Title:

Developing new follow up pathways for people with colorectal cancer:
A review of the evidence

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Summary of Key Messages

- There is currently widespread variation in cancer follow up practice and no consensus as to the intensity, duration or type of follow up required.
- Routine long term follow up has not been shown to be effective.
- Recurrence is infrequently detected through physical examination and routine review.
- Follow up appointments often do not meet the patients’ needs.
- While extensive evidence exists to support the promotion of a healthy lifestyle with physical activity, this is rarely incorporated into the current model of follow up.
- Traditional follow up has been framed around cancer as an acute illness, which does not fit with the changing pattern of cancer as a chronic illness.
- With cancer prevalence increasing by 3.2% per annum the current system of follow up will be unable to meet the increased demand on service.
- The key components of the new risk stratified model are concordant with NICE guidelines.
- Evidence beginning to emerge from test sites in England indicates the new model appears to be acceptable to patients, however further research is needed.
1. Introduction
Within cancer services in NI there is a regional move towards developing new approaches to cancer follow up in line with the National Cancer Survivorship Initiative (NCSI). This paper presents a review of the literature relating to traditional cancer colorectal follow up as well as considering the emerging evidence with regards to newer models of colorectal cancer follow up. Whilst acknowledging Sackett’s (1996) definition of evidence as ‘the integration of individual clinical expertise with the best available external clinical evidence from systematic research’, the paper concedes to Muir’s (1997) argument that patient preferences also need to be factored in to what constitutes evidence, and taken into account in determining appropriate options.

2. The current follow-up system
A review of current UK service provision following cancer treatment identified wide variation in practice, from no follow-up with rapid access, to lifelong follow-up visits combined with or without surveillance tests (NHS Improvement, Rapid Review of Follow-up, 2009). Most clinical teams who participated indicated they did have pathways of follow-up care, but few examples were provided. Where there were pathways either at consultant or network level, these were generally very detailed up to the time of treatment, but the follow-up element was poorly articulated. There were, however, exceptions to this with some clinical teams having pathways or protocol driven follow-up in which patients chose the model of follow-up (acute or community led) in partnership with their clinician.

Furthermore a systematic review to evaluate the clinical effectiveness and cost effectiveness of follow up services after cancer treatment (CRD, 2007) concluded there was a poor evidence base and no consensus as to the intensity, duration, setting or type of follow up required for most common forms of cancer.

