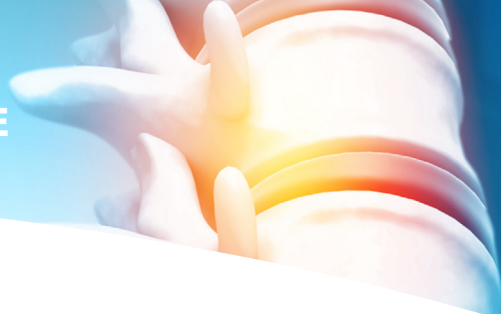


# PATIENTS' PERSPECTIVES AS A CATALYST FOR ACTION TO IMPROVING OSTEOPOROSIS CARE



## Acknowledgments

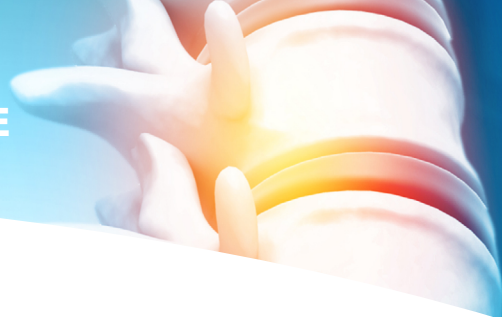
This report was prepared by Caroline Verdonck, Liesbeth Borgermans, and Ruben Willems.

The coordinating authors were Caroline Verdonck and Liesbeth Borgermans.

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## CONTENTS

<b>Backgrounds and Objectives</b> .....	3
<b>Methods</b> .....	4
<b>Study Findings</b> .....	4
1. Awareness of (the impact of) osteoporosis among the public .....	4
2. Awareness of (the impact of) osteoporosis among clinicians and allied health professionals .....	5
3. Needed improvements in care provision .....	5
<b>Policy Recommendations</b> .....	12



## BACKGROUND AND OBJECTIVES

Among the most important goals of the World Health Organization (WHO) Decade of Healthy Ageing (2021-2030) is aligning healthcare systems worldwide to meet the challenge of caring for the world's rapidly growing older population. This entails ensuring people have broad access to the most effective diagnostic and prevention strategies, treatments and care for diseases that disproportionately impact the aging. Osteoporosis is one of the most serious health threats that afflict the aging. It is a disease of the skeletal system characterized by losses in bone density and strength that predispose one to increased risk of fracture.<sup>1</sup> It has been estimated that some 500 million people over age 50, worldwide, have osteoporosis currently.<sup>2</sup>

Approximately 33% of women and 20% of men aged 50 and higher will experience a bone fracture related to osteoporosis.<sup>3</sup> One-third of people over 50 who suffer a hip fracture – commonly associated with osteoporosis – die within a year – and 50% have reduced mobility and independence<sup>4</sup>, Fractures are a major cause of morbidity and, in addition to causing pain, they are associated with reduced quality of life.<sup>5</sup>

Like the prevalence of other chronic diseases that affect the elderly disproportionately, the prevalence of osteoporosis is projected to increase markedly with population aging and thus to result in substantially more cases of osteoporosis-associated fracture. Compared to incidence rates in 1990, by the year 2050, the annual number of fractures attributable to osteoporosis is projected to have increased by 240% in women and by 310% in men.<sup>2</sup> Accordingly, it has been projected that this trend will lead to an additional 1 million hip fractures annually by 2050, compared to the incidence in 1990.<sup>3</sup> Osteoporosis also takes a financial toll on the individuals who suffer from it as well as on their caretakers and on society. Recent annual direct care expenditures for osteoporotic fractures alone are in the range of 20.3–25.3 billion US dollars.<sup>6</sup>

In recent decades, there have been major advances in osteoporosis prevention strategies, disease diagnosis and cost-effective treatments. Widespread use of these advances would have a tremendous impact on improving patient health and quality of life, as well as reducing health care expenditures that will continue to soar as more people are impacted by the disease. Yet for millions of people around the world, these advances remain unavailable. Today, a staggering 80 percent of people with osteoporosis-related fractures are not treated to reduce the risk of future fracture. This leaves them highly vulnerable since people with a previous fracture face an 86 percent higher risk of suffering an additional fracture.<sup>7</sup> The growing incidence of osteoporosis and the failure to embrace new strategies for preventing, diagnosing and treating the disease represent a major barrier to achieving WHO's goals for the Decade of Healthy Ageing.

The objectives of this study were firstly to provide an overview of gaps in osteoporosis care as experienced by patients and secondly to formulate policy recommendations that contribute to the development of people-centered and integrated osteoporosis care.

