

# **Cancer and Older People Advocacy (COPA): influencing policy, commissioning and practice briefing paper**

## **1. Introduction**

Promoting advocacy in the current economic climate presents a number of challenges. The NHS is under increasing pressures surrounding the delivery of direct services, particularly for older people and an ageing population. Funding for social care services is being reduced and Clinical Commissioning Groups (CCGs) are in the process of restructuring, merging and reviewing service configurations and priorities.

However, this briefing paper summarises the opportunities for COPA to influence cancer care services for older people at two levels: nationally and strategically as well as more locally and sub-regionally.

In both cases, advocacy services can contribute directly to assisting the NHS in achieving stated goals of:

- Reducing health inequalities
- Service improvements in terms both of effectiveness and the patient experience
- Enhanced health outcomes for patients
- Improving survival rates that currently lag behind those of other European Nations

Getting, and keeping, advocacy on health policy agendas – and into routine local practice – requires a powerful lobby. Macmillan and OPAAL are not alone in arguing for the importance of patient voice and choice within both the health and social care systems as a means of improving outcomes and the quality of life for patients. Building alliances with other national, and influential, voluntary organisations could assist this process. This applies to ‘consumer’ health care champions such as Healthwatch England, cancer specific organisations such as Cancer Research UK and those with wider concerns around the quality of services for older people (e.g. Age UK).

## **2. Pathways to Influence**

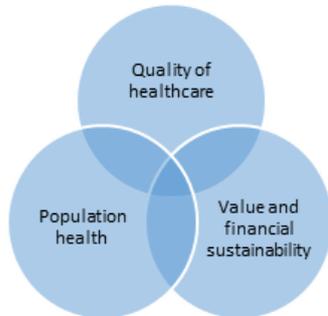
The NHS remains a heavily ‘top down’ organisation. Providers, whether in primary or acute services, are most likely to systematically respond to directives from Public Health England, NHS England and best practice guidance from NICE (National Institute for Health and Care Excellence) or robust data on the effectiveness of particular interventions from NIHR (the National Institute for Health Research). Advocacy as a means of influencing the practice of individual clinicians and other health care professionals remains important in improving services and outcomes at the local level. However, without those central policy directives, change at the local level may rely, not on strategic decision-making, but on individual advocacy champions within individual health care institutions. Our evaluation of the COPA programme suggests that local COPA services have relied significantly on the role of individual, committed champions of advocacy working within hospitals and GP surgeries to spread the word about the service and to generate referrals. Reach with commissioners varied across sites. Nurturing these relationships can be a time consuming process – firstly to identify those individual champions and subsequently maintain those contacts and sustain their commitment and enthusiasm.

Any strategy for promoting access to advocacy for older people with cancer has to be located within the [NHS Triple Aim](#) of:

- improving the quality of healthcare
- improving the health of the population, and

- achieving value and financial sustainability.

The Triple Aim has become the guiding set of principles in health service planning which then form other more specific policy documents that relate directly to older people and/or cancer.



<p><b>Key questions;</b> how does advocacy contribute to:</p> <ul style="list-style-type: none"> <li>• Quality of healthcare?</li> <li>• Population health?</li> <li>• Value and financial viability?</li> </ul>
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Within this overarching framework, the following tables summarise more specifically

- Key agencies to influence
- Their policy statements which relate directly to older people and cancer services
- The ‘levers’ COPA may have in demonstrating the contribution of advocacy to achieving stated policy and practice goals.

**2.1 National Pathways to Influence**

The following list of policies and procedures is, by no means exhaustive. However, in terms of understanding and framing the contribution of advocacy, we found four common themes and relevant ‘levers’ across agencies and documentation

- The principle of equity
- Access to information, advice and support
- Patient choice and active involvement in decision making
- Enhancing patient/service user experience and outcomes

Different aspects of these levers are reflected in the table that follows. The most recent cancer strategy (2015-2020) is discussed in more detail after the table.

