



The Bone and Joint Decade
Promoting musculoskeletal health

Keep people moving

National Collaborative Action on Musculoskeletal Health

**A “How-To” Guide for Developing and Maintaining
BJD National Action Networks**

**An Initiative of the Bone and Joint
Decade**



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Welcome!

This “How to” Guide has been put together to assist individuals interested in starting a NAN as well as existing and newly formed Bone and Joint Decade National Action Networks (NANs) in the aims and objectives of the Bone and Joint Decade (BJD) – The Global Alliance for Musculoskeletal Health - as the world musculoskeletal community continues its mission to “Keep People Moving” and to improve the lives of our citizens.

We hope you will find the guide to be of interest and support in looking at the development of new NANs, as a reference for the undertaking of new NAN initiatives, engaging with NANs who have projects you might like to be part of and/or as a general information guide for your NANs.

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www.boneandjointdecade.org

The Bone and Joint Decade’s strength lies in it being the only global alliance for musculoskeletal health that brings together all stakeholders, considering all musculoskeletal conditions working with policy makers at national, regional and global levels. The effectiveness of the National Action Networks is central to this. This guide will play a major role in bringing together all those organizations who have an interest in increasing the priority for musculoskeletal health and showing how working together with a common purpose is the best way of achieving this.



The Bone and Joint Decade is a global alliance of national and international patient, professional, and scientific organizations working together to make musculoskeletal health a priority. Our target audiences are patients, policy makers, health providers and the general public in all countries.



Introduction

The Burden of Musculoskeletal Disorders

The Global Burden of Disease Report (2012) has indicated that musculoskeletal disorders (MSDs) affect millions of people, of all ages, in all cultures and in all countries. Current estimates show that back and neck pain alone affect over 960,000 million people. MSDs are the second greatest cause of disability worldwide, the leading cause within this is low back pain. Osteoarthritis is the fastest growing major health condition, related to ageing of the population, increased obesity and lack of physical activity (Lancet, 15 December 2012).

Disability due to MSDs can be effectively prevented by currently available interventions, such as accident prevention, modern treatment of arthritis and injuries, by rehabilitation and through self-care. This growing burden of disease can be controlled if priority and resources are given to ensure access to interventions such as these.

Why the Bone and Joint Decade (BJD)?

In recognition of this increasing burden, the Bone and Joint Decade was formed during the late 1990's by a group of healthcare professionals and patients who shared the view that the significant impact from bone and joint disorders on society, the healthcare system and the individual, needed to be addressed on an international level with particular focus on the use of resources. An inaugural Consensus Meeting was held in Lund, Sweden in April 1998 which culminated in a proposal to form the Bone and Joint Decade. The launch of the BJD came on the heels of the November 30, 1999 endorsement of the BJD by the United Nations. UN Secretary General, Kofi Annan said, "There are effective ways to prevent and treat these disabling disorders, but we must act now. Joint diseases, back complaints, osteoporosis and limb trauma resulting from accidents have an enormous impact on individuals and societies, and on healthcare services and economies." A Consensus document and plans for continued work were drawn up, and then in January 13, 2000, the Bone and Joint Decade was formally launched at the headquarters of the World Health Organization in Geneva, Switzerland. It was re-mandated in 2010 and a Strategic Action Plan developed to make musculoskeletal health a public health priority.

From the outset, the goal of the Bone and Joint Decade was to improve the health-related quality of life for people with musculoskeletal disorders throughout the world by raising awareness and promoting positive actions to combat the suffering and costs to society associated with musculoskeletal disorders.

Recognising that no one single organisation alone could accomplish the desired benefits for the patient or their families, the BJD set out to become a multi-disciplinary, global organization capable of implementing and promoting initiatives in all parts of the world through the strength of National Action Networks in each

country. As the Global Alliance for Musculoskeletal Health, the BJD continues to advocate for priority of musculoskeletal health among policy makers and the public.

The Current Status of Musculoskeletal Disorders Globally

Musculoskeletal conditions are the most common cause of long-term disability and pain. They affect 1 in 4 adults. Musculoskeletal conditions have the fourth greatest impact on the health of the world population, contributing 6.8 % of the global disease burden (DALYs). They are the second greatest cause of disability (YLDs) accounting for over 21%. The common musculoskeletal conditions include:

- **Back pain (632.045 million people affected) and neck pain (332.049 million) and other spinal disorders**
- **Osteoarthritis (250.785 million)**
- **Inflammatory arthritis (principally, rheumatoid arthritis)**
- **Crystal arthritis (such as gout)**
- **Osteoporosis and fragility fractures**
- **Musculoskeletal injuries (such as occupational and sports injuries and road traffic trauma)**

According to the recent Global Burden of Disease report (2012), disability due to musculoskeletal disorders is estimated to have increased by 45% from 1990 – 2010 (Lancet) compared to a 33% average across all other disease areas. Osteoarthritis was identified as the fastest increasing major health condition. The burden of musculoskeletal conditions is expected to continue increasing with the ageing of our populations.

Affordable measures to prevent and treat musculoskeletal conditions are currently available. Lack of priority and policy at local, national and international levels means that these are not available with equity across and between countries. This results in avoidable disability.



Vision, Mission, Goal and Objectives of the BJD 2010-2020

The Bone and Joint Decade is dedicated to improving life for millions across the globe who are affected by Musculoskeletal Disorders (MSDs). It is the only organization that brings all stakeholders together, considering all MSDs, from across the globe, to work towards musculoskeletal health.

The BJD's **vision** is a world where musculoskeletal health is a priority: where the prevention, treatment and care of any musculoskeletal condition is of a high standard and consistently accessible in order to improve the health-related quality of life for people with, or at risk of, a musculoskeletal condition. The prevention and treatment of musculoskeletal conditions and injuries should be among the leading health concerns in the minds, actions and funding priorities of policy makers, health providers and the public.

Its **mission** is to promote musculoskeletal health and science worldwide.

Its **goal** is to raise the recognition of the importance of musculoskeletal conditions at the global, regional and national levels; and to reduce the burden and cost of musculoskeletal disorders to individuals, carers and society.

