Osteoporosis in the European Union: Overview and next steps

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Prepared by the International Osteoporosis Foundation, February 2004
Osteoporosis is a disease in which the density and quality of bone are reduced, leading to weakness of the skeleton and increased risk of fracture, particularly of the spine, wrist, hip, pelvis and upper arm. In many affected people, bone loss is gradual and occurs without symptoms or warning signs until the disease is advanced. Osteoporosis and associated fractures are an important cause of mortality and morbidity, with a profound effect on quality of life. Hip fractures are particularly serious, affecting the elderly, with one in five patients who sustain a hip fracture dying within six months. In addition to this tragic human cost, the disease poses a huge social and financial burden on society. In the EU alone, the number of osteoporotic hip fractures and their costs are predicted to at least double in the next 50 years unless effective preventive strategies are developed.¹

Osteoporosis in the European Union: Overview and next steps

The International Osteoporosis Foundation (IOF) is a non-governmental organisation with 162 member societies in 81 countries, regions and territories, including the European Union member and new member states. IOF’s scientific work is directed by 68 of the world’s leading osteoporosis researchers who are elected members of IOF’s Scientific Advisory Committee. IOF was founded in 1998 after the European Foundation for Osteoporosis (EFFO), created in 1987, merged with the International Federation of Societies on Skeletal Diseases (IFSSD), established in 1995. IOF and its member societies encourage awareness and prevention, access to and reimbursement of early detection for people at risk of fragility fractures and reimbursement of proven therapies for people at risk of fragility fractures. For more information visit www.osteofound.org

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Worrying statistics on the prevalence and cost of osteoporosis and related fractures coupled with increasing life expectancy led the European Parliament to request the European Commission to prepare recommendations aimed at making the prevention and care of osteoporosis and related fractures a healthcare priority in all member states. This was in 1996.

In 1998, the European Commission responded by publishing the results of their findings in a report, “Osteoporosis in the European Community – Action for Prevention”. The report detailed eight clear recommendations (see page 2).

Three years later, a member-state policy audit compiled by the International Osteoporosis Foundation showed that little progress had been made. To help stimulate much needed policy development, an informal group, the European Parliament Osteoporosis Interest Group, was founded in December 2001 by Mel Read, MEP. The Group issued a “Call to Action” elaborating five key points to national health authorities, health insurance agencies and to the European Commission. The “Call to Action” was welcomed by Health and Consumer Protection Commissioner, David Byrne, who stated that, “The European Commission will take action in the short term to stimulate this necessary response at national level. That includes better monitoring and data collection, and pushing for national measures to make people more aware of the disease, to make doctors recognize those at risk of osteoporosis and to make healthcare systems pay for appropriate diagnosis and treatment”.

In September 2002 the European Commission took the step to finance an 18-month initiative that saw the formation of the EU Osteoporosis Consultation Panel, mandated to work with stakeholders at both national and EU levels to implement practical, cost-effective solutions to prevent fragility fractures. At the EU level, to date, the Panel has met twice to share their national findings and ideas. The findings can be reviewed in detail in the publication “Osteoporosis in the European Union: Member States Policy Progress Report, February 2004”. Although significant progress has been made in a number of countries, much remains to be done to implement the eight recommendations.

To further promote real progress, in November 2003 the Consultation Panel published an Action Plan outlining the key next steps to fulfil the eight recommendations published by the Commission in 1998 (see enclosure). The full details of those steps, those responsible and target dates are described in the publication.

At a minimum three of the six steps detailed must be put in place in member and new member states, with support from the EU. Those three steps are:

1. Evidence-based guidelines for the prevention of osteoporotic fractures with government endorsement and financial support to ensure a minimum acceptable standard of prevention and care across Europe.

2. Adequate access to and reimbursement of diagnostic and therapeutic interventions for people at high risk of fracture.

3. Coordinated collection of fracture data on an ongoing basis to be included in the EU Health Information System (EUHIS), so that preventive strategies can be evaluated and to enable economic modeling and planning of health care resources for the future.

Important complementary steps to implement are:

4. Awareness-raising campaigns for both the general public and healthcare professionals.

5. Preventive strategies: public health campaigns for education on lifestyle measures to reduce risk of osteoporosis.


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**Key next steps for the European Commission**

The European Commission will review the Action Plan when they officially receive it at the end of the funding agreement with the International Osteoporosis Foundation on March 1, 2004.

**The European Commission is requested to:**

- Distribute the Action Plan to Ministries of Health of member and new member states.