Agency/organisation	Policy Statements	Policy levers: advocacy’s contribution to
NHS England	<p>Achieving World-Class Cancer Outcomes: Taking the strategy forward (2016)  <a href="https://www.england.nhs.uk/wp-content/uploads/2016/05/cancer-strategy.pdf">https://www.england.nhs.uk/wp-content/uploads/2016/05/cancer-strategy.pdf</a></p> <p>Achieving world class cancer outcomes: a strategy for England 2015-2020 (2015)  <a href="https://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf">https://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf</a></p>	<ul style="list-style-type: none"> <li>• Prevention and public health</li> <li>• Earlier and faster diagnosis</li> <li>• Putting patient experience on a par with clinical effectiveness and safety</li> <li>• Transforming our approach to living with and beyond cancer</li> </ul>

NHS England	Safe, compassionate care for frail older people using an integrated care pathway (2014) <a href="https://www.england.nhs.uk/wp-content/uploads/2014/02/safe-comp-care.pdf">https://www.england.nhs.uk/wp-content/uploads/2014/02/safe-comp-care.pdf</a>	<ul style="list-style-type: none"> <li>Promote person centred care planning and choice for frail older people/those with long term conditions and in planning end of life services</li> </ul>
NHS England	Five Year Forward View <a href="https://www.england.nhs.uk/five-year-forward-view/nhs-five-year-forward-view-web-version/">https://www.england.nhs.uk/five-year-forward-view/nhs-five-year-forward-view-web-version/</a>	<ul style="list-style-type: none"> <li>Faster diagnosis</li> <li>Supporting new models of integrated specialised care</li> </ul>
Public Health England	National Cancer Intelligence Network <a href="http://www.ncin.org.uk/home">http://www.ncin.org.uk/home</a>	<ul style="list-style-type: none"> <li>Reducing inequalities in access to cancer treatments and outcomes</li> </ul>
NHS Improvement	Delivering Cancer Waiting Times: a Good Practice Guide (2016) <a href="https://improvement.nhs.uk/uploads/documents/Delivering_cancer_waiting_times_update_July_2016.pdf">https://improvement.nhs.uk/uploads/documents/Delivering_cancer_waiting_times_update_July_2016.pdf</a>  See also Kings Fund (2015) Better value in the NHS The role of changes in clinical practice <a href="https://www.kingsfund.org.uk/sites/files/kf/field_publication_file/better-value-nhs-Kings-Fund-July%202015.pdf">https://www.kingsfund.org.uk/sites/files/kf/field_publication_file/better-value-nhs-Kings-Fund-July%202015.pdf</a>	<ul style="list-style-type: none"> <li>Equality in access to services and treatment</li> <li>Protecting patient rights</li> <li>Ensuring access to appropriate treatment</li> <li>Prevention of harm through un-necessary treatments/interventions</li> <li>Active involvement of patients in decision making</li> </ul>
National Institute for Health and Care Excellence	Older people with social care needs and multiple long-term conditions (2105) <a href="https://www.nice.org.uk/guidance/ng22/resources/older-people-with-social-care-needs-and-multiple-longterm-conditions-1837328537797">https://www.nice.org.uk/guidance/ng22/resources/older-people-with-social-care-needs-and-multiple-longterm-conditions-1837328537797</a> See also NICE Pathways Guidance <a href="https://www.nice.org.uk/guidance/population-groups/older-people">https://www.nice.org.uk/guidance/population-groups/older-people</a>	<ul style="list-style-type: none"> <li>Improved access to information</li> <li>Promoting independent living</li> <li>Personalised services and choice</li> <li>Active involvement of older people in care planning</li> <li>Address the social needs of older people</li> <li>Improved access to and experience of, service</li> <li>Inform an direct people to advocacy services</li> </ul>
National Institute for Health and Care Excellence	Suspected cancer: recognition and referral (2015)	<ul style="list-style-type: none"> <li>Improved access to information</li> </ul>
National Institute for Health and	Patient experience in adult NHS services: improving the experience of care for people using adult NHS services <a href="https://www.nice.org.uk/guidance/cg138/cha">https://www.nice.org.uk/guidance/cg138/cha</a>	<ul style="list-style-type: none"> <li>Tailored/personalised care</li> </ul>