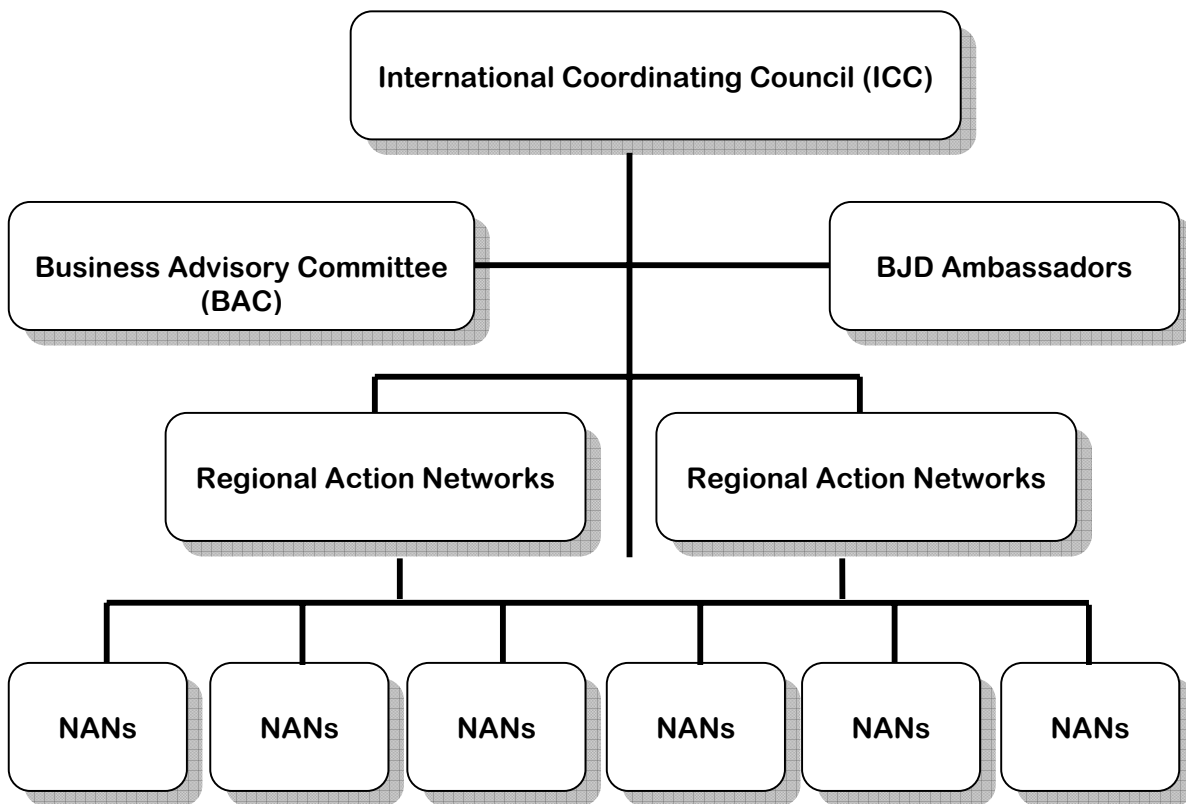
The strength of the BJD comes from its worldwide network. Led by the International Coordinating Council (ICC), the BJD is supported by more than a thousand national and international professional, scientific and patient organizations. BJD National Action Networks are currently established in over 60 countries and driving the BJD agenda in their local jurisdictions. These organizations work together both across countries globally and regionally as well as within countries through the National Action Networks (NANs). An annual meeting brings leaders of collaboration organizations and NANs together from around the world to develop strategies and actions to achieve the goals of the BJD.

Through working with its national networks, the BJD aims to:

- raise awareness of the burden of musculoskeletal conditions
- develop and support sustainable collaborative networks
- increase knowledge of the suffering and costs of musculoskeletal disorders
- empower people to prioritize their own care
- improve access to cost-effective prevention and treatment
- increase research into musculoskeletal disorders, prevention and treatment
- provide access to supportive information



Organizational Framework of the BJD



The Bone and Joint Decade is guided by an ICC of experts from various geographical regions and disciplines. The diversity of the ICC includes rheumatologists, researchers, orthopaedic surgeons, patient advocates, trauma specialists, rehabilitation providers, and emergency medicine specialists from across the globe.

The ICC is advised by the Business Advisory Committee (BAC) to ensure that commercial opportunities aligned to the delivery of the 2010 – 2020 Strategic Action Plan are identified, and that the ICC is informed of the activities required to secure and manage potential funding opportunities. The BAC is comprised of leaders from the business and voluntary sector with experience in musculoskeletal health along with other business-related specific and defined expertise.

The Bone and Joint Decade Ambassador programme honours outstanding service and achievement by leaders in the musculoskeletal community. Comprising both health care professionals and patient advocates, Ambassadors promote the mission of the BJD internationally and within their countries, assist National Action Network development, facilitate strategic contacts and work with the International Coordinating Council to achieve the goals of the BJD.

The need to work together – the importance of National Action Networks

Musculoskeletal disorders have an enormous impact on individuals and society but this is not reflected in priorities or resources. Why? Policy makers, non expert health professionals and public are often unaware of the impact of MSDs and of what can be done to prevent and treat them. People often consider musculoskeletal pain as something they have to put up with and do not seek help. Impaired musculoskeletal health is considered a natural part of ageing. Another key reason for lack of priority is that there are a wide range of conditions that affect musculoskeletal health managed by a wide spectrum of professions and disciplines who do not always work well together. Many patient organisations focus on the disease of interest to themselves, rather than for musculoskeletal health as a whole. The key strength of the BJD is to bring together all conditions that affect musculoskeletal health and all professions and disciplines to act as one in working for greater priority. Any campaign is greatly strengthened by having all relevant stakeholders speaking with one voice. That is why working together in a National Action Network is so important if we wish to raise priority for musculoskeletal health.

National Action Networks (NANs) – Fundamentals



A National Action Network is a BJD-affiliated alliance of organizations within a country, with a shared interest/goal in musculoskeletal health, working together nationally to raise priority about and to improve care for people with all forms of musculoskeletal disorders (MSDs).

Examples of Overarching Goals:

- Raise awareness of the priority of MSDs with government, policy makers and the public
- Improve care for people with MSDs and empowering them to participate in decisions about their care and treatment
- Support and strengthen the MSD community through research and education
- A financially secure, effective and sustainable NAN

Guiding Principles:

- Multidisciplinary and inclusive – engages professional, scientific and patient organizations
- Supports the goals and activities of the BJD
- Acts as a 2-way information conduit between the BJD ICC and its regional organizations
- Works in a coordinated way between all NAN supporting organizations
- Operates in an ethical and non-commercial manner

NANs have adopted a variety of approaches to determining their values, goals and guiding principles. Examples of these are included in Appendix A.



Effective NANs have described various processes which they have found effective in facilitating their development and maintenance. Some of these include:

1. Grant a charter for the operation of a National Action Network to carry out its purpose within any nation or other geographical area
2. Appoint a National Action Network Coordinator
3. Identify professional and patient organizations involved in musculoskeletal disorders and engage them early on in the development process - get their support and active participation
4. Identify champions for change in the organisations
5. Engage local BJD Ambassadors
6. Develop an organizational structure that promotes the inclusion of all appropriate stakeholders with a representative leadership team
7. Organize a round-table discussion with participation of interested groups to establish the initiative on a national level, to set local priorities and to build case statements, and to create a national plan to achieve government endorsement
8. Articulate a strategic plan, with a targeted time frame.
9. Publish editorial articles in the national professional journals explaining the initiative and its activities.
10. Publish articles in the medical as well as non-medical press
11. Participate in the Bone and Joint Action week with local and national activities promoting musculoskeletal health.
12. Work with the BJD ICC to gather data about the burden of musculoskeletal disorders in your national jurisdiction and globally
13. Communicate national activities to the BJD ICC.
14. Achieve National endorsement from your local government
15. Empower patient and patient advocacy group involvement

The National Action Networks are autonomous organizations, operating under the BJD ICC umbrella, working to leverage unique and different national relationships to accomplish the mission of the Bone and Joint Decade.

