The Discovery Programme and its impact on cancer diagnostics

Over the last 5 years the Discovery Programme, funded by the National Institute for Health Research (NIHR), has undertaken a wide-ranging programme of applied research to understand and improve cancer diagnostics in the UK. The UK has a poor record in cancer survival, particularly when compared to Europe (Coleman et al, 2011). It has been estimated that there are 10 000 lives lost from cancer annually in the UK, which would not have been lost had the UK matched the European average (Abdel-Rahman et al, 2009). Approximately half of these are thought to arise from delays in diagnosis (Richards, 2009). The Discovery Programme has focused on three key points of delay along the pathway.

Delays before presentation to health care: theme 1

Many cancers present insidiously, with their symptoms identical to benign conditions, and the patient has to decide when and whether to visit his/her GP. The SYMPTOM studies addressed this pre-presentational stage. Large scale questionnaire surveys of patients with symptoms of possible cancer (lung, colorectal and pancreas) were undertaken, supplemented by qualitative in-depth interview studies, to identify the barriers and facilitators to presentation.

Some key findings were common to all three SYMPTOM studies; all showed that multiple first symptoms were common, that symptoms evolved over time, and that there were few differences in symptoms and diagnostic intervals between people subsequently diagnosed with cancer and those diagnosed with non-cancer conditions. 'Alarm' symptoms, such as coughing up blood, rectal bleeding and jaundice, were significant predictors of cancer diagnosis but not commonly reported as any symptom, and uncommonly as a first symptom. Some symptoms and patient factors were associated with increased time to diagnosis, particularly co-morbid conditions like depression, which could mask new or changing symptoms for both people and their GPs. Some people reported more than one GP visit before investigations or referrals were initiated.

These findings will impact policy and clinical practice. Symptom awareness campaigns and cancer diagnostic guidelines should recognize the importance of multiple symptoms and evolution of symptoms over time, along with the value of social and family networks in endorsing help-seeking. GP education should emphasize the importance of appropriate advice, monitoring and safety-netting procedures for people with non-resolved or evolving symptoms.

Delays in the GP's consulting room: theme 2

Once a patient presents to primary care his/her GP has to:

1. Recognize the possibility of cancer, as initial symptoms are often subtle and match those seen in benign conditions
2. Consider whether the chance of cancer is high enough to warrant investigation, either by specialist referral or 'in house' investigation at primary care level (GPs have access to a limited number of cancer tests, e.g. chest X-ray for suspected lung cancer).

The Discovery Programme undertook several studies (the CAPER studies) using large primary care clinical datasets of symptoms, referrals and diagnoses. These enabled the team to quantify the risk of symptoms relevant to primary care. These were used to develop risk assessment tools which assist GPs in symptom assessment and decision making.

The CAPER studies have, to date, published papers covering eight cancer sites (oesophageal and gastric cancers were merged, as they share the same diagnostic test). A ninth paper, on leukaemia, has been provisionally accepted. This body of research has contributed to the development of risk assessment tools and there are now nine risk assessment tools used or being tested in the NHS: bladder, kidney, oesophago-gastric, pancreatic, uterus, colorectal, lung, ovarian, and prostate (lung and colorectal pre-date the Discovery Programme). This body of work strongly influenced the recent National Institute for Health and Care Excellence (2015) guidelines on selection of patient for cancer investigation.

Patient values in the diagnostic pathway: theme 3

The NHS mantra 'No decision about me without me' exemplifies this strand of work. It was clear to the programme team that patients' values were central to decisions about cancer investigation, and that they had largely been ignored to date. A sophisticated vignette-based study was designed to address this (the PIVOT study) in which members of the public considered hypothetical symptoms for colorectal, lung and pancreas cancers. The vignettes included the risk of cancer associated with symptoms along with the associated investigations. Participants were asked whether they would choose testing in such circumstances.

The recruitment target of 1428 was exceeded by some margin with over 3000 participants completing 6930 vignettes. The results point to a clear preference for investigation at levels of risk as low as 1%, which differed considerably from the then published National Institute for Health and Care Excellence guidelines, which recommended investigation at risks exceeding 5%. The successful recruitment and completion figures point to a public willingness to engage with the question of cancer symptoms, risk and investigation. The data showing variation by cancer and investigation type and by age indicate an awareness of the issues involved. This highlights the potential for greater levels of involvement by patients

in decision making, referral and investigation for cancer symptoms, particularly at the primary care level.

Using the same methodological platform the authors also examined patient preferences for testing for prostate cancer among men from different ethnic backgrounds and found a stronger preference for testing among white British men compared to black Afro-Caribbean men. This goes some way to explaining the poorer outcomes for black men for prostate cancer in the UK.

Conclusions

The Discovery Programme has moved cancer diagnostics forward in the last 5 years. We now have data that can improve public awareness campaigns around symptom recognition; in the past campaigns have focused on single symptoms but there is a case for highlighting multiple symptoms, particularly for lung cancer.

