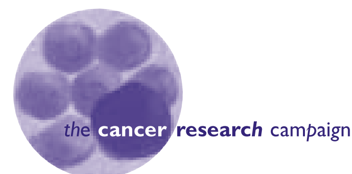
REDUCING INEQUALITIES IN BREAST CANCER

a guide for primary care



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PREFACE

There is unequivocal evidence that women with breast cancer who are from deprived areas have significantly lower survival rates than those from affluent areas. This guide highlights the influence of social deprivation on breast cancer and recommends actions that individual primary care practitioners can carry out to help reduce inequalities in breast cancer. Providing support to primary care practitioners working in deprived areas (or those with patient lists comprised mostly of 'high' consultors), and addressing issues such as the length of consultations and size of patient lists, will be vital if inequalities in health care are to be tackled.

This guide was initiated following findings from a study carried out in the Department of General Practice at the University of Glasgow. The Glasgow study investigated the balance of care for women with breast cancer in affluent and deprived areas and was funded by the National Lottery Charities Board Scotland. This guide incorporates the Glasgow study findings into the wider literature on social deprivation, practice patterns and breast cancer.

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The Glasgow research was conducted by Dr Una Macleod who would also like to acknowledge the contributions made to the study by Dr S Ross, Professor L Fallowfield, Mr D Hole and Dr C Twelves.

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INTRODUCTION

Breast cancer is the most common female cancer in the UK and deprivation has led to a large number of avoidable breast cancer deaths. Socio-economic inequalities in health have been found in many contemporary and past societies (1, 2). These differences have persisted despite the dramatic fall in mortality rates over the past century. Moreover, the difference in rates between those at the top and those at the bottom of the social scale is widening. Health inequalities exist whether measured in terms of socio-economic status, ethnicity, gender, mortality, life expectancy or health status. A key issue is the damage that persistent family and childhood poverty does to the health of future generations. It is sobering to acknowledge that in the mid 1990s, around one in four of the total population in Britain was living in poverty. Among children, the proportion was one in three.

In general, cancer survival for adults in Britain is significantly lower among patients in more deprived groups than those in affluent groups, even after allowance is made for the higher mortality from all causes of death in the more deprived groups (3, 4). The incidence of breast cancer is highest among women from upper socio-economic classes and overall survival rates are improving. However, it is now clear that women from deprived areas have significantly poorer survival rates, with a 5–10% lower chance of survival. Clear reasons for differences in survival have yet to be established. It is likely that a number of factors contribute: longer delays in diagnosis or more advanced cancers at diagnosis, worse general health or lower resistance to malignancy, different histological type or more aggressive disease, poorer access to optimal care, and lower compliance with treatment. Findings from the study conducted in Glasgow, which investigated the balance of care for women with breast cancer in affluent and deprived areas, found differences between the deprived and affluent groups in terms of consultation patterns and information seeking. Key differences identified by the Glasgow study, as well those described in the literature, are shown in Box 1.

Eliminating the difference in survival between deprived and affluent populations could lead to a significant overall reduction in breast cancer mortality. Actions need to occur within the NHS and on a broader front. A governing principle of the NHS is equitable access to effective health

Box 1 Breast cancer: differences between women from deprived and affluent groups

- Women from deprived areas have significantly lower rates of breast cancer survival
- More women from deprived populations present with large, advanced breast cancers
- There is greater co-morbidity in women from deprived areas
- Women from deprived areas have more emergency admissions and more general hospital admissions
- Women from deprived areas have greater rates of GP consultation
- Women from deprived areas have greater unmet psychological needs
- Women in deprived areas, who may need longer consultations for psychological support, are less likely to receive them
- More affluent women tend to ask more questions, be better informed, articulate questions about their treatment and demand better services
- Access to specialist cancer services varies across the UK for all women
- More affluent women receive both information and advice from a breast care nurse
- GPs are more likely to receive follow-up plans from surgeons for affluent women
- There is a tendency for women from deprived areas not to attend for follow-up
- Breast screening uptake is higher among affluent women

care for those who need it. However, it is evident that patients from deprived areas tend to receive less effective services and that an 'inverse care law' exists in relation to access to preventive services (including cancer screening programmes, health promotion and immunisation) and recruitment of primary care professionals. High GP consultation rates are another feature of areas of socio-economic deprivation. This may lead to shorter average consultation times, and less time within each consultation to address patients' multiple problems. To this end women with breast cancer in areas of socio-economic deprivation, namely women who may need longer consultations for psychological support, are less likely to receive adequate care.

