Title:

Developing new follow up pathways for people with breast 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 breast follow up as well considering the emerging evidence with regards to newer models of breast cancer follow up. Whilst acknowledging Sackett et al’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 Breast follow-up
Published guidelines differ, the National Institute for Clinical Excellence (NICE) produced guidelines in 2002, stating “routine long-term follow-up has not been shown to be effective” and “duration of follow-up outside the context of clinical trials should not exceed three years” (NICE 2002). The British Association of Surgical Oncology (BASO) suggest a follow-up period of five years, primarily to enable data collection regarding recurrence and survival rates (BASO, 2005). The American Society of Clinical Oncologists advocate 3-6 monthly appointments for 3 years, 6-12 monthly for years 4 and 5 with annual review thereafter (Khatcheressian, 2012). The Canadian Steering Committee on Clinical Practice Guidelines suggested in 1998 that frequency should be adjusted according to individual patient needs (CMAJ, 1998). This idea of individualised follow-up is promoted in the most recent NICE guidelines, February 2009 (NICE, 2009). These new guidelines, for patients with stage 1 or 2 disease, advise that options for follow-up should be discussed with the individual. Follow-up may be in secondary care, primary care or shared according to local
provision, with the facility for immediate referral to a specialist clinic if a problem arises (NICE, 2009).

It is evident that there is no consensus on current models of follow up. In addition there are a number of key levers why change is required within cancer follow care.

2.2 Current Breast Cancer follow-up

Studies indicate that neither the frequency nor the intensity of follow-up will influence the chances of cure (Kimman et al, 2007; Oltra et al, 2007), aid detection of recurrence or overall survival or quality of life (Rojas, 2008). Work at local, national and international level has shown that recurrence is infrequently detected through physical examination at routine review appointments (see table 1).

Women have high expectations from follow-up, viewing the detection of recurrence as the main purpose and believing that clinical review has significant ability to detect relapse (Montgomery et al., 2008b; McCaughan & McSorley, 2007; de Bock et al., 2004; Beaver & Luker, 2005). Evidence suggests that follow-up is actually ineffective in detecting recurrence and research has queried both the value of diagnostic tests and routine check-ups in detecting recurrence (De Bock et al., 2004). It seems that the focus of the current system on physical examination and detecting recurrence may only exacerbate the patient’s need for reassurance.

There is evidence that follow-up appointments often do not provide the level of psychological support required by patients. One documented reason for this is inadequate time during routine follow-up to address often complex psychosocial issues (Pennery& Mallet, 2000). Consultations are generally of a brief duration, approximately six minutes, with few opportunities to meet information or psychosocial needs (Beaver et al, 2005). Some patients report appointments causing increased anxiety (McCaughan et al, 2007). Frequent follow-up visits may create patient dependency, preventing the patient moving on to self-management and full rehabilitation. This dependency may have detrimental effects as research has shown that patients may delay seeking prompt advice if they know they have an appointment due in the next few months. Therefore rather than presenting when symptoms are initially detected they wait for their routine review and this may result in a potentially curable recurrence being untreated for several months (Sheppard et al, 2007). Appendix 1 provides a summary of the literature in relation to patient views on current and alternative methods of follow-up.

Davies and Batehup (2009) conclude that many appointments add little value to the patient or clinician as there is a lack of clarity regarding the benefits of cancer follow-up. 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.
Table 1: Studies investigating recurrences in breast cancer

