

National Institute for Health and Care Excellence

Advanced Breast Cancer (update) Addendum Consultation Table Consultation 12 March – 9 April 2014

Stakeholder	Order No	Document	Section No	Page No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment
Association for Palliative Medicine	1	Addendum	General		We would wish the guidance to stress that any patient with advanced breast cancer can be referred to palliative care services and this should be dependent on symptom need, rather than stage in disease. The inference throughout the document is that patients should be referred to palliative care services only when there is no active disease-modifying treatments that can be offered, whereas the 2 can run in parallel.	Thank you This update to the guideline relates specifically to lymphoedema and exercise. Other sections of this guideline are outside the remit of this update. However, the remainder of the advanced breast cancer guideline will remain in the NICE surveillance programme and will be assessed every 2 years for the need of update.
Association of Breast Surgery	1	Addendum	2.1.5		We conclude that it would be appropriate for the guidance to state that there is no convincing evidence in the medical literature to conclude the strenuous exercise of the ipsilateral arm after axillary lymph node dissection can provoke or hasten the onset of lymphoedema in that arm but the studies to definitively answer that question are not as yet	Thank you. The guidance does note within the 'linking evidence to recommendations' section that there are limitations to the

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					available.	evidence. The research recommendation has been developed in acknowledgement of the further research needed in this area
Breast Cancer Care	1	Addendum	General		I agree with the changes suggested in the general addendum. I hope further addendum will follow shortly and welcome the opportunity to act as a patient organisation representative.	Thank you
British Lymphology Society	1	Addendum	2.1.6		<p>The British Lymphology Society welcomes the update of the guideline but has one concern regarding the actual definition of exercise.</p> <p>Literature on the whole recognises exercise as an increase in exertion via activity. In the formal setting, exercise should be taught and encouraged to be delivered in a graduated, progressive manner which means that levels of exertion can be monitored against lymphatic stress.</p> <p>Alternatively there are the subjectively classified activities of daily living which are not usually progressive in nature, and tend to be sporadic and potential strenuous.</p> <p>The guideline committee had debated the use of strenuous versus non-strenuous terms, and the BLS agrees with their decision to avoid this clarification.</p>	<p>Thank you.</p> <p>An addition has been made to the linking evidence to recommendations section of this guideline addendum. The following text has been added, "The committee discussed the nature of the exercise programmes used in the included studies and noted that given the variety in the interventions undertaken in the included studies they could not be specific</p>

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					The BLS would suggest that the clarifying words “progressive and graduated” are included to inform the clinician and patient of the nature of activity advancement – which would be applicable to both pure exercise and activities of daily living.	about any particular form of exercise programme. Therefore, the committee agreed that it is not possible to more precisely describe the frequency and intensity of the exercise programmes that may be undertaken within the recommendation.” The lack of evidence related to activities of daily living is acknowledged in the linking evidence to recommendations section of this guideline addendum.
Dept of Health	1	Addendum			Thank you for the opportunity to comment on the draft addendum for the above clinical guideline. I wish to confirm that the Department of Health has no substantive comments to make, regarding this consultation.	Thank you
Macmillan Cancer Support	1	Addendum	2.1.6		Macmillan through its Lymphoedema Community of Practice welcomes and congratulates the contributors on this update. However as the evidence review finds, there is no evidence directly relating to activities of daily living as opposed to exercise, we consider that	Thank you. An addition has been made to the linking evidence to recommendations

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					<p>the translation across from one to the other requires some qualification. Exercise in a research environment will be graduated and progressive in intensity and frequency, where activities of daily living tend to be sporadic, we therefore suggest that the term 'graduated progressive' precede the word 'exercise' in both the summary recommendation sentences.</p> <p>Clearly, each patient's individual circumstances of pre-diagnosis fitness and activities of daily living should be assessed and taken into consideration when a professional is advising them.</p>	<p>section of this guideline addendum. The following text has been added, "The committee discussed the nature of the exercise programmes used in the included studies and noted that given the variety in the interventions undertaken in the included studies they could not be specific about any particular form of exercise programme. Therefore, the committee agreed that it is not possible to more precisely describe the frequency and intensity of the exercise programmes that may be undertaken within the recommendation." The lack of evidence related to activities of daily living is acknowledged in the linking evidence to</p>

