



National
Osteoporosis
Society



National Osteoporosis Society

Research Strategy

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1. Foreword

The National Osteoporosis Society is the only UK-wide Charity dedicated to preventing the pain and suffering caused by osteoporosis and its associated fractures. We help people with osteoporosis live the lives they want to lead.

Research into osteoporosis holds the key to providing a better future for the estimated three million people in the UK affected by the condition.¹ Over the years we have witnessed breakthroughs in the diagnosis, treatment and provision of services for the condition, and the Charity has played an important role in contributing to this research base. Since our creation in 1986, we have invested over £5.2 million in more than 130 research projects into all aspects of osteoporosis. This is an accomplishment only made possible thanks to the amazing generosity of our members and donors. Their support has helped greatly to enhance our knowledge and understanding of osteoporosis, leading to some remarkable advancements in osteoporosis research making a significant difference to the lives of people affected by this devastating condition.

In this Research Strategy, we build upon that work and present a vision of hope for our research agenda over the coming years. The strategy outlines how the Charity's research programme plans to bring about real improvements to the lives of people living with osteoporosis. On the path towards forming our strategy the Charity undertook an in-depth review of our past research portfolio and performance in order to determine how our future direction could be further improved. The review process involved consultation with people living with osteoporosis, researchers, healthcare professionals and our internal committees. The views and knowledge gathered throughout the review process were invaluable and we would like to thank everyone for their contribution. One of the key findings from this work is the importance of research to those affected by osteoporosis.

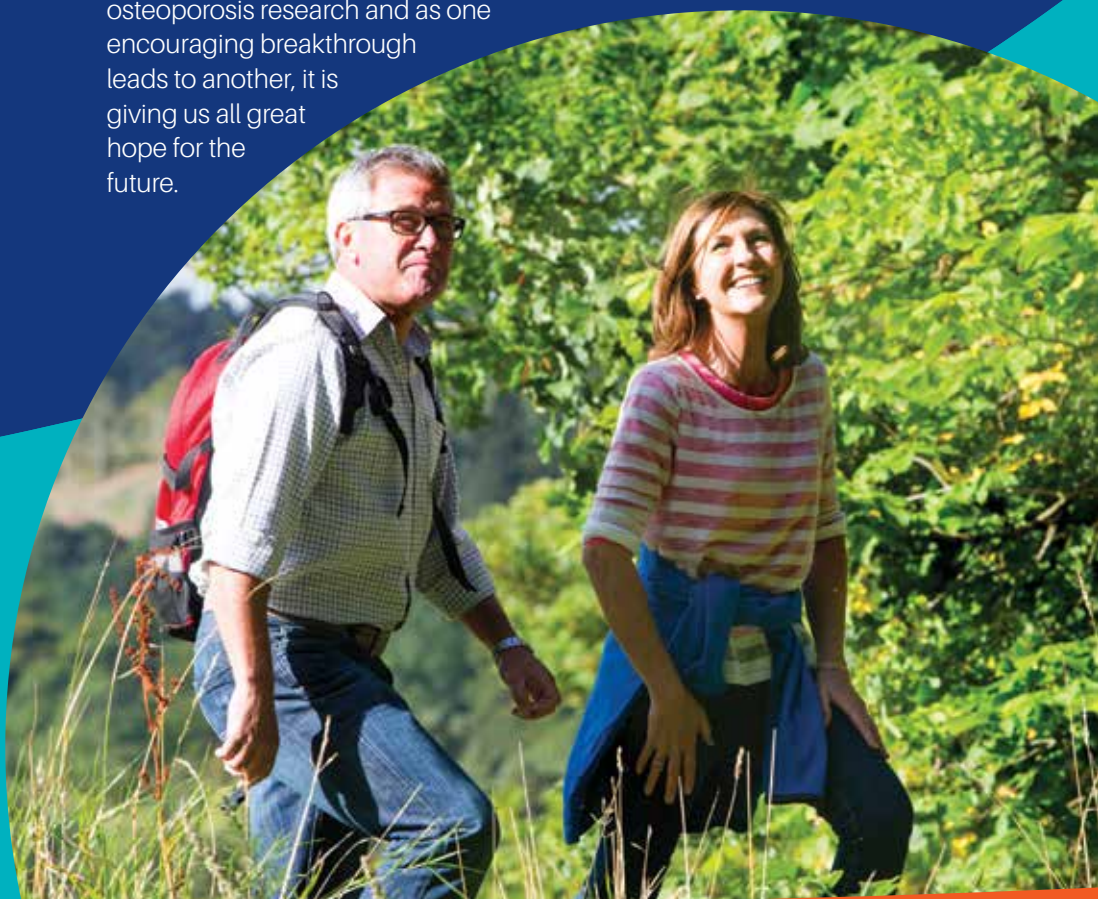
There is no doubt that these are incredibly exciting times for osteoporosis research and as one encouraging breakthrough leads to another, it is giving us all great hope for the future.

