) Coronary Artery Bypass Graft (CABG) or Percutaneous Transluminal Coronary Angioplasty (PTCA) ▪ Recent (≤ 6 months) coronary stent	▪ ECG or stress test evidence or catheterization evidence of coronary disease without symptoms ▪ Angina pectoris not requiring hospitalization ▪ CABG or PTCA (>6 mos.) ▪ Coronary stent (>6 mos.)
Congestive Heart Failure (CHF)	▪ Hospitalized for CHF within past 6 months ▪ Ejection fraction < 20%	▪ Hospitalized for CHF >6 months prior ▪ CHF with dyspnea which limits activities	▪ CHF with dyspnea which has responded to treatment ▪ Exertional dyspnea ▪ Paroxysmal Nocturnal Dyspnea (PND)
Arrhythmias	▪ Ventricular arrhythmia ≤ 6 months	▪ Ventricular arrhythmia > 6 months ago ▪ Chronic atrial fibrillation or flutter ▪ Pacemaker	▪ Sick Sinus Syndrome
Hypertension	▪ DBP≥130 mm Hg ▪ Severe malignant papilledema or other eye changes ▪ Encephalopathy	▪ DBP 115-129 mm Hg ▪ Secondary cardiovascular symptoms: vertigo, epistaxis, headaches	▪ DBP 90-114 mm Hg ▪ DBP <90 mm Hg while taking antihypertensive medications
Venous Disease	▪ Recent PE (≤ 6 mos.) ▪ Use of venous filter for PE's	▪ DVT controlled with Coumadin or heparin ▪ Old PE > 6 months	▪ Old DVT no longer treated with Coumadin or Heparin
Peripheral Arterial Disease	▪ Bypass or amputation for gangrene or arterial insufficiency < 6 months ago ▪ Untreated thoracic or abdominal aneurysm (≥6 cm)	▪ Bypass or amputation for gangrene or arterial insufficiency > 6 months ▪ Chronic insufficiency	▪ Intermittent claudication ▪ Untreated thoracic or abdominal aneurysm (< 6 cm) ▪ s/p abdominal or thoracic aortic aneurysm repair

