

# NCIN – what and why

Bill Allum

Chair

Upper GI Clinical Reference Group

# “The best cancer information service in the world”



- Build on current strengths of UK cancer registry system
- Collection of defined datasets on all cancer patients to be mandated through the national model contract. PCTs will be responsible for ensuring that this information is collected by MDTs and sent to cancer registries
- A new National Cancer Intelligence Network is being established to bring together relevant stakeholders and to act as a repository of cancer data.

**Cancer Reform Strategy 2007**

# NCIN Core Objectives



1. Promoting efficient and effective data collection throughout the cancer journey
2. Providing a common national repository for cancer datasets
3. Producing expert analyses, based on robust methodologies, to monitor patterns of cancer care
4. Exploiting information to drive improvements in standards of cancer care and clinical outcomes
5. Enabling use of cancer information to support audit and research programmes

# Essentials for success

- Clinical engagement
- Credible data
  - High level of data completeness
  - Case mix adjustment
  - Timely
- Reporting
  - Easy access to clear, 'bespoke' reports
  - 'Real time' – on line; Annual reports
  - Targeting reports: Clinicians; Trusts; SHAs ; PCTs etc
- Dissemination in Peer-reviewed settings
  - Publication, Conferences, Workshops, etc
- Incorporating performance and outcome data into:
  - Commissioning
  - Cancer Peer Review & Service Improvement

# Site-Specific Clinical Reference Groups - membership

- The relevant major colleges and professional groups (including pathology)
  - The lead cancer registry
  - Any national audit group (e.g. NCASP) relevant to the tumour site(s)
  - The relevant NCRI Clinical Study Group
  - Patients (minimum 2 – at least one of whom should ideally be a member of the relevant NCRI CSG)
  - The major, relevant voluntary sector groups/charities
  - The Director from the lead Cancer Network for the tumour site
  - A member from the ‘national cancer strategic team’ (DH, NCAT, Peer Review Team or NHS Improvement )
  - The NCIN core management team.
- ≤ 12

# Membership Upper GI SSCRG



ORGANISATION	REPRESENTATIVE
BSG	Mike Mendall
Clinical Oncology	Tom Crosby
Medical Oncology / NCRI	Daniel Hochhauser
AUGIS	David Berry
Pancreatic Society	Hemant Kocher
NOGCA	Richard Hardwick
Radiology	Clive Kay
Pathology	Marco Novelli
Patient Groups	Sue Ballard, David Kirby
Nursing	Tracey Heslop
PROMS	Jane Blazeby
NCAT	Andy McMeeking
Lead Registry	TCR: Henrik Moeller, Elizabeth Davies
Lead Network Director	Charlotte Joll
NCPR	Sue Knights

# Main issues for SSCRGs

- Identification of current initiatives
- Support for data set development
- Identification of main clinical indicators
- Advising on co-morbidity
- Improving staging (engaging pathologists)
- Promoting clinical (and public) engagement
- Advising on reporting
- Making the most of links with the research community
- Supporting the use of data to change clinical practice: **Improving Cancer Outcomes Group**

# NCIN - next 12 months



- Initial outputs “traditional” registry statistics
- Requirement to develop focus on cancer care and outcomes
  - Linked datasets (National Cancer Data Repository)
  - Lead registry support
- Exploit existing datasets
- Add further datasets to repository
- Improve data availability & quality standards



# DATA SOURCES

- Cancer Registry
- Cancer Waits
- Peer Review
- HES
- NOGCA

# NCIN: Reports 2009

- Incidence and mortality
- 1 year survival
- Deprivation
- Prevalence
- Ethnicity
- 'Microsites'
- Site-specific work

# By 2011

- Electronic transfer of Cancer Registration dataset
- Recognise multiple data sources
- Capture 'clinical' data via MDTs
  - Staging
  - Co-morbidity
  - Recurrence, etc



- AUGIS HPB Cancer Resection database
- ~ 50 data items for data-sets fro liver, biliary and pancreatic cancer
- Collected via nhs.net
- Coordinator based in Leicester

