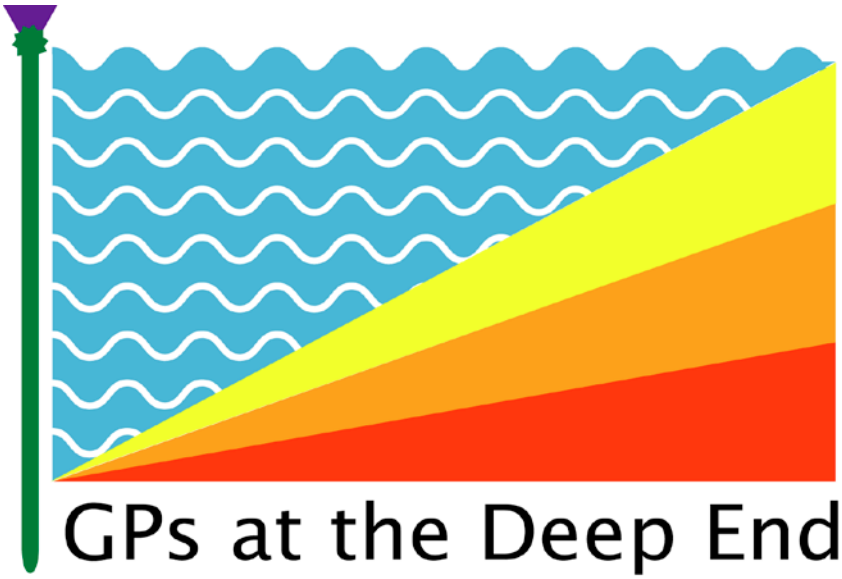

Deep End Report 17
Detecting cancer early

The Scottish Government has launched a programme, Detect Cancer Early, comprising a public awareness campaign (with TV adverts), support for primary care (guidelines, open access to imaging, audit), expansion of diagnostic capacity and improved data collection.

As with all programmes seeking to improve care, if the programme is not at its best where it is needed most, there is the prospect that inequalities in health may be widened.

The Detect Cancer Early Programme team wished to present and discuss these plans with General Practitioners at the Deep End, to identify the particular problems of early cancer detection in vey deprived areas, and how they might be addressed.

11 general practitioners and three observers met on Friday 20 April 2012 at the Department of General Practice and Primary Care, University of Glasgow for a meeting to review the challenge of “Detecting cancer early”.

Eleven Deep End GPs met on Friday 20 April 2012 at the University of Glasgow for a workshop on detecting cancer early in deprived areas with colleagues from the Scottish Government Cancer Team.

SUMMARY

- Early cancer detection is more difficult in deprived areas because of the vague nature of many early symptoms and the high prevalence of other medical, psychological and social problems.
- Deep End GPs felt disengaged from the national bowel cancer screening programme.
- Communications with patients were considered to have “too much writing” for the particular target group, given issues of health literacy.
- Mass media campaigns provide a starting point, but engagement with patients in deprived areas needs a more personal approach.
- The “hard to reach” are often in regular contact with practices, but these contacts are used for pressing needs, which are currently more social than medical.
- Postal approaches do not work well in deprived areas and are often no more effective than junk mail. Many Deep End practices have abandoned this method of contacting patients. Timely phone contact by a person known to the patients is more effective.
- Centrally determined targets are generally more effective in secondary care than they are in general practice, where HEAT targets have relatively little penetration and profile.
- A general finding from the Deep End Project is that referral pathways have to be short, familiar and local if patients are to attend. The generic role of lay link worker may help to establish and use such links.
- General practices are more likely to be effective in contributing to a series of well coordinated and supported short term campaigns on specific issues. Exhortation on “everything, all of the time” quickly loses any effect.
- “Bolt-on initiatives” with externally determined priorities are difficult to assimilate under the conditions of the inverse care law, where practices have insufficient time to address the multimorbidity and social complexity of many patients.
- The lack of GPs relative to patient need, and the consequent shortage of time within consultations, are major constraints in addressing the range and depth of patients' problems.

