**Institution:** 10007857 – Bangor University

**Unit of Assessment:** UoA 03

**Title of case study:**
Evidence-based primary care interventions to improve health benefits in cancer care

**1. Summary of the impact** (indicative maximum 100 words)

Bangor University staff (Neal & Wilkinson) are core members of a collaboration whose research since 2003 has had significant policy relevance and impact in the field of primary care oncology. Impact has been made in three areas:

- The role of primary care in the earlier diagnosis of symptomatic cancer; for example by determining the predictive value of symptoms and translating this into Risk Assessment Tools for clinical practice
- The contribution of primary care to cancer follow-up and the management of survivorship; for example by changing practice by illuminating poor care in prostate cancer
- Empowering patients through communication of new cancer-related science in primary care; for example by developing core messages for use in communication about HPV.

**2. Underpinning research** (indicative maximum 500 words)

Professors Neal and Wilkinson (whose research centre, the North Wales Centre for Primary Care Research, was absorbed into Bangor University from Cardiff University in 2011) are two leading members of a collaboration of UK academics committed to developing primary care oncology. Within this collaboration they have led key projects on early diagnosis and communication, and survivorship, and have made major contributions to others. Wilkinson's areas of expertise are in communication and survivorship. Neal's area of expertise is early diagnosis and its benefits. Other collaborators are Hamilton (Exeter), Rubin (Durham), Walter and Lyratzopoulos (Cambridge), Weller and Campbell (Edinburgh), Rose (Oxford), and Watson (Oxford Brookes).

***The role of primary care in the diagnosis of symptomatic cancer***.
Achieving diagnoses at a more treatable stage should subsequently improve survival. Our contribution in this area has focused on the measurement of diagnostic delays. A tool was developed in 2008 to measure diagnostic delays, and tested in an implementation trial in 2011-12 (Cancer Research UK, PI Neal). This informed the consensus statement on the design and reporting of early cancer diagnosis studies (3.1).The importance of the number of pre-diagnostic consultations has been established by this work and measured in different cancers to identify 'harder to diagnose' cancers (3.2). The outcomes of delay have been characterised by a major systematic review of the association of time to diagnosis in cancer with clinical outcomes (Cancer Research UK, PI Neal); there are very different associations in different cancers, and overall study qualities are poor. The predictive value of symptoms for bladder, kidney, pancreas, and upper gastrointestinal (3.3) cancers have been determined, and translated into Risk Assessment Tools for clinical practice by Macmillan Cancer Support (2012-13). The risk of an underlying, undiagnosed cancer has been determined for patients with herpes zoster (3.4 PI Neal).

***The contribution of primary care to cancer follow-up and the management of survivorship***
Two million people are now living with or beyond cancer in the UK. Three systematic reviews revealed little work in this emerging chronic disease area in primary care (2009, 3.5, PI Neal). Feasibility, piloting and development work ensued with prostate and lung cancer survivors as exemplar groups (2009, 3.6). UK wide clinical audits revealed dangerous deficiencies in follow-up systems such as lack of systematic follow-up and monitoring. Qualitative studies and needs measurement studies showed specific unmet needs such as asking about impotence and erectile function. And a case-series study illustrated primary care's role in the management of both cancer-specific issues and co-morbidity. This led to further work on personalised risk-stratification to allow targeted cancer related interventions (2011).

***Communication of new cancer related science in primary care to empower patients***
Wilkinson led research in this field using the exemplar of cervical cancer screening and HPV related cancers. Early intervention development research (1999, Wilkinson PI) used simple,

honest, pictorial risk information, including absolute and relative risk, delivered by health professionals to women with abnormal smears in colposcopy consultations, following a Randomised Control Trial (RCT) demonstrating a marked beneficial effect on anxiety. A further RCT (1999) using this individual risk communication / pictorial information (now called scripted consultations) showed persistent anxiety while under surveillance for pre-cancer is harder to alleviate (3.7). This led to a final RCT using an individualised risk communication package, showing that women's perception of risk contributes to determining screening intervals, and simple risk information delivered in primary care reduced women's stated preference for overly frequent tests by allaying anxiety and increasing knowledge. A multi-methods approach was used to build on this research programme to address the introduction of the new HPV technologies. A combination of two systematic reviews and qualitative studies revealed salient patient issues (3.8), and surveys were combined to produce the core messages for HPV to use in clinical situations (Cancer Research UK, PI Wilkinson).