Our Research Strategy reinforces our commitment to drive the research agenda through:

- Funding high-quality research
- Influencing and partnering with key bone health funders
- Supporting the next generation of osteoporosis research leaders
- Engaging the public with osteoporosis research.

We invite you to join us in working towards our vision of a future without fragility fractures in which a brighter future is provided for people with or at risk of osteoporosis.

“Research into osteoporosis holds the key to providing a better future for the estimated three million people in the UK affected by the condition.”¹



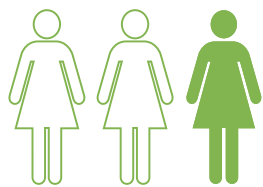
2. Where we are now

The Problem

Osteoporosis is a fragile bone condition and occurs when the bone's inner structure thins. This can cause bones to lose their strength and density, leading to painful and debilitating broken bones (fractures), usually following only a minor bump or fall. Broken bones that occur because of reduced bone strength are often referred to as 'fragility fractures'. The broken bones resulting from osteoporosis represent only one of the

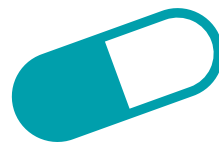
many difficulties experienced by those living with the condition, as it can have a profound social and emotional impact on people affected by the condition. For instance, it can lead to financial insecurity as a result of having to give up work, a loss of confidence and self-image due to a changing body shape, and living in fear of going out or having physical contact with anyone due to the risk and fear of fracturing.

More than **3 million people** in the UK are estimated to have osteoporosis.¹



1 in 3 people who have long-term pain from fractures describe it as severe or unbearable.²

Every year people in the UK suffer more than 500,000 fractures. That's **1 every minute.**¹



Only half of people in pain say they have effective medication to help manage it.²

The cost of hospital care for patients with hip fractures is estimated at over **£1.1 billion** every year.³



According to a survey by the National Osteoporosis Society, **a fifth of women** who have broken a bone...



...**break 3 or more** before their osteoporosis is diagnosed.⁴



The number of three million people in the UK living with osteoporosis¹ is rising rapidly due to the ageing population. Despite significant advances in osteoporosis research that have led to real improvements in people's lives, there are still considerable challenges.

Consequently, there is a desperate need to continue the search for answers that could help us beat this cruel condition once and for all, and prevent future generations from suffering the misery of broken bones.

The Solution

More ground-breaking research

National Osteoporosis Society

The National Osteoporosis Society is the only UK-wide Charity dedicated to ending the pain and suffering caused by osteoporosis, and the only UK funding body solely focused on research into the diagnosis, prevention and treatment of osteoporosis. The research that we have previously funded has been broad and far-reaching, enabling us to build a more complete picture of osteoporosis. For example, ground-breaking research has revealed that specific weight-bearing exercises are vital weapons in the fight against osteoporosis, giving people an effective way to help prevent agonising fractures; and pioneering research has helped develop potential new treatments aimed at reducing the pain associated with osteoporotic fractures whilst also advancing novel personalised treatment approaches.

The National Osteoporosis Society recognises the potential impact of working closely with other national research funding bodies, such as the Medical Research Council (MRC), National Institute for Health Research (NIHR), and other charities with an interest in osteoporosis, such as Arthritis Research UK (ARUK). The Charity will play an active role in influencing the wider research agenda, ensuring that these other funding organisations address the needs of those with or at risk of osteoporosis.



