

Standards of Care
for people with

Metabolic Bone Disease



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ARMA is the umbrella organisation for the UK musculoskeletal community. ARMA is a registered charity No 1108851. Our member organisations are:

- Arthritis Care
- Arthritis Research Campaign
- BackCare
- British Chiropractic Association
- British Coalition of Heritable Disorders of Connective Tissue
- British Health Professionals in Rheumatology
- British Institute of Musculoskeletal Medicine
- British Orthopaedic Association
- British Osteopathic Association
- British Pain Society
- British Sjögren's Syndrome Association
- British Society for Paediatric and Adolescent Rheumatology
- British Society for Rheumatology
- British Society of Rehabilitation Medicine
- Chartered Society of Physiotherapy
- Children's Chronic Arthritis Association
- CHOICES for Families of Children with Arthritis
- College of Occupational Therapy Specialist Section – Rheumatology
- Early Rheumatoid Arthritis Network
- Lupus UK
- Manipulation Association of Chartered Physiotherapists (UK)
- Marfan Association (UK)
- National Ankylosing Spondylitis Society
- National Association for the Relief of Paget's Disease
- National Osteoporosis Society
- National Rheumatoid Arthritis Society
- Podiatry Rheumatic Care Association
- Primary Care Rheumatology Society
- Psoriatic Arthropathy Alliance
- Raynaud's and Scleroderma Association
- Rheumatoid Arthritis Surgical Society
- Royal College of Nursing Rheumatology Forum
- Scleroderma Society
- Society for Back Pain Research

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The contents of this document and further resources including contact details for our member organisations, further information about our work and this project, including additional examples of good practice and resources to support implementation, are available on the ARMA website at www.arma.net.uk.

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Metabolic Bone Disease - The size of the problem

Metabolic Bone Disease is the term used to describe a range of conditions, including Osteoporosis, Paget's disease, Osteomalacia and Osteogenesis Imperfecta (OI), otherwise known as brittle bone disease. These are all diseases which cause bones to become fragile and break without too much force. Common fracture sites are the wrist, hip and vertebrae but fractures may occur throughout the skeleton.

Metabolic Bone Disease may be caused by genetic factors or lifestyle and can also be secondary to other problems, for example corticosteroid use¹. For some people there will be no obvious cause. There are other risk factors that increase the risk of osteoporosis and fractures, such as increasing age², falls³ and previous fracture⁴.

One in two women and one in five men will suffer a fracture after the age of 50⁵. There are more than 1.14 million postmenopausal women who have been diagnosed with osteoporosis after a DXA (bone density) scan of the hip in England and Wales⁶. Over 60,000 hip, 50,000 wrist and 120,000 vertebral fractures occur each year in the UK^{7,8,9}.

Paget's disease is the second most common metabolic bone disease, after osteoporosis, affecting about 2% of the UK population above the age of 55 years¹⁰. The incidence of Paget's disease increases with advancing age. Despite its prevalence, it is often neglected, as some clinicians consider it to be a benign but uncommon condition of the elderly, for which there is no treatment^{11,12}.

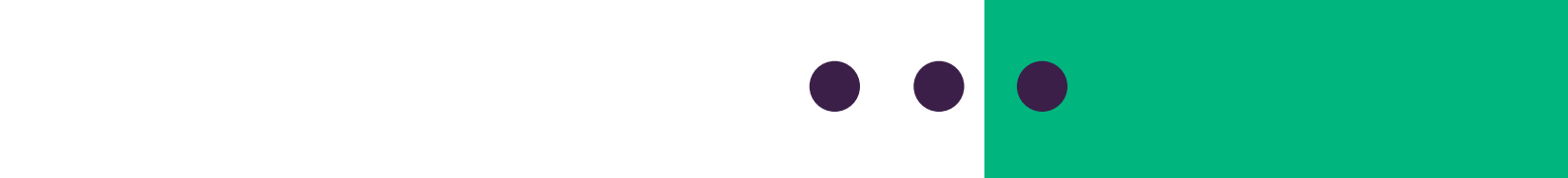
What is the impact of Metabolic Bone Disease?

Osteoporosis is a chronic disease with late clinical consequences. For this reason it has been termed the 'silent epidemic' since there are no associated symptoms or warning signs prior to fracture. Osteoporotic fractures can have an enormous personal cost.

In total, approximately 14,000 people die each year following a hip fracture in the UK¹³. 12 months after hip fracture 60% of patients are limited in at least one activity of daily living (e.g. feeding, dressing, toileting) and 80% are unable to undertake activities such as shopping, gardening and climbing stairs¹⁴.

The cost of osteoporosis to the NHS, individuals and their families is high. The combined cost of hospital and social care for patients with a hip fracture amounts to more than £1.73 billion per year in the UK¹⁵. The cost of treating all osteoporotic fractures in postmenopausal women alone has been predicted to rise to more than £2.1 billion in the year 2020¹⁶.