**3. References to the research** (indicative maximum of six references)

Bangor authors identified in **boldface**. Asterisked outputs are in the present REF2 submission.

**The role of primary care in the diagnosis of symptomatic cancer:**


3.1. Weller D, Vedsted P, Rubin G, Walter F, Emery J, Scott S, Campbell C, Andersen RS, Hamilton W, Olesen F, Rose P, **Nafees S**, van Rijswijk E, Muth C, Beyer M, **Neal RD**. The Aarhus Statement: Improving design and reporting of studies on early cancer diagnosis. *British Journal of Cancer* 2012;**106**:1262-1267. (Neal last author, funded by Cancer Research UK). DOI: 10.1038/bjc.2012.68

3.2. * Lyratzopoulos G, **Neal RD**, Barbiere JM, Rubin G, Abel G. Variation in the number of general practitioner consultations before hospital referral for cancer: findings from a national patient experience survey. *Lancet Oncology* 2012;**13**:353-65. (Neal senior author). REF Identifier 0322

3.3. * Stapley S, Peters TJ, **Neal RD**, Rose PW, Walter FM, Hamilton W. The risk of oesophago-gastric cancer in symptomatic patients in primary care: a large case-control study using electronic records. *British Journal of Cancer* 2013;**108**:25-31. (NIHR-funded). REF Identifier 0324

3.4. Cotton S, Belcher J, Rose P, Jagadeesan SK, **Neal RD**. The risk of a subsequent cancer diagnosis after herpes zoster infection: primary care database study. *British Journal of Cancer* 2013;**108**:721-726. (Neal PI). DOI: 10.1038/bjc.2013.13


**The contribution of primary care to cancer follow-up and the management of survivorship:**


3.5. **Lewis R**, **Neal RD**, **Williams NH**, **France B**, **Wilkinson C**, **Hendry M**, Russell D, **Hughes D**, Russell I, **Stuart N**, Weller D. Follow-up of cancer in primary care versus secondary care: systematic review. *British Journal of General Practice* 2009;**59:**525-532. (Neal PI and grant-holder, Wilkinson group leader; funded by Cancer Research UK). DOI: 10.3399/bjgp09X453567

3.6. M$^{c}$Intosh HM, **Neal RD**, Rose P, Watson E, **Wilkinson C**, Weller D, Campbell C. Follow-up care for men with prostate cancer and the role of primary care: a systematic review of international guidelines. *British Journal of Cancer* 2009;**100**:1852-1860. (Neal and Wilkinson co-applicants and senior authors; funded by Cancer Research UK). DOI: 10.1038/sj.bjc.6605080


**Communication of new cancer related science in primary care to empower patients:**


3.7. Peters TJ, Somerset ME, Baxter K, **Wilkinson C**. Anxiety amongst women with mild dyskaryosis: a randomised controlled trial of an educational intervention. *British Journal of General Practice* 1999;**49**:348–352. (Wilkinson PI, funded by Cancer Research Campaign). Availabel at: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1313418/pdf/10736883.pdf

3.8. * **Hendry M**, **Pasterfield D**, **Lewis R**, Clements A, Damery S, **Neal RD**, Adke R, Weller D, Campbell C, Patnick J, Sasieni P, Hurt C, Wilson S, **Wilkinson C**. Are women ready for the new cervical screening protocol in England? A systematic review and qualitative synthesis of views about human papillomavirus testing. *British Journal of Cancer* 2012:**107**:243-254, (Wilkinson PI and grant holder, Neal co-applicant and contributing author; funded by Cancer Research UK). DOI: 10.1038/bjc.2012.256 REF Identifier 0340


**4. Details of the impact** (indicative maximum 750 words)

***General impact on Primary Care Oncology***

The research of Neal and Wilkinson and their colleagues (in Bangor and elsewhere) has high policy relevance. They have been successful in obtaining funding from, and feeding results back to, the key stakeholders in the UK, such as The National Awareness and Early Diagnosis Initiative (a public sector/third sector partnership between the Department of Health, National Cancer Action Team, and Cancer Research UK). This has given opportunities to put new evidence into practice quickly, as the examples below illustrate.