Overall Co-Morbidity Score

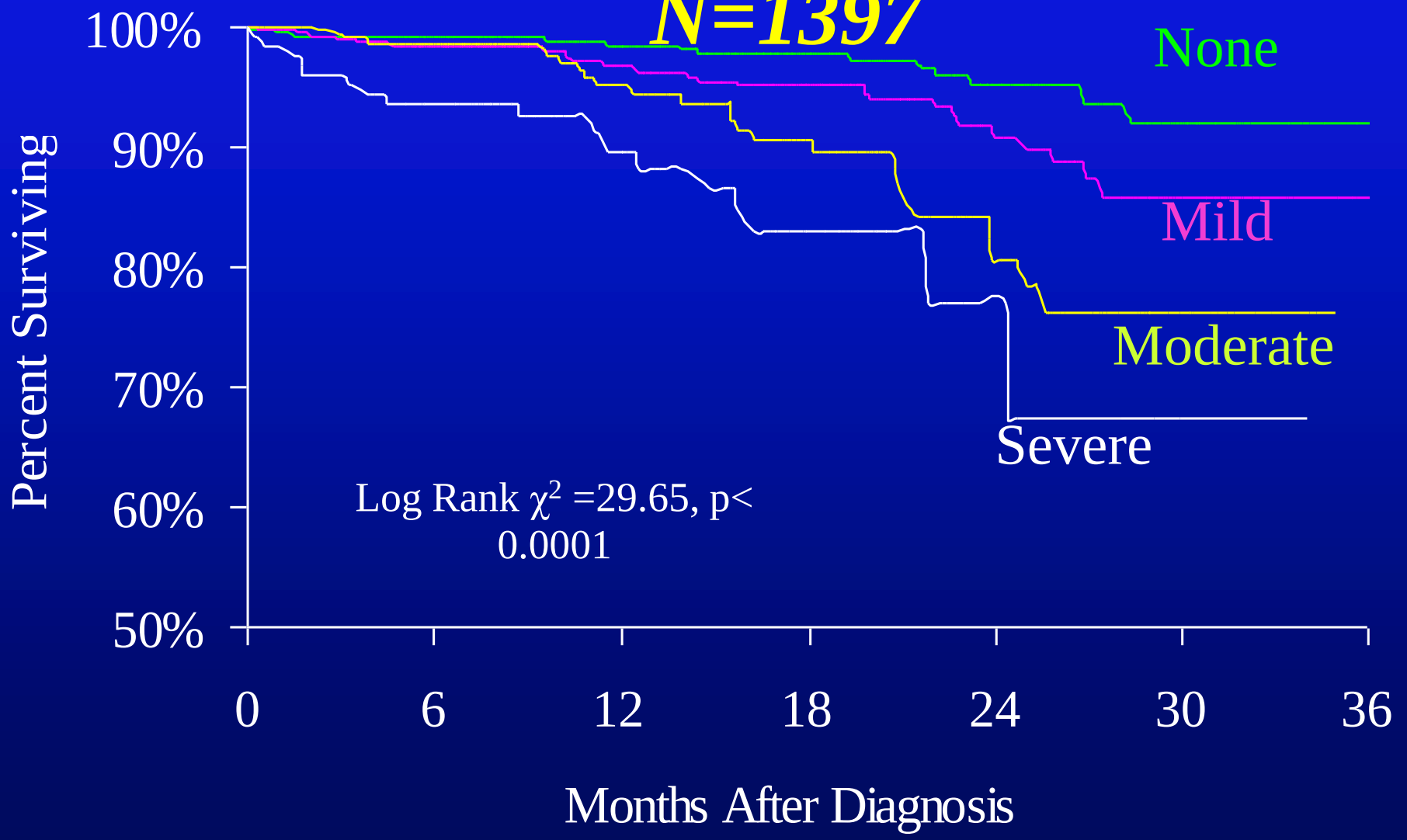
None, Mild, Moderate, or Severe

- Algorithm developed by Kaplan and Feinstein
- Highest ranked single ailment
- In cases where two or more Moderate ailments occur in different organ systems, the Overall Co-Morbidity Score should be designated as Severe

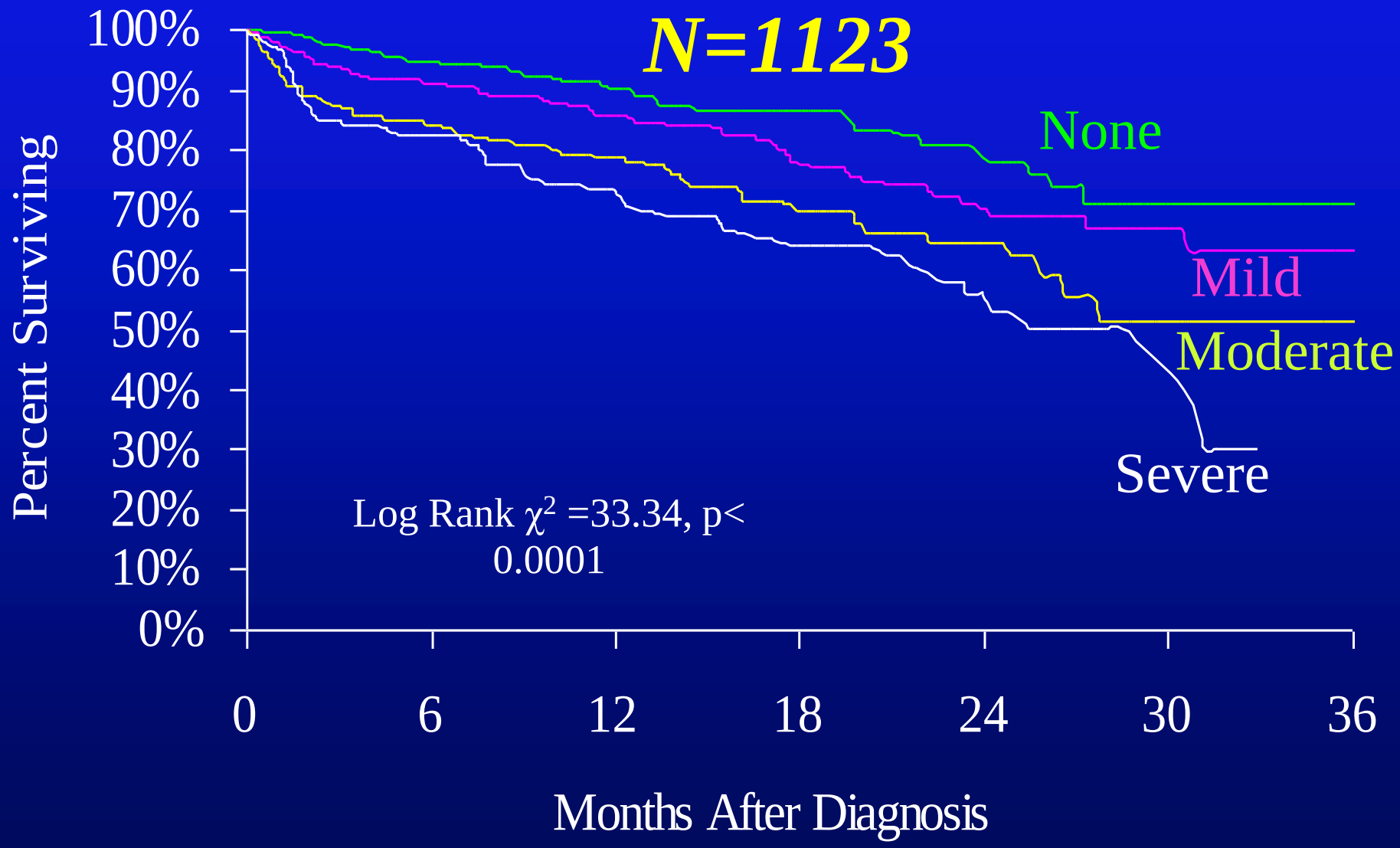
Impact of Co-Morbidity on Survival All Sites N=9092