This report is intended to be a catalyst for the advancement of policy making in osteoporosis care, and for accelerating the translation of patients' perspectives on how to improve care for osteoporosis into everyday practice.



## METHODS

This report is based on 35 in-depth interviews with patients (33 women and 2 men) diagnosed with primary or secondary osteoporosis. Participants were identified through osteoporosis and bone health advocacy (patient) organizations. Patients were considered eligible to participate in the study if they were 18 years or older, diagnosed with osteoporosis, and willing to provide informed consent prior to being interviewed. The 35 participants recruited into this study were from 14 countries (Argentina, Belgium, Canada, Finland, France, Malaysia, Mexico, Pakistan, Singapore, South Africa, Switzerland, The Netherlands, the UK, and the USA).

An interview guide was developed for this study. The guide's framework focused on patients' experiences with regard to the following five themes: **i.** societal awareness and support; **ii.** identification of high-risk patients; **iii.** diagnosis and evaluation of patients at high risk for fragility fractures; **iv.** treatment initiation; and **v.** patient follow-up and re-evaluation. Semi-structured interviews were conducted in English, Dutch, French, or Spanish. All interviews were carried out online. The interviews were video- and audio-recorded and then transcribed verbatim.

## STUDY FINDINGS

### 1. AWARENESS OF (THE IMPACT OF) OSTEOPOROSIS AMONG THE PUBLIC

Nearly all patients stated that osteoporosis should be recognized as a major public health problem. Generally, patients expressed the belief that the public should be much better informed about the disease in terms of how one is affected by it, its causes and risk factors, the magnitude of the problem (e.g. number of people affected, the incidence and prevalence of fractures, and the burden on individuals and on society), and how osteoporosis can be prevented and treated. Patients felt that the responsibility for improving public awareness should be shared among multiple stakeholders, including governments (public health departments and other government agencies) as well as professional associations, insurers, and potentially other facilitators, such as medical societies and patient organizations.

*"A major problem is the lack of awareness of osteoporosis among the public."  
- Maria, Argentina*

*"The impact of the fractures I suffered had devastating consequences for myself and my family members alike."  
- Chris, Canada*

Most patients described how osteoporosis was having a significant impact on their everyday lives and their families. Patients also expressed that they were often confronted with disbelief from friends and family members when they spoke about their disease and how it affected them on a day-to-day basis.

They indicated that their fractures caused tremendous pain, often lead to extended periods on medication, and in some cases required long hospital stays. Serial fractures often precipitated a downward spiral in physical and mental health that impaired the patients' quality of life dramatically. Commonly, patients with multiple fractures reported that they never returned to their pre-fracture functional status with respect to activities of daily living.

# PATIENTS' PERSPECTIVES AS A CATALYST FOR ACTION TO IMPROVING OSTEOPOROSIS CARE



Many patients who suffered fractures reported experiencing a loss of independence and diminished function, including losing the ability to dress oneself, walk, or even stand in some cases. Patients also reported their fractures led to height loss and had a negative impact on their self-esteem, body image, and mood. Some indicated that they were left feeling depressed, isolated, and helpless. Some patients lost mobility due to a fear of falling and suffering additional fractures. Spine fractures in particular, which are not as easily diagnosed and treated as are fractures at other sites, became a source of chronic pain, disability, and even disfigurement (spine deformity) in some patients. These findings are consistent with the available evidence on the impact of fragility fractures on activities of daily living and mental health in patients with osteoporosis.<sup>8,9</sup>

## 2. AWARENESS OF (THE IMPACT OF) OSTEOPOROSIS AMONG CLINICIANS AND ALLIED HEALTH PROFESSIONALS

*"I felt my family doctor didn't know sufficiently about the disease."*

*- Nel, The Netherlands*

Patients felt that many clinicians (and allied health professionals) they consulted with were often not sufficiently aware of osteoporosis, available diagnostic tools, treatment options, and the wide potential range of fractures patients are at risk of suffering across a variety of ages. Some patients reported that they were told osteoporosis is a natural consequence of aging and that nothing can be done about it.

Men who participated in this study shared that they often experienced osteoporosis and fragility fractures being viewed by healthcare practitioners as only being a problem for older (white) women. These commonly held but inaccurate views may delay prevention and treatment.<sup>10, 11</sup> Both men and women shared that they often felt that their osteoporosis received far less attention than their comorbid conditions, such as diabetes or arthritis.