<table>
<thead>
<tr>
<th>Author</th>
<th>Country</th>
<th>Patients (N)</th>
<th>Aim</th>
<th>Outcomes / Results</th>
<th>Conclusions</th>
</tr>
</thead>
<tbody>
<tr>
<td>TeBoekhorst (2001)</td>
<td>Netherlands</td>
<td>N=270 breast cancer recurrences</td>
<td>Retrospective review</td>
<td>63% of patients had symptomatic recurrence. There was no difference in disease free survival between symptomatic and asymptomatic recurrences</td>
<td>In the current management of breast cancer the medical impact of follow up is low, so follow up visits after treatment are hardly warranted.</td>
</tr>
<tr>
<td>De Bock (2004)</td>
<td>Netherlands</td>
<td>N= 5045 Breast cancer</td>
<td>Meta-analysis to determine the effectiveness of routine review to detect recurrence</td>
<td>378 loco regional recurrences detected. 40% diagnosed in asymptomatic patients during routine review. 41% diagnosed outside routine review</td>
<td>Although number diagnosed through routine review seems significant, overall incidence of recurrence is low. Using frequent routine review requires much effort to detect only a very small proportion of curable recurrences early.</td>
</tr>
<tr>
<td>Morris (2008), Cornwall, UK</td>
<td>N=500 patients diagnosed annually</td>
<td>Audit of follow-up clinics for breast cancer patients to determine the time and costs &amp; number of local recurrences detected</td>
<td>69 recurrences detected 15% detected at routine review 48% identified by patient 37% detected by routine mammography</td>
<td>Locoregional recurrence is generally detected between clinic appointments via patients with symptomatic recurrence or by mammogram. Alternative methods of follow up need to be implemented.</td>
<td></td>
</tr>
<tr>
<td>Magee (2011) Ulster Hospital NI</td>
<td>N=1303 Treated for primary breast cancer</td>
<td>To determine the effectiveness of a stratified follow-up programme in detecting recurrence</td>
<td>Median follow-up was 40 months. Overall survival rate was 96.9% (90.4% high, 97.3% moderate,99.5% low). Disease free survival was 94.1% (84.1% high, 94.7% moderate, 98.1% low). Seventy-seven recurrences were detected with 39 (51%) in the high risk group, 27 (35%) in the moderate risk group and 11 (14%) in the low risk group. Detection rate at a scheduled appointment was 0.27% overall (low risk 0.14%, moderate risk 0.27%, high risk 0.45%).</td>
<td>Over 70% of recurrences are detected outside routine reviews. NPI correlates with risk of recurrent disease. Scheduled follow-up yielded few recurrences, suggesting early discharge with open access to clinics could be a safe alternative. This type of follow-up may reduce demand on specialist clinics without significantly affecting patient care or overall survival.</td>
<td></td>
</tr>
<tr>
<td>Montgomery (2009), Scotland</td>
<td>N=198 patients with breast conserving surgery</td>
<td>Retrospective analysis of relapse and method of detection</td>
<td>12 recurrences detected No early peak in potentially treatable relapses 42% identified by patient 16% detected by clinical examination alone</td>
<td>Majority of recurrences were detected by means other than clinical examination. Mammography &amp; self-examination were more effective</td>
<td></td>
</tr>
<tr>
<td>Lu (2012) Netherlands</td>
<td></td>
<td>Simulation model to evaluate the clinical effects &amp; costs of 4 strategies for follow-up after treatment</td>
<td>Shortening the follow up period to 2 years instead of 5 and terminating annual examination by a GP did not decrease the detection of small tumours.</td>
<td>Decreasing hospital follow-up &amp; termination of annual physical examination would lead to substantial reduction in costs while maintaining the possibility of detecting small breast cancers</td>
<td></td>
</tr>
</tbody>
</table>
2.3 Patient needs

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).

A survey of 289 cancer survivors in NI in 2010 identified that 40% of patients have unmet needs that have not been resolved by the current follow-up system (Santin et al, 2011). 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).

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. 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 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 (Lauzier et al 2008).

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 breast 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

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 56,000 people living with or beyond cancer (Maddams et al, 2009). 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. Relative survival following differing breast cancer stages is depicted in Figure 1 (NI Cancer Registry).

Figure 1: Breast Cancer Survival (NI Cancer Registry)

Figure 2 conveys system wide and cross sector data related to breast cancer survival in NI. It highlights the critical need for the employment of survivorship services across the entire pathway whilst showing the survivorship population in
needs-based phases which will allow 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).

Figure 2: *NI figures regarding NI breast cancer incidence and prevalence

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.
3.1 Strategic Drivers

In recognition of the burden of cancer the National Cancer Survivorship Initiative (NCSI) was established in England following the publication of the Cancer Reform Strategy (DoH, 2007) and the international trend towards self-management for chronic conditions (Lorig et al, 2002). This includes considering approaches to cancer survivorship care and how it can best be tailored to meet individual’s 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. When transferable from the test sites to other organisations, will begin the process of spread across the NHS and provide national risk stratified effective pathways for breast, colorectal and prostate cancers.