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						recommendations section of this guideline addendum.
NCRI Breast Clinical Studies Group: Advanced Breast Cancer subgroup	1	Addendum			We would have expected to see this as an addendum to the early not the advanced breast cancer guidelines.	Thank you The treatment of lymphoedema is within the advanced breast cancer guideline and this addendum links to that section. This update does relate to both the advanced and the early breast cancer guidelines and links have been added into the NICE pathway, the early breast cancer guideline and the information for the public versions to reflect this.
NCRI Breast Clinical Studies Group: Advanced Breast Cancer subgroup	1	Addendum			We would support the recommendations	Thank you
NHS England	1	Addendum			Thank you for the opportunity to comment the consultation for the above clinical guideline I wish to confirm that NHS England has no substantive comments to make regarding this consultation.	Thank you

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Roche	1	Addendum			I can confirm that Roche Products Ltd. do not have any comments to make on the Advanced Breast Cancer CG addendum.	Thank you
Royal College of Nursing	1	Addendum	General		<p>The Royal College of Nursing is a registered stakeholder for CG81 Advanced Breast Cancer clinical guideline.</p> <p>The Royal College of Nursing was invited to comment on the consultation on the addendum to Chapter 6 of the guideline.</p> <p>The document was circulated to nurses caring for people with breast cancer for their views. Below are comments received from the reviewers</p>	Thank you
Royal College of Nursing	2	Addendum	2.1.2		Whilst post operative physiotherapy regimens were excluded it is important to recognise that many patients present with late onset symptoms contributing to a reduction in efficiency of lymphatic drainage such as complex scarring, myofascial tightness and radiation fibrosis. Assessments of likely contributing factors need to be noted and addressed prior to exercise interventions. Implications are for patients to access specialist assessment.	<p>Thank you.</p> <p>The remit of this update did not include the consideration of the presentation of lymphoedema, therefore issues relating to the assessment of lymphoedema is outside the remit of this update.</p>
Royal College of Nursing	3	Addendum	2.1.6		1) Should this discussion that current evidence indicates that evidence does not prevent, cause or exacerbate lymphoedema include, that evidence does show the benefits of graduated and progressive exercise regimes to reduce risk of injury and allow accommodation to increased demand of the tissues.	<p>Thank you.</p> <p>Due to the variety of exercise programmes used within the studies we cannot be specific about the types of</p>

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					<p>Experience from clinical practice suggests that patients do need some guidance here.</p>	<p>exercise. An addition has been made to the linking evidence to recommendations section of this guideline addendum. The following text has been added, "The committee discussed the nature of the exercise programmes used in the included studies and noted that given the variety in the interventions undertaken in the included studies they could not be specific about any particular form of exercise programme. Therefore, the committee agreed that it is not possible to more precisely describe the frequency and intensity of the exercise programmes that may be undertaken within the recommendation."</p>

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Royal College of Nursing	4	Addendum	2.1.6		2) <i>Exercise improves quality of life</i> – suggest add that exercise helps in weight management, (high BMI affects circulation and lymphoedema – evidenced) joint mobility and strength, well being etc. Difficulty of access to exercise groups, forums, socio economic background, ethnicity, body image concerns	Thank you. This update includes exercise in relation to those at risk of or with lymphoedema. It is not considering the overall effects of exercise. There was some evidence that considered quality of life in general, and following the standing committee's discussion, this was included in the recommendations. An explanatory sentence has been added to the linking evidence to recommendations section of the addendum.
Royal College of Nursing	5	Addendum	2.1.7.		1) Many established lymphoedema patients have adapted their own self care of lymphoedema and developed different habits. Any trials to compare interventions should first ensure that the four cornerstones of lymphoedema care are practiced and patients' self management techniques revisited much as manual lymphatic drainage techniques are reviewed at 2 yearly updates.	Thank you. The research recommendation does include investigating exercise as an adjunct to established lymphoedema treatments.
Royal College of Nursing	6	Addendum	2.1.7.		2) This must include assessment of factors likely to affect lymphatic flow such as complex scarring,	Thank you This research