2.1 Guidelines for Colorectal cancer follow-up
Published guidelines differ; the National Institute for Clinical Excellence (NICE) issued guidelines in 2011 which state, conventionally the rationale for follow up after curative resection for colorectal cancer recognised that local recurrence and/or metastatic disease rates were high and that early detection of metachronous disease offered a “second chance” at cure. However, it is increasingly recognised that follow up may have several additional benefits beyond this conventional model, which include: facilitation of audit, characterisation of late effects of treatment and health related opportunities. Treatment and care should also take into account patients needs and preferences. The optimal method of follow up for each of these end points may be different. However what should constitute good clinical practice in terms of follow-up has not been established and there is enormous variation in terms of frequency, duration, clinical setting and interventions employed. There is also a paucity of data on quality of life related issues and colorectal cancer follow up. Table 1 outlines recommendations from identified guidelines.
<table>
<thead>
<tr>
<th>Evaluation</th>
<th>BSG/ACGBI 2010 Stage not specified</th>
<th>ESMO 2010</th>
<th>ASCO 2005 Stage II or III</th>
<th>NICE 2011</th>
<th>NICaN Clinical Management Guidelines 2009</th>
<th>PEBC 2012 Ontario Stage 2 or 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical exam / History</td>
<td>Rectal 6mthly for 2yrs Colon: 3-6mthly for 3 yrs then 3-12mthly in years 4-5</td>
<td>3-6mthly first 3yrs 6mthly to 5yrs, then at the discretion of the physician</td>
<td>Offer follow up to all patients undergoing treatment with curative intent</td>
<td>4-6mthly for 2yrs, 6-12mthly for 3yrs</td>
<td>6mtly for 5 yrs</td>
<td></td>
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<tr>
<td>CEA</td>
<td>Colon 3-6mthly for 3yrs then 6-12mthly at years 4&amp;5</td>
<td>3mthly for at least 3yrs</td>
<td>At least 6mthly in the first 3 yrs</td>
<td>LFT,FBC and CEA 4-6mthly for 2yrs 6-12mthly for 3yrs</td>
<td>6mthly for 5 yrs</td>
<td></td>
</tr>
<tr>
<td>Abdominal imaging</td>
<td>CT: Within 2yrs after surgery</td>
<td>Colon: CT or contrast enhanced ultrasound 6-12mthly for first 3yrs Rectal: CT 1 and 3 year after surgery</td>
<td>CT annually for 3yrs</td>
<td>Minimum of 2 CT’s in the first 3 years</td>
<td>Min - Single CT chest, abdo and pelvis in asymptomatic patients offered during first 2 yrs post resection</td>
<td>Annually for 3 years</td>
</tr>
<tr>
<td>Pelvic CT</td>
<td>Rectal: Lung imaging at 1 &amp;3y after surgery Colon: CT 6-12mthly first 3yrs</td>
<td>Consider for rectal cancer patients</td>
<td>Minimum of 2 CT’s in the first 3 years</td>
<td>As above</td>
<td>Annually for 3yrs if primary tumour located in rectum</td>
<td></td>
</tr>
<tr>
<td>Chest imaging</td>
<td>Rectal 5yrs Colon: at year 1 then every 3-5yrs</td>
<td>CT: Annually for 3y CXR not recommended</td>
<td>Minimum of 2 CT’s in the first 3 years</td>
<td>As above</td>
<td>Annually for 3 yrs</td>
<td></td>
</tr>
<tr>
<td>Colonoscopy</td>
<td>Min 5yrs after surgery then 5yearly early intervals (adenoma free colon)</td>
<td>Rectal: 6mthly for 2yrs</td>
<td>At year 3, if normal then every 5y</td>
<td>Offer at 1yr after initial treatment. If normal consider further colonoscopy follow up after 5yrs</td>
<td>Min 5y after surgery then 5y early intervals (adenoma free colon)</td>
<td>At 1yr after surgery. Frequency of further colonoscopies dictated by findings of previous one. If findings normal then 5yrs</td>
</tr>
<tr>
<td>Recto-sigmoidoscopy</td>
<td>Every 6m for 5y for rectal cancer patients who have not received pelvic radiation</td>
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Notes: ACGBI – Association of Coloproctology for Great Britain and Ireland; ASCO- American Society of Clinical Oncology; BSG- British Society of Gastroenterology; CT- Computed tomography; CXR- chest x-ray; ESMO – European Society for Medical Oncology; m-months; Min- Minimum; PEBC- Program in Evidence-based Care
2.2 Current Colorectal Cancer follow-up

As eluded to above while the detection of recurrence at an early stage to improve survival is a key reason for follow up practices, improvement of symptom management and quality of life are equally important. More recently there has also been increasing precedence given to the monitoring of the long-term consequences of cancer and its treatment (Cured - but at what cost? Macmillan, July 2013). An effective model of surveillance and rehabilitation is thus required to ensure patient needs are addressed, outcomes are improved and an efficient service is delivered (McCullough and Young, 2011). Unfortunately, there is a dearth of literature on the effectiveness of different follow-up practices for patients with colorectal cancer. This has led to wide variation in practice and follow-up protocols locally, nationally and internationally (Lafata et al, 2005). A Cochrane systematic review (Jeffery et al, 2007) has suggested that intensive follow-up can offer survival advantages after curative surgery. However, due to the wide variation in the eight studies included it was not possible to recommend the best combination or frequency of clinic visits, blood tests, endoscopy procedures or radiological investigations to maximise the outcomes for these patients.