Attempts to re-distribute effective health care and improve recruitment of GPs to deprived areas have proven problematic. It has become apparent that deprivation payments and formulaic approaches are not sufficient and new initiatives are required. At the same time, existing structures continue to support re-distribution of effective care to those in need and initiatives such as health impact assessments and health improvement programmes are working to develop the capacity of the NHS to tackle health inequalities.

In relation to breast cancer, primary care professionals can work to reduce inequalities by ensuring that ALL women with breast problems and breast cancer receive care that is informed by national guidelines. It is a clear recommendation that newly referred patients be assessed in a dedicated breast clinic and be managed by a multidisciplinary specialist breast team.

Good communication between secondary and primary care providers is vital to ensure GPs have a clear understanding of what the specialist has discussed with the woman and what she understands of her situation. Effective communication is critical. An educated, middle-class woman with breast problems may already know what she is looking for, have a list of questions and provide pressure to get what she needs. However, primary care professionals should be aware that women who do not have prepared questions, or are unable to articulate their concerns, may need extra time to discover their informational and support requirements. Some evidence exists that doing this can greatly improve their outcomes. Promoting breast awareness to reduce delays in diagnosis and promoting screening among lower socio-economic groups may also improve ultimate prognosis.

Health inequalities can be remedied if policies that address the roots of deprivation are given priority. Such policies need to focus on improving general health and need to have the greatest impact on the least well off (see Box 2). This complex task requires multi-sector initiatives that involve government departments beyond the departments of health.

While it may be difficult for GPs and nurses to tackle social inequalities during routine consultations, they can participate in 'broad-based' initiatives. A recently published English White Paper, *Saving lives: our healthier nation*, acknowledges the 'widening of the health gap' between the better off and deprived communities and sets out at length ways of tackling health inequalities (5). Primary Care Groups and Trusts should be in a position to address inequalities and improve health in local communities. Voicing support for healthy and equitable policies formulated to reduce inequalities is one way for primary care to have an impact. Arranging for history-taking to include the routine eliciting and recording of societal risk factors may also be a way for primary care to work actively with both social and biological causes of illness.

References

1. Acheson D. *Independent inquiry into inequalities in health report*. London: The Stationery Office, 1998.

2. Black D, Morris J, Smith C, Townsend P. *Inequalities in health: report of a research working group*. London: Department of Health and Social Security, 1980.

3. The Cancer Research Campaign. *CancerStats: Survival England and Wales 1971–1995*. London: CRC, 1999.

4. Coleman M, Babb P, Damiecki P, Grosclaude P, Honjo S, Jones J, Knerer G, Pitard A, Quinn M, Sloggett A, De Stavola B. *Cancer survival trends in England and Wales,* 1971–1995*: deprivation and NHS Region. (Stud Med Popul Subj no 61).* London: The Stationery Office, 1999.

5. Department of Health. *Saving lives: our healthier nation*. London: The Stationery Office, 1999.

Box 2 Reducing inequalities: agenda for policy development

- Poverty, income distribution, tax and benefits *(e.g. establish minimum wage)*
- Education *(i.e. provide high quality pre-school education)*
- Employment *(i.e. reduce unemployment and provide a fair workplace)*
- Housing and environment *(i.e. improve social housing and its environment)*
- Mobility, transport and pollution *(i.e. provide affordable public transport for the least well off)*
- Nutrition *(i.e. ensure adequate retail of foodstuffs to those in deprived areas)*
- Mothers, children and families – priority area *(i.e. strengthen the health visitor role)*
- Young people and adults of working age *(i.e. promote healthy lifestyles)*
- Older people *(i.e. increase uptake of benefits among entitled groups and improve housing)*
- Ethnicity *(i.e. improve access to primary care through 'culture competency' training)*
- Gender *(i.e. reduce the number of accidents and suicides among young men, and disability in older women)*

METHODS

This guide was compiled by integrating the findings of the study conducted in Glasgow with existing published literature.

