Diagnosing Cancer Earlier: Evidence for a National Awareness and Early Diagnosis Initiative

Summary of the special supplement to the British Journal of Cancer
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1) The National Awareness and Early Diagnosis Initiative (NAEDI) in England: assembling the evidence
MA Richards

• The evidence base is complex and incomplete.
• This BJC supplement seeks to bring together available evidence with the aim of informing future research and policy.

NAEDI pathway
The NAEDI steering group developed the ‘NAEDI pathway’ (see next slide) to provide a framework for testing hypotheses about late diagnosis and its impact.
• Key hypothesis: delays (either at presentation, primary care or secondary care levels) lead to more advanced disease at diagnosis, hence poorer 1-year and 5-year survival rates.
• This could explain some of the disparity between outcomes for different ethnic and social groups, and also possibly the difference seen between survival rates in the UK and other comparable western European countries.
• While it may seem obvious that delays in diagnosis may lead to a poorer outcome, the evidence is not clear (with the exception of breast cancer).
2) Delay in diagnosis: the experience in Denmark
F Olesen, RP Hansen and P Vedsted

Denmark realised that their cancer survival was poor in comparison to other Western European countries and sought to address this through formation of a National Cancer Steering Group, which developed National Cancer Plans.

Actions/recommendations included:

- Initiatives to address lifestyle factors such as smoking, healthy diet, exercise and UV light exposure.
- Commencing a national breast cancer screening programme and planning colorectal screening (cervical screening is already in place).
- A new diagnostic strategy, launched in 2007, that established maximum acceptable waiting times at each phase of the pathway from time of referral. Commitments made to reduce bottlenecks in GP access to diagnostic investigations, to help GPs in difficult cases, to measure and report waiting times and to invest in equipment.
- Efforts to improve continuing medical education for GPs (although one survey has shown that this has not improved GP-related delays).
Olesen *et al*, *contd.*

• Full data are not yet available to assess the impacts of these efforts, but preliminary data show:
  - a reduction in delays, with evidence of patients being fast-tracked for diagnosis and treatment,
  - more satisfaction with the health system among the public,
  - and more optimism among professionals and lay people with regard to ‘the prospects of achieving medical excellence’.

• Efforts still need to be made to address problems particularly with patient delay, and research is underway to tackle this.
3) Do diagnostic delays in cancer matter?
RD Neal

• This paper reviews the published literature looking at the link between diagnostic delays and outcome.
• Although it seems intuitive that delay should lead to worse outcomes, in much of the existing literature, due to the methodology used, the converse can be shown to be true.
• When considering the evidence from studies investigating delay and outcome, it is important to ensure that the methods and definitions are comparable.
  • Consistency in definitions of delay, and measurement of delay and outcomes, is important.
  • Growth speed of tumours, lead-time bias and the comparison of cancers that behave very differently all need to be taken into account.
• When the literature is counter intuitive, it is not showing delay to be a good thing.
• Studies associating shorter delay with worse outcome are likely to represent patients presenting with severe symptoms indicative of late stage disease, who are unlikely to incur delays.
• Diagnostic delays do matter, but their impact on survival can be very difficult to determine for many cancers.
• More trial data are needed to prospectively investigate the impact of delays on outcome.
This paper describes the development of the first validated tool to assess cancer awareness in the general population – the Cancer Research UK ‘Cancer Awareness Measure’ (CAM).

The CAM comprises a range of questions covering:

- awareness of warning signs
- anticipated time to seeking medical advice
- barriers to seeking medical advice
- awareness of risk factors, cancer incidence and NHS screening programmes.

Site-specific modules, for breast, bowel, lung, ovarian and cervical cancer are also in development/have been developed.
• There has previously been disagreement in the literature regarding the best ways to measure cancer awareness, making it difficult to compare studies and determine current levels of awareness.

• Development of the CAM is, therefore, a great step forwards, as long as people use it, and use it consistently:
  • Questions within the CAM shouldn’t be changed (but leaving questions out is fine).

• The CAM toolkit can be requested by emailing naedi@cancer.org.uk
5) Public awareness of cancer in Britain: a population-based survey of adults
K Robb, S Stubbings, A Ramirez, U Macleod, J Austoker, J Waller, S Hiom and J Wardle

• 2208 respondents completed the CAM in September and October 2008.

Recall of warning signs
• Awareness of cancer warning signs (recall and recognition) was lower in those who were male, younger, and from lower socio-economic status groups or ethnic minorities.

• Recall and recognition of warning signs both increased as age increased, up to 64 years. However, the oldest age group (65 years and older) had lower recall and recognition, which is concerning because this age group is most at risk of cancer.