It has also been proposed that many review appointments add little value to the patient or clinician as there is a lack of clarity regarding the benefits of cancer follow-up (Davies and Batehup, 2009) and for some, follow-up can be expensive, inconvenient and increase anxiety (McCaughan et al, 2011; Department of Health, 2013). While fear of recurrence is recognised as a common cause of anxiety for many patients, regular hospital reviews may not alleviate this anxiety. This is due to a range of problems at hospital follow-up, including poor communication, information needs not being assessed or addressed, often poor continuity of care and a lack of time to address psychosocial issues (Rose & Watson, 2009). In addition traditional follow-up has been framed around cancer as an acute illness which does not fit with the changing picture of cancer as a chronic illness. A 2010 workshop in NI acknowledged that the current model of review required modernisation to ensure a system could be developed that would be clinically effective and cost effective in the future as the current system is unsustainable (NICaN, 2010).

2.2.1 Alternative models of follow-up:

Research suggests that different models of follow-up are acceptable to patients, if they are informed of the risks and benefits, given a choice, and have access to a rapid method of re-entry should they detect any problems (Department of Health, 2013). Indeed it has been proposed in some colorectal texts that there is no evidence to support a clinical review in asymptomatic patients (Primrose, 2011). Alternative models of review have developed in recent years and include nurse-led follow-up, telephone-based follow-up, primary care follow-up or patient-initiated follow-up.

Nurse-led services have been shown to be acceptable, appropriate and effective (Cox & Wilson, 2003) and when compared to the traditional medical model can offer greater efficiency, have a positive impact on waiting times and improve quality of care (Moore et al, 2002). Several studies of colorectal cancer patients in Scotland
have reported that nurse-led models result in higher satisfaction, a smoother pathway for patients, improved quality of life and acceptance of the new model by patients and clinicians (Knowles et al, 2007; Simpson & Whyte, 2006).

A systematic review has highlighted that patient-initiated or telephone follow-up could be practical alternatives to conventional care (Lewis et al, 2009). A recent survey of 187 colorectal patients in England (Beaver et al, 2011) indicated that 66% of patients expressed a willingness to receive telephone follow-up. This is supported by a number of large studies in breast cancer groups whereby RCTs of nurse-led telephone follow-up have found no difference in recurrence rates, patient anxiety and cost-effectiveness when compared to regular hospital review (Kimman et al, 2011 a & b; Beaver et al, 2009).

Randomised controlled trials comparing primary care-led follow-up and surgical based follow-up in colon cancer have indicated similar outcomes in both groups including recurrence rates, time to detection, death rates (Wattchow et al, 2006) and in relation to satisfaction and quality of life (Gall et al, 2007). Patients whose care is predominantly provided by primary care at the end of treatment have also evaluated their transition or continuity of care favourably (Sisler et al, 2012).

2.2.3 Discharge from Follow-up

Current guidelines recommend the discharge of patients from regular follow-up at 5 years. If we are to move to earlier discharge then we need to consider the process carefully and ensure the patients’ perspective is assessed and taken into consideration. Despite guidelines recommending the earlier discharge of patients from routine review a large UK study of breast, colorectal and prostate patients has shown that approximately one-third of patients surveyed were not discharged from follow-up 5-16 years post-diagnosis (Harrison et al, 2011). While extended follow-up may be valid for some, often follow-up beyond 5 years has occurred through custom and practice rather than for any clear clinical need. Despite this often extended follow-up many patients have unmet needs, as is evidenced in the following section.

2.3 Patient needs

It is well documented (Department of Health, 2013) at a national and local level that many cancer survivors have unmet needs (Armes, 2009; Santin, 2012), particularly at the end of treatment, whilst others are struggling with consequences of treatment that could either be avoided or managed (Audreyev, 2012; Reulan, 2011; Woodward, 2011). A local study, focussing on colorectal cancer survivors in NI reported that approximately 40% have unmet needs that are mainly psycho-social in nature (Santin, 2009). In addition those with unmet needs experience poorer quality of life. A larger follow on study of 289 cancer survivors in NI confirmed that regardless of tumour site 40% of patients have needs that have not been resolved by the current follow-up system (Santin et al, 2012). The top unmet needs include the need for better coordinated care and the need for support to manage concerns regarding recurrence. An earlier UK wide survey of over 2,000 survivors also indentified that 43% wanted more information and advice (Sheldon et al, 2008).
It is increasingly recognised that the impact of cancer does not end after treatment and that current approaches fail to address the full range of physical, psychological, social, spiritual and financial needs that cancer survivors may have after treatment (Feuerstein, 2008). Current models of follow up frequently fail to meet the supportive care needs, often resulting in feelings of abandonment during transition from patient to survivor (Cardy, 2006). Loss of self confidence in the first year after primary cancer treatment is often under-recognised (Foster & Fenlon, 2011).