## Resection For Pancreatic Cancer Page 1

developed by: **ardeo** **AUGIS**

eMDT - Edit Form - Mozilla Firefox

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System Data Entry eMDT Meetings Calendar Exit

ardeo eMDT

Page 1 (page 1 of 3) Page 1

**Data Entry**

Find Patient  
Create Patient

**Current Patient**

Forename:   
Surname:   
Sex:   
Age:   
NHS No.:

Patient Details  
Patient History  
Close Patient

**Forms**

--HPB Forms--  
Resection For Liver  
Resection For Pancreatic Cancer  
Resection For Biliary Cancer

**HPB Audit**  
Export for HPB Audit

**Resection For Pancreatic Cancer**

**Patient Details And Diagnosis / Staging**

Hospital:   
Date Of Admission:   
Date Of Operation:   
Date Of Discharge:   
BMI:   
Ultrasound: ☐ yes ☐ no  
CT: ☐ yes ☐ no  
MRI: ☐ yes ☐ no  
MRCP: ☐ yes ☐ no  
Laparoscopy +/- Intraoperative Ultrasound: ☐ yes ☐ no  
PET: ☐ yes ☐ no  
EUS: ☐ yes ☐ no

**Tumour Markers And ECOG (WHO) Performance Status**

CA19-9: ☐ Normal ☐ Raised ☐ Not Done  
ECOG (WHO) Performance Status  
Performance Status: ☐ 0-Fully active  
☐ 1-Light/office work  
☐ 2-Ambulatory/self care, up & about >50% of the time  
☐ 3-Limited self care, confined to bed/chair >50% waking hours  
☐ 4-Completely disabled

**Comorbidities (please tick all that are appropriate)**

Comorbidities ☐ None  
☐ Cardiovascular disease  
☐ Chronic renal impairment  
☐ Cerebro/periph vascular  
☐ Chronic respiratory disease (inc. COPD/asthma)  
☐ Liver failure or cirrhosis  
☐ Diabetes  
☐ Mental illness  
☐ Other significant condition

**Preoperative Variables**

Preoperative jaundice and intervention  
Jaundice: ☐ yes ☐ no  
Duration (days):   
Preoperative cholangitis: ☐ yes ☐ no  
Preoperative biliary drainage: ☐ yes ☐ no  
ERCP: ☐ yes ☐ no  
Antegrade stent: ☐ yes ☐ no  
PTC and drain: ☐ yes ☐ no  
Number of times attempted:   
Interval between jaundice and stenting (days):

Page 1 Print Cancel Save

## Resection For Pancreatic Cancer Page 2

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**Data Entry**

Find Patient  
Create Patient

**Current Patient**

Forename:  
Surname: 01  
Sex:  
Age: 0  
NHS No.: 0002

Patient Details  
Patient History  
Close Patient

**Forms**


-HPB Forms--  
Resection For Liver  
Resection For Pancreatic Cancer  
Resection For Biliary Cancer


**HPB Audit**  
Export for HPB Audit


**Resection For Pancreatic Cancer**


Operation (page 2 of 3) Operation

**Operation**

Consultant ☐ Primary Operator ☐ Assistant 


Trainee ☐ Primary Operator ☐ Assistant 

Fitness for Surgery ASA grade ☐ 1  
☐ 2  
☐ 3  
☐ 4  
☐ 5 

Resection ☐ Pancreaticoduodenectomy (HOP cancer)  
☐ Distal pancreatectomy (All left resections sparing the HOP/duodenum)  
☐ Total pancreatectomy 

**Continued**

Surgical Access - Please indicate the approach used for the operation


☐ Open  
☐ Laparoscopic  
☐ Laparoscopic converted to open 


Operation duration (min)


Intraoperative blood loss (mls)




Intraoperative blood transfusion - units

Total Blood Transfusion - Units

Other visceral resection ☐ yes ☐ no 

Splenectomy ☐ yes ☐ no 

Vascular resection ☐ yes ☐ no 

Operation  Print  Cancel  Save



## Resection For Pancreatic Cancer Page 3

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**Data Entry**

Find Patient  
Create Patient

**Current Patient**

Forename:  
Surname: 01  
Sex:  
Age: 0  
NHS No.: 0002

Patient Details  
Patient History  
Close Patient

**Forms**

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Resection For Liver  
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**HPB Audit**  
Export for HPB Audit