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					myofascial tightness, radiation fibrosis and also should these factors have been treated first or be part of the trials?	recommendation is considering the role of exercise. The design of future studies will be the remit of the researchers. These studies will have to attain ethical approval including inclusion criteria.

These organisations were approached but did not respond:

- 3M Health Care UK
- ABA Autism Education Ltd
- Abbott Molecular
- AbbVie
- Abertawe Bro Morgannwg University Health Board
- Action Cancer - NI
- Airedale NHS Trust
- Allergan Ltd UK
- Allocate Software PLC
- American Medical Systems Inc.
- Amgen UK
- Anglia cancer network
- Applied Medical UK Ltd
- Aspen Medical Europe
- Association for Dance Movement Psychotherapy UK

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Association for Family Therapy and Systemic Practice in the UK
Association of Anaesthetists of Great Britain and Ireland
Association of Breastfeeding Mothers
Association of British Insurers
Association of Chartered Physiotherapists in Oncology and Palliative Care
Astrazeneca UK Ltd
Autism in Mind
Barnsley Hospital NHS Foundation Trust
Basingstoke and North Hampshire NHS Foundation Trust
Baxter Healthcare
Bayer HealthCare
Betsi Cadwaladr University Health Board
BME cancer.communities
Boehringer Ingelheim
Bradford District Care Trust
Breakthrough Breast Cancer
Breast Cancer Campaign
Breast Cancer UK
Bristol and Avon Chinese Women's Group
Bristol-Myers Squibb Pharmaceuticals Ltd
British Academy of Childhood Disability
British Association for Counselling and Psychotherapy
British Association of Surgical Oncology
British Dietetic Association
British Geriatrics Society-Special Interest Group in Diabetes
British Hypertension Society
British Medical Association

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British Medical Journal
British National Formulary
British Nuclear Cardiology Society
British Pain Society
British Psychological Society
British Psychosocial Oncology Society
British Red Cross
British Society for Immunology
British Society of Breast Radiology
BUPA Foundation
C. R. Bard, Inc.
Cambridge University Hospitals NHS Foundation Trust
Camden Link
Cancer Commissioning Team
Cancer Network User Partnership
Cancer Phytotherapy Service
Cancer Research UK
Cancer Services Co-ordinating Group
Cancer Voices
Capsulation PPS
Capsulation PPS
Care Not Killing Alliance
Care Quality Commission
Celgene UK Ltd
Central & North West London NHS Foundation Trust
Central Manchester University Hospitals NHS Foundation Trust
Central South Coast Cancer Network

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Cephalon UK Ltd
Cepheid Uk Ltd
Chartered Society of Physiotherapy
Cheshire and Merseyside SCN
Citizens Commission on Human Rights
Clarity Informatics Ltd
Clatterbridge Cancer Centre
CLIC Sargent
College of Occupational Therapists
Coverage Care Services Ltd
Covidien Ltd.
Croydon Clinical Commissioning Group
Croydon Health Services NHS Trust
Croydon University Hospital
Department of Health, Social Services and Public Safety - Northern Ireland
Dudley PACT Patient Advisory Cancer Team
East and North Hertfordshire NHS Trust
East Kent Hospitals University NHS Foundation Trust
East Midlands Cancer Network
Economic and Social Research Council
Eisai Ltd
Eli Lilly and Company
Enfield Child and Adolescent Mental Health Service
Essex County Council
Ethical Medicines Industry Group
Faculty of Intensive Care Medicine
Faculty of Pharmaceutical Medicine