The period following treatment of cancer has been described as ‘the teachable moment’ and it is recognised that at this time patients are more susceptible to change their behaviour and lifestyles (Ganz, 2005). Colorectal specific studies have indicated that while this is also true for colorectal cancer patients, many report receiving insufficient information and support to make these changes (McCaughan et al, 2011; Pullar et al, 2012). While there is extensive evidence to support the promotion of a healthy lifestyle and physical activity in cancer survivorship, this is rarely incorporated into the current model of follow up. An updated review of survivorship studies has indicated that cancer patients would like to have a more active role in their health care and have a greater understanding of how to self-care, including what diet and lifestyle changes they should make (Davies et al, 2011). Physical activity in particular can assist in protecting against cancer recurrence and progression, with a dose–response for better outcomes (Davies et al, 2011). When taken with findings from a previous systematic review undertaken by the World Cancer Research Fund (Bekkering et al, 2006), evidence suggests that the mechanism of benefit from diet and physical activity relates to weight, with excess weight being a risk factor for recurrence.

In the UK it is estimated that there are 700,000 people of working age who have had a cancer diagnosis (ONS 2003). Many of these feel that they need to return to work when they feel fit and ready (Amir et al 2007); however a meta-analysis (DeBoer et al 2009) which compared cancer survivors to people with no cancer, found that cancer survivors are 1.37 times (95% cl; 1.21-1.55) more likely to be unemployed than those without cancer. Furthermore many people affected by cancer report some degree of economic hardship resulting from loss of income and extra costs incurred due to cancer (Shankaran et al, 2012).

The current review system does not have the capacity to deal with financial issues or to provide lifestyle or vocational rehabilitation. Furthermore with the heterogeneity in disease presentations and in patients coping styles following treatment it is not surprising that ‘one size does not fit all’. It is evident that with the emphasis on medical surveillance the current system does not address people’s needs:

- 26% feel a sense of abandonment after treatment
- 45% of people say the emotional effects of cancer are the most difficult to cope with
- 29% say they feel as if they have nobody to talk to
- 39% who completed treatment in 2009/10 say that no health or social care professional talked them through the needs they may have (Macmillan, 2012)

Clearly from the literature there is a lack of consensus on how patients should be followed up after treatment for colorectal cancer. In addition there are inherent
problems with the current system which result in it being less effective than it could be and unable to meet the needs of patients, hence the move initiated by the NCSI to identify alternative methods of follow up across the UK. The following section will outline the Northern Ireland cancer and policy context, both of which have a direct bearing on the proposed changes to follow up care.

3. Northern Ireland Context

3.1 Facts and Figures

Northern Ireland is becoming an older society. While the absolute size of the population is estimated to increase over the next 10 years, of greater significance to the demand for Health and Social Care is the likelihood that the average age of the population will also continue to increase at a faster rate. Estimates are that between 2008 and 2020 the Northern Ireland population will increase by 142,000 people (8%). The number of people over 75 years will increase by 40%.

There are 2 million people across the UK who have had a cancer diagnosis at some point in their lives. This is rising by 3.2% each year. In Northern Ireland there are more than 46,000 (excluding NMSC) people living with or beyond cancer (Donnelly, 2013). If current trends continue, this number could double over the next two decades, with breast, prostate and colorectal cancers accounting for over half.

The cancer landscape is changing with cancer increasingly being viewed as a chronic disease, yet services are framed around cancer as an acute illness. People are surviving longer and their needs are changing, hence it is argued that follow up services need to become more holistic in approach. Furthermore, the review system in its present form, will be unable to cope with increasing numbers into the future.

Information obtained from the NI Cancer Registry demonstrates an increase in earlier diagnosis of colorectal cancer (Figure 1). It is clear that there is an increase in earlier detection of Dukes A and B tumours which will impact on current follow up models.