*"Increasing awareness of osteoporosis in men among physicians and the lay public is critical for the prevention of fractures in our aging male population."*

*- Rudi, Belgium*

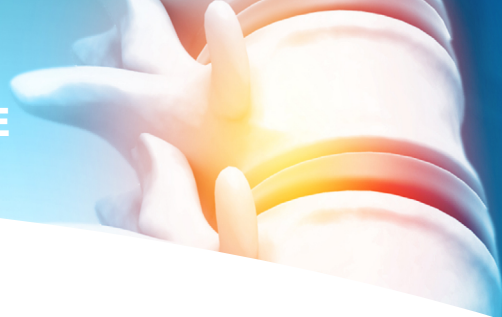
## 3. NEEDED IMPROVEMENTS IN CARE PROVISION

*"There is a lot we can do ourselves to maintain healthy bones, but often we are simply never told"*

*- Louisa, Malaysia*

### 1.1 Primary prevention

Many patients emphasized the importance of alerting individuals to the importance of bone health and the fact that people can do a great deal themselves to promote their own bone health. One patient stated, "everyone should be informed of the basic elements of preventing bone disease". Indeed, the importance of lifestyle factors to bone health has been documented extensively in the literature.<sup>12, 13</sup>



In this context, the importance of information on controllable lifestyle factors, such as diet (e.g., calcium, vitamin D, potassium intake through fruits and vegetables) and physical activity, were mentioned as factors that contribute to bone health for individuals of all ages. One patient stated that she wished she had known that even relatively small changes in bone mass can have a significant impact on overall bone health because she would have adjusted her diet immediately if she had been better informed.

The importance of disseminating information on behaviors that are harmful for bone health was mentioned. Patients, especially those who had been long-term smokers or regularly exposed to second-hand smoke, mentioned that they wished that they had known that smoke inhalation and excessive alcohol intake could reduce bone mass and increase fracture risk.

Patients felt it was important to emphasize existing guidelines on assessment of calcium and vitamin D intake, diet, and physical activity, and also to emphasize risk factors as a routine part of health care, especially for people over 65 years old. Patients also emphasized rightly that it is never too late for secondary prevention, as even older individuals with poor bone health can improve their bone health status through nutrition, exercise, and supplemental calcium and vitamin D intake.

## 1.2 Detection of high-risk patients

Patients placed much emphasis on the need to detect osteoporosis early and to identify those at high risk of fracture. They noted repeatedly that fractures need not be the first sign of poor bone health. Many patients reported that their first fracture was not considered a sentinel event that triggered a detailed assessment that could potentially have prevented additional fractures. This finding is in line with evidence suggesting that healthcare providers frequently fail to identify individuals at high risk for future osteoporosis, even among those patients who have already had a fracture.<sup>14, 16</sup>

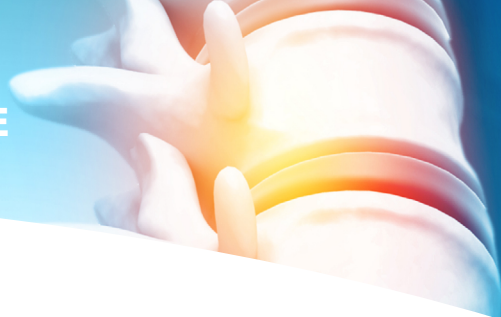
Individual patient stories highlighted the importance of red flags that signaled potential problems with their bone health, such as a history of low-trauma fracture, a family history of osteoporosis, and low body weight. A variety of assessment processes have been used to categorize patients into levels of risk, which in turn helps to determine appropriate next steps with respect to prevention, further diagnosis, and treatment.<sup>3, 17</sup>

*“Doctors need to identify high-risk individuals in need of further evaluation. I had a history of osteoporosis in my mother, but this was simply overlooked.”*  
- *Mickie, South Africa*

One patient reported on a good experience with a nurse who administered a risk factor assessment tool and interpreted the results. This proactive behavior thus allowed someone other than a physician, who may have quite limited time, to play a lead role in identifying at-risk individuals.

*“Medical professionals should have a much better understanding on the role of certain conditions and medications to the development of osteoporosis. I became ill with rheumatoid arthritis in my early teens, and they started talking about osteoporosis only 20 years later.”*  
- *Eva, Belgium*

# PATIENTS' PERSPECTIVES AS A CATALYST FOR ACTION TO IMPROVING OSTEOPOROSIS CARE



Several medical conditions and prescription medications can affect bone health through various mechanisms. Some patients with secondary osteoporosis reported serious delays (up to several decades) before healthcare professionals considered their primary condition and related treatments as risk factors for osteoporosis.