Following feedback from patients and carers at a NICaN workshop in 2009 that ‘aftercare is an afterthought’ and subsequent agreement at a multi-professional NICaN workshop in 2010 of the need to embrace the NCSI approach, the Northern Ireland Transforming Cancer Follow Up programme was launched by HSCB/PHA in November 2010. The programme aims to achieve a standard within the Northern Ireland Service Framework for Cancer Prevention, Treatment and Care (DHSSPS, 2011), 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, 2011), 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 (Keen 2010). 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 Long Term Conditions Framework NI (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 proposed new model encompasses 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**
  - 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 (Foster & Fenlon, 2009). The central tenet of many such 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. Evidence, incorporating a systematic review, randomised controlled trials testing this model and ongoing work is summarised in Table 4.

- **Effective remote monitoring**
  - Mammography can be separated from the outpatient visit. 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)

- **Appropriate timely access if required**
  - 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)
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 a joint decision will always occur between the patient and the team as to the most appropriate pathway for the individual. Some low risk patients prefer to continue with face-to-face contact while some patients with a poor prognosis opt for self-management and only contact the specialist when help is required. It is recognised that the new models of follow up should be more individualised and allow for incorporation of physical, dietary and vocational rehabilitation according to individual need.

Table 2: Data Available from Pilot Breast cancer sites in UK

<table>
<thead>
<tr>
<th>Pilot Site</th>
<th>New diagnosis per year (breast cancer)</th>
<th>% on SDA pathway</th>
<th>Timing – moved to SDA</th>
<th>Total on SDA in system</th>
<th>Rapid access - appts required</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hillingdon</td>
<td>148 new pts pa</td>
<td>60-65%</td>
<td>Exit interview with doctor immediately post treatment</td>
<td>300 over 5 years</td>
<td>1-2 appts per week</td>
</tr>
<tr>
<td>Ipswich</td>
<td>300 new pts pa</td>
<td>70%</td>
<td>90% onto SDA at 3 months, 10% onto SDA at 6 months</td>
<td>146</td>
<td>1-2 appts per month</td>
</tr>
<tr>
<td>Brighton</td>
<td>223</td>
<td>% on pathway not listed however state 77% are suitable</td>
<td>SDA offered at 1 year</td>
<td>Not specified</td>
<td>Not specified</td>
</tr>
<tr>
<td>Hull</td>
<td>174 new pts pa</td>
<td>As above 81% are suitable</td>
<td>After post treatment appt – pt invited to survivorship clinics at 12mths</td>
<td>600 + patients</td>
<td>4-5 appts per week</td>
</tr>
<tr>
<td>Bristol</td>
<td>382 new pts pa</td>
<td>As above 95% are suitable</td>
<td>No detail provided</td>
<td>Not specified</td>
<td>Not specified</td>
</tr>
</tbody>
</table>

Common themes from test sites
- Patient education events (H&WB) were held at most test sites
- All teams have utilised community schemes to promote and deliver physical activity
- All teams have introduced HNA & patient care plans
- All sites have separated the annual mammogram from the outpatient visit with results being sent by post to patients

Summary of learning from breast cancer test sites:
- Self-managed follow up is safe & acceptable for breast cancer patients
- Start small and increase scope as learning and confidence increases
- Only two pathway options were required; supported self-management and professionally led follow up
With any new system challenges and achievements can be found which are summarised in table 3.

Table 3: Achievements and challenges from test sites

<table>
<thead>
<tr>
<th>Achievements</th>
<th>Challenges</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mammography screening can be separated from the outpatient visit</td>
<td>The absence of coding within outpatients activity - patients with a cancer diagnosis had to be identified by clinic staff and manually recorded, or assumptions needed to be made.</td>
</tr>
<tr>
<td>GPs can be advised to stop hormones when required rather than recall to a clinic at 5 years</td>
<td>Resources may need to shift from medical to nursing budgets to support additional holistic needs assessments and educational initiatives.</td>
</tr>
<tr>
<td>TSR is a useful tool for patients and GP’s to understand the disease stage, what treatment the patient received, a management plan and what to look out for.</td>
<td>A few sites achieved limited roll out of new pathway within their team.</td>
</tr>
<tr>
<td>Information events are cost effective and offer value to patients.</td>
<td></td>
</tr>
<tr>
<td>Access to physical activity and other support services have been welcomed</td>
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</tr>
<tr>
<td>Self-management was suitable for around 77% patients treated with curative intent within one year of diagnosis as long as patient has a review of needs at end of treatment and continued open access to the specialist team</td>
<td>Variation in point of stratifying to self-managed pathway. Some patients were stratified at the point they became suitable for a self-managed pathway others were several years into follow up but could have been released earlier had the system been available.</td>
</tr>
</tbody>
</table>
### Table 4: Available evidence comparing differing follow-up systems for breast cancer