Case Example: Japan NAN – Patient Leadership

Mr. Shinji Kazama, who was appointed as BJD ambassador, went on his 2nd Trans-Japan “Ekiden” Campaign for Disabled People. This campaign stretched 3000 km from Sapporo, Hokkaido, to Naha, Okinawa, where a relay sash was passed on to be worn by the next disabled runner at each point. On April 28th, the team visited Miyagi prefecture, where people still suffer from effects of the 2011 Tohoku-Pacific Ocean Earthquake. Mr. Kazama started a prologue run with disabled people of this area. On May 4, 2012, they went north to Sapporo and restarted the run. A month later, on June 4th, they reached their goal in Naha. In total, 108 handicapped runners joined the campaign accompanied by 95 doctor runners. Many symposiums were held at every stop along the way to gain understanding for the importance of musculoskeletal health. People received the message of “challenge”, “never give up”, and “the significance of cooperation”.



Raising priority through public awareness and engagement

Identifying the Need

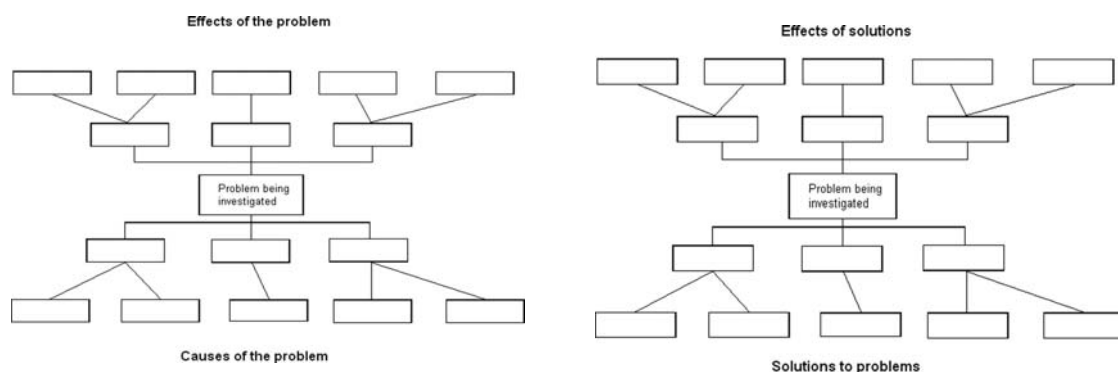
In order for National Action Networks to begin their development activities, it is essential to identify the need for bringing people together to create your organization. Once you have identified the problem, it is important for you to undertake the steps of analyzing the situation and generating the evidence. Undertaking these steps will help set the stage for your NAN to engage collaborators and choose its priorities.

Analyzing the Situation:

Undertaking a 'situation analysis' is essential for uncovering the problem that needs to be addressed, and it looks at ways in which it might be potentially solved. By creating a solid evidence base, the situation analysis provides a starting point for discussion and helps in priority setting. One tool that can be used in situation analysis is a Problem and Solutions Tree (PAST). The tree provides a visual representation of the problem you are hoping to address, for example; the lack of priority for musculoskeletal disorders, and helps you identify various issues which contribute to the problem. Once issues are identified, the solutions component of the tree is created to help address the issues leading to the problem. The structuring of the problem into a number of smaller components through the tree helps to identify clearer and more manageable tasks for stakeholders.

Start this process by drawing a simple flow chart and brainstorming as many causes or consequences you can think of. Also think of the 'cause' of the cause. Link these boxes by arrows to illustrate how they are connected. After you finish this process, look at the causes and identify those that can be changed or improved through your NAN's efforts. This is how you turn the problem tree into the solutions tree.

A typical PAST model may look like this:



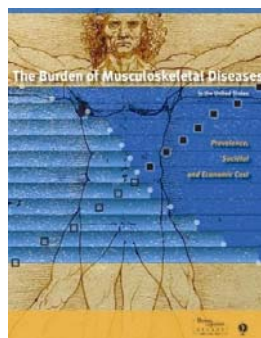
A NAN may consider following the example of a campaign planning cycle. This helps define a clear process on how the NAN can identify issues, develop an approach to address them, plan and implement the strategy and evaluate its outcome. A common model utilized for this is:



Generating the Evidence

It is essential to be able to support your NAN's perspectives with credible evidence. When you develop this evidence framework with partners it helps to generate shared 'ownership' of the issue. Shared ownership helps to increase 'buy-in' and shared responsibility by your stakeholders. Evidence provides legitimacy to your position and supports your goals and objectives. You gather evidence by looking to primary (such as scientific journal articles) and secondary sources (such as 'grey' literature – government publications for example). The BJD ICC has facilitated the gathering of evidence from a global perspective to support musculoskeletal advocacy and this is available on the website, www.boneandjointdecade.com. The Surveillance Task Force of the BJD, tasked with monitoring musculoskeletal burden of disease data, has the responsibility of updating the evidence around the incidence and prevalence of musculoskeletal disorders on an ongoing basis. Much of this material also contains country-specific information or is able to point you in the direction of where you may find it. Current evidence such as the recent publication of the Global Burden of Disease Report (Lancet, 2012) has provided a considerable amount of new evidence around the epidemiology of musculoskeletal conditions and the level of their impact on global populations, comparing against other diseases. This is available through the BJD website.

An example of a NAN initiative with respect to the gathering of such evidence is the publication from the US Bone and Joint Initiative: *The Burden of Musculoskeletal Disease in the United States: Prevalence, Societal and Economic Cost* (2011).



Choosing Your Priorities

Often times, while analyzing the situation and gathering evidence, many issues are identified that your NAN may want to address. However, it is important for a NAN to carefully choose which issues they wish to address and to also prioritize these issues. Prioritizing helps to ensure that efforts are focused and that achievable targets are met. These need to also be identified in the context of potential impact and required resources. There are common tools that organizations may use to help set their priorities. Such tools may be used as a guideline to help NANs plan, however it must be remembered that these may need to be modified according to your local NAN's criteria and needs.

On the following page you will find an example of a tool used by UNICEF in their Advocacy Toolkit (2). This is shown in a modified version for BJD collaborating organizations. You may utilize this tool and further modify it to meet your NAN's needs.

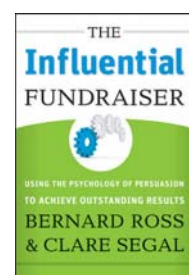
Tool to assist in utilizing your NAN criteria for prioritizing issues.