Healthcare professionals should be attentive to the presence of conditions that affect bone health (e.g., hyperthyroidism and rheumatoid arthritis) and the use of bone-affecting medications (e.g., glucocorticoids, high doses of thyroid hormone, sex hormone blockers, and certain blood thinners and anti-seizure drugs). The presence of such factors should signal a need for further assessments of bone health and other risk factors for bone disease. Patients emphasized that interventions should be targeted to minimizing the risk of bone disease in patients who are prescribed drugs that have the potential to affect bone health negatively.

## 1.3 Early diagnosis through bone mineral density testing

*“Patients should be referred for bone mineral density testing in a much timely manner.”*

*- Louisa, Malaysia*

Most patients demonstrated that they were well aware that it is possible to detect osteoporosis early. All of them were familiar with bone mineral density (BMD) testing and its use being warranted when risk factor analysis indicates a strong potential for osteoporosis.

BMD testing by means of dual-energy X-ray absorptiometry (DXA scan) remains the gold standard test for patients at risk of osteoporosis. For each standard deviation decrease in spine BMD (a one-standard deviation drop represents a 10–12% loss in BMD), the risk of fracture increases by 1.5–2.6 times.<sup>18</sup>

Patients expressed a strong need to understand why their doctors referred them for BMD testing, what they could expect, and the meaning of DXA scan scores. Moreover, they indicated that their doctors should provide proper explanations on potential treatment and selfcare options for BMD loss. Patients also emphasized that it is important for them to understand if and when they may benefit from a follow-up DXA scan. Male study participants noted that BMD testing may be under-utilized in men, particularly in men who have suffered fragility fractures, those receiving treatments that may cause bone loss (notably glucocorticoids or androgen deprivation), and those with multiple risk factors.

*“I had no idea what osteoporosis was all about or what the results of T-scores meant, and nobody ever explained.”*

*- Carine, United Kingdom*

Most patients reported that BMD testing was widely available in their countries. However, some patients reported experiencing difficulties in terms of financial or physical access, especially in rural areas. Limited reimbursement criteria have proven to be a barrier to DXA scan utilization and thus diagnosis of osteoporosis (Verdonck et al., in press).<sup>19</sup>



## 1.4 Initiation and follow-up of treatment

Nearly all patients emphasized the importance of improving medical practitioner training in the areas of osteoporosis detection and treatment. Because osteoporosis is a common disorder that can be diagnosed and treated in the primary care setting, much of the responsibility for promoting awareness, diagnosis, prevention, and treatment of osteoporosis

falls on healthcare professionals who provide primary care. Treatment initiation has been reported to be impeded by family physicians' lack of familiarity with the therapeutic arsenal and their associated uncertainty regarding choices of medication, duration of administration, possible side-effects, and effectiveness.<sup>15, 20, 21</sup>

*"As my treating physician was the first to intervene when I broke my foot and wrist, he held great responsibility to do the right things."*

*- Lohambal, Singapore*

The individual clinician was identified as having an important influence on the quality of osteoporosis care. In addition to educating themselves, physicians are in the position to inform their patients about bone health prevention, treatment, and assessments using (locally adapted) evidence-based practice guidelines. They can put into place systems that ensure that patients receive appropriate services based on their risks and needs.

Patients emphasized the role of 'clinical champions' (respected peers) in helping to persuade their colleagues to update their practice habits and to embrace and maintain innovations. Some patients suggested that guidelines and evidence-based reports should incorporate patient preferences.

## 1.5 Multidisciplinary and team-based care

A major concern expressed by patients was the lack of multidisciplinary and team-based service offerings. They felt that their osteoporosis care was "fragmented", "uncoordinated", and overall "considered less important" by healthcare professionals compared to other chronic conditions.

*"Osteoporosis takes a team. I had to create my own."*

*- Anne, Switzerland*

*"The doctor failed to recognize the underlying cause of my fracture. After I had healed, I was sent back home, and I broke another bone soon after."*

*- Diane, Canada*

*"I would like healthcare professionals to deliver holistic care."*

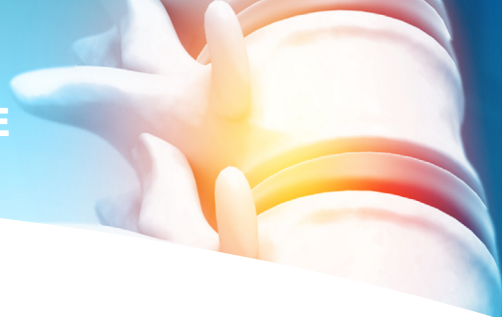
*- Nora, Argentina*

Only a few patients reported that they could rely on a highly functioning and integrated osteoporosis care team or Fracture Liaison Service operating in either primary or secondary care settings. These patients often expressed great satisfaction with regard to the comprehensiveness and continuity of the care provided. But the majority of patients felt they were left on their own, with just one medical provider taking care of them on an irregular basis.