CONTENTS

GENERAL PRACTITIONERS ATTENDING

Name	Location	List size	Deprivation ranking
Hugh Brown	Dalmellington	3625	85
Ronnie Burns	Parkhead HC	3051	8
Richard Groden	Tollcross	6776	76
Karen Hayes	Ibrox	3212	77
Alison Macbeth	Gilbertfield	4901	25
Pauline McAlavey	Royston	6113	29
William McPhee	Parkhead	4971	17
Alison Reid	Balmore Road	3375	3
Douglas Rigg	Possilpark	3085	1
Nicola Smeaton	Dundee	9365	85

OTHERS ATTENDING

Jim Little	Programme Manager, SGHD Cancer Team
David Linden	GP and Programme Manager, SGHD Cancer Team
Gail Lyall	Marketing Manager, SGHD Cancer Team
Annie Finnie	Marketing Manager, SGHD Cancer Team
Graham Watt	Professor of General Practice, University of Glasgow
Sara Macdonald	Lecturer, University of Glasgow

PROGRAMME

13.30	**Welcome and introductions**	Graham Watt, Jim Little
13.45	**Programme introduction**	David Linden, Gail Lyall
	Campaign to date	Annie Finnie
14.30	**Views and experience of Deep End practitioners**	
15.30	**Breast cancer campaign – looking ahead**	Gail Lyall
	Lung cancer and bowel cancer	Anne Finnie
16.30	**Summing up and close**	

INTRODUCTION

The UK compares poorly with other European countries in terms of cancer survival in the first year after diagnosis. Survival rates have improved, but the UK still lags behind.

Policies to address this issue have focused on waiting time targets, but such initiatives only come into effect after the patient has presented with symptoms. In general, survival rates are better in patients who present early.

The Detect Cancer Early campaign aims to improve cancer survival by increasing public awareness of cancer symptoms (via social marketing), increasing referral rates from primary care, increasing screening and diagnostic capacity, continuing to apply current waiting time standards and providing information and support for general practices.

The main focus of the campaign concerns lung, breast and bowel cancer and aims to raise awareness of cancer symptoms in the “unworried unwell”.

It was recognised that delays in cancer presentation have many possible causes including issues of awareness, access, patient delays, service delays and so on. There are several nodal points in the process of presentation and referral.

CONTEXT

As the average general practice may see only 8 new cases of cancer per year, early cancer detection is only a small part of the workload of general practices, especially in deprived areas where there is high prevalence of multiple morbidity and social complexity, including problems with benefits, housing, mental health and addiction.

The current austerity programme often puts health issues on the back burner, as consultations focus on the mental health consequences of benefit cuts.

Deep End general practices are also generally short of time within consultations to address patients’ needs, as a result of the inverse care law.

To separate cancer from other issues which patients may have, as part of the ubiquitous pattern of multimorbidity and social complexity, may add to the increasing problem of fragmentation of care. Such patients need unconditional continuity of comprehensive, coordinated care for whatever combinations of problems they have.

A Deep End GP described a consultation that morning which had resulted in three separate referrals as different problems had to be addressed by different specialist services.

Una Macleod, now Professor of General Practice at Hull/York University and formerly a GP in Shettleston and Senior Lecturer at Glasgow University, had studied why women with breast cancer have poorer outcomes in deprived areas. She found that the provision of the major treatments (surgery, radiotherapy, chemotherapy) appeared equitable, but women with breast cancer in deprived areas had greater stress (including causes of stress other than breast cancer), more unconnected health problems and more admissions to hospital in the year after their cancer

diagnosis, for reasons other than breast cancer. They also reported receiving less support, although this may have been confounded by issues of understanding and recall.

EXPERIENCE OF CANCER SCREENING PROGRAMMES

Deep End GPs felt disengaged from the national bowel cancer screening programme. Communications with patients were considered to have "too much writing" for the particular target group, given issues of general literacy and health literacy. The arms length approach of the campaign makes it less effective in deprived areas. Focused, short, local community campaigns could provide opportunities for GPs to be more involved and to make fuller use of their contacts with patients. In general, it was felt that uptake rates of bowel cancer screening could be improved if there were better engagement between the programme and general practices in local communities.

Bowel cancer screening is problematic because of the sensitive nature of the topic and the need to find appropriate language and opportunities.

Doubts were expressed about coverage rates for cervical screening, as a result of the process whereby patients may be excluded. GPs preferred the approach before the QOF when a simple target of 80% was easier to achieve. It was noted that high rates of coverage are hard to achieve in Asian communities.

The mobile breast screening unit in Glasgow had worked well in Govan, but no longer visited Possil because of concerns about safety and security.

ENGAGING WITH PATIENTS

It was recognised that the most likely responders to social marketing campaigns are the "worried well". In a previous Deep End meeting, concerning GP training, one of the concerns expressed by GP trainees in Deep End practices was that they had heard a great deal about the "worried well" but saw few such patients in Deep End practices.