- Support member and new member states in achieving a coordinated implementation of the key steps.

- Prepare a proposal for a EU Council Recommendation on the prevention of osteoporotic fractures.
Osteoporosis is a serious, debilitating disease affecting one in three women and one in eight men over the age of 50 years. As well as having a major impact on peoples' health and quality of life, fractures due to osteoporosis place an enormous economic burden on healthcare systems in Europe. As life expectancy increases the number of Europeans suffering as a result of osteoporosis is expected to reach epidemic proportions unless action is taken now. In response to these worrying statistics, in 1996 the European Parliament requested the European Commission to prepare recommendations aimed at making the prevention and care of osteoporosis and related fractures a healthcare priority in all member states. In 1998, the Commission responded by publishing eight recommendations in a “Report on Osteoporosis in the European Community – Action for Prevention”.1

The history and current actions


Recommendation 1
Osteoporosis is to be adopted as a major healthcare target by the EU and governments of the 15 member states.

Recommendation 2
More information is required about the incidence and prevalence of osteoporotic fractures.

Recommendation 3
Co-ordinate national systems throughout the EU to plan effectively for an increase in demand for healthcare and to institute appropriate resource allocation.

Recommendation 4
Develop and implement policies to advise the general public and health professionals about calcium and vitamin D nutrition.

Recommendation 5
Access to bone densitometry systems should be universal for people with accepted clinical indications and reimbursement should be available for such individuals.

Recommendation 6
Member states to use an evidence-based approach to determine which treatment should be advised. Reimbursement should be available for all patients receiving treatment according to accepted indications.

Recommendation 7
Governments should actively promote national patient and scientific societies, providing financial support and helping to publicise their cause. Appropriate training of healthcare professionals involved in the management of osteoporosis should also be an important priority.

Recommendation 8
Further research is urgently required in a number of areas, including:

- Modifiable determinants (such as exercise and calcium intake) of peak bone mass and how these might be used to achieve higher peak bone mass in the population.

- Identification of risk factors for falling and the effects of fall prevention strategies on fracture.

- Additional evaluation in different age groups of approaches to identify individuals at risk from fracture, for example the use of broadband ultrasound attenuation, biochemical markers of bone turnover and risk factors, either singly or in combination.

- Assessment of the cost/utility ratio of screening in older women.

- The causes and treatment of osteoporosis in men.

The launch of the “Report on Osteoporosis in the European Community: Action for Prevention” in June 1998 in the European Parliament was a milestone in raising awareness about osteoporosis and showing the urgent need to allocate greater resources to fight the disease. The report made important recommendations for action to prevent, diagnose and treat osteoporosis – serving as a model for government action in all countries.
Three years later, in 2001, a policy development audit compiled by the International Osteoporosis Foundation showed that little progress had been made in implementing those recommendations.2

As a result, an informal group, the European Parliament Osteoporosis Interest Group (see list of members on page 12), was founded by Mel Read, MEP in December 2001 to help stimulate much needed policy developments at both national and European levels. The Interest Group issued a “Call to Action” to national health authorities, health insurance agencies and the European Commission to prevent unnecessary suffering and healthcare costs associated with osteoporotic fractures.

The Call to Action included urging EU member states to provide appropriate access to and reimbursement of diagnostic and therapeutic interventions for people at high risk of fracture. It also urged the European Commission to support the coordinated collection of fracture data on an ongoing basis to include in the EU Health Information System so that preventive strategies can be evaluated and to enable economic modeling and planning of healthcare resources for the future.

Health and Consumer Protection Commissioner David Byrne welcomed the call to action launched by the EP Osteoporosis Interest Group and stated that “The European Commission will take action in the short term to stimulate this necessary policy response at national level. That includes better monitoring and data collection, and pushing for national measures to make people more aware of the disease, to make doctors recognize those at risk of osteoporosis and to make healthcare systems pay for appropriate diagnosis and treatment.”

The European Parliament Osteoporosis Interest Group's 2001 Call to Action

At a press conference on 1 December 2001 the European Parliament Osteoporosis Interest Group issued a Call to Action to prevent unnecessary suffering and costs associated with osteoporotic fractures. National health authorities and health insurance agencies were urged to:

- Financially support and participate in educational and awareness-raising campaigns;
- Improve access to, and funding for, bone density scans for individuals at high risk of osteoporosis-related fractures;
- Fund proven therapies for individuals at high-risk of osteoporosis-related fractures.

