TCFU - Colorectal Cancer Follow Up
Current challenges

- Missed follow up
- Costly ineffective follow up
- Over treatment
- 6 monthly clinical follow up wasteful
- Variation across sites and hospitals
- Over stretched outpatient waiting lists
Aim of follow up

- An individualised follow up of patients.
- Holistic and risk stratified
- Multidisciplinary decision making
- Patient led and nurse led
- Cost effective
- Better patient experience
Why bother?

- 80% recurrence <2.5 years
- 30%-50% resectable/treatable
- Surveillance for metachronous tumours 5-10%
- Early detection of liver mets-better survival?
- Psychological support
- National data collection
Impact of recurrence

Of those who had their recurrence resected (n=81):
- 49.3% Completed 5 year follow-up
- 2.5% Died of non-cancer related causes eg. MI

However,
- 46.9% had a cancer related death

<table>
<thead>
<tr>
<th>Causes</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not died during follow-up</td>
<td>40</td>
<td>49.38%</td>
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<tr>
<td>Death not cancer related</td>
<td>2</td>
<td>2.47%</td>
</tr>
<tr>
<td>Cancer related death</td>
<td>38</td>
<td>46.91%</td>
</tr>
<tr>
<td>Unknown Cause</td>
<td>1</td>
<td>1.23%</td>
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</tbody>
</table>
Colorectal cancer follow up in NI – local context
Variation in Colorectal Surgical Follow-up across Trusts

<table>
<thead>
<tr>
<th>Trust</th>
<th>Surgical outpatient appts</th>
<th></th>
<th></th>
<th></th>
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<tbody>
<tr>
<td></td>
<td>Average</td>
<td>Median</td>
<td>Range</td>
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<tr>
<td>Belfast</td>
<td>4</td>
<td>3</td>
<td>1-14 appts</td>
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<tr>
<td>Northern</td>
<td>6</td>
<td>5</td>
<td>0-15 appts</td>
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<tr>
<td>South Eastern</td>
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<td>7</td>
<td>1-11 appts</td>
<td></td>
</tr>
<tr>
<td>Southern</td>
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<td>4</td>
<td>1-16 appts</td>
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</tr>
<tr>
<td>Western</td>
<td>5</td>
<td>5</td>
<td>1-11 appts</td>
<td></td>
</tr>
</tbody>
</table>

Source: TCFU project team
Baseline Audit 50 patients per Trust - Diagnosed 2008 with colorectal cancer and tracked until 2013
Case for change
Surgical waiting lists Sept 14
(includes patients on follow-up for colorectal cancer)

<table>
<thead>
<tr>
<th>Trust</th>
<th>SEHSCT</th>
<th>SHSCT</th>
<th>BHSCT</th>
<th>WHSCT</th>
<th>NHSCT</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>On surgical waiting lists</td>
<td>1467</td>
<td>3797</td>
<td>1017</td>
<td>320</td>
<td>2822</td>
<td>9,423</td>
</tr>
<tr>
<td>On dual specialty follow-up</td>
<td>64</td>
<td>57</td>
<td>50</td>
<td>52</td>
<td>63</td>
<td>286</td>
</tr>
</tbody>
</table>

Source: PMSID / HSCB
Almost three quarters (74.2%) of the screen detected bowel cancers (n=271) were early stage bowel cancers; Dukes A*, Dukes A, Dukes B
The local plan
Regional Colorectal workshop
Oct 13

- Shared learning from Breast TCFU
- National Speakers from Colorectal Teams in Bradford & Southampton (nurse-led and self-directed follow-up approach)
- Local speaker from South Eastern Trust to showcase the colorectal TCFU pilot
Risk Stratification Model - NCSI

- **Remote surveillance**
  - Carcino-embryonic antigen monitoring
  - Colonoscopy
  - CT scanning
- **Equipping the patient to self manage**
  - Assessment & Information provision
  - Treatment summary record
  - Rapid Point of access
  - Health & Well Being Events & Support Services
Holistic approach to include Recovery and Rehabilitation