A major shortcoming was noted in secondary care provision when patients were admitted to a hospital for a first or repeated fracture. Patients reported many emergency department physicians, orthopedists, geriatricians, or internists failed to recognize the underlying cause of their fracture and, consequently, did not refer them to other specialists for further evaluation. The same observation was made by many patients who were treated exclusively in primary care settings, where they felt it was particularly critical for patients to receive intensive interventions designed to maximize recovery and prevent future fractures.



# PATIENTS' PERSPECTIVES AS A CATALYST FOR ACTION TO IMPROVING OSTEOPOROSIS CARE



*"There is no real consensus on where osteoporosis should be treated."*

*- Mimi, Singapore*

Osteoporosis is often diagnosed and treated in the primary care setting. Some patients noted that they benefited from specialists who assisted their primary care providers with additional expertise in managing their condition, such as in cases when long-term antiresorptive therapy was prescribed or when they did not tolerate or respond well to a therapy. However, few patients reported having benefitted from this type of integrated health service delivery.

Some patients shared that their quality of care was compromised by constant changes in physician-specialists in teaching hospitals, particularly when they found themselves frequently facing a new physician-specialist who was unfamiliar with the complexity of their situation. Other patients complained that they were referred for BMD re-evaluations, given prescription renewals, or instructed to take drug holidays without receiving clear explanations for the reasons for these actions.

*"Telehealth consultations were helpful to me, especially as I could speak to the osteoporosis team who helped me out."*

*- Rose-Hannah, Canada*

Some patients lauded the availability of telehealth consultations with an osteoporosis-specialist or a multidisciplinary osteoporosis team. These consultations were highly valued by patients owing to their reducing travel time and expenses for patients. These findings are in line with previous research on patient experiences with osteoporosis care delivered through virtual consultations.<sup>22, 23</sup>

*"It is frustrating if there is no team available and you have to look after yourself when feeling so tired and when you are in almost constant pain. I was fortunate to receive help from a local patient organization who helped me find a good doctor."*

*- Annikki, Finland*

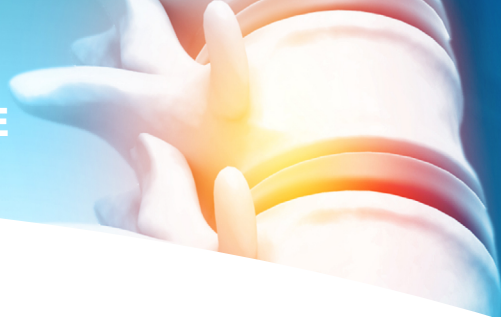
Overall, many patients had to contact specialists and allied health professionals themselves after exploring strategies to improve their often deteriorating health on the Internet or by talking to peers. Some patients received active guidance with finding the right provider from osteoporosis patient associations or patient experts. In cases of self-referral, patients stated it often took a long time to find the right medical specialist (osteoporosis specialist, endocrinologist, or rheumatologist) that supported them in their treatment. Some patients faced substantial waiting times during which they felt their health was deteriorating.

Some patients emphasized the important roles and responsibilities that nurses fulfil in primary and secondary care, particularly with respect to improving their understanding of the disease and ensuring their compliance with the therapeutic regimen. When they could not readily see signs that their therapy was working or failing, they felt supported by nurses who motivated them to comply long-term with their prescribed treatment regimens. Home visits by trained osteoporosis nurses were especially valued because they allowed patients to remain at home and provided patients with opportunities for in-depth conversations about their condition and its management.

*"I could rely on a rheumatology nurse who provided me with all necessary information."*

*- Lut, Belgium*

# PATIENTS' PERSPECTIVES AS A CATALYST FOR ACTION TO IMPROVING OSTEOPOROSIS CARE



Other strategies that were valued by patients were enlisting the support of their social networks, the sending of reminders about follow-up appointments, having their adherence efforts recognized, simplification and organization of treatment regimens, having their concerns about adverse drug effects addressed, and their healthcare providers maintaining an encouraging provider-patient relationship.