Additionally, to help member and new member states develop best practices and to evaluate the results of their actions, this Call to Action urges the European Commission to work in partnership with the International Osteoporosis Foundation to:

- Bring together national and European policy makers, and osteoporosis experts and concerned groups, to produce practical, cost effective strategies to prevent osteoporosis-related fractures. These strategies should specify measurable, realistic, time-based targets;
- Create a co-ordinated data collection system to monitor osteoporosis-related fractures across Europe.

Members of the European Parliament Osteoporosis Interest Group act as ambassadors for those with osteoporosis and fractures in member and new member states, and at the EU in order to help implement this Call to Action. After three years an audit was agreed to be conducted to monitor progress (completed in February 2004).1
In September 2002, with financial support from the European Communities, more than 40 health policy makers from the EU and member states, osteoporosis experts and project partners formed the EU Osteoporosis Consultation Panel (see list of members on page 12).

Consultation Panel members work with stakeholders at both national and EU levels on an ongoing basis to implement practical solutions to prevent fragility fractures. To date their findings have been formally shared at two meetings held in Leiden, The Netherlands, in September 2002 and September 2003 and can be reviewed in detail in “Osteoporosis in the European Union: Member States Policy Progress Report” (February 2004). This document is available in print and as a PDF from the IOF website, www.osteofound.org.

Encouraging actions are now underway in a number of countries to move towards making the prevention and care of osteoporosis and related fractures a governmental healthcare priority. Some highlights include:

- **Finland**: The government is supporting a major effort to improve the diagnosis and care of fragility fractures. All hospitals and health centres are required to assess the underlying cause of the fracture, with the help of trained osteoporosis nurses, and to take appropriate action as outlined in “quality criteria for the management of fracture patients.”

- **France**: Osteoporosis is included in the government’s new draft Public Health strategy. At the request of the Ministry of Health the impact of screening women over 60 years of age for osteoporotic fractures is currently being studied. Reimbursement for bone density testing in high risk individuals is officially approved and awaiting implementation.

- **Italy**: In May 2003 the Health Commission of the Italian Senate published the results of a National Survey on osteoporosis with specific recommendations aimed at promoting appropriate political actions to fight osteoporosis. In June 2003 the Italian Ministry of Health established a Working Group on Osteoporosis composed of relevant stakeholders to serve as a consulting body.

- **Luxembourg**: In 2002 a global programme on the prevention of osteoporosis was initiated by the department of preventive medicine, Ministry of Health.

- **The Netherlands**: A national system for collecting information on hip, wrist, vertebral and other fractures based on hospital admissions has been set up. Other countries should follow this lead in developing national registers for fragility fractures and contributing to a European database.

- **Portugal**: A national plan against rheumatic diseases, which includes osteoporosis, is under development. The plan is expected to obtain ministerial approval in 2004 and to be implemented within five years.

- **Several countries including Denmark, France, Germany, Italy, The Netherlands, Spain and the UK (England and Scotland)**, have evidence-based guidelines for the prevention of osteoporosis-related fractures. However these guidelines still need to be properly implemented with governmental endorsement and financial support and their use audited in order...
to improve the clinical prevention and care of fractures.

Although significant progress has been made in a number of countries, much still remains to be done to fulfill the eight recommendations issued by the Commission in 1998. Full details of the key next steps, including those responsible and target dates, are described in the EU Osteoporosis Consultation Panel’s November 2003 report:

“Osteoporosis in the European Community: Action Plan – a report of the key next steps towards a Europe free from fragility fractures”

At a minimum, the Consultation Panel urges that three of the six steps detailed be put in place in member and new member states, with support from the EU, namely steps 3, 5 and 6.

EU Osteoporosis Consultation Panel’s 2003 Action Plan – 6 key steps

Step 1: Awareness-raising campaigns
Promote a simple risk test for individuals at high risk such as post menopausal women (see page 9). Target key specialists including radiologists, orthopaedic surgeons, traumatologists and gynaecologists.

Step 2: Preventive strategies – lifestyle considerations.
Development of government-backed public health education programmes. Harmonisation of recommendations for calcium and vitamin D intake.

Step 3: Guidelines for the prevention of osteoporosis-related fractures
Make currently available evidence-based guidelines accessible to member and new member states via the International Osteoporosis Foundation’s website (www.osteofound.org). Develop and apply audit tools to assess the clinical impact of the guidelines.

Step 4: Fracture care, rehabilitation and prevention of falls
Development of evidence-based fracture care programmes. Development of multidisciplinary falls services with integrated care pathways that incorporate osteoporosis.