We conducted a systematic search of the literature to retrieve sources of published and unpublished (grey) literature concerned with social deprivation and breast cancer. Research on survival differences between affluent and deprived groups, reasons for survival differences, practice patterns and the impact of delay on breast cancer survival all contributed to a current understanding about deprivation and breast cancer. Additional literature concerned with health inequalities and the role of primary care provided a framework for adapting the findings to primary care. Clinical guidelines provided national best practice.

An explicit search strategy was used to ensure a reliable overview of the literature. Electronic database searching was conducted on Medline, Embase, CINAHL and PsychLit and was limited to articles in English from 1995 to 1999 in order to retrieve current work. Search terms covering deprivation, breast cancer, practice patterns, primary care and related synonyms were included and key authors were identified and searches conducted. The search strategy also involved hand searching relevant journals to ensure current work was not missed. The reference lists of retrieved articles were also inspected to identify relevant studies. Government reports on social inequalities and relevant grey literature such as PhD theses were accessed by contacting relevant organisations and health professionals working in the field and by searching the Internet.

A draft of the guide was sent to a large number of general practitioners and practice nurses from different areas in the country and caring for different populations, with the request that they comment on both the content and format of the guide. Additional comments were received from relevant researchers. Important changes to the guide were made in the light of the comments received.

A large number of references were used in compiling all statements in this guide. Including every reference would make the guide unwieldy and impractical to use. A full list of references is available on request. References for particular statements can also be provided.

DEPRIVATION AND BREAST CANCER

Background

- There is unequivocal evidence that women from deprived areas have significantly poorer survival
- Factors yet unknown may have an important bearing on the difference in breast cancer survival between affluent women and women from deprived areas

Factors associated with lower rates of survival for women in deprived areas

STRONG EVIDENCE

- Presenting with more advanced cancers (over 5 cms)

STRONGLY SUGGESTED

- Greater co-morbidity (worse host response)
- Receive different patterns of care (i.e. unmet psychological and informational needs for women in deprived areas)

MIXED EVIDENCE

- Delay in presenting for diagnosis

Factors NOT associated with lower rates of survival for women in deprived areas

STRONG EVIDENCE

- Prognostic factors on operable cancers (nodal involvement plus biology)
- System delays (i.e. clinic to surgery)
- Ethnicity
- Age

MIXED EVIDENCE

- Treatment received (i.e. surgical and adjuvant therapies)

Action

WITHIN THE PRACTICE

ENSURE

- That **all** women with breast problems and breast cancer receive care that is informed by national guidelines
  **See sources nos. 1–3, p. 20*

ENCOURAGE

- **All** women to be breast aware: to look at and feel their breasts in order to know what is normal for them and report any changes to their GP promptly
  **Particular role for practice nurses*

ADDRESS

- Possible factors that may be influenced in deprived populations:
  - general health (poor health may contribute to co-morbidity and less resistance to malignancy, and/or hinder recovery)
  - access to best treatment
  - delayed presentation *(see pp. 12–13)*
  - effective communication to meet psychological and informational needs
  - barriers to adopting a healthy personal lifestyle
  - promotion of breast awareness and screening

OUTSIDE THE PRACTICE

ADVOCATE

- Changes to education, employment, industrial structure, social policy and taxation
  **See sources nos. 4 –13, pp. 20–21*
- More funding for cancer centres and accessible support services in deprived areas
- More resources to reward GPs for providing longer consultations in deprived areas

DELAY ISSUES

Background

- Delays of more than 3– 6 months can affect survival
- Delays are associated with more advanced cancers and decreased survival
- Delays affect anywhere between 2.6 and 30% of women diagnosed with breast cancer in the UK (research evidence varies)

