

# Breast cancer screening in women with learning disabilities

## Current knowledge and considerations

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Updates from  
NHS Evidence - cancer

People with learning disabilities have a range of significant healthcare needs (van Schrojenstein Lantman-de Valk & Noonan Walsh, 2008), although they use primary care less than would be expected, receive fewer screening tests and have fewer health investigations.

Mainstream NHS responses to these issues have recently been criticised (Michael, 2008) leading to new guidance from the Department of Health on "reducing health inequalities; and ensuring high-quality evidence based specialist health services" (Department of Health, 2009).

The picture relating to establishing rates of incidence and prevalence of cancer in people with learning disabilities is complex with methodological issues highlighted in a recent review (Hogg J., & Tuffrey-Wijne I., 2008). The closure of long-stay hospitals and greater freedom of choice associated with community-based

living might increase risks, although there is as yet no coherent account of how such factors might influence cancer in people with learning disabilities.

The most recent review of literature relating to breast cancer screening in women with learning disabilities included 35 articles published between 1997 and 2007 (Willis et al, 2008). This review found limited evidence on the incidence of breast cancer in women with learning disabilities.

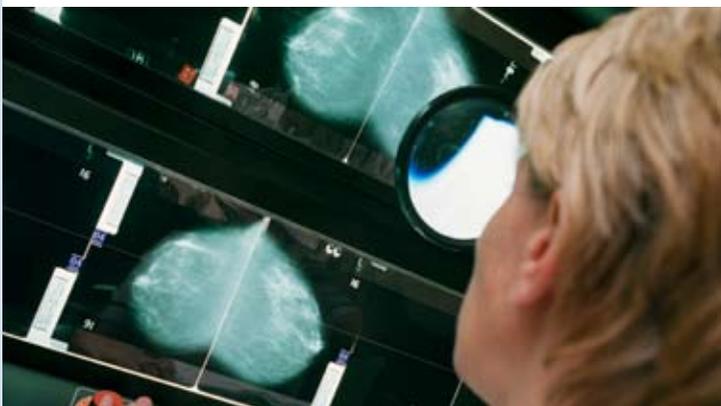
One major longitudinal study at Stoke Park hospitals over 65 years (1930-1995) reported lower incidence of breast cancer than found in the general population, although more recent studies that have included community-based samples report incidence comparable to the general population.

There was some suggestion that lower incidence may be related to aetiology - for example, in Trisomy 21, where expressions of genes on chromosome 21 have had a negative effect on tumour onset and progression. Breast cancer screening is lower in women with learning disabilities than in the general population. Two British studies reported higher uptake of breast screening of women with learning disabilities, one a postal questionnaire study of 99 women within a single community care provider.

The study had a 59% response rate and other methodological problems were pointed out by the authors. The second suggested one-to-one counselling would improve uptake and undertook an audit. From 160 women, 48 were found to be eligible for breast screening and the local mammography unit confirmed that 37/48 (77%) had attended. Key issues found in the literature relating to the uptake of screening included:

- Lack of information and support - one study reported that 23% of women had been given no explanation about the procedure
- Not receiving invitations to attend - being registered with a GP did not ensure invitation
- Poor literacy skills and/or low intellectual ability

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▶ See following pages for the latest additions to NHS Evidence - cancer

▶ The views expressed in this publication are not necessarily those of NHS Evidence - cancer



# 2009 Annual Evidence Update (AEU) on Breast Cancer

[www.library.nhs.uk/cancer](http://www.library.nhs.uk/cancer)

Annual Evidence Updates aim to support clinicians, commissioners and other health-care professionals to identify the best available, current evidence on key topics.

This AEU provides expert commentaries on a number of important topics including biological therapies for HER2 positive breast cancer, MRI for DCIS, post-operative radiotherapy for DCIS, Gabapentin for the treatment of hot flashes, breast cancer presentation and survival in relation to ethnicity and social deprivation, National Audit of cancer diagnosis in primary care, fertility related concerns of women with breast cancer, over diagnosis in publicly organised mammography screening programmes, the symptomatic breast two week wait standard, sentinel node biopsy: identification and classification after neoadjuvant chemotherapy.

Mr Clive Griffith, Breast cancer surgeon, Medical Director of Northern and Yorkshire Cancer Registry and National Clinical Advisor to NHS Improvement chaired the expert panel for the AEU and has written the editorial.

