Chapter 17
Cancer

17.1 Key audiences

Primary care trusts:

- chief executives
- directors of public health
- commissioners of services for older people/cancer/acute care.

NHS trusts and NHS foundation trusts:

- chief executives
- directors of nursing
- medical directors
- head of cancer services
- cancer clinicians.

Cancer networks:

- cancer network directors
- cancer network primary care leads.

Third sector providers of services for people with cancer:

- chief executives.

17.2 Key issues and concerns

The Cancer Reform Strategy (CRS)[507] said that there is some evidence that older people receive less intensive treatment than younger people even when they are fit enough to do so.[508] [509] The CRS clearly stated that age should not be a barrier to treatment. The assumption should be that older patients should receive the same level of treatment. This issue has been further highlighted by the work of the National Cancer Equality Initiative (NCEI). Among the issues highlighted by the literature are:

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[507] *Cancer Reform Strategy*, Department of Health, 2007
[508] *British Journal of Cancer*, Lavelle et al, 96; 1197-12-3, 2007
[509] *Age and Ageing*, Peake et al, 32; 171-177, 2003

- Cancer is more common in later life.
- Older people receive less active and intensive treatment than younger patients.
- Older people can often tolerate similar treatment regimes to younger people.
- Older people with cancer are more likely to be admitted as emergencies.
- Professional attitudes can be a barrier that may impede older people getting access to a full range of treatment options.
- Older people do not always get comprehensive information about treatment options in a manner which is appropriate and comprehensible.
- The difficulties for older people in accessing appropriate cancer services may be compounded by socio-economic deprivation, gender, sexuality, race and disability.
- The decrease in cancer mortality in older people has been less marked than for younger people.

Cancer is more common in later life

Cancer is predominantly a disease of older people – only 0.5 per cent of cases registered in 2006 were in children (aged under 15) and 26% were in people aged under 60.[510] Around one-third of all cancers are diagnosed in people over 75 who form just 7 per cent of the population.[511] However, this group is less extensively investigated and receives less treatment than younger patients; reduced levels of intervention are not wholly explained by appropriate adjustment for co-morbidity or frailty.[512]

For most cancers, such as breast, colorectal, lung and prostate, the risk of cancer increases with age.[513] However, the link between increasing age and increasing risk of developing cancer appears to be poorly understood by the public. For example a recent study found that over 50 per cent of women wrongly believe that the risk of breast cancer does not vary with age, with only one per cent correctly believing that the oldest women are at greatest risk. Lack of awareness that they are still at risk of developing breast cancer

[510] *NHS Choices website* www.nhs.uk/nhsengland/NSF/pages/Cancer.aspx
[511] NHS Scotland, 2001, Review cited in Centre for Policy on Ageing (CPA) *Ageism and age discrimination in secondary health care in the United Kingdom*, October 2009
[512] *Ageism and age discrimination in primary health care in the United Kingdom,* October 2009
[513] *Cancer Reform Strategy Equality Impact Assessment,* Department of Health, 2007

appears to be one of the major reasons why older women with breast cancer present later and with more advanced disease than younger women.[514]

Older people receive less active and intensive treatment than younger patients

Disease-specific survival rates decline with age.[515]

Fewer diagnostic procedures and less treatment are carried out with advancing age.[516]

Older patients are less likely to receive a full investigation, as indicated by histology, and also less likely to receive definitive surgery or chemotherapy.[517] [518]

Older women are less likely than younger women to receive 'standard' management for breast cancer. Older women are less likely than younger women to have surgery for operable breast cancer, even after accounting for differences in general health and co-morbidity. Women aged 70+ are less likely to be diagnosed via needle biopsy and triple assessment, or receive radiotherapy than younger women. When compared with a 65-69-year-old, a woman aged 80 or older is five and a half times less likely to receive triple assessment for operable breast cancer and 40 times less likely to undergo surgery. Even women as young as 70-74 are over seven times less likely to receive radiotherapy following breast conservation surgery.[519] [520]

Older people are less likely to receive breast conserving surgery and lung cancer resection.[521]

Older people can often tolerate similar treatment regimes to younger people

Some elderly people can tolerate chemotherapy, surgery, and radiotherapy just as well as younger patients, and regimens and protocols can be modified in less-fit patients.[522]