Step 5: Economic data
Adequate access to and reimbursement for diagnostic and therapeutic interventions, based on health economic analyses. Provision of adequate bone densitometry services throughout Europe. Analysis of cost-effectiveness of interventions in all member and new member states.

Step 6: Evaluation of actions and planning the allocation of future healthcare resources: the European fracture database
Collation of fracture data in member and new member states. Include fracture data in the EU Health Information System.

In Leiden, Ms. Elly Plooij von Gorsel (MEP, the Netherlands), member of the European Parliament Osteoporosis Interest Group, was one of many speakers to urge national health authorities to make osteoporosis a health care priority.

The European Commission will review the Action Plan when they officially receive it at the end of the funding agreement with the International Osteoporosis Foundation on March 1, 2004.

The European Commission is requested to:
- Distribute the Action Plan to Ministries of Health of member and new member states.
- Support member and new member states in achieving a coordinated implementation of the key steps.
- Prepare a proposal for a EU Council Recommendation on the prevention of osteoporotic fractures.
A major multi-element event to publicise the Action Plan was organised at the European Parliament in Brussels on November 12, 2003. The aim was to reach policy-makers and the media and at the same time demonstrate how awareness can be raised at a personal, individual level. To achieve this, staff and visitors at the European Parliament, as well as policy-makers and the media, were targeted.

The audiences were addressed through specific but related activities, namely:

- **Morning press briefing:** More than 30 journalists and photographers from 11 countries and the Brussels international press core attended the press briefing.

- **“Osteoporosis – a photographic vision”**. A dramatic, powerful three-part photo exhibition by renowned photographer Oliviero Toscani; it is being shown in several venues in Europe and was presented in the European Parliament (EP) for five days. The exhibition opens by exposing the burden of the disease with ten facts and moves to monumental three-metre tall photographs portraying 23 osteoporosis patients without clothes, both men and women of all ages, from 15 countries. It ends with a “video of hope”. The exhibition presents a realistic and informative vision of osteoporosis. The heroes are the patients who kindly agreed to be photographed.

EU Commissioner David Byrne welcomed the exhibition with a general statement of support (see page 8).

- **Bone health:** People were invited to complete a short, osteoporosis risk factor questionnaire, “The One Minute Risk Test” (see page 9), to understand their personal osteoporosis risk level. To complete the experience, two lumbar/hip bone-density scanning machines were installed in the EP and staffed over 3 days – 259 people took the opportunity to have their bone health checked, one in five of whom were men.

- **Lunch meeting:** Mel Read, MEP and chair of the EP Osteoporosis Interest Group, hosted a lunch with 50 guests including EP Osteoporosis Interest Group members, EU Osteoporosis Consultation Panel members, additional national and EU policy makers and advocates for improved prevention and care of osteoporosis and related fractures.

- **Launch of the Action Plan in the Press Room with over 130 participants:** As well as Prof. Juliet Compston, chair of the EU Osteoporosis Consultation Panel, presenting key messages from the Action Plan, Ms. Kinga Göncz, Secretary of State, Ministry of Health and Social Welfare, Hungary outlined Hungary’s strategy for preventing osteoporosis-related fractures, a national osteoporosis programme which continues to run successfully after eight years.

Prof. Sergio Ortolani delivered a supportive message from Prof. Girolamo Sirchia, Minister of Health, Italy explaining recent actions taken by Italy to improve policies and resources to prevent fragility fractures. Osteoporosis was also included in a “Conference on Healthy Lifestyles: Education, Information and Communication” in September, 2003, organised by the Italian Ministry of Health, as part of their programme during the Italian Presidency of the EU.

Ms. Imelda Farmer, an osteoporosis patient from Ireland, presented her story and hope for the future (see page 8).

Speaking at the event, Mr. Oliviero Toscani explained that he was intrigued by the concept of photographing people with osteoporosis “without the camouflage of clothing or props”, so that viewers could better understand the nature of the disease. Toscani said he saw “beauty in the tragedy” and that “the people in this exhibition have shown a large amount of generosity by revealing their physical situation in this way. Through the visual effects of the exhibition they will help other people to find out if they are also exposed to the risk”.

The November 12 launch day closed with an opportunity for all participants to informally share thoughts and feedback over drinks and calcium-rich snacks.
Hungary's Osteoporosis Programme for preventing osteoporotic fractures: an 8-year success story.