Paget's disease is a condition in which there is a marked increase in bone turnover in parts of the skeleton, resulting in the development of structurally weak abnormal bone, with an increased risk of pain, fracture, deformity, osteoarthritis of the large joints and deafness. It is estimated that it affects 2% of people over the age of 55 but only 5% of people with Paget's disease are symptomatic. There are wide variations in these estimates making it difficult to assess the true clinical burden of the condition. There is therefore no reliable information relating to the costs of Paget's disease and its treatment to the NHS¹⁷.



Despite there still being considerable debate surrounding the aetiology of Paget's disease, over the last few years a number of highly effective bisphosphonate treatments have been developed which can effectively suppress the symptoms and may prevent the development of complications.

Osteomalacia is a condition where there is a deficiency of mineral within the bone itself. This leads to bone pain, deformity and easy fracture. In growing bones, a related condition known as rickets may result in permanent skeletal deformity. By far the most common cause of osteomalacia is deficiency of vitamin D. This can be associated with a variety of disease states but is most commonly nutritional in origin. Vitamin D is usually obtained by the action of sunlight on the skin. The groups most frequently affected by vitamin D deficiency within the population include members of the South Asian community and elderly housebound patients.

Why we need Standards of Care

Evidence shows that people's experiences and the quality of care they receive varies a great deal across the UK depending on the approach and configuration of their local services. The care of people with metabolic bone disease requires self-management with the input of a range of health professionals and others in voluntary and public sector support roles.

There is good evidence for the effectiveness of many interventions and treatments. Furthermore, many services are delivering innovative and successful management of metabolic bone disease pain, but to date there has been no agreed common standard of how this should be best achieved.

For many years musculoskeletal conditions have not featured significantly in major health policies across the UK: The National Service Framework for long-term conditions in England mainly focuses on neurological conditions, and no musculoskeletal conditions feature in the Quality and Outcomes Framework of the current UK General Medical Services Contract. This has led to a lack of profile and priority for musculoskeletal conditions in the delivery of services.

The public policy agenda is better now for musculoskeletal conditions than when ARMA first published Standards of Care in 2004. In recent times there have been a number of policies published which have implications for musculoskeletal services. The publication of the *Our Health, Our Care, Our Say* White Paper in January 2006 outlined some important aims: better prevention services with earlier interventions; more choice and a louder voice; tackling inequalities and improving access to community services; and more support for people with long-term needs. These are also fundamental principles within the Standards of Care.

In addition the development of the Musculoskeletal Services Framework for England, a Welsh Arthritis Strategy and the ICATs scheme in Northern Ireland are welcome policy initiatives that will help service providers and commissioners to achieve the ARMA Standards of Care. People with metabolic bone disease are also likely to be affected by other areas of policy.

These Standards of Care aim to bring together existing evidence and good practice to create a framework for services which really meet the needs of the many people who experience metabolic bone disease. Implementation of these Standards should:

- Improve prevention and effective treatment of metabolic bone disease and so improve the quality of life of individuals who are affected by metabolic bone disease

- Identify for people with metabolic bone disease the care and treatment they can expect
- Enable the NHS to make more effective use of resources by helping to prevent avoidable disability and by reducing the number of return GP consultations and hospital appointments due to metabolic bone disease
- Promote consistent advice and treatment
- Reduce levels of disability due to metabolic bone disease
- Improve productivity and reduce the benefits bill by enabling people to stay in work

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- 1 van Staa TP, Leufkens HG, Cooper C. The epidemiology of corticosteroid-induced osteoporosis: a meta-analysis. *Osteoporosis International*, 2002, 13, pp. 777-87.
 - 2 Kanis JA, Borgstrom F, De Laet C, Johansson H, Johnell O, Jonsson B et al. Assessment of fracture risk. *Osteoporosis International*, 2005,16, pp.581-9.
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 - 4 Black DM, Arden NK, Palermo L, Pearson J, Cummings SR. Prevalent vertebral deformities predict hip fractures and new vertebral deformities but not wrist fractures, Study of Osteoporotic Fractures Research Group. *Journal of Bone and Mineral Research*, 1999, 14, pp. 821-8.
 - 5 van Staa TP, Dennison EM, Leufkens HG, Cooper C. Epidemiology of fractures in England and Wales. *Bone*, 2001, 29, pp. 517-22.
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 - 8 Keene GS, Parker MJ, Pryor GA. Mortality and morbidity after hip fractures, *British Medical Journal*, 1993, 307, pp. 1248-50.
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 - 10 Paget J. On a form of chronic inflammation of bones (osteitis deformans), *Medico-Chirurgical Transactions*, 1887, 16, pp. 37-63.
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 - 14 Cooper C. The crippling consequences of fractures and their impact on quality of life. *American Journal of Medicine*, 1997, 103, pp. 12S-17S.
 - 15 Torgerson D, Iglesias C, Reid DM. The economics of fracture prevention. In Barlow DH, Francis RM, Miles A, eds, *The Effective Management of Osteoporosis*. London, Aesculapius Medical Press, 2001.
 - 16 Burge RT. The cost of osteoporotic fractures in the UK. Projections for 2000-2020. *Journal of Medical Economics*, 2001, 4, pp. 51-62.
 17. Smith R. *Biochemical Disorders of the Skeleton*. London: Butterworth, 1992.