In Wales, Wilkinson and Neal's membership of the Cancer Implementation Group has allowed innovation from their research to feed through into the Wales Cancer Plan (2012). For example, the specific statement in the Plan that primary care oncology must be developed in Wales (5.1) is a direct result of their recommendations (5.2). Their work has led to 'early diagnosis' being a key priority, and to an 'Early Diagnosis Knowledge Sharing Workshop' (Cardiff, October 2013, funded by Cancer Research UK, 40 delegates - including three government/policy maker, 19 senior clinicians/cancer leads, seven cancer network/screening/registry, ten third sector). The Cancer Implementation Group is now measuring diagnostic times routinely as a direct result of their work.

Funding was secured in 2011 from Betsi Cadwaladr University Health Board (one of the largest healthcare providers in Europe with 17,000 employees and a turnover of ~£1.2bn per annum) for a programme of work to facilitate implementation of their cancer research into clinical practice and policy ('Diagnose quickly, follow-up safely'). In collaboration with Macmillan Cancer Support, the follow-up of patients with prostate cancer has been re-designed, to make it more evidence-based and patient centred, including progress towards introduction of a safer PSA surveillance system (5.8). There are also early indications of a major new investment in primary care oncology in Wales from Macmillan Cancer Support, as a result of their work.

***Improved primary care in the diagnosis of symptomatic cancer***

Work in the development and evaluation of a tool to measure diagnostic delay (section 2) has been influential in informing the production of the Aarhus Statement, the first international consensus guidelines on reporting early diagnosis studies (3.1), and the follow-on ASTRID study (Neal co-investigator). The tool has been adapted for use in major studies, and service evaluations in both the UK, (North-East and East of England, Fiona Walter, SYMPTOM study, 3653 participants to date) and in the PC4 study in Western Australia (Jon Emery, 66 participants in the published development phase and 620 to date in the main evaluation) (5.3). Thus this work has had an impact on the practice of health care professionals as well as on the health of the patients involved.

Neal's collaboration on the analysis of the National Cancer Experience Survey (3.2, 5.5), and the RCGP National Audit of Cancer Diagnosis, has already been impactful, informing policy and changing practice. This is evidenced by the 'National Cancer Action Team/Cancer Networks Supporting Primary Care 2011/2012' evaluation (5.4), which showed that the clinical audit and Risk Assessment Tools were two of the main approaches used nationally for quality improvement, and also provided evidence of the extent of their uptake and the impact they achieved. The work has also informed 'Improving diagnosis of cancer: a toolkit for general practice', which is published and disseminated by the Royal College of General Practitioners (5.4). The Risk Assessment Tools for cancer diagnosis are underpinned by case-control study evidence, including oesophago-gastric (3.3) cancer, pancreatic cancer, bladder cancer, and kidney cancer. They have been disseminated to all (~8500) general practices in England and Wales (5.4). Evaluation (Macmillan) of the implementation of similar tools in lung and colorectal cancers demonstrates that these have an important impact on the diagnosis of earlier stage cancers, for example by lowering GPs' threshold for investigating and referring patients with suspected cancers. By March 2012, Risk Assessment Tools were in use in at least 1104 general practices in England (5.4).