Care Excellence	<a href="#">pter/1-Guidance#knowing-the-patient-as-an-individual</a>	<ul style="list-style-type: none"> <li>• Active involvement of patients in decision making</li> <li>• Ensure equality of access to services</li> </ul>
Care Quality Commission	Fundamental Standards (2017)	<ul style="list-style-type: none"> <li>• Person centred care</li> <li>• Access to information/informed consent</li> <li>• Equality of access and service provision.</li> </ul>

There are particular levers for influence associated with the most recent strategy ('Achieving world class cancer outcomes: a strategy for England 2015-2020'). The Strategy identifies deficits around assessment methods and challenges older people face in deciding most appropriate treatment. There are recommendations to address this through integration of geriatricians into clinical decision-making and support routes. Our evaluation work has shown that engaging advocates can (a) help older people make better, more informed decisions on an individual basis but also (b) involving advocates in Multi-Disciplinary Team meetings (e.g. in the way they do with Wolverhampton Macmillan advocate team) can help to ensure discussion of issues of voice, choice and control are included in care planning etc. There is scope to talk to NHS England to persuade them that advocacy services would be a useful addition to the 'comprehensive care pathway' they plan to pilot for older people.

The Strategy also identifies need to undertake more targeted research work to understand barriers to outcomes for older people. Advocates have a unique insight into this and the challenges that older people face in making decisions, the relationships they have with the healthcare system and the challenges they face in conveying their needs and aspirations to healthcare professionals. There may be scope to argue that some of these research resources are channelled to COPA to help advocates capture and raise awareness about systemic challenges facing older people that contribute to the survival deficit.

## **2.2 Local Pathways to Influence**

There are perhaps two routes into influencing commissioning and practice in cancer services at the local level. Firstly, strategically, through

- Transformation and Sustainability Plans, which bring together Commissioners, health and social care providers and local authorities to plan services which respond to identified local health and care needs
- Cancer Alliances, which bring together local senior clinical and managerial leaders representing the whole cancer patient pathway across a specific geography
- Health Watch as the local voice of service users (<http://www.healthwatch.co.uk/>)
- Emerging models of care and new models of commissioning which will support these - see Five Year Forward View (Chapter 3).

The table below outlines some of the relevant policy levers COPA may seek to emphasise in their engagement with these different stakeholder groups. It will also be important to follow the publication of the Five Year Forward Delivery Plan (planned for April 2017) which is likely to provide more detail about plans for new models of care and commissioning. For example, we know there are

two accountable care organisations being created in shadow and it will be important to keep an eye on progress of these and other new structures (e.g. Vanguard).

Agency/Organisation	Policy Statements	Policy levers: advocacy's contribution to
NHS England	Transformation and Sustainability Plans (44 plans across England) available at <a href="https://improvement.nhs.uk/uploads/documents/Delivering_cancer_waiting_times_update_July_2016.pdf">https://improvement.nhs.uk/uploads/documents/Delivering_cancer_waiting_times_update_July_2016.pdf</a>	Common themes include: <ul style="list-style-type: none"> <li>• Improved outcomes: patient involvement in decision making</li> <li>• Smoother transitions from acute to community services</li> <li>• Access to information and support</li> <li>• Equity of access and service</li> </ul>
NHS England	Cancer Alliances/Delivering World-Class Cancer Outcomes: guidance on local delivery (2017) <a href="https://www.england.nhs.uk/wp-content/uploads/2017/02/cancer-alliance-guidance.pdf">https://www.england.nhs.uk/wp-content/uploads/2017/02/cancer-alliance-guidance.pdf</a>	<ul style="list-style-type: none"> <li>• Reduction in service inequalities</li> <li>• Improved survival rates</li> <li>• Access to cancer support networks/agencies for patients</li> <li>• Identifying and measuring 'hidden' inequalities experienced by older people across pathways</li> </ul>