ARMA's Standards of Care for people with metabolic bone disease are intended to support people of all ages with metabolic bone disease to lead independent lives and reach their full health potential through:

- access to information, support and knowledge that optimise musculoskeletal health for everyone and enable self-management
- access to the right services that enable early diagnosis and treatment
- access to ongoing and responsive treatment and support.

The Standards define what services are appropriate under these three themes and suggest ways of providing them effectively, and in a measurable way, in the form of key interventions. A detailed rationale for the Standards draws on available evidence and examples of good practice drawn from ARMA's ongoing call for good practice: a database giving details of these and other examples is available at www.arma.uk.net.

The Standards are not guidelines, or algorithms of care, though they refer to these where available.

The Standards of Care for people with metabolic bone disease form part of a suite of Standards; other Standards published to date are for back pain, connective tissue diseases, inflammatory arthritis, osteoarthritis and regional musculoskeletal pain.

The Standards acknowledge the fact that those planning and delivering services around the UK face differing demographic, geographic and economic factors, which will affect how the Standards are implemented in each locality. We hope the Standards will act as a tool for all stakeholders - service users, providers, commissioners and policy-makers - to work together to review and improve their local musculoskeletal services.

Key principles – the user-centred approach

The project has been driven by the needs of people living with musculoskeletal conditions. It began with the establishment of a set of key principles for care, developed by a group of people living with musculoskeletal conditions and consulted upon widely. These principles have underpinned the development of each set of condition-specific Standards. The key principles, which can be found on ARMA's website www.arma.uk.net, affirm that 'patients' are individuals who need different types of advice and support at different times; and who need integrated services providing advice and support that cover all aspects of managing and living with the condition – clinical, personal, social and employment/education. In particular, the Standards recognise that health services play a key role in supporting people to maintain or return to employment or education.

Nevertheless, while these standards focus on health services, it must be recognised that people with metabolic bone disease and other musculoskeletal conditions have wide-ranging needs. Social care often plays a key role in ensuring people can remain as active and independent as possible. Factors such as access to transport and the built environment may have a major impact on quality of life. More work is needed to understand and meet these needs.

Musculoskeletal conditions affect families and carers as well as individuals. Indeed, many people with these conditions may be carers themselves. The Standards do not make specific recommendations on issues relating to carers: this also needs to be the subject of further work to ensure that carers' needs are understood and addressed.



How the Standards were developed

The Standards of Care for people with metabolic bone disease were developed by an expert working group, facilitated by ARMA. The group included experienced service providers and experts from many professions, from around the UK. Starting with a review of the needs of people with metabolic bone disease, the group met 3 times between November 2005 and July 2006 to determine evidence-based Standards to meet those needs, consulting widely and publicly on the drafts. The Acknowledgements on page 19 give details of the working group membership.

Clinical experts have identified the evidence base, including relevant guidelines for the management of metabolic bone disease. References are shown as footnotes in the Standards. Evidence has not been graded for the purposes of this document. For further details on the evidence base, please refer to the references quoted in the document.

The resulting Standards are therefore based firmly on the experiences and preferences of people with metabolic bone disease, and on evidence and good practice where this is available. ARMA plans to review these Standards in 2009, or sooner if there are significant developments in care for people with metabolic bone disease.

Next steps

The publication of these Standards is the beginning of an ongoing programme involving the whole community to improve musculoskeletal services. We are circulating the Standards widely to people with musculoskeletal conditions, doctors, allied health professionals, providers and commissioners of health services, voluntary organisations and policy makers. We will publish audit tools to support the Standards' implementation. We are also collecting and sharing examples of good practice, which are accessible to everyone through our online database.

We invite all stakeholders to make a commitment to implementing the Standards. First steps might be to:

- audit existing services
- identify champions for change in musculoskeletal services, and set up a working group to develop your local strategy and priorities
- work in partnership with all stakeholders, including national and local voluntary organisations, to involve service users in designing and developing services.

Above all share your success! Tell us about your initiatives; send us examples of good practice; help to build a national resource for high-quality musculoskeletal services.