Osteoporotic patients who receive patient education and are monitored by a nurse have been reported to have improved therapy adherence and persistence over time. Importantly, better adherence has been shown to be associated with better outcomes.<sup>9, 24, 25</sup>

*“Dietary recommendations beyond calcium and vitamin D as provided by my dietician have been important to me to improve my osteoporosis.”*

*- Janet, Malaysia*

Some patients felt that referrals to dietitians were particularly helpful in implementing nutrition recommendations. However, the majority of patients never consulted with a dietician. Patients noted that all healthcare providers have opportunities at many patient encounters to establish and reinforce nutritional recommendations that benefit bone and overall health. Some patients also noted that it is of critical importance to go beyond calcium and vitamin D when discussing dietary requirements with patients, a recommendation that is in line with the available evidence.<sup>26, 27</sup>

Patients who consulted with physical therapists and engaged in individualized impact activities or resistance-training programs, such as walking, stationary bicycling, weightlifting, dancing, hiking, or stair-climbing experienced improvements in strength, mobility, and functional capacity. Patients reported benefiting from specific postural exercises aimed at strengthening back extensor muscles, which relieved their pain and reduced the development or progression of kyphosis.

*“My physiotherapist was truly important to me as he developed an individualized training program so I could re-gain my mobility.”*

*- Nel, The Netherlands*

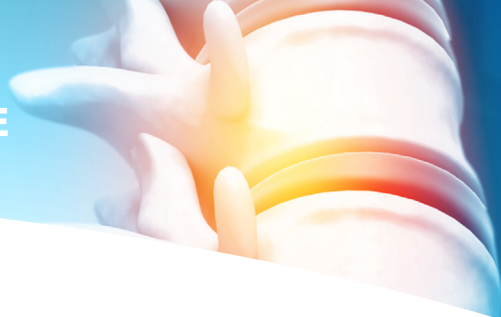
Patients indicated that it is important to discuss fall prevention strategies with every osteoporosis patient. This suggestion is consistent with the literature showing that individuals should be encouraged to find an activity they like enough to continue.<sup>28, 29, 30</sup>

Patients often emphasized a need to receive psychological support from psychologists to cope with their condition. Many patients had experienced chronic stress as well as negative and impactful events in their lives that had left them vulnerable to coping with the consequences of living with osteoporosis.

Some patients made reference to occupational therapists who helped them to evaluate their home environments, make modifications that minimize falling risks, and find suitable support devices, such as canes and walkers. However, relatively few patients were offered this service.

Other healthcare professionals, such as pharmacists, dentists, and optometrists, were not often mentioned. However, there is good evidence that pharmacists can provide valuable advice to patients concerning calcium and vitamin D supplementation, the best way to take medications, and any potential drug interactions. Meanwhile, optometrists can help by ensuring that the vision of their older patients is adequately corrected, which should decrease the risk of potentially debilitating falls. For their part, dentists may be able to act upon the antiresorptive effects of some agents that can cause bone loss in the jaw.

# PATIENTS' PERSPECTIVES AS A CATALYST FOR ACTION TO IMPROVING OSTEOPOROSIS CARE



Overall, patients expressed a strong need for integrated, team-based care. They recognized that their condition requires the expertise of multiple providers over time.

**“Patients should be granted access to osteoporosis care, free of charge.”**

*- Hilda, Mexico*

Many patients reported bearing substantial financial expenses related to their treatment, creating a financial burden for themselves and their families. Calcium and vitamin D supplementation are sold over the counter in most countries and are not included in national health coverage schemes. Additionally, DXA scan reimbursement criteria varies widely between countries. Consulting with (individual) clinicians, nurses, dieticians, physiotherapists, dentists, and psychologists for osteoporosis-related support was considered expensive; and only a few patients had these services (nearly) fully covered by their insurance schemes.

An area of particular concern expressed by some patients was related to serving underserved populations. For the poor (especially the low-income elderly population), individuals with disabilities, individuals living in rural areas, and other underserved populations, the lack of timely access to care represents an additional important barrier.

Some patients reported having poor access to care caused by a lack of available providers, inadequate income or insurance coverage, the high costs of diagnosis and treatment, a lack of transportation, or an inability to take time off from work to attend to personal or family care needs. Some patients reported observing underserved populations in their countries being reliant on an unorganized patchwork of providers that are ill-equipped to provide or even facilitate the coordinated, ongoing preventive and treatment services that are needed to maintain bone health, let alone overall health and well-being.

**“Patients in rural areas often have difficulties accessing care.”**

*- Luzja, Romania*

## 1.6 Patient-centered communication

**“I have experienced a great deal of variety in the quality of the communication provided by the health care professionals who treated me.”**

*- Mieke, Belgium*

A key issue patients put forward was the lack of patient-centered communication that they experienced from many health professionals throughout their journeys. While some patients reported being very satisfied, the majority of patients expressed serious disappointment and frustration over the amount and quality of information and communication provided by medical and allied health professionals.