Secondly, advocacy can also make a difference at the level of individual health care practitioners throughout the cancer pathway process: from the GP to Cancer Nurse Specialists and Consultants. brap's evaluation of the COPA programme identified a number of examples of COPA advocates influencing the behaviour of health and social care professionals and encouraging them to refer to / learn from the programme. However, it is important to note that building influencing these individuals (and CCGs and Cancer Alliances), particularly when there is no clear steer or instruction from the centre, can be time consuming and it is a difficult environment in which to bring about systemic change. There are two principle challenges. Firstly, Clinicians have to be persuaded of the value of advocacy to the service and how it can assist in achieving service targets and goals. To address this challenge we have produced a power-point presentation for COPA staff to use in their engagement with healthcare professionals. This highlights the unique role COPA advocates can play in responding to 'hidden' inequalities associated with voice, choice and control

Secondly, advocates require support to identify and capture and share some of the systemic inequality issues they see through their work. There are opportunities to share information about these patterns of inequality and what is causing them with healthcare professionals, Cancer Alliances and commissioners more systematically. To address this challenge we have produced a learning toolkit for COPA advocates to use as part of their training and development. We anticipate this could help advocates to recognise barriers to autonomy faced by older people affected by cancer and to use this information to develop effective advocacy responses / share information about patterns of inequality with healthcare professionals and commissioners.

### 3. Why support advocacy services: relevant evidence

Reading across the NHS Triple Aim as well as specific policy documents, there are a number of common goals, across policy statements (relevant at both local and national levels) where advocacy can make a contribution. We undertook a rapid review of available literature to identify relevant sources of evidence that COPA staff may want to use when making arguments to that effect.

In terms of older people with cancer, there is substantial anecdotal evidence of the impact advocacy can have on their quality of life, experience of treatment and in facilitating not only informed consent

around treatment options but transitions between acute and community services. This is often in the form of written testimonials or films – see for example <http://www.healthtalk.org> or <http://opaal.org.uk/older-peoples-cancer-voices/>

Such stories are powerful – but can, in the current economic climate, have limited impact at the point of commissioning services. Much more influential at this level is quantitative data that advocacy:

- Improves outcomes
- Is cost effective and can demonstrate clear costs benefits
- Creates efficiencies within the health care system
- Assists the service in achieving policy goals and targets.

Such hard economic evidence of the value of advocacy within the health care system is largely lacking (or draws exclusively on American data). As we outline in brap’s evaluation of COPA, some of this information is available locally, drawing upon work undertaken by different COPA sites using the SAM database and other sources of evidence. It is this gap across the whole COPA programme that COPA recognises it will need to address over time. In short building a stronger, quantitative, evidence base for advocacy services for older people with cancer must be a priority if commissioning practices are to change. That said, there is a more general literature on the impact and value of advocacy that still resonates with COPA’s ambitions to demonstrate it can help respond to NHS and social care policy goals. Some useful documents are listed below.

- Addressing health inequalities, including hidden inequalities (Macmillan/Copa evaluation)

Examples of evidence
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<p>Hutt, P. and Gilmour, S. (2010) <i>Tackling inequalities in general practice</i>. London, Kings Fund  <a href="https://www.kingsfund.org.uk/sites/files/kf/Health%20Inequalities.pdf">https://www.kingsfund.org.uk/sites/files/kf/Health%20Inequalities.pdf</a></p>
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<p>Smith, K and Stewart, E. (2014) Influencing policy – public health advocacy and health inequalities. <i>Journal of the Royal College of Physicians, Vol. 44</i> pp316-321  <a href="https://www.rcpe.ac.uk/sites/default/files/smith_1.pdf">https://www.rcpe.ac.uk/sites/default/files/smith_1.pdf</a></p>
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<p>Whitehead M, Dalgren G. Levelling up (part1) (2006) : A discussion paper on concepts and principles for tackling social inequalities in health, Copenhagen: WHO Regional Office for Europe;  <a href="http://www.who.int/social_determinants/resources/leveling_up_part1.pdf">http://www.who.int/social_determinants/resources/leveling_up_part1.pdf</a></p>
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<p>Qulsom, F., Aujla, N., Hale, C. and Kai. J. (2015) Unequal treatment: health care experiences and needs of patients with cancer from minority ethnic communities. <i>Diversity and Equality in Health and Care, Vol 12</i>(3): pp 95-103 <a href="http://diversityhealthcare.imedpub.com/unequal-treatment-health-care-experiences-andneeds-of-patients-with-cancer-from-minorityethnic-communities.php?aid=7412">http://diversityhealthcare.imedpub.com/unequal-treatment-health-care-experiences-andneeds-of-patients-with-cancer-from-minorityethnic-communities.php?aid=7412</a></p>
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- More appropriate access to, and use of, services