Criteria for Prioritizing Issues	Does It Meet the Criteria	Comment
Importance of the Issue		
Does it result in improvement in people's musculoskeletal health?		
Does it address underlying problems?		
Does it address the most vulnerable populations?		
Is the issue widely felt?		
Is the issue deeply felt?		
Is the issue a priority expressed by patients?		
Practical Considerations		
Is it achievable?		
Will it be easy to communicate and understand?		
Are there opportunities for patients to engage in the issue?		
Are there clear decision makers that can make the change happen?		
Are you able to identify a clear time frame?		
Are there opportunities to influence policies?		
Is the issue grounded in solid evidence and expertise?		
Is there existing momentum?		
Are there partnership opportunities to collaborate on the issue?		
Does it link local issues with global issues?		
Organizational Support		
Is it consistent with global priorities?		
Are governments or policy makers interested in this change?		
Is it consistent with BJD's mission and aims		
Does it help raise the NAN and BJD profile and strategic position?		
Is there synergy with potential fund raising schemes?		

Developing Your Case Statement

A Case Statement is a detailed written rationale for a fundraising campaign. It is specifically designed for both internal and external supporters, or stakeholders. (10) Your case statement is your NAN's core document that forms the centre of your plan and strategy. It explains to your potential funders what you need the money for and what the benefits will be if the funding is received. Case Statements can be used in any fundraising campaign, but they are particularly useful in **major gift campaigns, capital campaigns, and endowment campaigns.** Your case statement should appeal to a wide range of your supporters, or stakeholders. It should be directed at both external and internal stakeholders. Write your case for your donors and supporters, in such a way that the "nut" of your case is simple and easy to express

Bernard Ross & Clare Segal, in their book, *The Influential Fundraiser*, point out that a good case statement needs to answer five key questions:



1. **What is the need? Specify precisely what the need is, and who exactly will benefit when that need is met. Be sure to make the need manageable so that supporters will feel that they can make a difference.**
2. **What evidence is there that this is a pressing need? Make it clear that the need is now, and that it needs to be addressed soon. Include research papers, expert opinions, government documents or statements from patients.**
3. **How is your organization uniquely qualified to tackle this need? While there may be several organizations that could tackle this issue, what is special about you? Is it your track record, the newness of your approach?**
4. **What will be the benefits of your action? If you take action now, what will be the positive consequences, both major and minor? What can be guaranteed, and what is possible?**
5. **What are the negative consequences if you fail? Sometimes this is the strongest motivator for donors, so lay out clearly the major and minor negative consequences if you do not act.**

The Community of Foundations Canada (11) prepared a step-by-step guide for the preparation and writing of a case statement. They proposed a standard outline that your NAN can use to guide your statement development.

CASE STATEMENT: STANDARD OUTLINE
Section 1: Introduction
Section 2: Background on the Organization
Section 3: Statement of Need
Section 4: Related Objectives
Section 5: Summary of Longer Range Goals
Section 6: Financial Information
Section 7: Leadership and Partnership profile
Section 8: Support Options
Section 9: Recognition Opportunities
Section 10: Conclusion and Wrap-up

Essentially, a Case Statement presents the need for the BJD in your country and thus your NAN. Having stated the need, it might then go on to present the purpose and goals of your NAN. The case statement should begin with a statement about the importance of musculoskeletal health, and what major conditions are comprised. It might then present data that lays out the big picture detailing how many people suffer from musculoskeletal conditions, general demographic population trends, and go on to provide increasingly more detailed data on the number of people affected for each of the major conditions, followed by some cost data to illustrate the importance on the economy, in terms of direct and indirect costs. Effectively this statement presents the burden of musculoskeletal conditions in your country.

The statement might then provide some comparisons, say with other disease areas, or proportion of overall health expenditures, and how musculoskeletal conditions fit in this picture, including the proportion invested in research compared with prevalence levels. What conclusions or statements are you able to make as a result of the above? Can you say that musculoskeletal conditions are under-recognized in your country, or that they are under-funded, or that research, the foundation for improving care and health, is not in line with the level of prevalence?

Your conclusions should lead you to a case for the need for the Bone and Joint Decade in your country, and for your National Action Network. It might also propose goals and strategies to address the shortcomings such as the need to raise the priority for musculoskeletal health within your government, health ministry and other official agencies, or in the legislative body. It might suggest the need for public awareness campaigns or prevention education, or for healthcare professionals to work more closely together to design better care delivery models.

It is important to always encourage input from all of your NAN stakeholders during the creation of the case statement. Once drafted, it should be sent out to stakeholders for review and feedback. Often times it is helpful to have 'external eyes,' such as an expert or a reference group with expertise in this type of work review your case statement to provide an outside perspective on your document.

Case Example: Australian BJD NAN AMSEC Improving Health Professional Education

Based on recent published literature, the Australian BJD NAN identified that education of primary care physicians was inadequate with respect to their core understanding of musculoskeletal conditions. They recognized that a large percentage of a physician's primary care practice is to address patient's musculoskeletal complaints. They initiated a collaborative, interprofessional project around defining core competencies for medical students around musculoskeletal education resulting in the funding of a new Musculoskeletal Core Curriculum for undergraduate medical students by the government.



Building Your Community:

Of course, in order to be able to do all of the work we spoke about in the previous section, you have first build your 'community' or your network. Building your network involves identifying stakeholders (patients, providers, institutions, organizations, policy makers) who have common concerns and interests. This involves utilizing your existing network of people who work in the musculoskeletal field, but also actively seeking other groups and organizations who are involved in the area of musculoskeletal health. One priority for the BJD is to ensure inclusion of all relevant stakeholders in all of its activities. This translates to the NANs enabling opportunities for involvement of all relevant stakeholders, whether they are patients, patient advocacy groups, health providers and/or their associations, research institutions and other organizations with common interests. It is important for the NAN and its leadership group to be reflective of the different types of stakeholders that musculoskeletal conditions impact on and to be seen as equitable. Engagement of a variety of stakeholders facilitates a broader vision of the issue, more potential for creativity and innovation, and a stronger NAN. It also ensures that NAN activities are relevant and continue to be relevant to its stakeholders over time. This results in a NAN that is reflective and responsive. Wide buy-in and participation from stakeholders also enables access to more resources, both human and financial, and it has the potential to significantly raise the profile of your National Action Network through its multiple connections. Policy makers and governments are also usually much more readily willing to listen to organizations that represent a broad range of stakeholders, rather than a particular interest group.

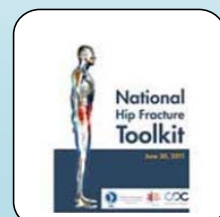
Keeping this in mind, it is important to reach out broadly to the musculoskeletal community in your country and also to respect and consider the views of different stakeholders that may contribute to your efforts.

A problem in many countries is the lack of patient organisations. You may need to initially identify individuals with a musculoskeletal condition who want to make change happen and help them work together to develop a patient organisation.