**Resection For Pancreatic Cancer**

**Outcome Mortality And Morbidity And Post Op Pathology And Histology**  
(page 3 of 3)

**Outcome Mortality And Morbidity**

Mortality

Date Of Death

In hospital Mortality ☐ yes ☐ no

30 Day Mortality ☐ yes ☐ no

60 Day Mortality ☐ yes ☐ no

90 Day Mortality ☐ yes ☐ no

Morbidity

Major Complications -  
(Requires intervention/admit to ITU)

☐ Bile leak  
☐ Pancreatic leak  
☐ Bleed  
☐ Percutaneous drainage of collection  
☐ Return to theatre  
☐ Anastomotic leak requiring return to theatre  
☐ Other  
☐ None

Minor

☐ None  
☐ Wound infection  
☐ Chest infection  
☐ Urinary infection

**Post Op Pathology And Histology**

Tumour Type ☐ Adenocarcinoma  
☐ Cyst adenocarcinoma  
☐ Ampullary cancer  
☐ Duodenal cancer  
☐ Other

Other Cancer ☐ IPMN ☐ Neuroendocrine ☐ Benign ☐ Other

Resection Type ☐ R0 ☐ R1

T

N

M

Tumour Size (mm)

Tumour location (P) ☐ Head ☐ Uncinate ☐ Body ☐ Tail

Outcome Mortality An... Print Cancel Save



# HPB Audit

- Expand to include all HPB patients
- Funded by AUGIS



# NATIONAL POLICY INITIATIVES



- Cancer Reform Strategy – 2007
- Earlier presentation – National Awareness and Earlier Diagnosis Initiative (NAEDI)
- Living with and beyond cancer – Survivorship
- Effective use of inpatient facilities – Enhanced Recovery
- End of life care - choices

# NATIONAL POLICY INITIATIVES



- DH – *Quality and Productivity*  
Clinical pathway redesign  
Commissioners  
Providers  
National policy changes and supporting  
workstreams
- 2011 – 2014:           £15 – 20bn savings

# NATIONAL POLICY INITIATIVES



- MDT effectiveness
- National Peer Review
- Enhanced Recovery Programmes



# ENHANCED RECOVERY UPPER GI



- Is it possible?
- What are the problems?
- What can we learn from other sites?

# ENHANCED RECOVERY UPPER GI – is it possible?



- US experience
- Financially driven
- O-G resection discharge in 7 days
- Readmissions or failures



# ENHANCED RECOVERY UPPER GI – is it possible



- Italian experience – pancreatic resection
- Discharge day 13 vs day 15
- Reduced delayed gastric emptying