Impact of Co-Morbidity on Survival Breast Cancer N=1397



Impact of Co-Morbidity on Survival Colorectal Cancer N=1123



UK Experience

- Pilot Project – January 2002 to June 2002
  - South Tees
  - Royal Orthopaedic Hospital Birmingham
  - Christie Hospital, Manchester
- Aims of Pilot Project
  - Skills required
  - Retrospective collection
  - Process of collection
    - Who, how, when
    - Lessons learned
  - Time burden
  - Perform validation checks
  - Ease of use

Time to Collect

- South Tees for Head and Neck Patients
  - Patient-based questionnaire took patients 8.3 minutes
  - Doctors performing retrospective review 16.8 minutes
- Royal Orthopaedic Hospital for Sarcoma Patients
  - No time reported
- Christie Hospital, Manchester for Women with Endometrial Cancer

  5-10 minutes

Problems Encountered

- Various co-morbidities not included
- Laboratory values not in UK units – conversion mandatory
- Renal system has extended definitions – confusing
- Pancreas – co-morbidity form varies from coding book
- Differences in terminology (e.g., “s/p” instead of “previous”)

Additional Feedback from Users

- South Tees for Head and Neck Patients
  - Very positive
  - Comorbidity added to presentations and publications
- Royal Orthopaedic Hospital
  - ACE-27 is easy to use
  - Training needed to be more in-depth
- Christie Hospital
  - Relationship between co-morbidity and survival significant
  - ACE-27 has important omissions and must be adapted to UK

How can ACE-27 be Applied to CTYA Cancer Patients?

- Co-morbidities in young cancer patients largely seen as presence of congenital anomalies and syndromes that increase cancer risk
- ACE-27 is system-based .'. could include congenital heart anomalies under “Cardiovascular system” co-morbidities
- But note that co-morbid condition would be the result of a congenital anomaly and not the anomaly itself e.g. congestive heart failure / VSDs

How can ACE-27 be Applied to CTYA Cancer Patients?

- Affects of co-morbidities on survival not looked at in CTYA cancer patients (possible exception Down Syndrome)
- Currently collection of congenital anomaly etc data via registration forms is incomplete / inaccurate
- Need to look at available data, including HES, to gauge what is important and how to translate into ACE-27 format

Recording Co-Morbidity in the Children's and Young Person's Cancer Dataset (C&YP DS)

- Items specific to the C&YP DS, relevant to the co-morbidity, but not the co-morbid conditions themselves:
  - Multiple birth
  - Congenital anomalies and syndromes
  - Other diagnosed cancer predisposition syndromes
- Co-morbidity index included in the main Cancer Dataset but may need modifications / additions to accommodate conditions relevant to young people

Conclusions

1. The Cancer Dataset project presents us with opportunities to improve and extend collection of data on conditions relevant to survival and long-term outcome in young people with cancer

2. We need to make best use of data already available to us to assess effects of conditions / co-morbidities on outcome so that recording and measuring through the C&YP DS can be optimised

Conclusions

3. We need to consider ways of collecting co-morbidity data including abstraction of records and specific questions to parents / patients at time of diagnosis

4. We should also consider the possibility of developing a self-completed questionnaire. (Not to be undertaken lightly but could yield valuable information.)