Facilitating an initial meeting of your interested stakeholders is the next step in developing your network. Providing these stakeholders with initial information that you have collected in advance of the meeting is advisable. Asking them to come prepared to discuss the common issues, identify their own priorities and to be open to collaboration are good preparatory steps. In some countries, government funding agencies will facilitate these initial meetings through providing funding to underwrite the cost of meeting space, travel and

Case Example: BJ Canada

In Canada, collaborative action was taken around the burden of hip fractures and the poor level of access patients had to timely hip and knee replacements. The Canada BJD worked closely with stakeholders and the federal government (who provided funding) to develop a Hip Fracture National Model of Care and Tool Kit which has been validated and is now being implemented in each province.



accommodation. For example, the Bone and Joint Canada has been successful in receiving funding from the Canadian Institutes for Health Research (CIHR) in the way of a planning grant to support the initial meeting of people with the intent of developing a working collaboration on an important health issue. It is critical, when applying for these types of grants, that the application focuses on health issues which are a priority for the public and for government. In the Canadian example, funding was provided to bring stakeholders from across Canada together to develop a national effort to address hip and knee arthroplasty wait times as well as hip fractures.

Look into governmental priorities, as these usually will reflect important patient issues. Listen to your stakeholders as they will help to shape your NAN and identify its priorities.

It is also very important for your NAN to clearly identify its activities as not competing with or duplicating those of its members. The NAN needs to be seen as helping its members attain their goals as much as possible. Setting out small, achievable goals and 'wins' for the NAN towards its overarching goal will help in its early development and solidify ongoing commitment from its members. The NAN should also be flexible and evolving as goals are achieved, issues change and new priorities emerge.



Case Example: United States Bone and Joint Initiative

A joint program of several network member organizations of the USBJI developed a resource, with charts and graphs, which provides data on the prevalence, societal and economic cost of fractures, back pain, arthritis, carpal tunnel, osteoporosis and other musculoskeletal conditions. An important reference to grant applicants, it is also used to promote awareness to the public and to policy makers. The Fit to a T public education campaign was developed in response to the U.S. Surgeon General's Report on osteoporosis. Over 17,000 members of the public and patients have participated in the program which has been presented over 460 times at public libraries, corporations, community venues including hospitals, clinics, churches, schools, health clubs, seniors centres, etc. This program was a collaboration between USBJI network organizations as well as non-network organizations.

Public Advocacy through NAN collaboration.



Determining Your Organizational Structure – Some Examples

NANs will also need to develop an organizational structure that reflects its vision, mission and aims. Around the world, NANs have adopted differing organizational structures, relevant to their local needs.

For example, the USBJI is overseen by a Board composed of 22 individuals representing various professions, patient groups and societies (5). The Board representation is broad and reflective of the musculoskeletal community in the United States. Each Board member is able to bring their unique perspective to the table, resulting in a rich mosaic of information contributing to the Initiatives' efforts. Similarly, ARMA, out of the United Kingdom, represents a broad network of individuals from the full spectrum of musculoskeletal health. Acting as the BJD National Action Network in the UK is only one of ARMA's strategic activities (6).

In the US, numerous other collaborating organizations have representative involvement in the NAN though belonging as a "Friend of the USBJI, either as a dues paying Participating Member, or as a Participating Organization." This forms a unique coalition of health care organizations, industry, government and individuals who care about improving bone and joint health.

In Norway, the MST (Muskel Og Skjelett Tiaret), Norway consists of a board, a broad-based advisory board, a research group, an intermediate group and a finance group. A total of 11 specialist associations, health professional associations and patient organizations are involved in the network, led by a network coordinator. MST is led by a board consisting of 11 persons, representing medical specialties, patient organizations and health authorities. There are permanent observers as well. In addition, MST has an executive committee consisting of the Chairman and 2 Vice-Chairs, as well as a nomination committee. (7)

The Australian BJD National Action Network was initially established by the Australian Orthopaedic Association, Australian Rheumatology Association and Arthritis Australia and its state branches. Over time other musculoskeletal disciplines have participated in the NAN including The Australian Physiotherapy Association, Sports Medicine Australia, Osteoporosis Australia and the Australian and New Zealand Bone and Mineral Society, Australia and New Zealand Society of Biomechanics, Australian Faculty of Rehabilitation Medicine, Australian Musculoskeletal Imaging Group, Chiropractors' Association of Australia, Matrix Biology Society of Australia and New Zealand, Australian Pilates Method Association and the Commonwealth Department of Health and Ageing. Support has also been provided by partners in the pharmaceutical and device industries. Stewardship has occurred through rotating leadership amongst its member organizations, including patient leadership (8).

Organizational toolkits available in the literature offer tips on how to successfully establish collaborations within a network framework (2). They recommend that

developing networks carefully consider their relationships – considering both the potential positives and the potential negatives that may arise from them. The UNICEF toolkit provides some tips that groups may use in the establishment of networks or coalitions, in order to assist in successful relationship-building. These tips, listed below, have been modified slightly to reflect the context of the BJD National Action Networks.

Tips for Establishing a Network

Be clear about the advocacy issue proposed as the focus of the network
With a large group, select a steering committee of 5 to 7 people who are representative of your stakeholders
Establish a task force to plan and coordinate activities
Assess progress periodically and adjust accordingly
Develop a code of conduct to ensure mutual respect and responsibility
State clearly what you have in common and what you don't so that goals can be clear
Let the membership and the issues suggest the network's structure and style
Reach out for a membership that is diverse – but certain
Choose interim (short term) objectives strategically with the opportunity for early, quick wins
Stay open to partnerships outside of the formal network structure
Maintain strong ties between the network's leaders and its major partner organizations
Make fair, clear agreements and stick to them

As you can see from the above examples of NAN organizational structures, each NAN must consider an organizational structure that is appropriate to their own country, one which reflects the diversity of people involved in musculoskeletal health and one which encourages input from all participants.





Starting a NAN from ‘Scratch’

Many NANs have been initiated by individuals, or ‘champions’ in countries where no musculoskeletal alliances have existed. In these environments, individuals can effectively initiate the development of a NAN through a variety of initial steps. These include:

1) Gathering the evidence

As noted earlier in this guide, a primary step in the development of a NAN is to collect the evidence to support your actions. The BJD website contains a wealth of information about the burden of musculoskeletal diseases and is an excellent resource for developing NANs. The GBD report recently published in the Lancet, December 2012 is also available from the BJD website. In addition, it is important to gather data from your own country to support the relevancy of your argument in your own jurisdiction. Local information is often gathered by national governments and should be available from their websites or by direct inquiry.

2) Preparing a letter of introduction to the issue

A second step that a champion may take is to prepare a letter that succinctly speaks to the issue and to send this out to identified stakeholders which you would like to attract to your NAN. A sample of this type of letter for your reference can be found in Appendix D.