Listening to people living with osteoporosis

As a patient-driven organisation, we always listen to people living with osteoporosis in order to be innovative in our approach to tackling osteoporosis. In 2015 the Charity undertook *A Good Life with Osteoporosis* study, which received over 3,500 responses. When asked about priorities for the future, over 80% of respondents stated that a major priority for the Charity should be to support and raise funds for research² into:

- Osteoporosis diagnostics and treatments
- The scientific causes of osteoporosis
- Issues to help improve the lives of people with osteoporosis.

Alongside this, people wanted to be made aware of important medical research findings. This deeper understanding of our beneficiaries has been fundamental to underpinning the development of our Research Strategy.

80% of respondents stated that a major priority for the Charity should be to support and raise funds for research²



Our Research Strategy

The National Osteoporosis Society's overall vision is an end to osteoporosis and to achieve this, the Charity follows four key aims:



Aim 1: Care Ensure people with osteoporosis have access to quality healthcare



Aim 2: Support Empower people with osteoporosis to manage their condition



Aim 3: Prevent Promote bone health to prevent osteoporosis



Aim 4: Cure Pursue a cure for osteoporosis

Our Research Strategy is central to achieving the aims, hence it sets out the broad focus for the Charity's research agenda which will be built upon three core goals:

Goal 1: Research to make a difference

Goal 2: Support for researchers

Goal 3: Research for people affected by osteoporosis

Support of the highest-quality research

As the National Osteoporosis Society receives no government funding, our research programme is only made possible thanks to the generous support of our members and donors. Every one of them should feel proud of the progress we are making and their personal contribution. For over 15 years the National Osteoporosis Society has been a member of the Association of Medical Research Charities (AMRC), the national membership organisation of leading medical and health research charities. In accordance with AMRC's high-standards and governance guidelines, the Charity ensures that the money so generously raised by the public is put to the best possible use to support the highest-quality research.



National Osteoporosis Society Strategic Direction To **Care, Support, Prevent** and **Cure** Osteoporosis

National Osteoporosis Society Research Strategy

Core research areas and priorities
Shaped by both researchers and people affected by osteoporosis

Three main goals



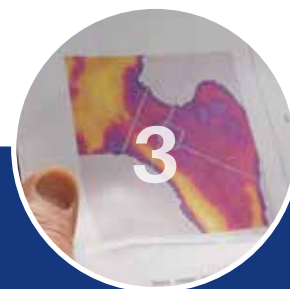
1 Research that makes a difference

- Influencing and Partnerships
- Strategic Development
- Research Grants



2 Supporting researchers

- Dialogue and Networking
- Investment in Future Leaders



3 Research for people affected by osteoporosis

- Research Dissemination
- Engagement
- Public & Patient Involvement (PPI)

Measurement of success and impact



Academic



Economic



Societal



Public Engagement

To achieve our Research Strategy, all our work will be underpinned by the following principles:

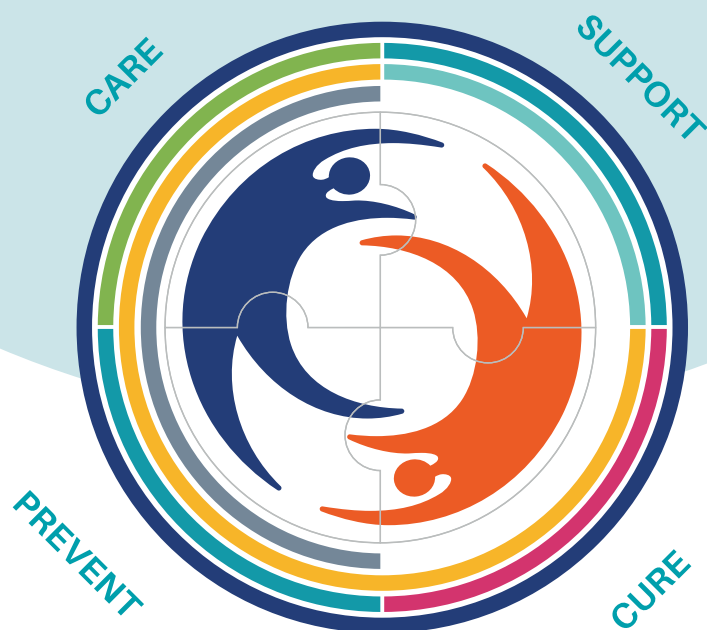
- Excellence
- Relevance
- Originality
- Pathway to Impact
- Sustainability
- Financial Need