Figure 1: NI Cancer Registry - Age at diagnosis - five-year group * Year of diagnosis * Dukes stage (colorectal)
Figures 2 and 3 convey NICR data related to colorectal cancer prevalence within NI. It highlights the critical need for the employment of survivorship services across the entire pathway.

The 18-year prevalence represents all patients diagnosed with colorectal cancer during 1993-2010 who were still alive at the end of 2010. Other prevalence measures commonly used, which depend upon the diagnosis period considered, include:

- One-year prevalence (patients diagnosed in 2010) which at the end of 2010 was 954
- Five-year prevalence (patients diagnosed in 2006-2010) which at the end of 2010 was 3,355
- Ten-year prevalence (patients diagnosed in 2001-2010) which at the end of 2010 was 5,049 (Fig. 3)

**Figure 2:** 18-year prevalence of colorectal cancer by sex and time since diagnosis
Figure 3: Different prevalence measures (based upon time since diagnosis) for colorectal cancer by sex (Donnelly, 2013)

With the introduction of a regional bowel screening programme in April 2010 it has been possible to examine its early impact. From April 2010 to end March 2013 there have been 224 screen detected cancers (QARC, 2013). There is a notable difference between the number of male (68%) and female (32%) screen detected cancers diagnosed.

Most screen detected cancers (62.5%) were located in the rectum and sigmoid.

The aim of bowel cancer screening is to identify the early stages of bowel cancer where chances of full recovery are greater than the cases that present in the symptomatic service.

Figure 4: Dukes Stage as a percentage of all screen detected cancers from April 2010 to end March 2012.

Dukes A* The cancer is located within the polyp and has not spread to the lining of the colon - no lymph nodes available for evaluation.
Almost three quarters of the screen detected cancers (74.2%) were early stage bowel cancers; Dukes A*, Dukes A, Dukes B and those specimens recorded as N/A. Reassuringly only 2.3% of cancers detected were Dukes D.

By showing the survivorship population in needs-based phases allows targeting of interventions and redistribution of resources (Maher and McConnell, 2011).

The five main phases on the care pathway have been identified:
- diagnosis and treatment (assumed to be the year from diagnosis),
- rehabilitation (assumed to be the year after treatment, estimated as the second year after diagnosis),
- monitoring (includes those at risk of recurrence or treatment complications but with no active cancer or treatment-related illness, and is split here between early and later monitoring),
- progressive illness (includes incurable cancer, but not those in the last year of life, and significant treatment-related illness)
- end of life (includes those in the last year of life presented with a subset diagnosed in the same year).

As pressures on the NHS continue to increase partly through the increase in cancer incidence and prevalence and the need to provide efficient service delivery and quality outcomes for patients, the evidence suggests that the current traditional model is unsuitable and unsustainable in its current form.

3.2 National and Local Strategic Drivers

Nationally, due to the recognition of the burden of cancer and the international trend towards self-management for chronic conditions (Lorig, 2002) have led to the establishment of the National Cancer Survivorship Initiative (NCSI) in England following the publication of the Cancer Reform Strategy (DoH, 2007). This includes considering approaches to cancer survivorship care and how it can best be tailored to meet individuals' needs. The NCSI has called for a fundamental shift in the way cancer survivors are supported, moving from a formulaic medical emphasis in follow-up to an approach based on individualised needs and preferences and the promotion of recovery, health and well-being.

The NCSI is a partnership between the Department of Health, Macmillan Cancer Support and NHS Improvement. As part of this initiative, NHS Improvement is testing approaches to care and support that ensures that we are moving to a position of not only supporting patients’ recovery from their disease, but also their future health and wellbeing through sustaining that recovery. During the last few years, a proof of principle has been established across several different tumour sites. When transferable from the 9 colorectal test sites, 9 breast test sites and 9 prostate test sites to other organisations, this will begin the process of spread across the NHS and provide national risk stratified effective pathways for breast, colorectal and prostate cancers.

Locally, patients and carers at a NICaN workshop in 2009 identified that ‘aftercare was an afterthought’ and subsequent agreement at a multi-professional NICaN
workshop in 2010 supported the need to embrace the NCSI approach. The Northern Ireland Transforming Cancer Follow Up programme was launched by HSCB/PHA in November 2010 (Henderson, 2009: NiCaN, 2010). The programme aims to achieve a standard within the Northern Ireland Service Framework for Cancer Prevention, Treatment and Care (DHSSPS, 2011a), which advocates the need for holistic assessment, survivorship care plans and the introduction of a more individualized model of aftercare.