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[514] *Cancer Reform Strategy*, Department of Health, 2007
[515] *Ageism and age discrimination in secondary health care in the United Kingdom*, Centre for Policy on Ageing (CPA), October 2009
[516] *Reducing cancer inequality: evidence, progress and making it happen – a report by the National Cancer Equality Initiative*, Department of Health, March 2010
[517] *Ageism and age discrimination in secondary health care in the United Kingdom*, CPA, October 2009
[518] Macmillan Cancer Support's response to the *APPG on Cancer's Inquiry into cancer inequalities*, Clarke J, June 2009
[519] *Ageism and age discrimination in secondary health care in the United Kingdom*, CPA, October 2009
[520] Age Concern/Help the Aged's *Response to the National Review of Age Discrimination in Health and Social Care,* July 2009
[521] *Social variations in access to hospital care for patients with colorectal, breast, and lung cancer between 1999 and 2006: retrospective analysis of hospital episode statistics*, Raine et al, 2010BMJ 2010;340:b5479

Older people with cancer are more likely to be admitted as emergency cases

Older people (over 80s), patients from deprived areas and women are more likely to be admitted as emergency cases.[523]

Professional attitudes can be a barrier that may impede older people's access to a full range of treatment options

Oncology professionals may have negative attitudes towards older people.[524] [525]

Late presentations amongst older people are common resulting in significantly higher mortality for some cancers as symptoms may be dismissed as a sign of old age by health professionals.[526] [527]

Older people do not always get comprehensive information about treatment options in a manner which is appropriate and comprehensible

Older people may be more likely to follow their doctor's recommendations without question, but the way in which treatment options are presented can influence their choice.[528]

One of the key barriers to equality is poor communication - information not being given appropriately.[529]

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[522] *Ageism and age discrimination in primary health care in the United Kingdom*, CPA, October 2009
[523] *Social variations in access to hospital care for patients with colorectal, breast, and lung cancer between 1999 and 2006: retrospective analysis of hospital episode statistics*, Raine et al, 2010BMJ 2010; 340:b5479
[524] *Ageism and age discrimination in secondary health care in the United Kingdom*, CPA, October 2009
[525] *Macmillan Cancer Support's response to the APPG on Cancer's Inquiry into cancer inequalities*, Clarke J, June 2009
[526] *Myths and biases related to cancer in the elderly*, Berkman B, Rohan B and Sampson S, 1994, Cancer 74 (7, Suppl): 2004-2008
[527] *Ageism in chemotherapy*, The Internet Journal of World Health and Societal Politics 6 (1), Dockter L and Keene S, 2009, cited in *Ageism and age discrimination in primary health care in the United Kingdom*, October 2009
[528] *Ageism and age discrimination in primary health care in the United Kingdom*, CPA, October 2009
[529] *Macmillan Cancer Support's response to the APPG on Cancer's Inquiry into cancer inequalities*, Clarke J, June 2009

Older people experience language barriers, including generational language barriers and complex language/jargon barriers in addition to barriers for those whose first language is not English.[530]

The difficulties for older people in accessing appropriate cancer services may be compounded by socio-economic deprivation, gender, sexuality, race and disability

Services can be ethnocentric and fail to provide appropriately for black people. For example, prostheses (limbs and breasts) are often not the right colour and wigs are not appropriate for African and Caribbean people.[531] There can be a lack of information about skin care after treatment for black people and a lack of appropriate dietary advice which takes into account various black and minority ethnic (BME) diets.[532]

There are 25,000 older people with learning disabilities in the UK and this is set to rise over the next decade. People with learning disabilities have higher rates of cancer than the general population and particular needs when accessing services.[533]

These factors can compound issues for older people in accessing cancer services. Problems in ensuring appropriate communication of information about cancer treatments and services to those who may have language or comprehension difficulties, due to race or disability, is of particular concern. Local health organisations will want to ensure that they avoid the potential for dual or multi discrimination. This may require a particular focus on action to address the issues outlined above.

The decrease in cancer mortality in older people has been less marked than for younger people

Compared with Europe and America little progress has been made in the last decade in cancer death rates in the over 75s in the UK, and the gap in death rates between over and under 75s is getting wider.[534] The 2nd CRS Annual Report noted that the decrease in cancer mortality in older people has clearly been less marked than for younger people, and this is a matter of concern now being investigated further.