3) Identification of potential stakeholders

As discussed earlier in this guide, it is important to develop your network through involvement of a variety of musculoskeletal (MSC) health stakeholders. These include organizations that work for advocacy in MSC health, providers who manage these conditions, educational training institutions, researchers, governmental agencies, health providers (and their associations) and patients. If there are not appropriate organisations, then you may need to involve enthusiastic individuals. In many countries there are not patient organisations but the input of people with personal experience of musculoskeletal conditions is essential. You will be more successful if individuals from stakeholder organisations also see the need for change and the need to work together to achieve it. A guiding NAN principle is that of inclusion. All stakeholders interested in participating and who can contribute to the initiative should be welcome to participate. This will help increase the NAN’s reach and capacity.

4) Approaching organizations, governments for initial support

Once you have begun to develop interest in your NAN initiative amongst stakeholders, it is important to bring them together to begin work on your NAN development. You can facilitate this early gathering of your NAN through approaching organizations, donors or government for a small planning grant or funding to support the bringing of people together. In the past, NANs have been successful in receiving initial support to begin planning their organization.

5) **Bringing interested stakeholders together to develop your network**

As noted earlier in the guide, once you have developed a group of interested stakeholders you need to bring them together to begin discussing the development of your NAN. Providing them with a copy of this guide as well as your supporting documentation prior to attending the meeting is recommended. Ideally, for initial group development, meeting face-to-face is preferred. Setting out initial meeting guidelines (eg. Inclusive participation, consensus-decision-making processes, open discussion, a non-hierarchical structure, etc) will facilitate your meeting. Establishing the overarching goals that are relevant to all participants, not focused on any one specialty or area, early in the process will be important. Each stakeholder must be made to feel that their input is valued, considered and important. A widely accepted model for group/team development is that proposed by Bruce Tuckman: *Forming, Storming, Norming and Performing* [12]. This model has evolved over a twenty year period through long term research about successful group development and team functioning. There is an excellent You Tube video describing Tuckman's model which you may access at: http://www.youtube.com/watch?v=P_HZd5rAF6g



Once you have begun to develop your NAN, you would follow the steps outlined earlier and following in this guide.

Producing a Strategic Plan

Being strategic is essential to achieving success in your NAN planning and outcomes. Developing a strategy entails figuring out how to reach interim outcomes while keeping the long-term vision of your NAN alive. A good strategy supports a quick initiative or a long-term programme and it creates opportunities to advance efforts and protect gains. (UNICEF Advocacy Toolkit 2010).

Now that you have identified your need and have built your NAN ‘community’, there are essential steps for planning your NAN strategy:

1. Build your NAN vision and mission

- **Vision:** This is a statement of what the program wants to be in the future (5 to 10 years from now). The Vision Statement provides the major long-term direction for the organization's planning and is the ultimate outcome to be achieved through the planning process. (4) It should have a time horizon of a decade or more and represents a Dream that is Beyond What you Think is Possible.
- **Mission:** A mission statement is a statement of an organization’s purpose. It is useful for putting the spotlight on what area of work the organization is presently in and who it is presently endeavouring to serve. A mission statement deals with the present and answers the question “What is our organization’s focus and what are we trying to accomplish on behalf of our stakeholders?” A mission statement is a logical vantage point from which to look down the road. (9)

2. Define your NAN ‘values’

- **A Value:** A declaration of what you stand for and believe in. Examples of premier values include:
 - **Passion** - to be passionate about winning and about our organizational goals, structure and people, thereby delivering on our promises to our stakeholders.
 - **Risk Tolerance** - to create a culture where creativity and prudent risk taking are encouraged and rewarded.
 - **Excellence** - to be the best in quality and in everything we do.
 - **Motivation** - to celebrate success, recognizing and rewarding the achievements of individuals and teams.
 - **Innovation** - to innovate in everything, from products to processes.
 - **Empowerment** - to empower our talented people to take the initiative and to do what’s right. Adapted from My Strategic Plan (9)

3. Describe your NAN aims and objectives - both short and long term goals

4. Identify next steps to making it happen
5. Identify who will be responsible for each step
6. Develop an evaluation framework to help you tell if your plan is working
7. Renew stakeholder engagement and priorities on an ongoing basis

NANs have adopted a variety of approaches to determining their values, goals and guiding principles. Examples of these are included in Appendix A.

Case Example: ARMA – UK BJD NAN
(The Arthritis and Musculoskeletal Alliance)

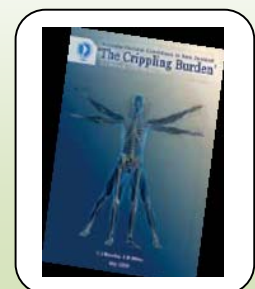
ARMA works with its members on every aspect of its aims and objectives as detailed in its 3 year Strategic Plan, which explicitly recognises the key role of members. Members meet regularly to discuss and act on key issues, and *ad hoc* working groups are established to focus attention on priority areas. For instance, there is a Clinical Networks group which discusses models of integrated care in the context of the new NHS architecture, and specifically the new commissioning process. Members actively contribute to monthly newsletters and share information via a new ‘member’s area’ of the website. Local ARMA networks also have their own dedicated page on our website.



NANs around the world have utilized their strategic frameworks to mobilize into action. Building on their vision, mission and goals, they target their priorities into achievable objectives. An example of this is the development of a lobby campaign by the New Zealand NAN.

Case Example: New Zealand NAN

In New Zealand, every 4 years the Ministry of Health undertakes an in-depth National Health Survey and for the first time in the early part of the decade, musculoskeletal questions were included. Members of the New Zealand NAN produced excellent work on the burden of arthritis and osteoporosis. This information was used as the basis of a broader study on the burden of MSC conditions in New Zealand. This was published as a booklet entitled “The Crippling Burden” and launched at a Parliamentary Function in 2009. The NAN used these statistics to influence Government and policy makers to consider musculoskeletal conditions as a key health priority.



Raising Priority with Government and Policy Makers

Budgeting, Funding and Resourcing

Budget:

You will need a budget to establish the financial resources your NAN will need. This is generally done on a project-by-project/activity basis and then adding the general operating overhead expenses your NAN will have. For example, a NAN may develop a general operating budget on an annual basis, and then separate out resources required for specific programs. Recent experience has shown that funding directed to targeted projects has a higher likelihood of being supported by external funding agencies compared to requests for support of ongoing operational costs.

Funding:

A NAN might try to establish reasonable dues or contributions that each member of your NAN contributes annually. This may entail tiers with patient groups contributing less, or whatever they can afford. Obtaining funding support is becoming increasingly difficult but is not impossible, and a part of this should be set aside to develop programs in coming years. You might then decide that individual programs should be self-financing, in which case you will need to develop a solid case for soliciting funding and measurable outcomes so that funding sources are encouraged to continue their support in subsequent years. Meetings can also be a good way to raise funding and many commercial companies favor this kind of support. Government agencies or departments may also be sources for funding. It is increasingly difficult to secure multi-year funding, but if this is possible with your government sources, or otherwise in your country, this will provide some extra security to your NAN, its programs and activities, and the ability to plan further in advance.