Examples of evidence
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Williams, C *et al* (undated) *Transforming adult social care: access to information, advice and advocacy*. London, IdEA [http://www.local.gov.uk/c/document\\_library/get\\_file?uuid=4eb0f9f9-b4f8-4344-892d-8c893f806746&groupId=10180](http://www.local.gov.uk/c/document_library/get_file?uuid=4eb0f9f9-b4f8-4344-892d-8c893f806746&groupId=10180)

Dunning, A. (2010) *A Scoping Study of Advocacy with Older People in Wales*. Swansea Older People's Commissioner for Wales  
[http://www.olderpeoplewales.com/Libraries/OPCW\\_Publications/Advocacy\\_Report\\_E.sflb.ashx](http://www.olderpeoplewales.com/Libraries/OPCW_Publications/Advocacy_Report_E.sflb.ashx)

- Improving commissioning, the quality of care and outcomes

#### Examples of evidence

Newbigging, K., Ridley, J. and Sadd, J. (2107) *COMMISSIONING CARE ACT ADVOCACY: A WORK IN PROGRESS*. University of Birmingham, Birmingham

<http://www.birmingham.ac.uk/Documents/college-social-sciences/social-policy/HSMC/publications/2016/CA-advocacy-commissioning-research-report.pdf>

Townsley, R,Marriott, A. and Ward, L. (2009) *Access to independent advocacy: an evidence review*. Office for Disability Issues, HM Government, London <http://www.bristol.ac.uk/media-library/sites/sps/migrated/documents/iar-full.pdf>

- Enhancing the quality of the patient experience

#### Examples of evidence

Department of Health (2012) *Cancer Services Coming of Age: Learning from the Improving Cancer Treatment Assessment and Support for Older People Project*. London, DoH  
[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/213205/DH\\_Macmillan\\_Age-UK\\_Report\\_Final.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213205/DH_Macmillan_Age-UK_Report_Final.pdf)

Ipsos MORI (2015) *Exploring the attitudes and behaviours of older people living with cancer*. London, Macmillan Cancer Care [https://www.ipsos-mori.com/Assets/Docs/Publications/SRI\\_Health\\_Macmillan\\_Older\\_People\\_August\\_2015.pdf](https://www.ipsos-mori.com/Assets/Docs/Publications/SRI_Health_Macmillan_Older_People_August_2015.pdf)

Cancer Patient Experience Survey (2015)

<https://www.quality-health.co.uk/surveys/national-cancer-patient-experience-survey>

Some indicators particularly demonstrate the need for advocacy support. For example: being informed of side effects at start of treatment; receiving information about how to get financial help; having someone to talk to about their worries and fears.

- Enhancing the quality of life for patients, their families and survivors

#### Examples of evidence

OPAAL (2016) *Every Step of the Way*. Stoke on Trent, OPAAL  
<http://opaal.org.uk/app/uploads/2015/09/Advocacy-Stories.pdf>

IPSOS Mori (2015) *Later Life in 2015: An analysis of the views and experiences of people aged 50 and over*. Centre for Better Aging, London <https://16881-presscdn-0-15-pagely.netdna-ssl.com/wp-content/uploads/2015/12/Later-life-in-2015-Ipsos-MORI-Ageing-Better1.pdf>

Carlsson, H. (2104) *"Advocacy changed my life" Research into the impact of independent advocacy on the lives of people experiencing mental illness*. Edinburgh, The Scottish Independent Advocacy Alliance <https://www.siaa.org.uk/wp-content/uploads/2014/11/Hanna-report-final-version-31.pdf>

Usher, J., Kirsten, L., Butow, L. and Sandoval, J. (2006) What do cancer support groups provide which other supportive relationships do not? The experience of peer support groups for people with cancer. *Social Science and Medicine* Vol 62 pp.2565 - 2576

- Smoothing transitions through services (eg from primary to acute services/from acute services to the community).