Many patients felt that communication from health professionals was not patient-centered in terms of the provision of prompt attention, choice, trust, confidentiality, dignity, shared decision-making, and holistic (whole-person) care. Many patients reported having to search the Internet for additional information and/or having to consult with national or local patient associations to obtain answers.

**“Patient educational materials are a valuable source of information. We need them readily available, but it takes some time before you fully understand what osteoporosis is about.”**

*- Anita, Canada*

# PATIENTS' PERSPECTIVES AS A CATALYST FOR ACTION TO IMPROVING OSTEOPOROSIS CARE



Many patients valued the availability of trustworthy patient education materials that provide comprehensive information. However, few reported being offered this information as part of an integrated osteoporosis care program. Many patients reported receiving little or even no information on the selection of therapeutic agents available and how particular prescriptions were tailored to the severity of their bone loss and other comorbid conditions. Only a few patients indicated that they were able to discuss the risks and benefits of these agents with their physicians, and those who did indicated that they had to ask their physician explicitly to obtain the information. Some patients expressed the need for detailed information, such as the utility of bone resorption markers in monitoring therapeutic response, whereas others preferred to receive less information related to their therapeutic regimen.

Patients proposed a wide range of topics for health literacy improvement efforts, including risk factors for osteoporosis, the meaning of BMD measurements, effective treatment options, potential side effects of drugs, fall prevention strategies, and self-management strategies (e.g. diet and exercise). The available evidence underscores the importance of health literacy in people with osteoporosis for improving outcomes. In other words, it is important to ensure that individuals can access, understand, and use health-related information and services in order to empower them to make appropriate health decisions.<sup>31, 32</sup>

Patients put forward the good practices that they valued and believed were important for improving health literacy on osteoporosis. In particular, patients appreciated the availability of a dedicated and well-trained osteoporosis nurse who makes home visits and who has adequate time to address questions and concerns as well as support from osteoporosis patient organizations, support from patient experts, and national osteoporosis campaigns. They reported valuing the availability of an integrated osteoporosis clinic, in which they could encounter different providers at the same time, which reduced the time and effort needed to obtain all of the information they needed.

Some patients stated that they referred themselves to alternative medicine practitioners when they identified potentially helpful strategies (e.g. meditation techniques). Unfortunately, some patients sought alternative practitioners because they had lost faith in the regular healthcare system due to the poor communication they had experienced.

*"My doctor didn't recommend any websites or support groups or anyone else to speak to."  
- Dorothy, United Kingdom*

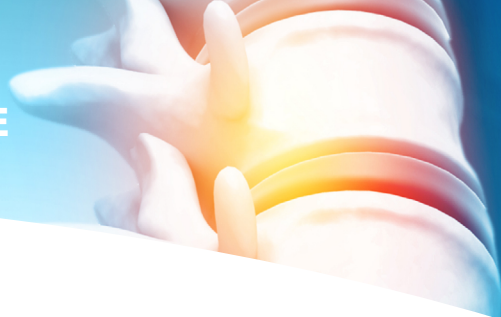
*"There's no one out there to help you."  
- Deborah, USA*

*"I have found benefit in alternative medicine, especially homeopathy."  
- Loes, The Netherlands*

## POLICY RECOMMENDATIONS

Given the current and imminent future burdens imposed by osteoporosis, policymakers in all countries should elevate osteoporosis to a national health priority. And, most importantly, based on all the above patient experiences and observations, a systematic effort by all stakeholders including international health organizations, governments, individual clinicians, hospitals, post-acute facilities, nursing homes, insurers, professional and patient associations, academic institutions, healthcare purchasers and the industry is needed to advocate for and implement priority interventions (Table 1).

# PATIENTS' PERSPECTIVES AS A CATALYST FOR ACTION TO IMPROVING OSTEOPOROSIS CARE



The world needs a global strategy to fight a global challenge and from a patient perspective, policy makers should especially focus on those aspects of healthcare that patients value highly when they seek and receive osteoporosis care. These include: first contact accessibility; continuity of care (longitudinal, interpersonal, informational, and management); comprehensiveness of care (health promotion and prevention over the life course, treatment, rehabilitation); coordination of care (care plan), people-centered care (prompt attention, choice, trust confidentiality, dignity, shared decision, whole person); professional competence (technical, communication, cultural); safety; and overall experience.

The World Health Organization (WHO) - with partners in bone health and aging spaces- has a major opportunity to provide leadership on osteoporosis that currently represents one of the most formidable barriers to healthy, active aging.