3. Where we want to get to



Our Research Strategy sets out the Charity's ambition to further our understanding across a broad scope of core research areas through both quantitative and qualitative research. In order to achieve our vision of ending osteoporosis, we will tackle these core areas for all types of osteoporosis including the several rare forms of the condition (idiopathic juvenile osteoporosis, transient migratory osteoporosis and osteoporosis associated with pregnancy). Ten core research areas have been identified that support progress for the Charity's mission to **Care, Support, Prevent** and **Cure** osteoporosis.

Core Research Areas



- 1 Diagnosis and Risk Assessment:** Development of new, quicker, more accurate and cost effective ways of diagnosing osteoporosis; or identifying those at risk of developing the condition (such as FRAX and QFracture).
- 2 Lifestyle Management:** Understanding the relationship between risk factors such as diet, exercise, environmental and other lifestyle choices and the development of osteoporosis and prevention of fractures.
- 3 Access to Information:** Investigation of the best methods of informing and educating the public and health professionals about osteoporosis.
- 4 Systems of Care:** Study of service delivery, including settings of care (primary/ secondary), patient care pathways, follow-up monitoring, and the economic costs associated with these.
- 5 Pain:** Discovery of new ways of treating the acute and long term/chronic pain associated with osteoporotic fractures.
- 6 Mechanisms of Disease:** Exploration of the pathogenesis of osteoporosis (including specific fracture sites) and further understanding of the genetics behind osteoporosis.
- 7 Medication and Supplements:** Discovery of new effective treatments for osteoporosis and osteoporotic fracture healing, including investigation into the safety and benefit of current medications, use of supplements, and compliance of taking medications.
- 8 Living with Osteoporosis:** Understanding of the impact that osteoporosis and osteoporotic fractures have on people's lives (e.g. confidence and fear of fracture) and how people with osteoporosis can best be supported.
- 9 Osteoporosis and Comorbidities:** Understanding of the relationship between osteoporosis and other medical conditions (including but not limited to sarcopenia, diabetes, obesity, frailty, renal disease, eating disorders).
- 10 Epidemiology:** Understanding of the burden of osteoporosis related to fractures in different population groups and the health economic costs associated with these.

Please note these are not in order of priority

4. How our research strategy will help us get there

4.1 Research to Make a Difference

Commission research to support the Charity's strategic development

The Charity will explore new ideas for commissioned projects designed to provide the evidence needed to achieve the Charity's main strategic aims. This could include qualitative research (survey) to obtain people's views on a particular issue or evaluation research to systematically assess and to provide feedback on specific Charity work programmes. For example, the Charity successfully commissioned a ground-breaking project titled *Life with Osteoporosis*. The project provided for the first time an in-depth qualitative analysis detailing more about the physical and emotional impact osteoporosis has on the everyday lives of those affected by the condition. This new evidence crucially highlighted the burden of the condition in the UK, and was utilised to raise the issue with parliamentarians, research funders and the public.

Influence the research agenda

The Charity will engage with other major research funders with an interest in osteoporosis to influence them to facilitate and fund the research which we believe needs to be done but is beyond our own resources. Working with other research funding organisations is vital to delivering the vision of the Charity. This will also involve effective use of results from our own funded research in order to inform other areas of the Charity's work, particularly policy and campaigning, as well as being utilised by other funders.

Maximise impact through partnerships

The Charity will use our membership of the AMRC and other professional organisations, to actively identify potential research collaborators with an interest in bone health with whom we can establish strong partnerships. We recognise the importance of working in partnership with other funders in order to merge our financial resources and expertise to achieve common goals. Over the past five years, we have forged successful collaborations with other funders, such as Orthopaedic Research UK, to raise awareness of osteoporosis and increase the annual spend on osteoporosis research.