Projects undertaken by trusts to specifically tackle cancer inequalities are significantly more likely to be focused on awareness and early detection,

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[530] *Cancer inequalities – Focus groups with people affected by cancer – report*, Macmillan Cancer Support, June 2009
[531] Cancerbacup, 2006
http://path-finderhd.com/conf/blackpool/Cancer%20Services%20Engaging%20with%20BME%20communities.ppt
[532] Afiya Trust
[533] *Healthcare for All, Report of the Independent Inquiry into access to healthcare for people with learning disabilities*, Sir Jonathan Michael, 2008
[534] *Ageism and age discrimination in secondary health care in the United Kingdom*, CPA, October 2009

rather than on treatment, patient information or living with and beyond cancer.[535]

The Cancer Reform Strategy[536] recognised that some of the measures being taken may, at least initially, widen inequalities. This includes measures to improve awareness of prevention messages as well as the signs and symptoms of cancer, which are likely to be disproportionately acted upon by the informed and articulate. The strategy also noted that expanding screening will benefit everyone who is eligible, but groups with lower levels of uptake will experience less benefit.

In order to tackle these inequalities, the CRS set up the National Cancer Equality Initiative (NCEI) to improve data collection, identify research gaps and spread best practice.

Access to screening

The recent review of age discrimination in health and social care recommended that the Department of Health and the Breast Cancer Screening Advisory Committee ensure there is evidence to justify the age criteria for breast cancer screening.[537] This is being examined at national level. However, people above the age range for breast (70) and bowel (69) cancer screening can self-refer. This right should be communicated to older people, together with their increasing risk of developing the disease.

17.3 Drivers and policy imperatives

The *Cancer Reform Strategy*[538] acknowledged inequalities in cancer incidence, access to services and outcomes according to deprivation, race, age, gender, disability, religion and sexual orientation and places a high priority on ensuring that action is taken to reduce these inequalities.

Through NCEI, the *Cancer Reform Strategy* set in train work to explore best practice and what can be done to reduce age inequality in cancer care. The strategy states: "*In the meantime, we do not believe that age should be used as a barrier to treatment. The assumption should be that older patients should receive the same level of treatment. The only acceptable criteria for not giving a clinically-appropriate and cost-effective treatment should be poor patient health or a patient themselves making a choice not to receive further treatment. We will explore ways of making this more explicit when guidance is issued on interventions where clinical trials may have excluded older people.*"

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[535] *Inquiry into equalities in cancer*, All Party Parliamentary Group on Cancer, 2009 www.appg-cancer.org.uk
[536] *The Cancer Reform Strategy,* Department of Health, December 2007
[537] *Achieving age equality in health and social care*, Sir Ian Carruthers and Jan Ormondroyd, Department of Health, 2009
[538] *Cancer Reform Strategy*, Department of Health, December 2007

The strategy also stated that "*people affected by cancer should be offered high quality information, at key points in their cancer journey, tailored to their individual needs*". And noted that "*some patients will need additional support to understand and act upon the information they are given"*.

17.4 What good age equal practice might look like

Key principles and practical guidance for reducing inequalities in commissioning cancer services, as set out by the National Cancer Equalities Initiative (NCEI), would be put into practice:

→ www.cancerinfo.nhs.uk/images/stories/ncei_docs_/final_principles__guidance_doc.pdf

In addition, throughout 2009, NCEI held events with key stakeholders and professionals across the six equality strands, including age and socio-economic deprivation. The events have informed practical actions which are included in an NCEI report.[539]

It is also important to ensure that:

- Information is evidence based, balanced, regularly updated and written in plain language. Also that it is culturally sensitive and available in a variety of formats. It should include personalised details and be locally customised and suitable to the patient's needs at a given point in time. The Department of Health is working with Macmillan Cancer Support to pilot a range of approaches to formally assessing frailty in older people when considering treatment options.[540] [541] Also see *Useful resources* section later in this chapter for cancer information materials.
- There is adequate access for older people from BME communities to interpreting and advocacy services in order to promote informed choice on treatment. The Cancer Patient Experience Survey, taking place in spring 2010, will provide data sufficient to get a comprehensive view of whether, and to what extent, experience varies by age, gender, deprivation and ethnicity. It will also seek information on patients' sexual orientation and disability.[542]
- Staff are trained in advanced communication skills. (Since July 2008 nearly 3,000 senior cancer healthcare professionals have been trained by *Connected* - advanced communication skills training programme.)

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[539] *Reducing cancer inequality: evidence, progress and making it happen – a report by the National Cancer Equality Initiative*, Department of Health, March 2010
[540] Macmillan Cancer Support's response to the *APPG on Cancer's Inquiry into cancer inequalities*, Clarke J, June 2009
[541] *Cancer Strategy,* Department of Health, 2007
[542] *Reducing cancer inequality: evidence, progress and making it happen – a report by the National Cancer Equality Initiative*, Department of Health, March 2010

- Systems for care navigation are set up that particularly help and support those who are currently falling through the gaps in cancer care, including older people.[543]
- Treatment decisions are based on assessment of biological rather than chronological age, so that older people who are sufficiently fit are offered active treatments.[544]
- Information about local variations in access to cancer treatments and screening and mortality by age is regularly monitored and reported. Data related to cancer and equalities will soon be made available by NCEI through the National Cancer Intelligence Network (NCIN).