Social class variations

- Patients with a close relationship with their GP are less likely to delay. The patient / GP relationship may be closer in affluent areas possibly due to more continuous care, more available time and similar social class

Factors associated with patient delay

STRONG EVIDENCE

- Symptoms other than a breast lump (can lead to both patient and GP delay)
  See source no. 14, p. 21

MIXED EVIDENCE

- Above 65 years of age
- Below 50 years of age (i.e. symptoms in younger women are likely to be considered benign)
- Deprivation (it is uncertain whether delay is due to misinformation, other responsibilities, access or poverty itself)
- Motivation: presenting as a result of another person's encouragement
- Failure to disclose symptoms to family or significant others
- History of cancer in the family (fear)

Action

ENCOURAGE

- **All** women to be breast aware: to look at and feel their breasts in order to know what is normal for them and report any changes to their GP promptly
  **Particular role for practice nurses*

PROVIDE

- Information about symptoms other than lumps
  **See sources nos. 14 –15 and national patient information, p. 21*

- Information about the breast screening programme to women 50–64 years old

ADDRESS

- Fears about breast cancer and breast screening

ESTABLISH

- When the woman first discovered a symptom

REFER IF APPROPRIATE

- To a surgeon with a special interest in breast cancer
  ** See source no. 14, p. 21*

GP PRACTICE PATTERNS

Background

- Most GPs make prompt and appropriate referrals
- GPs' explanation of risks and benefits of treatment may differ for older women (e.g. due to greater toxicity concerns)

Social class variations

- Women from deprived areas have greater rates of GP consultation than affluent women
- GP practices in deprived areas may have shorter than average consultation times
- Women with breast cancer who may need longer consultations for psychological support are less likely to receive them in deprived areas than in affluent areas
- Women from deprived areas have more emergency admissions with newly diagnosed and advanced cancers and more general hospital admissions than affluent women

Action

REQUEST LOCAL PROTOCOLS

- For referral, management and follow-up from the treating hospital

ONLY REFER TO SPECIALIST BREAST SURGEON (SURGEON WITH SPECIAL INTEREST AND TRAINING IN BREAST CANCER)

ESTABLISH

- That treatment options have been fully discussed with the patient, including the topic of adjuvant therapy if appropriate

ENCOURAGE

- **All** women to ask questions, express concerns etc

ADVOCATE

- More resources to reward GPs for providing longer consultations

Remember:
that women from deprived areas tend to ask fewer questions, and may be less well informed, less able to articulate questions about their management or demand better services than affluent women.

BALANCE OF CARE

Background

- There is some evidence of overall variations in care in:
  - provision of triple assessment for diagnosis of primary disease at first visit

    Triple assessment consists of:
    - clinical examination
    - imaging (mammography and/or ultrasound)
    - fine needle aspiration cytology

  - access to and use of adjuvant therapy and multidisciplinary teams

  - follow-up arrangements for patients after treatment for primary breast cancer

Social class variations

SCREENING

- Uptake is higher among affluent women than among women from deprived areas

ASSESSMENT

- Social class does not affect the information the GP receives from the surgeon about diagnosis

TREATMENT

- GPs are more likely to receive management plans promptly for affluent women

- The Glasgow study found no difference between women from deprived and affluent areas in terms of NHS hospital treatment (surgical and non-surgical). Other studies have found geographical variation in treatment

- Differences in patterns of care may not reflect the type of treatment received but the organisation and effectiveness of care

FOLLOW-UP

- GPs are more likely to receive follow-up plans for affluent than for poor women

- There is a tendency for women from deprived groups not to attend follow-up. (It is uncertain whether this is due to access or attitude problems)

Action

PROMOTE

- Breast screening to **ALL** women 50-64 years old

REQUEST

- A management plan from specialist / surgeon including details of further treatment
  The GP should receive a care plan within one week after a patient's clinic appointment

- Discharge letter indicating immediate management

- Written report of planned further management for individual patient (with toxicity profile of any proposed systemic treatment)
  The GP should receive further management plans after the first post-operative review and after any changes in treatment