Implement a research grants programme to fund high-quality research

The Charity will continue to implement a research grants programme, building on our previous successes, in order to fund high-quality research. This Research Strategy will continue to support the best researchers at all stages of their career via a diverse portfolio of funding schemes as outlined in *Section 5.1*. Where Charity research funds permit, the Charity will also pursue the development of new initiatives/schemes. The Charity remains committed to the AMRC governance guidelines of accountability and probity in the allocation of grants and awards for research in order to uphold the standards which enabled the Charity to obtain a certificate in 'Best Practice in Medical and Health Research Peer Review'.





The biennial UK scientific Osteoporosis Conference was attended by over **700 delegates**



4.2 Supporting Researchers

Stimulate networking and collaborations within the research community

The Charity will continue to engage in dialogue and networking with research audiences in order to encourage researchers and clinicians to communicate and collaborate with one another. The Charity has a strong track record in developing effective working relationships with researchers/clinicians. We will continue to do so through our health professional networks/membership, scientific journal *Osteoporosis Review* and biennial UK scientific Osteoporosis Conference (attended by over 700 delegates with presentations, workshops and exhibitions).

Support development of future osteoporosis research leaders

The Charity will support the development of the next generation of osteoporosis research leaders, ensuring that the highest quality research continues to be performed in the UK in this important field. For instance, the *Early Careers Grants* scheme will offer support to excellent young researchers with a commitment to the osteoporosis or bone health field when they most need it at the start of their clinical/non-clinical careers. This is during the critical point when transitioning to undertaking independent research. The scheme aims to provide the opportunity to build research portfolios; secure further funding and develop strong project management and leadership skills.

4.3 Research for People Affected by Osteoporosis

Disseminate the latest research findings

The Charity will ensure that the latest research findings (including those from our own research) are disseminated in a way that is accessible to all. Our recent *A Good Life with Osteoporosis* study revealed that information on important medical research findings can make a significant difference to people affected by osteoporosis. Therefore, as a patient driven organisation, we will aim to provide our beneficiaries with timely, accurate and up-to-date information in order to support and empower them to manage their condition. To enhance our activities in this area we will develop our current media technologies and also explore new digital streams.

Patient and public involvement (PPI) in research

The Charity will ensure that the opportunity for patient and public involvement (PPI) is available to all those wishing to participate in research. PPI can provide empowerment by giving people with experience of osteoporosis a voice, and thus aligns with the Charity's strategic aim of *Support*. The Charity is strongly positioned to ensure that patients and the public are actively involved in research at all stages, from identifying research questions, developing applications for funding, designing protocols, and finally participating in studies. The Charity currently employs a research support request process for researchers wishing to request help with PPI and will continue with this approach and explore other innovative methods to get people involved in research.

Engage researchers with the Charity

The Charity will ensure engagement of researchers with the Charity and the public. This could be through our Support Groups, *Osteoporosis News* quarterly magazine, and fundraising appeals. This engagement can not only benefit people affected by osteoporosis but crucially can also help researchers to improve their understanding of the realities of living with osteoporosis. We hope that in the process this will inspire them to continue to pursue osteoporosis research.



5. Research grants programme

5.1 Funding Schemes

The Charity believes that the most effective way of tackling osteoporosis is to allow the research community to identify the gaps in knowledge and generate the research ideas and approaches needed to fill those gaps. Therefore, calls for applications will be across our broad core research areas (*Section 3*) with each grant round consisting of either an open call, where the Charity is accepting submissions on any relevant core area or a *themed call*, where the Charity will give priority to research proposals focused on the particular theme/area which has been identified (e.g. vertebral fractures).

The Charity will be supporting the following research grant funding schemes:

Innovative (Pump-Priming) Grants: To support a highly innovative pilot study for a maximum of twelve months in order to allow a researcher to test cutting-edge hypotheses, and provide the critical data required to apply for funding from larger funding organisations.

Project Grants: To provide support to an established world-leading osteoporosis researcher for a maximum of three years in order to undertake a pioneering research project designed to answer a single question or a small group of related questions.