***Contribution of primary care to follow-up and the management of survivorship issues***

The National Cancer Survivorship Initiative has been informed by their work on personalised risk-stratification (5.6) in 2012, leading directly to measures to improve risk management. The Initiative's models for 'key workers' in cancer survivorship are partly designed according to findings

from their Cancer Research UK prostate studies. Systematic reviews (3.3) and the body of work on prostate follow-up (3.4) has led to the Prostate Cancer Charity funded PROSPECTIV trial, field testing a psycho-social nurse intervention (5.7), which is improving care for a neglected group. Wilkinson & Neal have worked with the third sector (Macmillan and Prostate Cancer UK) to achieve an impact on prostate cancer care after treatment is complete, in North Wales. Further evidence for such impact comes from a Macmillan project (£250K to re-design the system for follow up care of prostate cancer patients) in place in Betsi Cadwaladr University Health Board (5.8), informed by the body of prostate cancer work. A particular focus is the exposure of men's unmet needs, and system errors, and to embed new nursing roles to deliver the interventions Wilkinson & Neal helped to design. This was presented at the North Wales Urology Meeting in October 2013, with the outcome being an agreement to harmonise follow-up practice and implement an automated PSA surveillance system. This will affect 5000 patients with prostate cancer across the region. There have been further similar interactions with England's National Cancer Initiative pilot sites.

***Communication of new cancer related science in primary care to empower patients***

The trials of risk communication in cervical cancer screening (3.5) are part of the original body of work that led to the way cervical screening information is now presented to women to achieve informed uptake and limit anxiety. The early work (3.7) was highly cited, and many health boards used the information to inform their patient materials for screening. It was also taken up by Cervical Screening Programme in the UK. The HPV core messages project (3.5) has already been disseminated widely throughout the cervical screening programme (5.9, 5.10), impacting on patients' wellbeing since 2011.

**5. Sources to corroborate the impact** (indicative maximum of 10 references)

**5.1** Together for Health – Cancer Delivery Plan pages 15 and 25, available at: http://wales.gov.uk/topics/health/publications/health/strategies/cancer/?lang=en
**5.2** Statement of support from Chief of Staff: Cancer Clinical Programme Group, Betsi Caldwaladr University Health Board, 3 Nov 2013.
**5.3** Use of C-SIM tool: Emery JD, Walter FM, Gray V, Sinclair C, Howting D, Bulsara M, Bulsara C, Webster A, Auret K, Saunders C, Nowak A, Holman CD. Diagnosing cancer in the bush: a mixed-methods study of symptom appraisal and help-seeking behaviour in people with cancer from rural Western Australia. *Family Practice* 2013 DOI:10.1093/fampra/cms087 (PI Jon Emery)
**5.4** Risk Assessment Tools: Ablett-Spense I, Howse J, Rubin G. NCAT/Cancer Networks Supporting Primary Care. Final Report. University of Durham 2012. http://webarchive.nationalarchives.gov.uk/20130513211237/http://www.ncat.nhs.uk/sites/default/files/work-docs/NAEDI%20Cancer%20Networks%20supporting%20primary%20care%20Final%20report.pdf
**5.5** National Cancer Experience Survey analysis:
Press: 'Cancer patients have to see GP three times before it is detected' Daily Telegraph Feb 24 2012: http://www.telegraph.co.uk/health/healthnews/9101153/GPs-slow-to-refer-14-of-cancer-patients.html
**5.6** National Cancer Survivorship Initiative & risk stratification http://www.ncsi.org.uk/what-we-are-doing/
**5.7** PROSPECTIV http://www.wspcr.ac.uk/prospectiv.php (PI Eila Watson)
**5.8** Betsi Cadwaladr University Health Board / Macmillan initiative http://www.macmillan.org.uk/Fundraising/Inyourarea/Wales/Latest_News/Macmillaninvests300,000toimproveprostatecancercareinNorthWales.aspx & 'Charity in £300k care for cancer sufferers' The Daily Post – 11 March 2013 & 'Donation to improve prostate cancer care in North-East Wales' The Western Mail – 11 March 2013
**5.9** Oncolink recording 2010-12 on HPV Core Messages concept had 3000+ hits when hosted at http://ecancer.org/ - now found at: www.youtube.com/watch?v=sMnqhtNuL6Uwww.youtube.com/watch?v=sMnqhtNuL6U
**5.10** CancerHelp (part of Cancer Research UK) has taken framework of HPV Core Messages project forward – this is a heavily used website with traffic increasing by 17% year on year. (http://www.cancerresearchuk.org/cancer-help/type/cervical-cancer/about/cervical-cancer-risks-and-causes#hpv)