17.5 Case studies of illustrative / good practice

Don't Be a Cancer Chancer campaign - Manchester

This campaign targets the areas of Manchester where cancer causes the greatest loss of life. The campaign strapline is strong and simple: '*Catching it early could save your life*'. It uses a range of eye-catching materials containing the key messages, including posters, leaflets, car stickers, tissues, beer mats and toilet rolls.

The campaign is supported by NHS Manchester, the Christie Hospital and Manchester City Council. Funding has also been used for a campaign bus to visit sites, including shopping centres and supermarket car parks, to make it easier for people to access information and chat with advisers.

In local initiatives designed to complement the campaign, residents have also been supported in working with health professionals to help educate the local community and develop new approaches to the promotion of early patient presentation.

Further information
Julie Jerram, Programme Manager
0161 234 4276

[543] *Macmillan Cancer Support's response to the APPG on Cancer's Inquiry into cancer inequalities*, Clarke J, June 2009
[544] *Reducing cancer inequality: evidence, progress and making it happen – a report by the National Cancer Equality Initiative*, Department of Health, March 2010

Cancer Help for Ethnic Communities service (CHEC) Bristol and South Gloucestershire

The CHEC service is for black and minority ethnic (BME) people with cancer, at any stage of their illness, who live in Bristol or South Gloucestershire. This is just one service that the NHS offers to assist in meeting the needs of BME people and ensuring that a person is not disadvantaged as a result of individual needs relating to their culture or ethnicity.

Anyone can make a referral to the CHEC service if they are aware of someone from a BME background who is affected by cancer. Referral forms are available to download from the service's website and referrals can also be made by telephone. Once a referral has been received, the support and development worker will make contact to offer a visit at home, hospital or wherever the person may be. Referrals usually receive a speedy response though this may be affected by factors such as the need for an interpreter.

Once the CHEC worker has met with the service user, they will agree a support plan together, taking into consideration the needs of other family members and/or carers. Each case is assessed on its own merit, and needs are identified accordingly but examples of support CHEC has provided include:

Emotional support – telephone calls and home visits.

Practical support – helping the patient to access charity grants and – where necessary – helping them to complete applications; making referrals to appropriate agencies such as Care Direct for social care needs, Avon & Bristol Law Centre or Immigration Advice Service for legal and immigration advice or the Benefits Agency for benefits assessment; advice and assistance with applications.

Language support – arranging for interpreting or translation where appropriate.

General advice and information – his has often included introducing the patient to services they may not have known about such as hospices, Macmillan Cancer Support and local minority ethnic community groups and agencies who can provide additional support.

Cancer awareness sessions – where groups of people can learn more about cancer, the risk factors and the services available to them.

General support and advice for other healthcare professionals and others involved with the care of the patient.

An evaluation of the CHEC service carried out in 2006 by the University of the West of England concluded that it is cost-effective and that it is helping to improve cancer care for BME people.[545] The service regularly receives positive feedback from patients, their families and other healthcare professionals.

Further information
Marion Burrell, Support & Development Worker
Cancer Help for Minority Ethnic Communities
Hosted by Bristol Community Health
Serving Bristol and South Gloucestershire NHS areas
marion.burrell@nhs.net
0117 982 8549

PRIDE Process – NHS Bury

NHS Bury aims to transform the way services in the community are commissioned and provided, with great emphasis on dignity and respect through the PRIDE model (personal, respect, inclusion, dignity and experience). PRIDE provides a systematic process to gather experiences and uses this to identify opportunities for improvement. It also offers insight on what a service feels like from the patient's perspective and ensures their needs are met.

Frontline clinical staff work with patients and carers to improve the cancer end of life care pathway by providing seamless care for patients and their carers/families. Through working directly with clinical staff, the aim is to understand the reality of the service experience for staff, patients and carers. The initiative is looking at:

- what a 'good' service looks and feels like from a patient's/carers' and staff perspectives
- how to ensure that the individual's journey through a care pathway is seamless with a continuity of standards and experience received.

NHS Bury has now identified the eight key metrics which they are arranging to place in contracts to ensure that future services are commissioned according to users' needs.