The SYMPTOM studies tell us the real importance of GP safety netting and tracking potential cancer symptoms. The CAPER studies have been integrated into GP software to develop user-friendly risk assessment tools and have fed into the new National Institute for Health and Care Excellence guidelines, particularly the lowering of referral thresholds from 5% to around 3%. The PIVOT study results have demonstrated the potential for patient involvement and the patient appetite for testing and have also fed into the development of new National Institute for Health and Care Excellence guidelines and the current 'Accelerate, Coordinate, Evaluate' programme (a wide-ranging programme of early diagnosis initiatives currently running across the UK). Most importantly, this programme has raised the profile of cancer diagnostics in UK primary care. GPs now think about cancer more. It is part of a quiet revolution that will contribute to better cancer outcomes. BJHM

Jon Banks
Research Fellow and Programme Manager for the Discovery Programme
Centre for Academic Primary Care
School of Social and Community Medicine
University of Bristol
Bristol BS8 2PS
(Jon.Banks@bristol.ac.uk)
Willie Hamilton
Professor of Primary Care Diagnostics and Chief Investigator for the Discovery Programme
University of Exeter
Medical School
St Luke's Campus
Exeter
Fiona Walter
Clinical Principal Researcher and Deputy Chief Investigator for the Discovery Programme
University of Cambridge
Primary Care Unit
Strangeways Research Laboratory
Cambridge

The Discovery Programme is funded by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research Scheme (RP-PG-0608-10045). The views expressed in this article are those of the Discovery Programme team and are not necessarily those of the NHS, the NIHR or the Department of Health.

Conflict of interest: Professor W Hamilton was the clinical lead for the revision of the National Institute for Health and Care Excellence (2015) guidance. His contribution to this article is in a personal capacity, and is not to be interpreted as representing the view of the Guideline Development Group, or of the National Institute for Health and Care Excellence itself; Dr J Banks and Dr F Walter: none.

KEY POINTS

- The Discovery Programme is a programme of research which examined multiple points along the cancer pathway.
- The SYMPTOM studies highlight the importance of GP safety netting for patients with symptoms which could indicate early stages of cancer.
- CAPER studies have quantified symptom risk across a range of cancers.
- Risk assessment tools for cancers are widely available for GPs in paper and electronic formats.
- The PIVOT studies highlight the importance of incorporating patient preferences in the development of diagnostic pathways.
- Studies from the Discovery Programme have made significant contributions to current National Institute for Health and Care Excellence guidelines.

Abdel-Rahman M, Stockton D, Rachet B et al (2009) What if cancer survival in Britain were the same as in Europe: how many deaths are avoidable? *Br J Cancer* **101**(S2): S115–24 (doi: 10.1038/sj.bjc.6605387)

Coleman MP, Forman D, Bryant H et al (2011) Cancer survival in Australia, Canada, Denmark, Norway, Sweden, and the UK, 1995-2007 (the International Cancer Benchmarking Partnership): an analysis of population-based cancer registry data. *The Lancet* **377**(9760): 127–38 (doi: 10.1016/S0140-6736(10)62231-3)

National Institute for Health and Care Excellence (2015) Suspected cancer: recognition and referral. www.nice.org.uk/guidance/ng12 (accessed 28 September 2015)

Richards MA (2009) The size of the prize for earlier diagnosis of cancer in England. *Br J Cancer* **101**(S2): S125–9 (doi: 10.1038/sj.bjc.6605402)

Further reading

A selection of references from the Discovery Programme (for full details on all outputs go to http://discovery-programme.org/)

Banks J, Hollinghurst S, Bigwood L, Peters TJ, Walter FM, Hamilton W (2014a) Preferences for cancer investigation: a vignette-based study of primary-care attendees. *Lancet Oncol* **15**(2): 232–40 (doi:10.1016/S1470-2045(13)70588-6)

Banks J, Walter FM, Hall N, Mills K, Hamilton W, Turner K (2014b) Decision making and referral from primary care for possible lung and colorectal cancer: a qualitative study of patients' experiences. *Br J Gen Pract* **64**(629): e775–82 (doi: 10.3399/bjgp14X682849)

Birt L, Hall N, Emery J et al (2014) Responding to symptoms suggestive of lung cancer: a qualitative interview study. *BMJ Open Respiratory Research* **1**: e000067 (doi: 10.1136/bmjresp-2014-000067)

Martins T, Ukoumunne OC, Banks J, Raine R, Hamilton W (2015) Ethnic differences in patients' preferences for prostate cancer investigation: a vignette-based survey in primary care. *Br J Gen Pract* **65**(632): e161–70 (doi: 10.3399/bjgp15X683965)

Shephard EA, Stapley S, Neal RD, Rose P, Walter FM, Hamilton WT (2012) Clinical features of bladder cancer in primary care. *Br J Gen Pract* **62**(602): e598–604 (DOI: 10.3399/bjgp12X654560)

Stapley S, Peters TJ, Neal RD, Rose PW, Walter FM, Hamilton W (2012) The risk of pancreatic cancer in symptomatic patients in primary care: a large case-control study using electronic records. *Br J Cancer* **106**(12): 1940–4 (doi: 10.1038/bjc.2012.190)

Stapley S, Peters TJ, Neal RD, Rose PW, Walter FM, Hamilton W (2013) The risk of oesophago-gastric cancer in symptomatic patients in primary care: a large case-control study using electronic records. *Br J Cancer* **108**(1): 25–31 (doi: 10.1038/bjc.2012.551)

Walter FM, Rubin G, Bankhead C et al (2015) Symptoms and other factors associated with time to diagnosis and stage of lung cancer: a prospective cohort study. *Br J Cancer* **112**: S6–S13 (doi: 10.1038/bjc.2015.30)