## Key recommendations:

### Raise awareness on osteoporosis, fragility fractures, and fall prevention

- Policymakers need to make a determined effort, involving healthcare professionals and their organizations and patient societies, to ensure the public is provided with clear, consistent, and compelling evidence-based messages regarding healthy lifestyles and behaviors that are helpful for maintaining good bone health, including the preventive options that are available to people.

### Close the gender gap

- Policymakers need to close the gender gap in osteoporosis care. Gender bias can impede osteoporosis diagnosis and effective treatment in people at risk of a fragility fracture. The perception that osteoporosis affects only women means men are less often screened and treated for osteoporosis following a fracture.

### Close the care gap

- Policymakers should foster the use of existing evidence-based, effective strategies for risk identification and management in both primary and secondary care settings. This includes ensuring appropriate clinical training on risk identification and management tools in primary care settings to ensure appropriate referral and treatment options. Particular attention should be paid to the detection and management of secondary osteoporosis among individuals who suffer from diseases that are common comorbidities of osteoporosis.

### Promote multidisciplinary and integrated osteoporosis care

- Policymakers should provide the legal frameworks and financing needed to update models of care. Multidisciplinary osteoporosis care teams are needed in both primary and secondary care settings with Fracture Liaison Services to bridge primary and secondary care. As part of multidisciplinary services, all patients should receive a wide range of personalized preventive and curative services. Patient education is a critical service that should be provided to all patients on an ongoing basis.

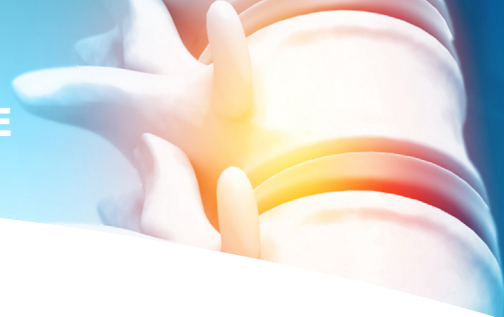
### Ensure reimbursement structures reflect national scientific consensus on detection, care, and prevention for osteoporosis and fragility fractures

- Policymakers need to assure that adequate reimbursement is in place to ensure access to best-practice care at all levels of service delivery. Reimbursement decisions should reflect the true costs of fragility fractures to the wider healthcare system and society. At a minimum, there should be reimbursement for nationally recommended diagnostic tools, such as DXA scanning and the Fracture Risk Assessment Tool (FRAX®), and treatments.

### Develop nationwide registries and audits to enable local-level monitoring and surveillance of patient health outcomes

- Policymakers need to promote the availability of high-quality data on osteoporosis and fragility fractures (spanning hip and vertebral fractures at a minimum) to safeguard effective scrutiny, performance management, and planning, and also to allow for vital feedback at the national and local level. Policymakers should consider how these data could be used to incentivize quality-of-care improvements.

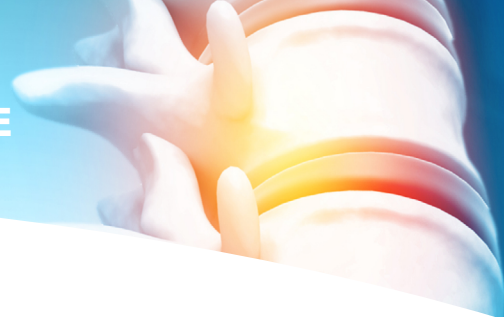
# PATIENTS' PERSPECTIVES AS A CATALYST FOR ACTION TO IMPROVING OSTEOPOROSIS CARE



**Table 1. Associations of international priority interventions with particular stakeholders.**

INTERVENTION	GOVERNMENT	INDIVIDUAL CLINICIAN	HOSPITAL	POST-ACUTE FACILITY	NURSING HOME	INSURER	PROFESSIONAL ASSOCIATIONS	PATIENT ASSOCIATIONS	ACADEMIC INSTITUTIONS	HEALTH CARE PURCHASER	INDUSTRY
Promoting bone healthy lifestyles	X	X	X	X	X	X		X			X
Awareness campaigns	X										
Clinical guidelines		X	X	X	X						
Training of professionals			X				X		X		
Continuing education			X	X	X		X				X
Integrated, team-based care		X	X	X	X						
Quality improvement initiatives	X	X	X	X	X	X	X	X	X	X	X
Patient registries	X	X	X	X	X						
Performance reporting		X	X		X						
Monitoring and surveillance	X										
Policy interventions	X					X	X		X	X	

# PATIENTS' PERSPECTIVES AS A CATALYST FOR ACTION TO IMPROVING OSTEOPOROSIS CARE



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