- 40% of cancer patients have been found to have malnutrition
- 70% of cancer patients receiving anti cancer treatments are affected by fatigue that may persist for years
- 30% of cancer patients have unmet needs after treatment for cancer, which could be addressed by rehabilitation
- 22% of cancer patients report moderate or severe problems with their mobility and carrying out usual activities
- 19% of colorectal patients have difficulty controlling their bowels, and are twice as likely as others to report lower quality of life
Need for holistic approach

- Introduction of recovery package
Where we are at present

- Pathway-2 agreed regionally
- Agreed guidelines
- Treatment summary record
- Agreement with IT to include in ECR
- Additional Clinical Nurse Specialists in some trusts
Appendix 1

Colorectal Cancer Pathway for Stage 1
Self-directed aftercare

MDM Decision
Patient suitable for self-directed aftercare pathway
Specify colonoscopy surveillance
MDM outcome letter copied to CNS and record SDA pathway on QAPPs
Completion of staging colonoscopy (if required) and baseline CEA

Consultant Surgeon Results Appointment
Approx 2-4 weeks post-surgery
For routine review if ongoing surgery / complications until resolved
Treatment plan discussed & Patient informed of SDA pathway
Treatment summary record provided
Surveillance colonoscopy booked by consultant secretary
Allocate Picd ‘Discharge Code’
Referral to CNS

Colorectal Nurse Specialist Appointment
Holistic Needs Assessment
(4-12 weeks post-operative)
Patient led assessment
Colonoscopy surveillance discussed
Information pack provided
Rapid access service explained
Health and Well being event offered
Support to survivorship services

Surveillance
- CEA
6 monthly as per clinical protocol
- Colonoscopy
1 year and 3 or 5 years unless otherwise indicated
Consultant to review outcomes

Open rapid access to colorectal team or MDM

Patient / GP Concern

Colorectal Nurse Specialist triage call as appropriate
(Max within 48 hours / 2 working days)

Education and Information: Clinical Support Services: Physical Activity; Other Support Services

Survivornship
Appendix 2

Colorectal Cancer Pathway for Stage 2
Nurse led follow-up Shared Care - No adjuvant chemotherapy

MDM Decision
Patient suitable for shared care pathway
Specify colonoscopy surveillance
MDM outcome letter, record pathway on QPPIs, copied to CNS
Completion of stasine colonoscopy (if required) and baseline CEA

Consultant Results Appointment
Approx 24 weeks post-surgery
Treatment plan discussed & Surveillance colonoscopy booked by consultant secretary
Referral to CNS

Colorectal Nurse Specialist
Holistic Needs Assessment appointment
(6-12 weeks post-operate)
Patient led assessment
Colonoscopy surveillance discussed
Information pack provided
Rapid access service explained
Health and Well Being event offered
Support to survivorship services

Consultant Review
(6 monthly)
Until suitable for CNS review
CEA at each visit

Colonoscopy 1 year and 3 or 5 years unless indicated
CT Scan annually for 3 years
Arrange ESFR prior to CT Scan

Surveillance

Colorectal Nurse Specialist Review
6 monthly CNS review until year 3
Patient history, physical examination, CEA
As per clinical protocol
At Year 3 – discuss ongoing surveillance with consultant surgeon prior to discharge

Patient / GP Concern

Colonoscopy 1 year
and 3 or 5 years
unless otherwise indicated
CT Scan annually
for 3 years
Arrange ESFR prior to CT Scan

Survivorship
Education and Information: Clinical Support Services: Physical Activity: Other Support Services
Barriers to progress

- Documentation
- ECR
- Only few specialist nurses
- Differing medical attitude to change
- Difficulty regarding CEA testing-complex
The future

- Plans to progress with implementation
- Belfast and South-Eastern trusts currently using system
- Establish further clarification of role of primary and secondary care
- Increase number of clinical nurse specialists/redefining traditional roles