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Faculty of Public Health
Faculty of Sport and Exercise Medicine
Five Boroughs Partnership NHS Trust
Foundation for People with Learning Disabilities
GE Healthcare
General Medical Council
George Eliot Hospital NHS Trust
GfK Bridgehead
GlaxoSmithKline
Gloucestershire Hospitals NHS Foundation Trust
Gloucestershire LINK
Great Western Hospitals NHS Foundation Trust
Greater Manchester and Cheshire Cancer Network
Greater Manchester, Lancashire, South Cumbria Strategic Clinical Network
Greater Midlands Cancer Network
Grunenthal Ltd
Harrow Local Involvement Network
Haven Trust, The
Health & Social Care Information Centre
Health and Care Professions Council
Healthcare Improvement Scotland
Healthcare Infection Society
Healthcare Inspectorate Wales
Healthcare Quality Improvement Partnership
Healthwatch East Sussex
Heart of England NHS Foundation Trust
Herts Valleys Clinical Commissioning Group

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Hindu Council UK
Hockley Medical Practice
Hospira UK Limited
Hull and East Yorkshire Hospitals NHS Trust
Humber NHS Foundation Trust
IGEA Medical
Impact of Neutropenia in Chemotherapy European study group
Independent Cancer Patients' Voice
Institute of Biomedical Science
Integrity Care Services Ltd.
Isabel Hospice
Janssen
Johnson & Johnson Medical Ltd
KCARE
Lancashire Care NHS Foundation Trust
Lancashire Teaching Hospitals NHS Trust
Leeds Community Healthcare NHS Trust
Leicester Royal Infirmary
Local Government Association
London Cancer
London cancer alliance
Luton and Dunstable Hospital NHS Trust
Marie Curie Cancer Care
Medicines and Healthcare products Regulatory Agency
Merck Sharp & Dohme UK Ltd
Mid Yorkshire Hospitals NHS Trust
Milton Keynes Hospital NHS Foundation Trust

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Ministry of Defence (MOD)
Monash Health
Muslim Council of Britain
Muslim Doctors and Dentists Association
National Autistic Society
National Cancer Action Team
National Cancer Intelligence Network
National Clinical Guideline Centre
National Collaborating Centre for Cancer
National Collaborating Centre for Mental Health
National Collaborating Centre for Women's and Children's Health
National Co-ordination Group for Nurses in Breast Screening
National Council for Palliative Care
National Deaf Children's Society
National Institute for Health Research Health Technology Assessment Programme
National Institute for Health Research
National Patient Safety Agency
National Public Health Service for Wales

National Radiotherapy Implementation Group
NHS Barnsley Clinical Commissioning Group
NHS Connecting for Health
NHS Cumbria Clinical Commissioning Group
NHS Health at Work
NHS Improvement
NHS Medway Clinical Commissioning Group
NHS National Specialised Commissioning Team
NHS Plus

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NHS Sheffield CCG
NHS South Cheshire CCG
NHS Wakefield CCG
NHS Warwickshire North CCG
Nordion
Norgine Limited
North of England Cancer Network
North of England Commissioning Support
North Trent Cancer Network
North West London Hospitals NHS Trust
Northern Ireland Cancer Network
Nottingham City Council
Nottingham City Hospital
Nottingham University Hospitals NHS Trust
Nova Healthcare
Novartis Pharmaceuticals
Nucletron
Nursing and Midwifery Council
Oxford Health NHS Foundation Trust
Oxford University Hospitals NHS Trust
Oxfordshire Clinical Commissioning Group
Pan Birmingham Cancer Network
Parenteral and Enteral Nutrition Group
Partneriaeth Prifysgol Abertawe
Patient Assembly
Peninsula Cancer Network
Peterborough and Stamford Hospitals NHS Foundation Trust

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Pfizer
Pharmametrics GmbH
PHE Alcohol and Drugs, Health & Wellbeing Directorate
Pierre Fabre Ltd
Pilgrim Projects
Pilgrims Hospices in East Kent
PrescQIPP NHS Programme