Mass media campaigns provide a starting point, but engagement with patients in deprived areas needs a more personal approach.

Postal approaches do not work well in deprived areas, and are often no more effective than junk mail. Many Deep End practices have abandoned this method of contacting patients. Timely phone contact by a person known to the patient is more effective.

It was felt that men were particularly hard to engage, but that wives and daughters could exert family pressure to better effect.

The chaotic nature of many patients' lives, dealing with multiple problems and social complexity, means that cancer risks are often "off the radar". Such patients are less

likely to attend for screening, as in the Keep well programme (which doesn't specifically address cancer). They are not necessarily "hard to reach", and may be in regular contact with their general practice, but at present, social concerns are taking priority over medical concerns. The vague nature of the early symptoms of many cancers means that other issues are likely to take precedence.

Much health promotion activity seemed based on the notion of transformative encounters in which single professional interventions result in major behavioural change. The reality is that behavioural change is more often achieved over the long term, by "chipping away" at problems and developing a long term relationship based on mutuality and trust.

Poverty of resource is often associated with poverty of aspiration. An important task of GPs can be to boost patient morale so that they feel worthy of investigation and preventive measures.

ENGAGING WITH GENERAL PRACTICES

It needs to be recognised that targets are generally more difficult to achieve in deprived areas. Several patients may need to be approached per successful attendance or referral. Concern was expressed about whether the Beatson Centre in Glasgow had the capacity to deal with a large increase in referrals.

Centrally determined targets (e.g. waiting times) are generally more effective within secondary care than they are in general practice (where HEAT targets have relatively little penetration and profile).

Doubt was expressed about the prospect of improving early cancer detection rates via "bolt on" initiatives that focus specifically on cancer, attempting to give this issue a higher priority than it may usually receive. Both patients and practices are struggling as a result of the high burden of need and the inverse care law, which limits the time available to address patients' problems.

If these general circumstances of practice could be improved, it was felt that early cancer detection would improve as part of a general improvement of the capacity of patients and practitioners to address their problems.

The lack of GPs relative to patient need, and the consequent shortage of time within consultations, are major constraints in addressing the range and depth of patients' problems.

LOOKING AHEAD

Deep End GPs from the East End of Glasgow spoke positively about health stalls established in The Forge shopping centre, for Keep Well and Citizen's Advice. Other communal places, such as pubs and bookies provided potential points of contact, but in every case there is a need for effective and accurate signposting to other resources. While generalists could identify issues, they often needed to refer to other professions and services that have greater knowledge, expertise or time.

Stories of what had happened to local people could be more persuasive than factual information about cancer screening and detection.

A general finding from the Deep End project is that referral pathways have to be short, local and familiar if patients are to attend. The generic role of lay link worker may help to establish and use such links.

General practices are more likely to be effective in contributing to a series of well coordinated and supported short term campaigns on specific issues. Exhortation on "everything, all of the time" quickly loses any effect.

February and March are best avoided as practices are busy during these months with end of year contract reporting.

The Primary Care Collaborative (PCC) approach had been shown to be both acceptable and effective with Deep End practices. It involved groups of five to six practices working together on shared activities, with GP leadership and central support. The best way of engaging with general practices is to work around what they do well, rather than exhorting them to do new things.

ANNEX

Background information provided by the Detect Cancer Early Programme team

Introduction

Cancer survival is a key measure of the effectiveness of health care systems and survival rates will remain a key indicator of progress. In an effort to improve Scotland's five year survival rates relative to the best performing countries in Europe and the world, the Scottish Government has embarked upon a 'Detect Cancer Early' Programme. This is because much of the survival deficit is due to differences in survival at year one, suggesting that late presentation and advanced disease at diagnosis are responsible.

The Cabinet Secretary launched a stakeholder engagement period following publication of the draft Implementation Plan on 01 August 2011 and in the five months since then much progress has been made to facilitate and prepare for the programme of high profile social marketing campaigns and the impact that these are anticipated to have on the NHS.

The Detect Cancer Early Programme has four main work streams:

1. **Public awareness and behaviour influencing**

   Considerable insight gathering and research has informed a programme of social marketing campaigns. The first phase of these will be an overarching empowerment campaign to raise awareness of the benefits of early detection. This aims to tackle fear and apprehension about seeing a doctor and to reaffirm that treatment and survival has improved in the last 30 years. This activity will be followed by a series of tumour specific campaigns to raise awareness of the symptoms and signs that could indicate cancer and that should prompt help seeking behaviour.