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## Breast screening for people with learning disabilities

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>>> Attempts are being made to improve the uptake of screening services, including:

- developing a joint health/social services protocol involving a liaison nurse to ensure awareness
- providing training and education to women and their families up to three months before breast screening (reporting of this study made it difficult to link outcomes with training inputs)
- local learning disability teams working in residential settings to increase breast awareness and uptake of breast screening using a teaching pack, checklist and resource pack for staff (this study had positive evaluations although there was no evidence of improved uptake)

The question of whether breast screening is appropriate for all women with learning disabilities is raised by a number of authors, with growing evidence to suggest women with Down syndrome should not be repeatedly screened, due to reported lower incidence and increased vulnerability to ionising radiations. Alternative means of breast surveillance are recommended. However, it is possible that many women with learning disabilities will not have the motor or cognitive skills to perform or understand breast checks. This raises issues for carers on whom this responsibility may fall.

The difficulty in detecting cancer in people with learning disabilities impacts on incidence rates and may also be masking breast cancer incidence in women with learning disabilities. The current evidence base suggesting low incidence of breast cancer and low uptake of breast screening should not be used to discourage women learning disabilities from attending breast screening.

## REFERENCES AND LINKS

Department of Health (2009); Valuing People Now: a new three-year strategy for people with learning disabilities, HMSO

Hogg.J., & Tuffrey-Wijne, I., (2008); Cancer and Intellectual Disability: A Review of Some Key Contextual Issues; in *Journal of Applied Research in Intellectual Disabilities* 2008, 21, 509–518

Michael J (2008); Healthcare for All. Report of the Independent Inquiry into access to healthcare for people with learning disabilities; Department of Health

van Schrojenstein Lantman-de Valk H, & Noonan Walsh P, (2008); Managing health problems in people with intellectual disabilities, in *British Medical Journal*, 13.12.08, 1408-1412

Willis D.S.; Kennedy C.M.; Kilbride L., (2008); Breast Cancer Screening in Women with Learning Disabilities: Current Knowledge and Considerations, in *British Journal of Learning Disabilities*, 36, 3, 171-184

Good practice in breast and cervical screening for women with learning disabilities [library.nhs.uk/learningdisabilities/ViewResource.aspx?resID=64040&tabID=288](http://library.nhs.uk/learningdisabilities/ViewResource.aspx?resID=64040&tabID=288)

## New content:

### All cancers

[The effect of provider case volume on cancer mortality: systematic review and meta-analysis, 2009.](#)

Brain metastases, 2009.

A narrative review of interventions to support family carers who provide physical care to family members with cancer, 2009.

Aurora kinase inhibitors in preclinical and clinical testing, 2009.

Preferences of Cancer Patients Regarding Communication of Bad News: A Systematic Literature Review, 2009.

Comparative survival with diverse chemotherapy regimens for cancer of unknown primary site: Multiple-treatments meta-analysis, 2009.

Effect of Surgeon Training, Specialization, and Experience on Outcomes for Cancer Surgery: A Systematic Review of the Literature, 2009.

Single-center series and systematic review of randomized controlled trials of malignancies in patients with rheumatoid arthritis, psoriatic arthritis, and ankylosing spondylitis receiving anti-tumor necrosis factor alpha therapy: Is there a need for more comprehensive screening procedures?, 2009.

**NHS Evidence - cancer** keeps its collections up to date.

These are some of the latest additions. Items in **blue** are 'Editor's pick' highlighted by Dr Chris Alcock, our Clinical Lead.

**NHS Evidence - cancer** has not performed in-depth appraisal for the systematic reviews and meta-analyses but has applied rigorous methods to select them.

We recommend that a full appraisal is completed using the appropriate tools provided by the Centre for Evidence-Based Medicine.

### Breast cancer

[A systematic review of FDG-PET in breast cancer, 2009.](#)

Post-operative radiotherapy for ductal carcinoma in situ of the breast - A systematic review of the randomised trials, 2009.

Return to work of breast cancer survivors: a systematic review of intervention studies, 2009.

[A meta-analysis of neoadjuvant chemotherapy combined with trastuzumab for HER2-positive breast cancers.], 2009.

Systematic Review of Day Surgery for Breast Cancer, 2009.