#### Examples of evidence

Cancer Campaigning Group (2012) *Patients' experience of integrated care A report from the Cancer Campaigning Group* <http://www.cancercampaigninggroup.org.uk/wp-content/uploads/2012/11/Patients%E2%80%99-experience-of-integrated-care-A-report-from-the-Cancer-Campaigning-Group.pdf>

Ellins J, Glasby J, Tanner D, McIver S, Davidson D, Littlechild R, Snelling I, Miller R, Hall K. Spence K. (2012). *Understanding and improving transitions of older people: a user and carer centred approach*. National Institute for Health Research (NIHR), Southampton <http://www.birmingham.ac.uk/documents/news/sdotransitions-report.pdf>

Note\*\* An important gap here is evidence that advocacy can facilitate early discharge from acute services.

- Improving patient outcomes where patients are actively involved in understanding, and making informed choices) about treatment options

#### Examples of evidence

Prime Minister's Strategy Unit (2015) *Improving the life chances of disabled people*. London, PMSU <http://webarchive.nationalarchives.gov.uk/+http://www.cabinetoffice.gov.uk/media/cabinetoffice/strategy/assets/disability.pdf>

Pohwer (2016) *Putting People First: Community Advocacy Impact Report*. Birmingham, Pohwer <http://www.socialvalueuk.org/app/uploads/2016/03/pohwer-community-impact-report-for-web-final.pdf>

Macadam, A., Watts, R. and Greig, R. (2013) *The Impact of Advocacy for People Who Use Social Care Services*. London, NHIR School of Social Care Research [https://www.ndti.org.uk/uploads/files/SSCR\\_Advocacy\\_Scoping\\_Review\\_Jan\\_2014.pdf](https://www.ndti.org.uk/uploads/files/SSCR_Advocacy_Scoping_Review_Jan_2014.pdf)

- Promoting public health where advocates play a wider educational role to facilitate earlier take up of diagnostic and related services (promoting early detection)

#### Examples of evidence

Thurston, M. (2014) *Key Themes in Public Health*. London, Routledge

Loue, S (2006) Community health advocacy. *Journal of Epidemiology and Community Health*, Vol 60, Issue 6 pp.458-463 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2563937/>

See also: Public Health Alliance (2007) *Public Health Advocacy Toolkit*. Belfast/Dublin Public Health Alliance [http://www.cieh-nireland.org/uploadedFiles/core/policy/public\\_health\\_advocacy\\_toolkit\\_07.pdf](http://www.cieh-nireland.org/uploadedFiles/core/policy/public_health_advocacy_toolkit_07.pdf)

- International comparisons

#### **Examples of evidence**

One final policy lever is the relatively poor position of the UK in terms of treatment and survival relative to other European countries<sup>1</sup>. Comparative data on cancer outcomes generally, and older people specifically, are available through

- British Journal of Cancer

<http://www.nature.com/bjc/journal/v113/n5/full/bjc2015265a.html>

- International Cancer Benchmarking Project

[http://www.cancerresearchuk.org/health-professional/early-diagnosis-activities/international-cancer-benchmarking-partnership-icbp?\\_ga=1.73061402.825532548.1489576332](http://www.cancerresearchuk.org/health-professional/early-diagnosis-activities/international-cancer-benchmarking-partnership-icbp?_ga=1.73061402.825532548.1489576332)

- In terms of the wider European policy and practice context, Rare Cancers Europe also produces a useful toolkit on strategies for lobbying for advocacy support:

<http://www.rarecancerseurope.org/Patient-Advocacy-Toolkit/Why-Speak-Up>

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<sup>1</sup> See also media coverage of this issue: for example

<https://www.theguardian.com/society/2015/mar/24/uk-cancer-survival-rates-trail-10-years-behind-those-in-european-countries>

<http://www.telegraph.co.uk/news/health/news/11891554/UK-cancer-survival-worst-in-western-Europe.html>