Early Career Grants: To support both a researcher and a project for a maximum of two years through specific funding which invests in the development of the next generation of outstanding osteoporosis researchers. Applicants will need to have demonstrated that they are on an upward trajectory with great potential, and are now ready to take the next step towards becoming an independent principal investigator.

In addition to calls for research grant applications, the Charity will also continue to develop its award schemes in association with our biennial scientific conference which includes:

Young Scientist Prize: The purpose of this award is to recognise the outstanding work of a young investigator pursuing research into osteoporosis and/or fragility fractures, contribute to the costs of initiating and supporting research and attract young researchers to the National Osteoporosis Society.

Research Bursaries: Awards will be available to those presenting their research at the National Osteoporosis Society Osteoporosis Conference to contribute towards the costs of registration, travel and accommodation.

The award of all grants is subject to the availability of suitable applications and funding, and where Charity research funds permit, the Charity will pursue the development of new initiatives/schemes.

“We’ve received so many research applications”

Some of our brightest minds in the scientific community are interested in doing research into osteoporosis and over the past 22 years we have received hundreds of research applications. The National Osteoporosis Society is determined to fund the most promising of these projects and to select those that will have the biggest impact on the lives of people with osteoporosis, not just today but for generations to come.

Professor Elaine Dennison, Chair of Research Grants Committee

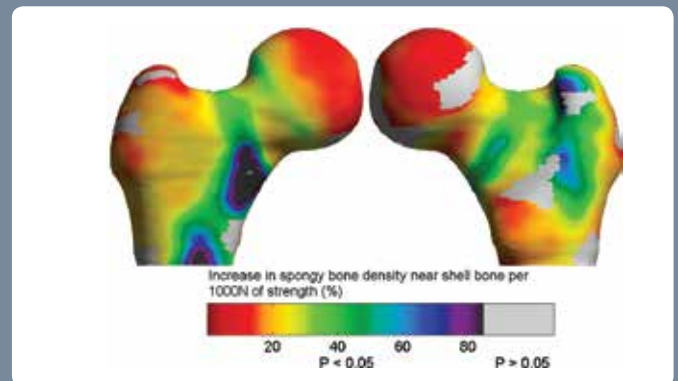




Fjola Johannesdottir

What inspired you to pursue a career in musculoskeletal research?

I became interested in medicine at a very early age. But I got interested in engineering in high school. I decided to study mechanical engineering with the focus on going into orthopaedic design to combine my fields of interest, engineering and medicine. My motivation has always been to help others to build a better life by developing a useful product, therapy or service. It was my M.Sc. study that sparked my interest in research, particularly in bone and muscle, and ever since have I committed myself to musculoskeletal research.



Do you have any personal connection to osteoporosis?

Yes, my grandma has severe osteoporosis. She has sustained 5 vertebral fractures and fractured a few ribs. It has been painful to watch her but at the same time inspired me to dedicate myself more to research of vertebral fractures. Even though hip fractures are the most serious of all osteoporotic fractures, vertebral fractures are more painful and you can suffer from them for years.

What impact has the award had on your research and career?

With the great support of the National Osteoporosis Society, along with support from the Bone Research Society, I got the unique opportunity to be a visiting research fellow in Mary L. Bouxsein lab (BIDMC & Harvard Medical School, Boston). This experience gave me the opportunity to link two major themes of fracture prediction: the patient-based imaging with laboratory-based measures of bone mechanical properties. Furthermore, I was exposed to a variety of experimental techniques used to assess bone strength and widened my professional network which I believe will lead to collaboration in the future.

5.2 Key Criteria

- To qualify for a research grant, proposals must demonstrate the following principles: excellence, financial need, sustainability, relevance, originality and pathway to impact.
- To be eligible to apply, applicants must be based at a university, postgraduate institute, medical school, NHS trust or Health Board in the UK or other British Islands.
- Applications for any one grant round will be restricted to one per lead investigator.
- The Charity will consider “top up” funding, when a grant is awarded to supplement funds that have already been secured by another funder in order to support ambitious projects.
- The Charity will only fund direct costs in line with the AMRC policy. This may include: salary of the applicant (and/or scientific/technical assistant excluding PhD), the running costs (consumables) of the project and/or the purchase of items of essential equipment (justified).
- All applications must include a clear plan for public and patient involvement (PPI).
- Given the significant cost of conducting phase II/III clinical trials, direct support by the Charity for numerous large-scale trials is not a viable option.
- The Charity does **not** fund animal research.