The recent review of health and social care services in Northern Ireland, and the subsequent report Transforming Your Care (DHSSPS, 2011b), sets out a vision for an integrated health and social care service, with quality and outcomes remaining the determining factor in shaping services. Acknowledging the growing aging population, increase in poor health and chronic conditions, along with the current instability of health and social care services, it makes a compelling case for radical change. Personalization of care, prompt discharge, care closer to home, and enabling individual responsibility for health and wellbeing are among the central principles for change.

Living with Long Term Conditions: A Policy Framework (2012), cancer is increasingly being viewed as a long term condition with improved prognosis and late effects of treatments impacting on people’s lives. Having a long term condition can have a significant effect on a person’s life; physically, emotionally, psychologically and socially; as well as on the lives of those who care for them. The DHSSPS NI Long Term Conditions Framework (2012) aims to ensure that people with long term conditions are able to maintain or enhance their quality of life through high quality services and supported self-management. New models of follow-up for patients after primary cancer treatment embrace the supported self-management concept.

### 4. New Models of Cancer Follow Up

The new models of follow-up currently emerging encompass the following key components:

- **Risk stratification**
  - Clinicians should have the flexibility to identify the most appropriate patients for self-management based on clinical expertise and knowledge of individual patient’s needs.

- **Supported self-management or Self Directed Aftercare**
  - Self-management has been defined as ‘*awareness and active participation by the person in their recovery, recuperation and rehabilitation, to minimise the consequences of treatment, promote survival, health and well-being*’ (Foster & Fenlon, 2011).
  - Self-management programmes, such as the Expert Patient Programme have been shown to improve self-efficacy and health status (Fenlon & Foster, 2009). The central tenet of programmes is that patients can be educated to self-manage their condition (Lorig, 2002), and this will increase their self-efficacy to manage their own illness.
Where self-efficacy is increased in cancer, improved healthcare outcomes have also been identified. These include improved quality of life, reduced symptom distress (Lev et al, 2001), reduced caregiver stress (Lev and Owen, 1996), increased adherence to treatment, increased self-care behaviours and decreased physical and psychological symptoms (Lev, 1997).

Supported self-management has been described in the literature as patient-initiated follow up, point of need access or on-demand follow up.

- **Effective remote monitoring**
  
  A proof of principle has been established that risk stratification is achievable and that robust remote monitoring is an appropriate way of managing patients treated with curative intent with their cancer in remission as an alternative to face-to-face consultation (NHS Improvement, Adult Survivorship from Concept to Innovation, 2012)

Remote monitoring has been successfully implemented to enable the specialist to schedule and monitor surveillance tests without the need for face to face follow up for breast, prostate and colorectal cancer across test sites in the UK (NHS Improvement, 2013). This has been successfully reflected in Northern Ireland, as remote mammography has been established in all of the 5 Trusts for breast cancer patients. Remote monitoring solutions in Colorectal varied across test sites with four options preferred.

- Option 1. Use functionality within existing IT systems
- Option 2. Develop a bespoke remote monitoring solution (Guys and St. Thomas’ Hospital NHS Foundation Trust)
- Option 3. National Cancer Survivorship Initiative (NCSI) solution (St George’s NHS Foundation Trust)
- Option 4. Primary Care Solution (Derby Royal Hospital)

Pros and cons of each option can be found in the ‘how to guide’ (NHS Improvement, 2013).

Local advancements for remote monitoring: Within the statement of requirements for a new Regional Information System for Oncology Haematology (RISOH), for Northern Ireland, functionality has been requested to support an IT PSA tracking system. It may be that this system could also support a local solution for remote monitoring of tumour markers in colorectal patients. RISOH is expected to go live in September 2014. Further development of this type of system to support remote monitoring of CT Scans and Colonoscopies for Colorectal patients would also be favourable.