## Annual Evidence Update (AEU)

An Annual Evidence Update (AEU) presents the incidence of new high-quality research evidence during a specific time period. The aim is to 'fill the gaps' between major guidelines or systematic reviews. They provide an opportunity to highlight significant new evidence that has emerged in the preceding year and to provide commentaries where possible to interpret or put that evidence into the context for current clinical practice.

**For full details on the 2009 breast cancer AEU see page 2**  
**2009 lung cancer AEU launch: 16 November**

# New content:

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## Endocrine

Adjuvant radiotherapy for thymic epithelial tumors: a systematic review and meta-analysis, 2009.

Molecularly targeted therapies for thyroid cancers, 2009.

Recommended evaluation of adrenal incidentalomas is costly, has high false positive rates and confers a risk of fatal cancer that is similar to the risk of the adrenal lesion becoming malignant; time for a re-think?, 2009.

## Gynaecological cancer

A decision theory perspective on why women do or do not decide to have cancer screening: systematic review, 2009.

Comparison of laparoscopy and laparotomy for management of endometrial carcinoma: a meta-analysis, 2009.

Estimates of global research productivity in gynecologic oncology, 2009.

Post-treatment human papillomavirus testing for recurrent cervical intraepithelial neoplasia: a systematic review, 2009.

## Haematological cancer

Allogeneic stem cell transplantation for acute myeloid leukemia in first complete remission: systematic review and meta-analysis of prospective clinical trials, 2009.

Orbital lymphoma: Role of radiation, 2009.

## Head and neck cancer

Aldehyde Dehydrogenase 2 and Head and Neck Cancer: A Meta-analysis Implementing a Mendelian Randomization Approach, 2009.

MultiModality surgical and hyperbaric management of mandibular osteoradionecrosis, 2009.

Biomarkers in dysplasia of the oral cavity: A systematic review, 2009.

## Lower GI

Genetics of the hamartomatous polyposis syndromes: a molecular review, 2009.

**The effect of provider case volume on cancer mortality: systematic review and meta-analysis, 2009.**

Colon cancer: preventive agents and the present status of chemoprevention, 2009.

A systematic review and meta-analysis of cytoreductive surgery with perioperative intraperitoneal chemotherapy for peritoneal carcinomatosis of colorectal origin, 2009.

## Lung

Endobronchial ultrasound and transbronchial needle aspiration biopsy for mediastinal staging in patients with lung cancer: systematic review and meta-analysis, 2009.

Systematic review and meta-analysis of randomized and nonrandomized trials on safety and efficacy of video-assisted thoracic surgery lobectomy for early-stage non-small-cell lung cancer, 2009.

## Musculoskeletal

Bilateral adrenal metastases and metastatic subcutaneous deposit in the chest wall from osteosarcoma of the mandible: utility of (18)F-FDG-PET, 2009.

Prognostic factors in localized extremity osteosarcoma: A systematic review.

## Paediatric / adolescent cancer

Gender differences in the psychosocial experience of parents of children with cancer: a review of the literature, 2009.

Risk of second malignant neoplasms among childhood cancer survivors treated with radiotherapy: meta-analysis of nine epidemiological studies, 2009.

## Side-effects of treatment

Managing adverse events in the use of bevacizumab and chemotherapy, 2009.

Psychological aspects of fertility preservation in men and women affected by cancer and other life-threatening diseases, 2009.

## Symptom management

Cupping for Treating Pain: A Systematic Review, 2009.

## Upper GI

Liver ablation techniques: a review, 2009.

Impact of human immunodeficiency virus infection on the course of hepatitis C virus infection: A meta-analysis, 2009.

Octreotide for advanced hepatocellular carcinoma: a meta-analysis of randomized controlled trials, 2009.

Surgery versus radical endotherapies for early cancer and high grade dysplasia in Barrett's oesophagus, 2009.

Meta-analysis of percutaneous radiofrequency ablation versus ethanol injection in hepatocellular carcinoma, 2009.

## Urological

**Review of the efficacy and safety of radiofrequency ablation for the treatment of small renal masses, 2009.**

Clinical indications for Gallium-68 positron emission tomography imaging, 2009.

An Individual Patient Data Meta-Analysis of the Long-Term Outcome of Randomised Studies Comparing Intravesical Mitomycin C versus Bacillus Calmette-Guerin for Non-Muscle-Invasive Bladder Cancer, 2009.

Life course sun exposure and risk of prostate cancer: Population-based nested case-control study and meta-analysis, 2009.

The association risk of male subfertility and testicular cancer: a systematic review, 2009.