Promoting bone health

Standard 1

Health, community and education services should make information available to the public (in a range of languages and formats) on lifestyle choices that promote bone health and prevent bone deterioration. This should include information on exercise, nutrition and the prevention of injuries, falls in older people and broken bones. In addition to general information available through organisations such as NHS Direct, there should be targeted information for at-risk groups. Information should be available in many settings including GP surgeries, accident and emergency departments, secondary care, pharmacies and schools.

Self-management

Standard 2

Health and community services, the voluntary sector and other agencies should provide up

to date information through a range of media, offering advice and support. This should aim to help people identify the signs and symptoms of, or risk factors for, metabolic bone diseases. It should highlight possible complications and address pain management, remaining active and other lifestyle measures and knowing how and when to seek professional advice. Healthcare professionals and people with metabolic bone disease should be made aware of local and national service user support organisations.

Information on services, treatments and providers

Standard 3

Healthcare professionals should ensure that people with metabolic bone disease, or at high risk of developing it, have access to information and guidance that enables them to make informed choices of service providers, the treatments they offer and the facilities in which they are delivered.


The rationale

- There are many lifestyle factors that lead to good bone health. Ensuring that people avoid smoking, undertake appropriate exercise and have a well-balanced diet from a young age and throughout their life can help to prevent the occurrence of metabolic bone disease.
- There is evidence that weight bearing exercise improves bone health. Bone is a living tissue, which reacts to increases in loads and forces by growing stronger. Weight-bearing exercise can increase bone density by stimulating the bone building cells. Evidence suggests that maintenance of good nutrition and exercise is likely to be useful to children in developing a healthy skeleton in adult life.
- Exercises designed to improve muscle strength and balance, when maintained regularly over time, have been shown to prevent falls.
- Nutrition is an important factor in determining bone health. Having a healthy, balanced diet that includes sufficient quantities of calcium and other vitamins and minerals is essential to create healthy bones.
- Having a healthy body mass index is also important, as being over or under weight can lead to poor bone health.

- Very low levels of vitamin D lead to osteomalacia (and rickets in children), while reduced levels may contribute to osteoporosis. It is possible to maintain healthy levels of vitamin D by 15-20 minutes daily exposure of the face and arms to sunlight without sunscreen during summer months or by taking supplements. Making people aware of the benefits of supplements and sunlight can help prevent the development of bone disease. It is particularly important that this information reaches Asian communities as low levels of vitamin D and osteomalacia are prevalent amongst this population in the UK.
- Other lifestyle factors also contribute to bone health; smoking leads to poor bone health and whilst a moderate intake of alcohol may be beneficial for bone health, an excessive intake of alcohol is detrimental.
- More public awareness of metabolic bone diseases can help people with signs and symptoms of disease to manage them effectively and seek professional advice appropriately.
- In order for people with metabolic bone disease to become active and equal partners in their own care, they need to be well-informed about their condition, empowered to take responsibility for their musculoskeletal health, and able to make informed choices about treatments, providers and settings for care.

Putting the Standards into practice: **key interventions**

- i Health, community and education services should make information available to the public on lifestyle choices that promote bone health and prevent bone deterioration. This should include information about:
 - exercise
 - nutrition
 - smoking cessation
 - prevention of falls and injuries
- ii Health agencies should provide appropriate information on the range of treatments and management options, providers and settings for care. Information should be accurate, consistent, clear and accessible. It should be available in a variety of formats and in a range of languages where appropriate.
- iii Healthcare providers/commissioners, social services, voluntary sector and leisure services should develop partnerships to deliver seamless comprehensive services to support people with metabolic bone disease.
- iv At risk groups should be targeted with relevant information:
 - a. The Asian and Middle Eastern population should receive information about the importance of having adequate levels of vitamin D and how they can achieve this
 - b. The frail and/or housebound elderly should be given information about how to prevent falls and low levels of vitamin D
 - c. Patients taking glucocorticoids, e.g. prednisolone, should be advised of the risks of excess bone loss and osteoporosis and fractures.

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- v The following groups of people should be targeted for investigation (including DXA scanning, x-rays or spinal radiographs where appropriate) and/or treatment in accordance with current UK guidelines¹⁸⁻¹⁹:
 - a. People with a fragility fracture, as they are at high risk of further fractures
 - b. People taking glucocorticoids, e.g. prednisolone, as they are at risk of excess bone loss, osteoporosis and fractures
 - c. People who present with height loss and/or kyphosis
 - d. People who present with bone pain and/or deformity
 - e. People who present with biochemical abnormalities e.g., elevated serum calcium or alkaline phosphatase
 - f. People suffering long periods of immobility, who are consequently at increased risk of osteoporosis and fractures
 - g. Women experiencing an early menopause (before age 45). This is a risk factor for osteoporosis.
 - h. Pre-menopausal women who have amenorrhoea (apart from when due to pregnancy) for more than six months or who have low body mass index or amenorrhoea due to over-exercising or eating disorders
 - i. People with gastrointestinal (GI) disorders associated with malabsorption such as coeliac disease and inflammatory bowel disease, especially Crohn's disease, as well as chronic liver disease (CLD) as these are associated with osteoporosis, osteomalacia and excess fracture risk
 - j. People receiving breast cancer treatments, such as aromatase inhibitors which can induce excess bone loss
 - k. Untreated hypogonadal men and those receiving androgen deprivation therapy for prostate cancer