AGREE FOLLOW-UP ARRANGEMENT WITH PATIENT

Stress availability of immediate access to care in the event of any concerns and symptoms

INFORMATION AND SUPPORT

Background

- Doctors underestimate the amount of information that patients want
- Patients who request information are more likely to receive it
- Doctors / nurses could improve their ability to detect patients' emotional and practical needs
- Information should be provided in a way that allows the woman to absorb it
- Providing complete information increases satisfaction without increasing anxiety
- Psychotherapeutic counselling and educational intervention can improve quality of life and may improve life expectancy

Social class variations

- Class and race may influence patient–doctor communication
- More affluent women tend to ask more questions, be better informed, articulate questions about their treatment and demand better services

PSYCHOLOGICAL

- Cancer-related anxiety is no different between affluent and poor women
- Women from deprived areas:
  - have greater unmet psychological needs than affluent women
  - have more detrimental changes in health status (determined by the SF-36 health status questionnaire) and worse psychological morbidity following mastectomy
  - are more anxious regarding money and have other health and family problems

INFORMATIONAL

- Affluent women are more likely to request and therefore receive information
- Affluent women receive both more information and advice from a breast care nurse
- Women from deprived areas are less likely to use printed sources of information
- Women with a good prognosis, or younger, educated women, receive more information

INFORMATION AND SUPPORT

Action

EXPLORE

- Every woman's ideas, concerns and expectations about her disease, treatment, follow-up and support

ENCOURAGE

- All women to ask questions, express concerns etc

ESTABLISH

- What practical support may be required (i.e. childcare, benefits/subsidies, home help)
- That the woman knows how to access breast care services for support / advice
  **See sources nos. 16–21, p. 21*

PROVIDE

- Psychosocial support to the woman and family
- Verbal and written information in a staged way and in the woman's chosen language

REFER IF APPROPRIATE

- To specialist care (psychologist)

DEVELOP

- Effective interprofessional communication strategies
- Patient communication strategies

APPENDIX

FURTHER SOURCES OF INFORMATION

BREAST CANCER MANAGEMENT

1. DOCUMENT: *Guidelines for surgeons in the management of symptomatic breast disease in the United Kingdom (1998 revision)*
AUTHORS: British Association of Surgical Oncology, The BASO Breast Group
PUBLISHERS: W.B. Saunders Company Ltd
COPIES FROM: BASO Royal College of Surgeons of England, 5-43 Lincoln's Inn Fields, London WC2A 3PN
Phone: 020 7405 5612

2. DOCUMENT: *Improving outcomes in breast cancer. The manual, the research evidence, the guidelines for GPs (1996)*
AUTHORS: NHS Executive: Cancer Guidance Sub-Group of the Clinical Outcomes
PUBLISHERS: Department of Health Publications
COPIES FROM: Health Literature Line
PO Box 777,
London SE1 6XH
Phone: 0800 555 777

3. DOCUMENT: *Breast cancer in women. A national clinical guideline and quick reference guide (1998)*
AUTHORS: Scottish Intercollegiate Guidelines Network and the Scottish Cancer Therapy Network
PUBLISHERS: Scottish Intercollegiate Guidelines Network
COPIES FROM: http://www.show.scot.nhs.uk/sign/home.htm
SIGN Secretariat, 9 Queen Street, Edinburgh EH2 1JQ

INEQUALITY AND HEALTH

4. DOCUMENT: *Working towards a healthier Scotland (Feb 1999)*
AUTHORS: Scottish Office Department of Health
PUBLISHERS: The Stationery Office
COPIES FROM: http://www.scotland.gov.uk

5. DOCUMENT: *Saving lives: our healthier nation (White Paper July 1999)*
AUTHORS: Department of Health
PUBLISHERS: The Stationery Office
COPIES FROM: http://www.official-documents.co.uk/document/cm43/4386/4386.htm

6. DOCUMENT: *Better health / better Wales. Strategic framework (Oct 1998)*
AUTHORS: Public Health Division, National Assembly for Wales
PUBLISHERS: The Stationery Office
COPIES FROM: Phone: 029 2082 5417