2. **Primary care**

   There are several elements to this work. This will include urgent cancer suspected referral profiling, 'Think cancer' education and training, cancer risk assessment – guidance and tools for referral and investigation, refresh of the Scottish Referral Guidelines for Suspected Cancer, exploring open access to investigations and the development of practice profiles that will enable practices to compare data and performance with peers.

3. **Screening and diagnostic capacity**

   Significant expansion of diagnostic capacity will be required and will be funded. This will allow current performance against the 62 and 31 day cancer waiting times standards to be maintained in anticipation of the increase in numbers of those people requiring investigation. Work will be taken forward to improve uptake of the national cancer screening programmes using informed consent as the basis.

4. **Data collation and publication**

   Better and more timely recording of staging data by NHS Boards will be encouraged that will facilitate up-to-date monitoring of progress against the programme aims and objectives including NHS Board achievement of the HEAT target associated with the programme.

Social marketing overview

Background

The number of people diagnosed with cancer is projected to rise to around 35,000 per annum between 2016 – 2020 (compared to around 30,000 a year between 2006 and 2010). This reflects the impact of Scotland's ageing population as well as improvements in diagnosis.

Over recent years, positive progress has been made in reducing cancer waiting times. However, too often in Scotland, cancers are not detected early enough and late detection means poorer survival rates.

Scotland lags behind the European average for five-year survival rates from all types of cancer.

The SNP manifesto included a commitment to increasing the number of cancers detected at the first stage of the disease by 25 per cent - with an initial emphasis on lung cancer, breast cancer and colorectal cancer. If successful, this initiative could save an additional 300 lives a year by the end of 2016.

NHS Scotland has been tasked with improving survival outcomes for people with cancer to amongst the best in Europe, managing the expected increase in incidence with limited increase in resource and continuing to improve patient and carer experience.

One way of achieving this is through earlier diagnosis. Earlier diagnosis means simpler, less expensive and less toxic treatments given. There are also fewer recurrences and longer-term wider benefits for society. The key phrase is 'the earlier the better': cancers which present at an advanced stage and are less amenable to treatment, have poorer survival outcomes.

Breast, colorectal (bowel) and lung cancer accounts for about half of the avoidable deaths. This is because diagnosis is being made when tumours are at a stage when life-saving (usually surgical) treatment can't contain the cancer's impact and spread.

The social marketing issue

There are three main behaviour changes required as part of this campaign:

1. Maximising informed consent to participate in the national bowel and breast screening programmes
2. Enabling people to look out for and recognise potential early signs and symptoms of cancer
3. Encouraging people to act on these signs and symptoms as early as possible by visiting their GP

Learning from research

Qualitative research was conducted in late 2011 with the main target audience, as well as with cancer patients, survivors and health professionals in Scotland. This suggested that the 'early detection of cancer' message makes sense to most people on a rational level, although it doesn't always translate into reality.

The word 'cancer' can prompt a negative and irrational emotional response, which is referred to as an 'affect heuristic', where people have a strong emotional response to a word or concept, that alters a person's judgment.

The reasons for this are often complex, involving factors such as people's current health, lifestage, emotional outlook, experience of cancer within their friends and family and attitudes and experiences around the health service.

However, three over-arching barriers to action were identified which often overlap:

1. Fear of facing up to cancer
2. Lack of knowledge of relevant signs and symptoms
3. Concern over wasting GPs' time

In addition, specific barriers exist in relation to lung, breast and bowel cancer, which will require targeted messaging to overcome them.

This research suggested that symptoms-based messages might be more effective if the other barriers (fear of cancer and of wasting GP time) could be addressed first.

In addition, consultation was conducted with a range of health professionals, including cancer consultants, screening nurses, and public health consultants. This suggested:

- Support for the initiative's aims from health professionals
- A pragmatic view that while a campaign will potentially increase patient numbers and resource uptake, this has been dealt with in the past (e.g. the Jade Goody effect) and so ought to be manageable

Strategic marketing recommendation

As a result of the qualitative research, a number of key decisions were made about the implementation of the social marketing campaign.

- The public campaign would launch in its first phase with communications designed to allay people's generalised fears about cancer and encourage them to see their GP with possible early signs and symptoms
- This would be followed by the first of three cancer-specific and symptoms-based adverts (around breast cancer). Campaigns around bowel cancer and lung cancer would then follow later in 2012.