18 Royal College of Physicians. *Osteoporosis clinical guidelines for prevention and treatment*. London: RCP, 1999.

19 National Institute for Clinical Excellence. *Bisphosphonates (alendronate, etidronate, risedronate), selective oestrogen receptor modulators (raloxifene) and parathyroid hormone (teriparatide) for the secondary prevention of osteoporotic fragility fractures in postmenopausal women*. London: NICE, 2005.

Access to diagnosis

Standard 4

People with symptoms or signs of metabolic bone disease or who have been identified as being at risk of metabolic bone disease (e.g. people with fractures, or bone pain, or height loss confirmed to be due to spine fractures, or people on glucocorticoids etc.) should have access to health professionals in an appropriate care setting. These professionals should be well trained and informed about the full range of metabolic bone diseases. They should have local access to the necessary diagnostic equipment (including axial DXA scanners) to make a diagnosis, and where appropriate, a timely referral to appropriate secondary care services.

Assessment of needs

Standard 5

On diagnosis, people with metabolic bone disease should be offered an assessment of their disease and advice on treatment and lifestyle measures. People may also benefit from an assessment of their general health and psychosocial needs. The assessment should involve the full multidisciplinary team, and any other relevant specialities. Where appropriate, referrals should be made to community health and social services to identify any further needs.

Those diagnosed should be given a detailed explanation of their disease and information to take away to read after the consultation. They should also have ongoing access to a trained health professional of whom they can ask general questions about their condition.

Future care

Standard 6

On diagnosis, people should be offered a plan for their future care. This should give constructive messages about their condition and the roles for the patient and the

multidisciplinary team in the management of their disease. This care plan should draw on good clinical practice and be evidence based.

Support to remain in, or return to, education or work

Standard 7

People with metabolic bone disease should be encouraged to remain active and mobile as far as possible and be supported to remain in or return to education, work or active retirement. They should have access to information and services such as physiotherapy and occupational therapy and support and rehabilitation services, as well as advice on benefits and how to access other services beyond health services.

Involvement of people with metabolic bone disease in service development

Standard 8

Healthcare organisations should involve people with metabolic bone disease in the planning and development of services for metabolic bone disease and other musculoskeletal conditions.

Pain relief

Standard 9

Although not all people with metabolic bone disease experience pain related to their condition, those who do should be offered a choice of appropriate pain management strategies and symptomatic pain relief. These should be in accordance with the best available evidence and national/international guidance and guidelines.



The rationale

- Appropriate treatment of metabolic bone disease reduces the risk of fracture²⁰. Falls prevention measures can also prevent fractures.
- Paget's disease may lead to bone pain and deformity which usually responds to appropriate treatment. Early, accurate diagnosis and timely management may reduce the risk of deformity and secondary osteoarthritis. Secondary osteoarthritis can be treated by joint surgery if necessary.
- With the appropriate treatment, osteomalacia can be cured. People with osteomalacia should be made aware of this and be helped to manage their condition jointly with the multidisciplinary team.
- "Fracture Liaison Services" have proved successful in a number of areas as a tool for identifying those in need of therapy to prevent further fractures²¹. Other centres should be encouraged to set up such services.
- While many people at present visit their GP to report symptoms and gain advice and treatment, the GP should not be regarded as their only point of contact with the health service. Other healthcare professionals in primary care, such as physiotherapists or nurses, may also be able to offer detailed advice and management. Community pharmacists are also a key provider of information and advice.
- A diagnosis of metabolic bone disease can be helpful for many people, as it recognises their experience, enables them to 'rule out' other conditions and can help them to self-manage. A diagnosis can be distressing if the person is left feeling that 'nothing can be done' but with effective management, many people with metabolic bone disease can enjoy a good quality of life and level of independence and/or be cured. People diagnosed with a metabolic bone disease need to be offered constructive messages about how they can manage their condition.
- People need to be able to make informed choices about treatments, healthcare providers and services. Involving individuals in decision-making and enabling informed choice can improve concordance (a person's adherence to a treatment plan). Health professionals need to support individuals in exercising choice.
- Metabolic bone disease is not just a medical diagnosis. People may have other health and social care requirements, including psychological support, which need to be recognised and evaluated. Services should be designed to maintain and improve their quality of life, to enable them to be as independent as possible, to empower them to manage their condition effectively and to limit the impact of bone pain, if any, on their work and activities of daily life.
- There is strong evidence for the effectiveness of both pharmacological and non-pharmacological treatments in pain management. People should have access to appropriate pain management, in line with evidence-based guidelines. Pain management should allow the person to express their experience of pain, and allow time for assessment. People should receive guidance on how to administer pharmacological and non-pharmacological pain relief themselves.