<table>
<thead>
<tr>
<th>Author (Year) Country</th>
<th>Patients (N)</th>
<th>Aim</th>
<th>Outcomes / Results</th>
<th>Conclusions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sheppard (2009) Portsmouth, UK</td>
<td>N=237 breast patients 2 years post-diagnosis. All diagnostic groups included: DCIS (29) – grade 3 (34) &amp; node involvement (52)</td>
<td>RCT comparing point of need (PON) access versus routine 6 monthly clinical review</td>
<td>After 18 mths: No increased psychological morbidity (p=0.767), no decreased QoL (0.282), no feeling of isolation and 95% on PON did not wish to return to routine follow-up. Routine review did not identify a larger number of recurrences. 9 recurrences over 18 mth period (5 in PON arm : 4 in routine) insufficient numbers to test significance. N.B. 1 patient delayed presentation in routine arm, waiting for her next review appt.</td>
<td>Point of need access is acceptable to the majority of patients. Findings suggest that over two thirds of patients would be willing to stop routine review. There is no evidence to support that regular clinical review improves psychological morbidity or Quality of Life (QoL). Patients not compromised in terms early detection of recurrence.</td>
</tr>
<tr>
<td>Koinberg (2009) Sweden</td>
<td>N=264 stage I &amp; II breast cancer patients</td>
<td>RCT to determine the most cost-effective method of follow-up: standard physician led reviews versus nurse led on demand reviews</td>
<td>Nurse led on demand reviews were 20% less expensive. There were 21% more contacts with the physician than with the nurse</td>
<td>Nurse led on demand follow-up offers a substantial opportunity for reallocating resources.</td>
</tr>
<tr>
<td>Brown (2002)</td>
<td>N=61 patients with stage 1 breast cancer</td>
<td>RCT assessing standard clinic review (SC) versus patient initiated (PI) review with telephone access to the breast care nurse</td>
<td>Over 12 months the BCN received 3 phone calls (1 from SC arm and 2 from PI arm). There were 7 referrals from GPs, 3 from SC arm &amp; 4 from PI arm. 4 women developed recurrences, 2 in each arm. Both women in the PI arm were referred in by their GP. QoL and psychological morbidity showed no difference between the groups.</td>
<td>Patient initiated review was safe and cost-effective.</td>
</tr>
<tr>
<td>Lewis et al (2009) North Wales</td>
<td>Systematic review: Follow-up of cancer in primary care versus secondary care</td>
<td>Included comparative studies or economic evaluations of primary versus secondary care follow-up, hospital follow-up with formal primary care involvement versus conventional hospital follow-up, and hospital follow-up versus patient-initiated or minimal follow-up if the study reported the impact on primary care</td>
<td>No statistically significant difference for patient wellbeing, recurrence rate, survival, recurrence-related serious clinical events, diagnostic delay, or patient satisfaction. GP-led breast cancer follow-up was cheaper than hospital follow-up. Evaluation of patient-initiated or minimal follow-up found no statistically significant impact on the number of GP consultations or cancer-related referrals.</td>
<td>Weak evidence suggests that breast cancer follow-up in primary care is effective. Interventions improving communication between primary and secondary care could lead to greater GP involvement. Discontinuation of formal follow-up may not increase GP workload. However, the quality of the data in general was poor, and no firm conclusions can be reached.</td>
</tr>
<tr>
<td>Study</td>
<td>N=</td>
<td>Methodology</td>
<td>Findings</td>
<td>Implications</td>
</tr>
<tr>
<td>-------------------------------------------</td>
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<tr>
<td>Maher et al., (2009) Hillingdon</td>
<td>300</td>
<td>Ongoing study</td>
<td>Follow-up approach discussed with patient preference for follow-up management (i.e. traditional follow-up or a self-management approach with early mammography for five-years and direct access to the clinic via the BCN) Follow-up appointments have dropped by 30% Evaluation of the new process shows that 89% of GPs were happy with the new model 83% of patients were happy with the contact they received post-treatment 92% of patients felt secure with the new system</td>
<td>This model of follow-up has been found to be acceptable to patients, the hospital, and primary care staff, and access through a BCN appears feasible and safe without undue increased workload.</td>
</tr>
<tr>
<td>Chapman (2009) Cambridge, UK</td>
<td>130</td>
<td>N= 130 breast patients with good prognosis</td>
<td>Audit to assess patient satisfaction and GP workload following introduction of patient-led follow up (PLFU) 97% (n=126) of patients knew how to contact the breast care unit, all were satisfied with PLFU, only 4% (n=5) required a breast clinic appointment &amp; 3.6% of GPs (10/277) reported referring a PLFU patient back to the breast unit.</td>
<td>PLFU was well received by patients following breast cancer treatment with little increased workload for GPs.</td>
</tr>
<tr>
<td>Montgomery et al. (2008a)</td>
<td>79</td>
<td>Cohort Study N= 79</td>
<td>Patients expectations for follow-up in breast cancer Most women expect some follow-up, but expectations for length and frequency vary dramatically. Most believe follow-up is for the detection of relapse, but very few see psychological support or side effect detection as being central to clinicians’ aims. One third of women would be happy to not come back to clinic at all when told how infrequently routine clinical examination detects metastatic disease.</td>
<td>Study size was quite small. Characteristics of those who didn’t respond were not examined.</td>
</tr>
<tr>
<td>Montgomery et al. (2008b)</td>
<td>75</td>
<td>Cohort Study N= 75</td>
<td>Examine the acceptability &amp; feasibility of remote automated questionnaire-based telephone follow-up after breast cancer. 71 of the 75 patients found system easy to use. 49 of the 75 (65.33%) liked the system &amp; were happy to use it as their sole method of follow-up. 12% were happy to use it as part of their follow-up. 10.66% of participants raised concerns which led to clinic attendance. Automated questionnaire-based telephone follow-up is acceptable to women &amp; has the potential to reduce attendance at clinic.</td>
<td>Small sample. The methods utilized in the pilot will not be the same as in the proper implementation (i.e. no phonecalls from doctors) and therefore results may not be a true reflection of patients acceptability of the real mode.</td>
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</table>
5. Conclusion