Resources:

There are many approaches to establishing the human resources you will need. You may be fortunate that volunteers are able to offer a significant amount of time, enough to get the job done, and also to offer the assistance of people in their office, family or friends. Patients with MSDs are often willing to offer time. In the case of meetings, you may find a university or collaborating organization with a meeting department may be willing to offer that service. Alternatively you may decide you need some part- or full-time staff to manage your communications (website, phone, email).



Making it Work! National Dissemination – A Plan for Action

The Australian Bone and Joint Decade National Action Network commented in their 10-year BJD report that:

“The greatest achievement from the BJD to date is the increased level of networking that has facilitated a greater level of awareness of the burden of musculoskeletal disease and trauma. Patients have embraced the team approach to treating these issues and now we are seeing professional bodies collaborating to a much greater extent. The success of the BJD will ultimately be measured by the outcomes from this continued collaboration and the improvements which patients can measure.” (8)

Keeping people engaged and active is critically important to sustain your National Action Network. Bringing your stakeholders together on an annual basis or otherwise (as appropriate), helps to maintain relationships and reaffirm commitments to continue working together. During ‘renewal’ meetings it is important to review your NAN’s priorities and action steps and to critically evaluate your outcomes. Remember to celebrate your achievements. This is an opportunity to motivate your stakeholders to continue in their efforts to raise priority for musculoskeletal conditions.

Ongoing communication is pivotal to a NAN’s success. Different NANs use a variety of communication mechanisms to share information with their network. With current technology this may be quite inexpensive. Regular E-newsletters, posting information via social media pages and web-based teleconferencing are useful mechanisms which are not as draining on financial resources as traditional methods.

Regular, broad external communication to your target populations will help to raise the profile of your NAN and further engage the public as well as policy makers. Engaging local communities and organizations will help to spread the message you are sharing with the public. Community activities motivate government representatives to participate, garnering additional public support for your initiative.

Many active NANs are open to providing mentorship for new National Action Networks, or existing ones as needed, so please do not be shy about asking your NAN colleagues for assistance. The BJD ICC is also available for consultation and support. Please do not hesitate to contact the ICC at any time.

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Appendix A: Examples of NAN Guiding Principles

Guiding Values: ARMA is:

Authoritative:

We bring together patient-led, professional and research organizations, and will speak for all groups working to improve services for people with musculoskeletal disorders (MSDs). Our policies will be based on strong evidence and informed by all ARMA members and their stakeholders.

Inclusive:

We value all of our members as integral parts of the ARMA community and work with a variety of stakeholders through memberships, partnerships and collaborations in order to safeguard and champion the interests of people with musculoskeletal disorders in healthcare.

Accountable:

Our Board is elected by our members, who help set the strategic plan for ARMA and have regular opportunities to discuss and agree all relevant matters at the AGM and through regular CEO and policy group meetings.

Transparent:

We have clear processes for our work, including our decision-making processes, utilizing all appropriate means and communication tools. We have an open, transparent framework to guide our funding agreements.

Independent:

We are a charity and umbrella organization independent of government, industry and other organizations, and have a strong corporate partnership policy.

USBJI:

Value for Belonging

- Only organization that assembles the broad musculoskeletal community and has patient advocacy organizations and MSK professional organizations as members.
- Has and will continue to provide a forum for communication among patients, patient advocacy groups, providers, payers, and industry representatives for collaboration on optimal treatment and prevention of MSK disorders.
- Offers a single credible voice for all segments of the organization on issues of common concern.
- Offers problem solving abilities on MSK issues that are truly a multidisciplinary collaboration.

Guiding Principles

- Remaining an organization of organizations;
- Ensuring the core disciplines remain involved;
- Recognizing multidisciplinary healthcare professional and patient advocacy (volunteer health agency) organizations are the principal organizational drivers;
- Ensuring achievable objectives on a programmatic level;

Appendix B: Example of a Case Statement



WHY IS THE BONE AND JOINT DECADE IMPORTANT?

The Bone and Joint Decade initiative is a global campaign to improve quality of life for people with musculoskeletal conditions and to advance understanding and treatment of these conditions through research, prevention, and education.¹ The Decade aims to raise the awareness of the increasing societal impact of musculoskeletal injuries and disorders; empower patients to participate in decisions about their care; increase funding for prevention activities and research; and promote cost-effective prevention and treatment of musculoskeletal injuries and disorders.

On January 13, 2000 **The Bone and Joint Decade** was formally launched at the World Health Organization headquarters in Geneva, Switzerland. This came on the heels of the November 30, 1999 endorsement of the initiative by the United Nations.² **The Bone and Joint Decade** has thus far has been endorsed by thirty-eight nations, by all 50 U.S. States; and by more than 750 organizations worldwide. Fifty multi-disciplinary National Action Networks have been formed around the world and steering committees coordinate the activities of member organizations.

Musculoskeletal conditions affect hundreds of millions of people around the world, and this figure is projected to increase sharply due to the predicted doubling of the number of people over 50 by the year 2020.³ Musculoskeletal conditions, injuries and deformities also deprive children of normal development. In the United States alone, musculoskeletal conditions rank first among diseases using measures of disability; visits to physicians offices; and among impairments. Musculoskeletal impairments are the number 1 reported category of reported impairment according to the National Health Interview Survey.⁴

Musculoskeletal impairments are reported by 1 out of every 7 Americans.⁶ In 1995, 28.6 million persons incurred a musculoskeletal injury, accounting for more than one-half of all injuries in that year. Sprains, dislocations, and fractures account for nearly one-half (46%) of all musculoskeletal injuries.⁴ Musculoskeletal conditions and injuries accounted for more than three million hospitalizations and rank fourth among system or disease categories.⁵ Musculoskeletal conditions and injuries accounted for 130.7 million visits to physicians' offices and hospital outpatient and emergency departments. More than 5.7 million hospitalizations or patient visits resulted in 7.3 million musculoskeletal procedures. Musculoskeletal conditions were estimated to cost \$215 billion direct and indirect (mortality and morbidity) in 1995 and \$254 billion in 2000.⁶

Arthritis is the leading chronic condition reported by the elderly affecting 1 out of every 8 Americans of all ages, and being reported by almost 50 percent of people age 65 and older. Today, arthritis is a more frequent cause of limitation of activity than heart disease, cancer or diabetes. Back and spine impairments are the most prevalent among musculoskeletal impairments and account for approximately one-half of the restricted activity days and slightly over sixty percent (61%) of the bed days.⁴ 75-85% of all people will experience some form of back pain during their lifetime. About 1% of the United States population is chronically disabled because of back pain and an additional 1% is temporarily disabled. Two percent of the United States work force has compensable back injuries each year. Almost 16.2 million office visits result from back pain conditions.⁶