- People need access to the full range of support in the community, including physical therapies and rehabilitation services. This includes physiotherapy and occupational therapy as well as support from community pharmacy and social services, including home assessment and adaptations as appropriate. This is particularly important for older people with metabolic bone disease.

Putting the Standards into practice: key interventions

- vi Women over 75 who have had a fracture should be offered appropriate bone sparing treatment according to current NICE guidance in the UK²².
- vii People who are otherwise at risk of osteoporosis should have access to an axial DXA scan within 13 weeks by March 2007 and by March 2008, 6 weeks²³.
- viii Elderly people living in a care home setting may benefit from calcium and vitamin D supplements²⁴.
- ix People with pain due to Paget's Disease will benefit from appropriate pharmacological and non-pharmacological interventions²⁵.
- x Health services should provide lifestyle advice that informs and supports people with metabolic bone disease in making changes to their diet, exercise regime etc, to help them manage their condition. People with metabolic bone disease should also have access to exercise classes appropriate to their condition.
- xi People at high risk of vitamin D deficiency, especially in the Asian community, should be informed about the need for and how to maintain adequate levels of vitamin D.
- xii The primary care health professional should assess whether people need immediate

Good Practice Example - A Fracture Risk Assessment Service sited within Fracture Clinic

A general hospital has established a full-time Fracture Risk Assessment Service sited in the Fracture Clinic. This offers a 'one-stop' clinical assessment, including bone density measurements at the spine and hip, to all patients over the age of 50 with a low trauma fracture. A full-time specialist nurse performs the bone density measurements and clinical assessment, making treatment recommendations where necessary to the GP. In the first year, 800 patients underwent assessment and in 50% of these, it was recommended that treatment should be started by their GP. The service has improved access to osteoporosis assessment and treatment for people at high risk of further fracture and has proved to be convenient and popular with patients, orthopaedic surgeons and GPs.

Good Practice Example - B Clinical Audit of Standards in Primary Care Falls and Bone Health Services

An NHS audit group focusing on primary and community care audited the prevention of osteoporotic fractures across a population of 530,000 using electronic data collection and analysis tools. The audit was undertaken in response to a lack of strategic level organisation and poor data quality on many GP systems.

The audit group provided 82 general practices with individual patient data to target the assessment of patients whose care is not meeting the current national guidance (such as NICE guidelines). The audit areas included the proportion of people with a diagnostic code for osteoporosis who had a documented assessment or treatment, the proportion of females over 75 with a recorded fracture since the age of 45 with documented assessment or treatment for the secondary prevention of osteoporotic fracture, the proportion of high risk patients who have been offered referral to a falls service, etc.

The results of the audit were fed into a multidisciplinary service planning team working with a national service user group. The audit data has also been made available on an online public website and a study day on the results follows the audit cycle.

specialist review. This should include screening for 'red flags' such as warning signs of serious disease, and signs of other conditions. People who require access to secondary care should be offered an appointment within 13 weeks of referral (in accordance with Department of Health guidance, which may be subject to change) or sooner if clinically indicated, and within 6 weeks of referral by 2008.

- xiii People should be given a diagnosis if possible. This should always be given with positive and constructive messages, including written information about managing pain and advice on accessing additional support, e.g. from the GP or other health professionals, voluntary organisations, telephone advice lines. This should form part of a care plan given to the person with metabolic bone disease. The care plan should include:
 - information about the choice of treatments, care providers and services
 - information on how to self-manage
 - what to do if symptoms get worse
 - contact details for national and/or local support groups
 - information on pathways for ongoing care and treatment review (i.e. information about the care people can expect, and when; and when they will have a review of their treatment).
- xiv Treatment options should include education, nutrition advice, exercise, pain relief, ergonomic and falls assessment and advice where appropriate and other interventions. People should have information on the benefits and risks of taking and not taking treatments to enable them to make informed choices in line with their preferences. Treatment options may also include referral to health professionals such as physiotherapists, occupational therapists, dieticians, podiatrists or other members of the multidisciplinary team.
- xv Treatments should be tailored to the individual and should take into account factors such as

the person's age; co-morbidity; the severity of their symptoms; their own preferences²⁶; and the side effects of treatment.