Hungary has a strictly controlled National Osteoporosis Programme, which includes yearly-updated evidence-based guidelines for healthcare professionals. This enables people at high risk of osteoporotic fractures to obtain free diagnosis and people with osteoporosis access to 90% reimbursed treatment. The Programme is evaluated on an ongoing basis and coordinated collection of fracture data demonstrates that the Programme is successfully starting to slow down hip fracture rates. Hungary is a small country with many health-related challenges yet it has achieved encouraging results by introducing a National Osteoporosis Programme. Recently, in a New Europe Consensus meeting on Osteoporosis, Hungary's National Osteoporosis Programme was discussed and accepted in principle by the countries present. These countries included many of the new member states who will join the European Union in May 2004.

"We hope our experience inspires you to participate in similar actions in your own country, as outlined in the EU Osteoporosis Consultation Panel's Action Plan."

Official opening of “A Photographic Vision by Oliviero Toscani”: Commissioner David Byrne’s statement of general support.

Osteoporosis is a silent epidemic. It affects millions of Europeans. Regrettably, public debate is all too silent on this largely preventable condition. Today’s exhibition speaks more loudly than any words on the need for action. These individual stories of people who live with this disease, illustrate graphically the need for action.

The Commission is very much aware of the need for action on osteoporosis. We have financed a number of osteoporosis-related activities under the former Health Promotion, Health Monitoring and Injuries Prevention programmes.

In the European Commission’s report on osteoporosis in 1998, a list of recommendations for the prevention of osteoporosis and associated fractures in Europe was published. Based on this, in 2002 the Community began to fund a major project carried out by the International Osteoporosis Foundation. This project, led by the European Union Osteoporosis Consultation Panel, will analyse how the recommendations established by the Commission have been acted on by the Member States. It will also provide a practical and cost effective plan outlining the next policy steps in this area. I am looking forward to seeing the final fruits of this cooperation in 2004.

In meeting today to draw attention to this silent epidemic, we need to begin to set out the key next steps towards a Europe free from fragility fractures. We need to change the context by reinforcing prevention and promotion from childhood, through improved diet and regular physical activity. And we need to make the case for the benefits of screening before the first fracture. We must exploit the data gathered by the projects financed in the past. And we will continue to collect and analyse data on this disease in order to follow the spread of the disease within the new Public Health Programme.

However, Community action alone will not be sufficient to tackle osteoporosis, even more so as the Treaty only gives us a limited competence in Public Health. The organisation and delivery of health services and medical care – including appropriate diagnosis and treatment of osteoporosis – is the responsibility of Member States. It is therefore important that we work together at all levels to ensure that those most at risk are identified and advised before the first fracture occurs, and that known ways of reducing the risk for this disease are widely promoted.

Let me finish by saying that I very strongly acknowledge the firm commitment of the Osteoporosis Interest Group of the European Parliament and of the International Osteoporosis Foundation. I wish you continued success in your efforts to prevent the suffering which osteoporosis causes.

This has been a silent epidemic. But it is time to end the suffering in silence. Time to offer a decent future to those in need.

Our health is our wealth. This means it is also time to invest in a healthy, mobile, productive ageing population. Time to work together, to build a healthy future for our citizens in this new Europe. A Europe of health.

A personal story from Ireland

Ms. Imelda Farmer, an osteoporosis patient from Ireland, suffers from corticosteroid-induced osteoporosis. Ms. Farmer, who volunteered to be photographed for the Toscani photographic exhibit, spoke at the November 12 launch of the “Action Plan”. She courageously related her personal story in the hope that policy makers will pay more attention to osteoporosis and related fractures so that others will avoid her fate.

Photo left: Imelda Farmer, 19 years old, at a wedding enjoying life to it’s fullest. Photo right: Imelda, 52 years old, with photographer Oliviero Toscani.

“Our health is our wealth. This means it is also time to invest in a healthy, mobile, productive ageing population.”

Osteoporosis statistics in Europe at a glance

- 1 in 3 women and 1 in 8 men over the age of 50 will suffer at least one osteoporotic fracture during their lifetime.\(^6\)
- Osteoporotic fractures impose a huge social and financial burden in Europe.\(^1, 2, 4\)
- The first year total annual cost of all osteoporotic fractures in Europe as a whole is estimated at euro 25 billion.\(^4\)
- The number of osteoporotic hip fractures and their costs are predicted to at least double in the next 50 years unless effective preventive strategies are developed.\(^1\)

References

5. Osteoporosis: A Photographic Vision is an international project developed by the International Osteoporosis Foundation and the German Green Cross
### European Parliament Osteoporosis Interest Group Members

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