Further information
Elaina Dinerstein, Organisational Transformation
Telephone: 0161 762 7983

→ www.bury.nhs.uk

[545] *Cancer Help for Ethnic Communities (CHEC) An evaluation of the service*, Naidoo et al, 2006

Care coordination - Bridges Support Service West Midlands

The Bridges Support Service is based in Sandwell (West Midlands). The service is managed by Murray Hall Community Trust, a registered charity, and is just one of their programmes. Staff costs are funded by local primary care trusts (PCTs). The service currently supports people in Sandwell and Heart of Birmingham PCT areas and the Birmingham East and North NHS areas.

Following referral people are put in touch with a care coordinator who links people with the services they need. The Bridges assessment is integrated with the Single Assessment Process (SAP), where this is appropriate and is in use. This is important as people do not always want different people coming to assess them, so district nurses and others can assess and refer to Bridges without a new assessment process having to take place. Bridges has developed what is called a 'narrative-based assessment' where patient and carers are given the opportunity to share their story so that assessors understand their supportive care needs.

Bridges Support Service supports people with cancer and palliative care needs, by providing:

- a range of social support
- carer support
- domestic help
- respite care
- child care
- transport to hospital appointments
- volunteer befrienders
- information
- advocacy
- complementary therapy
- support tailored to individual needs (e.g. finding a dog-sitting service)
- staff who act as key workers in small number of cases. (Bridges Care Coordinators support patients and their carers; all referrals are treated as cases.)

Key points for success are:

- flexibility about route in/referral process
- easy to access
- integrated into SAP
- not means tested

- links in to supportive care pathway (developed locally)
- hand-held resource (the directory)
- holistic – not restricted to health/social care issues
- run by voluntary sector, which enables it to cross boundaries
- high level of user involvement in all aspects(user involvement has been key in the development of the service)
- narrative-based assessments - supports Bridges' person-centred care model.

Further information
Manjula Patel, Manager
bridges.support@nhs.net

The Macmillan Mobile Information Service

The Macmillan Mobile Information Service in the London, Anglia and South East Region offers a flexible and adaptable service to the region's diverse population. Its remit is to reduce the inequality of access to cancer information and support.

The service is set in safe, welcoming environments, with anonymity if required. It includes a mobile information centre that visits high streets in the region, and an indoor Infozone that can provide information in a variety of settings. Cancer information specialists also talk to community groups.

The service brings face-to-face cancer information and support to older people so that they don't have to travel distances to other sources of support. It also supports community organisations working with older people through a programme of talks, and information stands, manned by specialists, at health events and awareness activities targeted at the older population.

Further information
Rowena Howell, Operations Manager, Mobile Cancer Information Service (London, Anglia and the South East Region)
020 8222 9043
rhowell@macmillan.org.uk

17.6 Suggestions for quick wins / what you can do now

- Commission the cancer network to report on current inequalities in cancer care and use of screening services, specifically including age, and age together with other characteristics, and propose actions.
- There is variation of rates of treatment of older people by trust, so a local audit could be undertaken of intervention rates for a range of procedures (surgery, chemotherapy and radiotherapy) and tests, by age, to assess your current situation.
- Promote cancer awareness for older people and information about age-related risks. Particular attention should be paid to BME and refugee communities and other groups who may not be aware of the signs of cancer, the treatments available, or their risk factors.
- Promote to people above the routine screening age ranges their right to self-refer for breast (over 70) and bowel (over 69) cancer screening programmes. Particular attention should be paid to promoting the benefits of screening to BME and refugee communities and other groups who may not understand, or be aware of, the screening programmes.
- Providers could consider how they can best audit information delivered to individual patients and whether this is meeting patients' needs. Particular attention should be paid to the needs of at-risk groups including older people, (as recommended by the Cancer Reform Strategy 2007), and those with other protected characteristics, in order to avoid dual or multiple discrimination.

17.7 Useful resources

Macmillan Directory of Information materials

This directory for people affected by cancer has details of over 1,000 leaflets, booklets, books and audiovisual materials on cancer. All the items listed were produced in the UK within the last five years and are available nationwide. Some are available in languages other than English. The books and audiovisual materials have been reviewed by over 200 people affected by cancer.

The directory is available free from Macmillan Cancer Support on 0800 500 800, or you can order online:

→ be.macmillan.org.uk

Cancer and Diet Information Project – Cancer Equality

This is a three-year project funded by the Department of Health to develop dietary information for people from Asian, African, Caribbean and Chinese communities whose lives are affected by cancer:

→ www.cancerequality.org.uk/

The NHS Cancer Screening website

This site has a number of resources for promoting screening programmes to the public, including information targeted at people with disabilities and material in languages other than English:

→ www.cancerscreening.nhs.uk/index.html