- xvi People should be offered a choice of care providers where available, with appropriate information to help them make decisions about their care. Appropriate specialist care may include: nurse specialist, physiotherapist, GP with a Special Interest, or secondary care physician.
- xvii Clear pathways (routes through care and different services) need to be determined and configured by local services so that people can be referred between healthcare professionals as part of an integrated musculoskeletal service. These will often be led by a local musculoskeletal champion.
- xviii Occupational health services, where available, should provide advice to employers. Health services should provide access to vocational rehabilitation services.
- xix Health service providers should involve people with metabolic bone disease in helping to plan and develop services at both a local and national level.

20 Black DM, Thompson DE, Bauer DC, et al. Fracture risk reduction with alendronate in women with osteoporosis: the Fracture Intervention Trial. FIT Research Group, *Journal of Clinical Endocrinology and Metabolism*, 2000, 85, pp. 4118-4124.

21 McLellan AR, Gallacher SJ, Fraser M, McQuillian C. The fracture liaison service: success of a program for the evaluation and management of patients with osteoporotic fracture. *Osteoporosis International*, 2003, 14 (12) pp. 1028-1034.

22 National Institute for Clinical Excellence. 2005. Op cit.

23 Department of Health *Choice of Scan, Phase 3: Guidance*

24 Lips P, Chapuy MC, Dawson-Hughes B, Pols HAP, Holick MF. An International Comparison of Serum 25-Hydroxyvitamin D Measurements. *Osteoporosis International*, 1999, 9(5), 394 – 397.

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The multidisciplinary team

Standard 10

People with metabolic bone disease should have ongoing access to a local multidisciplinary team who should have had training, ideally post-graduate or specialist training in the management of musculoskeletal conditions including metabolic bone disease.

Regular review of treatment

Standard 11

People with metabolic bone diseases should be offered a treatment review at regular intervals. This could include concordance with medication, where appropriate, medication review, and an opportunity to discuss treatment, pain assessment and social needs assessment.

Management of complications

Standard 12

People with metabolic bone disease and those responsible for their care, should be made aware of possible complications of their disease and possible side effects of

treatments and who to contact should these occur.

If side effects worsen or complications occur, people with metabolic bone disease should have timely access to appropriately trained health professionals that can carry out specific care or treatment.

Self-management

Standard 13

People with metabolic bone diseases should have access to ongoing information, advice and support for self-management. This could include:

- A telephone advice line
- National and local voluntary organisations, including access to other people with their condition

They should be informed about their condition, and supported to make the necessary life style changes to manage it, e.g. nutrition, pain management, appropriate exercise, ergonomics, exposure to sunlight, prevention of falls, taking prescribed medicines appropriately etc.

The rationale

- It is possible to assess the disease activity of osteoporosis relatively easily using DXA scans, other imaging techniques and biochemical tests which can also be used for assessing Paget's disease. Regular checks and monitoring, including reviews at appropriate intervals for people with the diseases, would prove effective tools in the management of their condition.
- Every effort should be made to enable people with metabolic bone disease to remain as independent as possible. Evidence suggests that people with chronic disease who are able to remain active and in work or education are better able to cope with their disease and have less depression.
- Evidence shows that approaches such as pain management programmes, exercise programmes and access to self-management programmes promote and help people to develop ways of coping with their chronic conditions.

- Research has shown that greater involvement of the individual in understanding, monitoring, reviewing and deciding their care needs is beneficial, particularly for people living with long term conditions. People who are more involved in their care may:
 - manage their condition more effectively
 - feel better
 - manage risks to their health more effectively
 - have less pain
 - be less depressed
 - use health services less.
- Studies have shown that educational interventions can provide significant benefits for people who have a range of chronic diseases. There needs to be wider recognition of the importance of self-management initiatives led by people with chronic conditions (such as the Expert Patient Programme) and support networks or self-help groups.
- People with metabolic bone disease should be involved in and consulted about the development of healthcare policy and practice, at both a local and national level. Their perspective on service delivery can lead to imaginative solutions and improvements to healthcare services, helping services to meet people's real needs.

Good Practice Example - C Osteoporosis Education and Exercise Group

A physiotherapy department within an acute NHS trust has developed an Osteoporosis Group to minimise the risk of osteoporotic fractures through education, increased physical fitness and improved balance.

People with osteoporosis are referred to the group through their care providers, and the group offers a 6 week programme of 1 hour sessions, in which 30 minutes are dedicated to education and 30 minutes to exercise. The sessions are based on educational and exercise recommendations from the National Osteoporosis Society and the Chartered Society of Physiotherapy.

Everyone referred to the group is provided with advice on diet, medication and exercise, as well as learning a home exercise programme and receiving information about suitable exercise opportunities in the community. A standardised assessment is completed at the beginning and end of the group treatment, thereby allowing analysis of how effective the intervention has been.