Remote monitoring will require a health professional to manage the caseload of patients on the system according to agreed protocol and guidelines. Consideration needs to be given to this in terms of resource.
• **Appropriate timely access if required**
  o Efficient and reliable processes for re-accessing the system, if required is a key principle to support self-management (NHS Improvement, Adult Survivorship from Concept to Innovation 2012)

This model is based on work being conducted in England through the NCSI test sites (see Table 2 test sites). The key components of the new model are fully concordant with NICE guidelines which are embedded in the national aftercare pathway. The work conducted at the test sites and the progress to date is summarised in a report: Adult Survivorship from Concept to Innovation (2012) ([http://www.improvement.nhs.uk/documents/Concept_to_Innovation.pdf](http://www.improvement.nhs.uk/documents/Concept_to_Innovation.pdf))

### 4.1 Emerging evidence from new cancer follow-up models in England

The test sites work on an ‘opt out’ approach i.e. all patients are offered the new model unless complex criteria apply. It is recognised that circumstances differ for individuals but pathway choice is a joint decision between the patient and the team, as to the most appropriate pathway for the individual. This should be based on clinical and individual needs and applied to all patients whether they have been treated with curative or palliative intent. It is recognised that some patients may want to continue with face-to-face contact and others will opt for the self-directed pathway, as long as they can see a specialist when required. Information, advice and support will be tailored to individual needs and allow for incorporation of physical, dietary and vocational rehabilitation according to individual need. Nine test sites have utilised risk stratified follow-up care for colorectal cancer patients. The common themes from the test sites include patient education events (H&WB), inclusion of holistic needs assessment and care planning and the need to develop a remote surveillance mechanism to ensure colonoscopies, CT scans and CEsAs are undertaken at the appropriate times. The learning from the colorectal cancer test sites demonstrates self-directed aftercare (SDA) is safe and effective for colorectal cancer patients. It is important to start small and increase scope as learning and confidence increases. Finally only two pathway options were required; supported self-management (or SDA) and professionally led follow up.

With any new system, challenges and achievements can be found which are summarised in Table 2.

#### Table 2: Achievements and challenges from test sites

<table>
<thead>
<tr>
<th>Achievements</th>
<th>Challenges</th>
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<tbody>
<tr>
<td>Remote surveillance system established - local I.T support imperative</td>
<td>Developing the remote monitoring system</td>
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<td></td>
<td>Having a co-ordinator to be dedicated to managing the database, also having contingency plan for sickness</td>
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<td>Updating and improving the database</td>
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<tr>
<td>Reduced clinic appointments, increase capacity for new patients.</td>
<td>Getting everyone on board and signed up to the concept. It was a new way of working for all the team.</td>
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<tr>
<td>Greater job satisfaction through better structured clinical appointments</td>
<td>Facilitating this new follow-up process into daily workload – Administrative support is essential</td>
</tr>
<tr>
<td>Information events that patients feel empowered and in control of their life</td>
<td>Patients already in the review system - It was a new follow-up and they required more information and support</td>
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### 5. Conclusion

It is evident, that a change in ethos toward a partnership model of care where the patient is in control of any decision making about his/her care is required for colorectal cancer follow-up (Taylor & Odey, 2011, Samarasinghe & Wiles, 2012). There is high satisfaction with patient-led follow-up by low to moderate risk colorectal cancer survivors, as long as:

- They are confident to assess their own symptoms,
- They have a clear indication of their future risk profile,
- They receive surveillance i.e. CT scans, colonoscopy, CEA tumour marker, and
- They are provided with a safe, reliable and quick route back to specialist care if needed

The focus for follow-up is more on meeting individual care needs as opposed to the notion of ‘one size fits all.’ The challenge is achieving this in a cost-effective way that is either as equally effective, or more so, than traditional clinical models of aftercare. If the emphasis on cancer aftercare is towards empowering and supporting patients to engage in self-management and to be able to make informed choices about the type of support they need, then alternative models of aftercare such as self-initiated could provide a means for achieving this.
References


DHSSPS, NI. (2012) Living With Long Term Conditions - A Policy Framework


DHSSPS, NI. (2011b) Transforming Your Care - A Review of Health and Social Care in Northern Ireland


NHS Improvement Cancer (2009) *Rapid review of current service provision following cancer treatment*