Primary Care Partnerships
Primary Care Pharmacists Association
Primary Care Society for Gastroenterology
Primrose Bank Medical Centre
Public Health England
Public Health Wales NHS Trust
Queen Elizabeth Hospital King's Lynn NHS Trust
Queen Mary University of London
Rarer Cancers Foundation
Roche Diagnostics
ROCK Medical Communications
Royal Berkshire NHS Foundation Trust
Royal Brompton Hospital & Harefield NHS Trust
Royal College of Anaesthetists
Royal College of General Practitioners
Royal College of General Practitioners in Wales
Royal College of Midwives
Royal College of Midwives
Royal College of Obstetricians and Gynaecologists
Royal College of Paediatrics and Child Health

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Royal College of Paediatrics and Child Health , Gastroenterology, Hepatology and Nutrition
Royal College of Pathologists
Royal College of Physicians
Royal College of Physicians and Surgeons of Glasgow
Royal College of Psychiatrists
Royal College of Radiologists
Royal College of Surgeons of Edinburgh
Royal College of Surgeons of England
Royal Free Hospital NHS Foundation Trust
Royal Free London NHS Foundation Trust
Royal Manchester Children's Hospital
Royal Marsden NHS Foundation Trust
Royal Pharmaceutical Society
Royal Society of Medicine
Royal Surrey County Hospital NHS Foundation Trust
Royal Surrey County Hospital NHS Trust
Sandoz Ltd
Sanofi
Scottish Intercollegiate Guidelines Network
SEE Pfizer - DO NOT USE Wyeth Pharmaceuticals
Sheffield Teaching Hospitals NHS Foundation Trust
Shropshire & Mid Wales Cancer Forum
SNDRi
Sobell House Hospice Charity
Social Care Institute for Excellence
Society and College of Radiographers
Society for Endocrinology

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Society for the Protection of Unborn Children
South Asian Health Foundation
South London & Maudsley NHS Trust
South Wales Cancer Network
South West Thames Regional Genetics Service
South West Yorkshire Partnership NHS Foundation Trust
Southern Health Foundation Trust
Southport and Ormskirk Hospital NHS Trust
Spinda Bifida . Hydrocephalus . Information . Networking . Equality
St Christophers Hospice
St Mary's Hospital
St Nicholas Hospice
Staffordshire and Stoke on Trent Partnership NHS Trust
Step4Ward Adult Mental Health
Stockport Clinical Commissioning Group
Surrey, West Sussex and Hampshire Cancer Network
Sussex Cancer Network
Teenagers and Young Adults with Cancer
Tenovus Cancer Information Centre
Teva UK
The African Eye Trust
The Association for Cancer Surgery
The Association of the British Pharmaceutical Industry
The British In Vitro Diagnostics Association
The Christie NHS Foundation Trust
The Institute of Cancer Research
The National LGB&T Partnership

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The Patients Association
The Rotherham NHS Foundation Trust
The Royal Centre for Defence Medicine
UCL Partners
UCL/UCLH Institute for Women's Health
UK Clinical Pharmacy Association
UK Pain Society
Unison
University College London Hospital NHS Foundation Trust
University College London Hospitals NHS Foundation Trust
University Hospital Birmingham NHS Foundation Trust
University Hospital Of South Manchester NHS Foundation Trust
University Hospitals Birmingham
Velindre NHS Trust
Vygon
Walsall Local Involvement Network

Warrington and Halton Hospitals NHS Foundation Trust
Welsh Cancer Services Coordinating Group
Welsh Government
Welsh Scientific Advisory Committee
West Midlands Ambulance Service NHS Trust
West Suffolk Hospital NHS Trust
Western Sussex Hospitals NHS Trust
Westminster Local Involvement Network
Wigan Borough Clinical Commissioning Group
Women's Support Network
Wye Valley NHS Trust

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York Hospitals NHS Foundation Trust
Yorkshire Ambulance Service NHS Trust
Yorkshire Cancer Network

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