• People who recognised more warning signs anticipated less delay in seeking help, supporting the view that increasing awareness could aid earlier detection.
• All barriers were endorsed to some extent, but these were the most common.
• Emotional barriers more prominent in lower SES groups, and practical barriers more prominent in higher SES groups.
6) Awareness of cancer symptoms and anticipated help seeking among ethnic minority groups in England.
J Waller, K Robb, S Stubbings, A Ramirez, U Macleod, J Austoker, S Hiom and J Wardle

• 1500 respondents from the six largest ethnic minority groups in England (Indian, Pakistani, Bangladeshi, Caribbean, African and Chinese) completed the CAM in October and November 2008.

• Awareness of warning signs was low across all ethnic groups.
  • Significant differences in recognition between ethnic groups.

• People for whom English was not the main language spoken at home had poorer awareness.
  • Highlights the need for better information provision for non-English speakers.

• Anticipated delay in help-seeking couldn’t simply be explained by lack of awareness – supports need to understand cultural factors which influence help-seeking.
All barriers were endorsed to some extent, but these were the most common.
• Review of published literature – very little published which shows long-term gain.
• Didn’t review ‘grey literature’, so many of the interventions, improvements and services PCTs and Networks hear about won’t have been considered.
• Review found that interventions delivered to individuals may increase awareness.
  • Tailored print information seemed more effective than general information.
• Interventions delivered to communities may promote cancer awareness and early presentation, but the evidence is limited.
8) A randomised controlled trial of an intervention to promote early presentation of breast cancer in older women: effect on breast cancer awareness
L Linsell, LJL Forbes, M Kapari, C Burgess, L Omar, L Tucker and AJ Ramirez

• Women attending for their final breast screening appointment received either
  • a booklet conveying important breast cancer awareness messages as well as a ten minute interaction with a radiographer,
  • just the booklet, or
  • just usual care.

• Intervention improved breast cancer awareness
  • 33% receiving interaction and booklet and 13% receiving just booklet were breast cancer aware after one month compared with 4% of women who received usual care. Improvements were maintained at 12 months, although they were less marked than at one month.

• Intervention also improved knowledge of age-related risk.

• Do not know yet whether increasing breast cancer awareness will promote earlier presentation/diagnosis.
Improving the early presentation of cancer symptoms in disadvantaged communities: putting local people in control
D Lyon, J Knowles, B Slater and R Kennedy

- The ‘Healthy Communities’ approach, commissioned by the Department of Health’s Health Inequalities Unit, supported community volunteers, working with primary care and other specialists, to lead improvement locally.
- Teams used a variety of methods to engage with the local community, taking messages about cancer myths and preconceptions into community and bingo halls, pubs, and in minority groups, mosques and temples.
- Difficulties in obtaining data to measure outcomes.
- Interim results report increase in number of urgent 2 week wait referrals and proportion of cancers diagnosed through this route, but not possible to be certain that it was HCC activity which drove the change.
Ethnicity, social deprivation and gender are the main overall predictors of screening uptake, but different approaches are needed for different contexts, type of screening and target group.

Multi-faceted approaches that consider cultural and health literacy differences may help to address inequalities in uptake.

- It is important that materials produced to promote screening are appropriate to all levels of health literacy.
- Ensuring participants can make informed decisions on screening is important.
11) Inequalities in colorectal cancer screening participation in the first round of the national screening programme in England
C von Wagner, A Good, D Wright, B Rachet, A Obichere, S Bloom and J Wardle

- Analysed test FOBT kit return rates for 401,197 participants aged 60-69 in London.
- Striking socio-economic gradient in uptake.

![Percentage of FOBT kits returned](chart)

Quintiles of area-level deprivation

- Quintile 1
- Quintile 2
- Quintile 3
- Quintile 4
- Quintile 5
• Interestingly, areas with more people reporting poor health had a higher uptake rate, a trend which has also been reported in other studies.
  • Emphasises the need to raise awareness that screening is important for people without symptoms.
• Approaches to improve perception of cancer outcomes could help, as previous research has shown that fatalism is associated with SES.
• It is hoped that, as was seen with the cervical screening programme, inequalities in uptake will narrow with time. But in the meantime it is important to attempt to minimise this effect.
NHS Tower Hamlets developed a multi-faceted, whole systems approach to address breast screening uptake (and variations across GP practices), including:

- Targeted outreach through respected community organisations
- ‘Bosom Buddy’ pilot
- Training provided to GP practices, and each practice nominated a cancer screening lead
- GP practices set up alerts for eligible women to provide opportunistic reminders
- Text message reminders to women
- Dedicated call centre for the breast screening service
- Customer service training for breast screening service staff

Screening uptake was 63.4% in 2008/9, up from 44.5% in 2005.
• The Bangladeshi community have a high risk of oral cancer as they exhibit a number of risk factors such as smoking, chewing tobacco and chewing areca nut.

• 34 case-finding sessions, using a mobile dental unit, were conducted, with 1,320 individuals screened.
  • Bilingual ‘advocates’ were used to encourage participation and facilitate the referral process.

• 75 were referred for further investigation (27% did not attend).
  • 17 (31%) diagnosed with potentially malignant disorders.