# ENHANCED RECOVERY UPPER GI – what are the problems?

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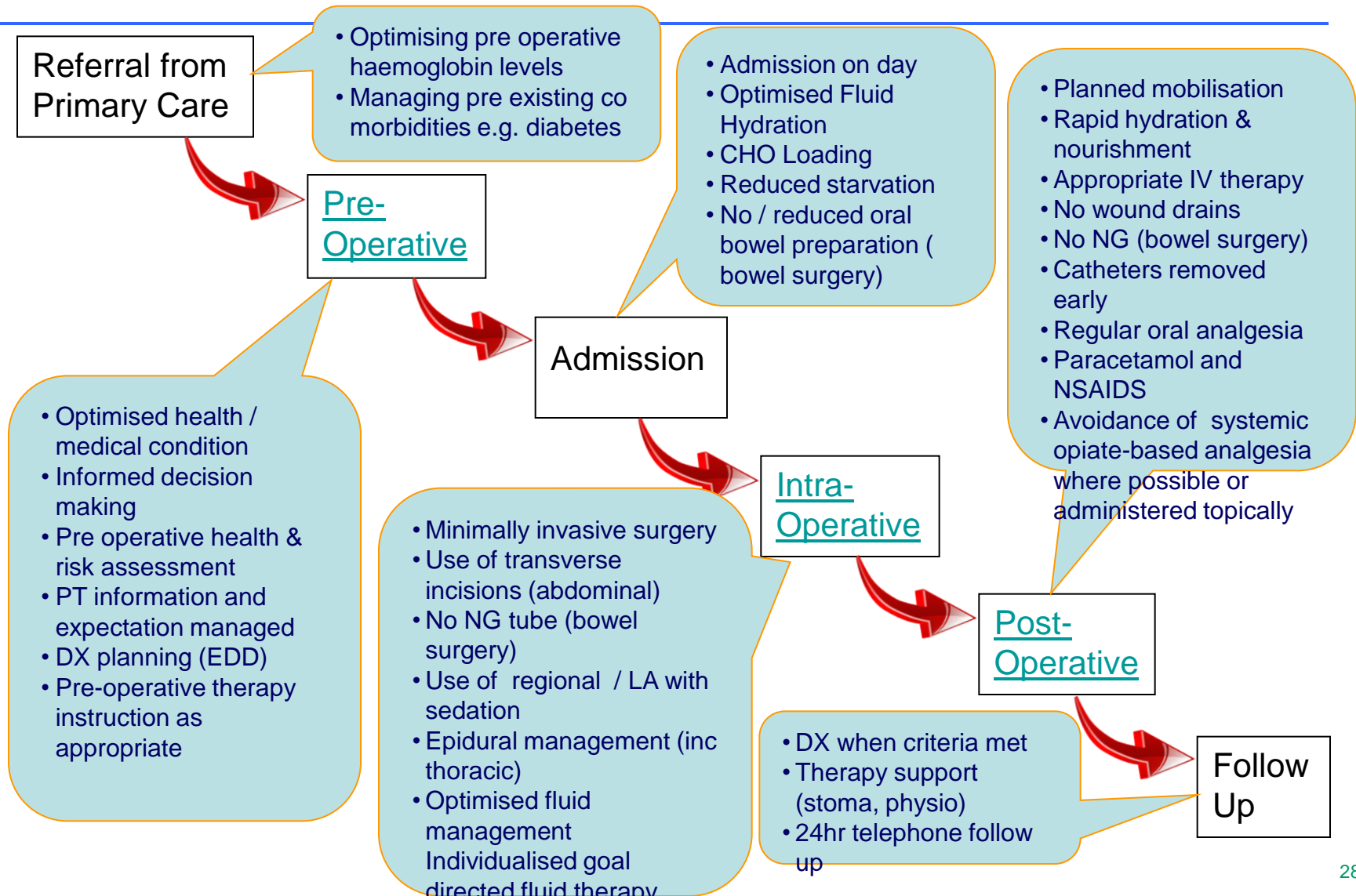
- Comorbidity
- Clinical staff “customs”
- Proximal anastomosis

# ENHANCED RECOVERY UPPER GI



- What can we learn from other sites?

# Example of enhanced recovery elements



### Traditional pathway

**Day 0** Surgery performed  
Drip, fluids, drain(s)  
Catheter/nasogastric tube

**Day 1** Monitoring post op/sit out

**Day 2** Monitoring post op/?  
Short walks/sips

**Day 3** Monitoring post op/nasogastric  
down/flatus passed/sips

**Day 4** Oral fluids/short walk

**Day 5** Drip down/drain out

**Day 6** ?Small soft diet

**Day 7** Diet if tolerated/monitor bowel  
movements/walking

**Day 8** ?Wound clips removed

**Day 9** Patient independent

**Day 10** ?Discharge depending on  
patient recovery/complications

### Enhanced Recovery Pathway

**Day 0** Surgery performed  
Drips, fluids, drain(s), catheter  
Drinking tea/juice  
Walking short distance  
Pain relief via PCA/epidural  
Catheter in

**Day 1** Eating food  
Walking around ward  
Pain relief orally

**Day 2** Epidural down  
Drip down  
Catheter out

**Day 3** Patient independent

**Day 4** Discharged

# ENHANCED RECOVERY UPPER GI – what can we learn from other sites?

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- Team working
- Pathway planning
- Patient education and explanation
- Careful outcome audit

# ENHANCED RECOVERY UPPER GI

- Outpatient  
    medical assessment  
    dietician  
    physio
- Preadmission Assessment  
    meet the team  
    explanation of journey  
    immunonutrition  
    physio details
- Perioperative  
    protocol for car pathway