Putting the Standards into practice: key interventions

- xx Regular treatment reviews should be undertaken. The extent and intervals of these reviews will be different for the different conditions. In osteomalacia, the reviews will need to be intensive until the condition has been stabilised or cured. In osteoporosis the frequency of the reviews will vary greatly depending on the severity of the condition, but should definitely take place if a re-fracture has occurred or the individual feels the need to stop medication for any reason. In Paget's disease the reviews will need to be intensive until the condition has been stabilised, from this point they should take place annually.
- xxi People whose condition is complex or is not responding to simple therapy should be referred to appropriate specialist care.



- xxii Healthcare providers should proactively identify and contact people who may require treatment review.
- xxiii Pre- and post-registration curricula for all relevant health professionals and for those specialising in musculoskeletal health should be reformed to include a greater emphasis on metabolic bone health. Clinical governance teams should ensure that there is access to training on the needs and care of people with bone pain and metabolic bone disease for all professionals involved in their care and support and that these professionals audit the management of such patients.
- xxiv Health services should support people in developing ways of coping with and managing their condition by providing evidence-based strategies including pain management programmes, exercise programmes and nutritional advice.
- xxv Health services should provide information on local and national voluntary organisations.
- xxvi Health service planners and providers should actively engage local service users in reviewing and, if necessary, reconfiguring local service provision.

aetiology

the science of the causes of disease.

Allied Health Professional (AHP)

a person who offers advice and clinical care who is not necessarily medically qualified. For example, this would include a nurse, pharmacist, physiotherapist, occupational therapist and podiatrist. These healthcare professionals are registered with, and regulated by the Health Professions Council. Other healthcare professionals, such as manual therapists (osteopaths and chiropractors) should also be qualified and registered with their own professional body.

amenorrhoea

the absence of periods (menstruation).

androgen deprivation therapy

drugs used in the management of males with prostate cancer to reduce risk of spread or recurrence by reducing the male sex hormone, testosterone.

aromatase inhibitors

drugs used in treatment of breast cancer which block all production of female sex hormone, oestrogen.

biochemical abnormalities

abnormal levels of minerals and/or enzymes in the blood.

biochemical test

tests on blood for minerals and enzymes.

biphosphonates

group of drugs which reduce the removal of bone by reducing the activity of the cell which removes bone.

bone sparing treatment

drugs, or potentially life-style changes, used to prevent bone loss.

care plan

a written statement about a person's health needs; the treatment, support and advice they should have; who should provide these and when.

chronic disease

a long-term illness for which there is no cure but where the activity of the disease can be controlled.

co-morbidity

other diseases that one person might have.

Crohn's disease

an inflammatory disease of the small intestine.

deformity

change in the shape of bone.

fragility fracture

fracture resulting from a fall from standing height or less in those over the age of 50.

GPwSI

General Practitioner with a special interest in a certain area of medicine, e.g. musculoskeletal conditions.

hypogonadal

abnormally low levels of the sex hormones.

ICATs

Integrated Clinical Assessment and Treatment Services – a way of organising services that is designed to ensure that people referred by GPs are assessed by teams and further referrals to hospital consultants are provided only where necessary.

interventions

a general term covering treatments, advice, education, and other care that a practitioner may give.

kyphosis

an abnormal outward curving of the spine in the chest area, causing the back to appear even more rounded than usual²⁷.

multidisciplinary team

a healthcare team that includes professionals from different disciplines, working together to provide a comprehensive service for people with joint pain and osteoarthritis.

pathway

a person's route or journey through care, which can include a range of different treatments and services.

pain management programmes

combinations of treatments, advice and education designed to enable people to manage and cope with pain. They may include, for example, cognitive behavioural therapy, relaxation training, pacing of activities, use of Transcutaneous Electrical Nerve Stimulation (TENS).

pharmacological

drug-based treatments.

primary care

care services available in the community, for example through a community pharmacist or the care provided by a GP. This is often a person's first point of contact for advice, information and treatment.

red flags

a group of signs or symptoms (clinical indicators) that suggest there is a possibility of serious disease (pathology).

re-fracture

the occurrence of another fracture after treatment to reduce fracture risk in osteoporosis has been started.

rickets

the failure to add minerals to the bone proteins causing muscle weakness, deformities of the spine and limb bones, causing a waddling gait and an increased risk of fractures in children.

community pharmacists

independent practitioners who work in high street pharmacies and supermarkets providing the public with health information, advice and support, as well as dispensing medicines.

secondary care

care available usually in a hospital setting. People generally need referral from a professional in primary care.

secondary osteoarthritis

wear and tear changes in joints because of a change in bone metabolism from Paget's disease. This usually affects weight-bearing joints such as the hip and knee.

self-management

learning a range of techniques to help manage life with a condition more effectively, including exercise, eating healthily, etc.

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Standards of Care
for people with

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