Musculoskeletal impairments will increase over the next 30 years as they are most prevalent in older segments of the population and the population is aging. The number of individuals over age 50 is expected to double between 1990 and 2020. In Europe by 2010, for the first time, there will be more people over 60 years of age than people less than 20 years of age.³

Osteoporosis affects 10 million Americans and 18 million more are at risk, 80% of whom are women.⁷ Every year almost 1.3 million fractures are attributed to osteoporosis, including 5000,000 vertebral fractures. The cost of these treatments is expected to double over the next fifty years unless prevention and treatment strategies are initiated. Two-thirds of the people who have a hip fracture do not return to their pre-fracture level of functioning. Approximately 1 in every 6 Caucasian women will have a hip fracture in their lifetime. Hip fracture rates increase exponentially with increasing age. Beginning at age 65 the rates double for men and women in each decade of their life.⁶ One-half of all American women over age 50 years are expected to suffer an osteoporosis related fracture in their lifetime.⁷

Despite this current formation on burden of disease, and with costs currently more than \$250 billion per year, current orthopaedic research expenditures are estimated to total only about \$92 million per year. Of that total only \$16 million is devoted to clinical research.⁸ In addition, the amount of time spent on musculoskeletal education in many medical schools is minimal. In a recent study, one third of physician participants graduated from medical schools with no rotation (either elective or required) in orthopaedics.⁹

Through the partnerships facilitated and promoted by ***The Bone and Joint Decade***, musculoskeletal care providers, patients, patient advocacy groups, government and industry will be better able to achieve the goals of ***The Bone and Joint Decade*** initiative.

¹ The Bone and Joint Decade 2000-2010 for prevention and treatment of musculoskeletal disorders, Acta Orthopaedica Scandinavica 1998; suppl.281, vol. 69, no 3, June 1998.

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³ Murray, CJL, Lopez, AD (eds) The Global Burden of Disease. A Comprehensive Assessment of Mortality and Disability from Diseases, Injuries, and Risk Factors in 1990 and Projected to 2020. Published by the Harvard School of Public Health on behalf of the WHO and the World Bank, Harvard University Press, 1996.

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⁶ Praemer, A; Furner, S; Rice, DP: Musculoskeletal Conditions in the United States, published by the American Academy of Orthopaedic Surgeons; Rosemont, IL, 1999.

⁷ National Osteoporosis Foundation. 1996 and 2015 Osteoporosis Figures. State by State Prevalence Report, 1997.

⁸ American Academy of Orthopaedic Surgeons. Unpublished Data. 1999. Orthopaedic Research: Resources and Areas of Study, 1996.

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Appendix C: Other NAN Case Examples:



BJD NAN Japan: Public Education Campaigns

In 2012 we published “Moving”, a free magazine about musculoskeletal health. This was launched to promote the importance of musculoskeletal health throughout Japan. 5 issues have been published and already 131,138 copies have been disseminated.

BJD NAN Russia: Children’s MSC Health

- Promotion of healthy lifestyle, involving patients in recreational and leisure-time activities during hospitalisation.
- Constructing a playground for kids.
- Children’s Day celebrations, Art Contest for Kids, *Gulliver* puppet shows, Kurgan philharmonic society concerts, Easter celebration.



MST – BJD NAN Norway – Working with Government

Consists of 11 non-commercial members (health professionals and patient organizations and the Norwegian Directorate of Health). Successfully initiated the establishment of a state-sponsored national musculoskeletal research forum (MUSS)

Croatia: Promoting Public Awareness

- Round tables and lectures were organized for World arthritis day
- World spine day was covered well by national and local TV and radio, magazines and newspapers
- April 2012. – The Day of Early Recognition of Arthritis (Croatian rheumatologists volunteered to give 500 examinations for free)

Case Example: ARMA - UK BJD NAN Clinical Networks Project:

The ARMA Clinical Networks Project developed as a result of ARMA establishing a diverse stakeholder group to facilitate the development of MSK clinical networks in England. Subsequently, in mid-2012 ARMA established a strategic partnership with the Department of Health to support this development, which included funding for a 1-year Project Manager post to work closely with the new MSK National Clinical Director. The project aims to break down the barriers between primary and secondary care; establish a “critical mass” of local MSK clinical champions; identify the key elements of “what good looks like” for MSK; and develop tools to assist clinicians and commissioners in delivering high-value, integrated MSK care.



BJD NAN Thailand: Advocating to Policy Makers
With aging society in the horizon, investment in prevention now is a cost-effective measure against massive health care burden for otherwise unabated patients in the future. The BJD met with the Minister of Public Health on the topic of raising awareness and to prepare for intermediate and long-term plans to tackle MSC in the ageing society.

Appendix D: Sample Introductory Letter

Musculoskeletal conditions (MSCs) are the most common cause of longterm disability and pain. They affect 1 in 4 adults. MSCs have the fourth greatest impact on the health of the world population, contributing 6.8% of the global disease burden (DALYs). They are the second greatest cause of disability (YLDs) accounting for over 20%. Globally, the number of people suffering from MSCs has increased by 25% over the past decade. This is expected to continue increasing with the ageing of our populations. Affordable measures to prevent and treat musculoskeletal conditions are available. Lack of priority and policy around MSCs means that these measures are not readily available, with equity, across and between countries.

The Bone and Joint Decade (BJD) – the Global Alliance for Musculoskeletal Health, has been working to raise awareness and priority around the world regarding this issue. The BJD is focused on influencing health policy through evidence and advocacy, using its unified voice and global reach.

The BJD, established in 2000 after endorsement from the United Nations, was created to develop an international alliance of stakeholders around musculoskeletal health. The BJD structure involves an International Coordinating Council, working in the global area and National Action Networks which coordinate efforts and action in their national jurisdictions. Since the onset of the decade over 60 countries have developed National Action Networks (NANs). These have worked toward supporting the aims of the BJD in each country.

In, *(name of country)* a group of concerned individuals is interested in the development of a BJD NAN here. MSCs are an enormous burden in our country and we believe that there has been inadequate focus given to the burden of MSCs by our local and federal governments. We believe that people have the equitable right to access quality musculoskeletal health care, that the public would benefit from education regarding management and prevention of these disorders, that increased funding should be made available to research these conditions, and that governments need to prioritize MSCs within their health programs in order to improve the lives of their citizens.

We would like to invite you to participate in the development of a NAN here in *(name of country)*. Enclosed with this letter is some preliminary information regarding the burden of MSCs globally and in *(name of country)*. You may also visit the BJD website to find out additional information at www.boneandjointdecade.org.

We are hoping to organize an initial meeting of interested stakeholders and would be pleased for you to participate. Please let us know if you would be interested in attending a preliminary meeting to discuss the development of a NAN in *(name of country)*. Please do not hesitate to contact me at *(insert email address/phone number)* should you require additional information. Thank you very much.

Yours in health,

Appendix E: National Action Network Country Contacts:

Please visit the BJD website @ www.boneandjointdecade.org for a list of all National Action Networks with their contact information.