• The project demonstrates successful implementation of a targeted ‘screening’ activity.

• The project also brought tobacco users into cessation services - in Phase II, 40% of tobacco users were successfully recruited.
14) Development and evaluation of an early detection intervention for mouth cancer using a mass media approach.
D Eadie, AM MacKintosh, S MacAskill and A Brown

- Mass media campaign sought to raise awareness of mouth cancer and increase early detection of signs/symptoms.
  - Target audience: people aged 40 and over, from lower socio-economic groups.
- Awareness was higher in the target population than in the control population at 7 and 12 months post-campaign.
  - This was largely attributable to television media.
- Campaign was most successful at raising awareness in the short-term, rather than longer-term.
  - But contamination of the control population may have undermined the campaign’s impact.
- Cost-effectiveness and sustainability are key issues with this approach.
The CAPER studies: five case-control studies aimed at identifying and quantifying the risk of cancer in symptomatic primary care patients

W Hamilton

- ‘CAPER’ studies have investigated:
  - Particular features of cancer as reported to primary care.
  - The risk of cancer for symptoms and primary care investigations.
- Studies have been conducted for colorectal, lung, prostate, brain and ovarian cancers (ovarian is reported separately).
- Data were analysed to produce positive predictive values for reported symptoms.
- Validates the emphasis on certain symptoms for certain cancers, but highlights the problem of determining what level of risk warrants referral.
- Results identify areas where current referral guidance could be improved.
16) Auditing the diagnosis of cancer in primary care: the experience in Scotland
P Baughan, B O’Neill and E Fletcher

• Reports analysis on 7,430 of 12,294 patients identified in year 2 (2007-08) of the Scottish primary care audit.
• Time taken for patients to present varied greatly.

**Median time (days) from first noticing symptoms to first presentation with a GP**
• The delay for lung and prostate cancer can be explained by the requirement to complete appropriate investigations before referral.
Baughan et al, contd.

- Priority of referral also varied across cancer types.

![Bar chart showing priority of referral across cancer types: Breast, Colorectal, Lung, and Prostate. The legend indicates Emergency, Urgent, Routine, and Other referrals.](chart.png)
• Looking at the various aspects of delay along a patient’s diagnostic pathway highlights areas where improvements can be made.
• The audit has been a useful educational exercise – many GPs reflected that they should have referred their patient more quickly.
• Such event analysis has become part of the annual appraisal system.
• Risk factors associated with patient and practitioner delay are complex and can vary depending on cancer type.

• The main factor for patient delay across cancer types was lack of appreciation of the seriousness/significance of symptoms.

• There was also strong evidence of an association between older age and patient delay in breast cancer, between lower SES and delay for upper GI and urological cancers, and between lower education level and delay for breast and colorectal cancers.

• Presentation with cancer is not a straightforward or linear process.

• Need to address more than just knowledge of symptoms to facilitate help seeking in cancer
Cancer survival in England and the influence of early diagnosis: what can we learn from recent EUROCARE results?
CS Thomson and D Forman

- Presents 1- and 5-year survival data, and 5|1 year survival (to disentangle contribution of early and late effects).
- Earlier diagnosis is likely to benefit all cancers, but the study highlights cancers where prognosis appears to be particularly affected by early effects such as stage of disease at diagnosis, including:
  - bone and cartilage
  - soft tissue
  - uterus
  - bladder
  - non-Hodgkin lymphoma
This paper uses already published (EUROCARE-4) 1-year and 5|11-year survival estimates for 42 types of cancer in 23 European countries, representing them as a one-page visual summary.

- The summary highlights the countries with survival in the upper (green) and lower (red) quintiles.
- When comparing 1-year survival, the results clearly show countries with consistently higher survival estimates.
- Results for 5|1 year survival show much less variation.
- In the analysis, all four UK countries have lower 1- and 1|5-year survival than Norway, Finland and Sweden.
- A likely explanation for the short-term survival deficit is unfavourable stage distribution in the UK compared to Nordic countries.
20) **What if cancer survival in Britain were the same as in Europe: how many deaths are avoidable?**
M Abdel-Rahman, D Stockton, B Rachet, T Hakulinen and MP Coleman

- Significant numbers of deaths within five years of diagnosis could be avoided if cancer survival in Britain matched the best, or even the average, in Europe.
- Based on the most recent data (patients diagnosed between 1995 and 1999):
  - Just under 7,000 deaths within five years of diagnosis could have been avoided if GB survival matched the European mean.
  - More than 11,000 deaths within five years of diagnosis could have been avoided if GB survival matched the highest survival estimate in Europe.
The paper discusses the possible reasons for poor survival for breast, colorectal and lung cancer, which together account for a significant proportion of the ‘avoidable deaths’.

It is estimated that between 5,000 and 10,000 deaths within five years of diagnosis could be avoided if efforts to promote earlier diagnosis and appropriate surgical management are successful.