7. DOCUMENT: *Well into 2000*
AUTHORS: Department of Health and Social Services, Northern Ireland
PUBLISHERS: Department of Health and Social Services
COPIES FROM: http://www.dhssni.gov.uk/the-department/publications/well2000/index.html

8. DOCUMENT: *Our healthier nation: a contract for health (Green Paper 1998)*
AUTHORS: Department of Health
PUBLISHERS: The Stationery Office
COPIES FROM: http://www.doh.gov.uk/ohn/ohnexec.htm

9. DOCUMENT: *Health 21 – health for all in the 21st century (1998)*
AUTHORS: World Health Organisation, Regional Office in Europe
PUBLISHERS: World Health Organisation
COPIES FROM: http://www.who.dk

10. DOCUMENT: *Independent inquiry into inequalities in health report (1998)*
AUTHORS: Sir Donald Acheson
PUBLISHERS: The Stationery Office
COPIES FROM: Phone: 0345 023474
INTERNET: http://www.official-documents.co.uk/document/doh/ih/ih.htm

11. DOCUMENT: *Social determinants of health (1999) (ISBN 0-19-263069-5)*
AUTHORS: Marmot M & Wilkinson R
PUBLISHERS: World Health Organisation / Oxford University Press
COPIES FROM: Phone: 01536 454 534
http://www.who.dk/document/E59555.pdf

12. DOCUMENT: *Healthy living centres (1998)*
AUTHORS: Department of Health
PUBLISHERS: Department of Health Publications
COPIES FROM: http://www.doh.gov.uk/pub/docs/doh/healthy.pdf

13. DOCUMENT: *Tackling inequalities in health (1995)*
AUTHORS: Benzeval M, Judge K, and Whitehead M
PUBLISHERS: The King's Fund
COPIES FROM: Grantham Book Services Limited
Isaac Newton Way, Alma Park
Industrial Estate, Grantham,
NG31 9SD
Phone: 01476 541 080

BREAST CANCER REFERRAL GUIDELINES

14. DOCUMENT: *Guidelines for referral of patients with breast problems (1999 2nd Edition)*
AUTHORS: Austoker J & Mansel R
PUBLISHERS: NHS Breast Screening Programme and The Cancer Research Campaign
COPIES FROM: CRC Primary Care Education Research Group
Phone: 01865 226788

BREAST AWARENESS

15. DOCUMENT: *Training resource pack for promoting breast awareness in primary care (October 1999)*
AUTHORS: Brett J and Austoker J
PUBLISHERS: NHS Breast Screening Programme and The Cancer Research Campaign
COPIES FROM: Health Promotion Units and Breast Screening Units or CRC Primary Care Education Research Group
Phone: 01865 226788

NATIONAL PATIENT INFORMATION (RESOURCES AND SUPPORT)

16. Breast Cancer Care
Kiln House, 210 New King's Road, London, SW6 4NZ
HELPLINE: 0808 800 6000
INTERNET: http://www.breastcancercare.org.uk

17. CancerBACUP
3 Bath Place, Rivington Street, London, EC2A 3JR
HELPLINE: 0808 800 1234
INTERNET: http://www.bacup.org.uk

18. Cancerlink
11-12 Northdown Street, London, N1 9BN
HELPLINE: 0800 132905

19. The Cancer Research Campaign
10 Cambridge Terrace, London, NW1 4JL
TELEPHONE: 020 7224 1333
INTERNET: http://www.crc.org.uk

20. Health Information Service
Regional offices throughout the UK
HELPLINE: 0800 66 55 44

21. Macmillan Cancer Relief
Anchor House, 15/19 Britten Street, London, SW3 3TZ
INFORMATION LINE: 0845 601 6161 (local rate charge)
INTERNET: http://www.macmillan.org.uk

NATIONAL
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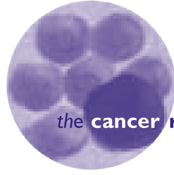
the cancer research campaign