Giving patients the option to initiate their own contact with specialist nurses based on self-assessed need is a growing trend (Sheppard et al, 2009; Koinberg & Engholm 2009; Maher & Jackson, 2009). In the main, there is high satisfaction with patient-led follow-up by low to moderate risk breast cancer survivors, as long as they are

- confident to assess their own symptoms,
- have a clear indication of their future risk profile,
- receive annual mammographic surveillance, and
- 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


Cancer Reform Strategy


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Magee CE.; Hillan JA.; Badger SA.; Kennedy RJ.; Kirk SJ. (2011) Risk stratification as a means of reducing the burden of follow-up after completion of initial treatment for breast cancer. The Surgeon 9: 61-64


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TeBoekhorst DS.; Peer NG.; van der Sluis RF.; Wobbers T. &Ruers TJ. (2001) Periodic follow up after breast cancer and the effect on survival. European J of Surgery 167(7):490-6

Appendix One: Patients views on current and alternative methods of follow-up

<table>
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<tr>
<th>Research Article</th>
<th>Views on current follow-up</th>
<th>Views on alternative methods</th>
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<tr>
<td></td>
<td>Follow-up provides reassurance to pts with fear of recurrence</td>
<td>Continuity of care is important</td>
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<td>Koinberg et al. (2004)</td>
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<td>Gulliford et al. (1997)</td>
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<td>Earnshaw and Stephenson (1997)</td>
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<td>Renton et al. (2002)</td>
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<td>Thomas and Chait (1997)</td>
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<td>Kimman, Bloebaum et al. (2010)</td>
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<td>Pennery and Mallet *(2000)</td>
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<td>Koinberg, Holmberg et al *(2002)</td>
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<td>McCaughan and McSorley (2007)</td>
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<td>Beaver and Luker * (2005)</td>
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<td>Adewuyi-Dalton et al. (1998)</td>
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<td>Brown et al. (2002)</td>
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