Further information on each funding scheme will be available on the Charity’s website, including details on: funding envelopes, the application process, deadlines, and specific eligibility criteria.

6. How we will ensure we achieve our research strategy

The National Osteoporosis Society will keep our Research Strategy under review to ensure that its implementation is in line with our strategic intent, and will perform a formal review after five years.

The review process will aim to identify the return on investment and impact of our research activities and investments in achieving our three main research strategy goals. It is crucial that the Charity demonstrates the **academic, economic, societal and public engagement** impact of its research related activities in order to show the difference our generous donors' funding has made to the lives of people affected by osteoporosis (see page 7 for more details). The Charity will utilise internal reporting measures to benchmark our ongoing progress against our research strategy objectives. We will also employ additional research reporting tools, such as Researchfish, in order to effectively gather and monitor the outcomes and impact of all our funded research grants.

In the allocation of research grants the Charity operates according to the AMRC's rigorous principles of peer review. Following an AMRC audit in 2015 the Charity was awarded a certificate in **'Best Practice in Medical and Health Research Peer Review'**, a demonstration to our stakeholders, including the government, researchers and funders, of our continued commitment to accountability and probity in the allocation of grants and awards for research.

Our **Research Grants Committee** plays a central role in overseeing the research programme and allocation of research funding in line with the Charity's Research Strategy and overall strategic direction. The committee comprises experts from a wide range of professional scientific/clinical disciplines and lay patient representative members, as we recognise the value that people affected by osteoporosis bring to research and the need to ensure their views help shape our research activities. The committee aims to reflect a fair balance of experience and scientific disciplines, with views from all members given equal weighting.

"The committee comprises experts from a wide range of professional scientific/clinical disciplines and lay patient representative members, as we recognise the value that people affected by osteoporosis bring to research and the need to ensure their views help shape our research activities."

"We're making breakthroughs all the time"

It's a really exciting time for osteoporosis research. The scientific community is making breakthroughs all the time and we are learning from one another. In our own research, we've demonstrated that women who take vitamin D during pregnancy can improve bone health in their baby, which should reduce the likelihood of the child suffering fractures as they grow older. If these effects are sustained, this could help have a major impact on public health and help to prevent future generations from suffering the agony of broken bones. But as ever, more work needs to be done.

Professor Nicholas Harvey, MRC Lifecourse Epidemiology Unit, University of Southampton



7. Development of our research strategy

The overall development of our Research Strategy involved consultation with people living with osteoporosis, researchers and healthcare professionals and included engagement with our Clinical & Scientific Committee, Research Grants Committee and Members & Volunteers Committee.

Independent review of our past research portfolio and external landscape

To ensure that the National Osteoporosis Society continues to use its funds to best effect, the Charity commissioned the Wessex Institute at University of Southampton to analyse the outcomes and impact of our past research and our place within the external osteoporosis research landscape. This included a survey of our past research grant holders to establish the impact of previous National Osteoporosis Society funding. The comprehensive report gave insight into the role the Charity can play within the osteoporosis research community. It provided powerful evidence to guide our future strategy and identify our key research objectives.

3,597
people who have osteoporosis
completed our *A Good Life with
Osteoporosis* study questionnaire²



Views of people affected by osteoporosis

The Charity supported Dr Paskins' pioneering research project at Keele University, which involved over 1,100 participants, and provided a unique perspective into the public's priorities concerning osteoporosis research. The findings from this work were critical in deriving our core research areas.

A Good Life with Osteoporosis study was conducted by the Charity in partnership with Alterline, an independent research agency. The questionnaire requested people's views on their information and support needs and views on what the priorities for the Charity should be over the next five years. In total 3,597 people who have osteoporosis (or someone on their behalf) completed the questionnaire between 1st September and 8th November 2015, offering us an unparalleled insight into views of people affected by osteoporosis in the UK.



National
Osteoporosis
Society



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