How do we get policy makers to take musculoskeletal conditions seriously?

Advocacy Toolkit

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Chair, Bone and Joint Decade 2010-20
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Musculoskeletal conditions - some reasons for lack of priorities and policies

• Lack of awareness by policy makers, non-expert health workers and public about
  • the impact of musculoskeletal conditions (incidence, prevalence, morbidity, costs etc.)
  • what can be achieved by prevention and treatment
  • how to implement evidence to optimise prevention and management of musculoskeletal conditions
• An acceptance of pain and limited function as part of “normal” ageing
Musculoskeletal conditions - gaining priority

How do we ensure that musculoskeletal conditions are among the leading major health concerns in the minds and actions of opinion formers and policy makers throughout the world?

Bone and Joint Decade 2010 – 2020 Strategic Action Plan
Factors that influence health policy

- Competing priorities
- Evidence
- Expert opinion
- Public opinion
- Economic climate
- Opportunities
- Lobbying
- NGOs
- Commercial interests
- Cost effectiveness
- What is achievable
- Needs

HEALTH POLICY
What is advocacy

- Advocacy is generally understood as a process that aims to bring about change in process, policy or practice to achieve ones goals.
- It is a deliberate and planned process, and takes place around a policy position held by an organisation.
- This position may or may not be evidence based, but it is increasingly the case that advocacy work should be based on evidence if it is to be taken seriously.
What is advocacy

- Advocacy originates from *advocare*, ‘call to one’s aid’ or to speak out on behalf of someone, as a legal counsellor.
- Conceptually, advocacy fits into a range of activities that include organizing, lobbying and campaigning.
- Advocacy is the deliberate process, based on demonstrated evidence, to directly and indirectly influence decision makers, stakeholders and relevant audiences to support and implement actions that contribute to the fulfilment of your goals.
Advocacy Toolkit

3 phases

1. Develop the Toolkit to provide a web-based information and educational resource to empower advocates in
   – Raising awareness of the impact and morbidity of musculoskeletal conditions
   – Increasing priority given to musculoskeletal conditions in health systems globally
   – Obtaining equitable access to efficacious treatments
   – Improving standards of care
   – Reducing disparities

2. To adapt to local needs and to develop a training programme

3. To implement global, regional and local advocacy campaigns
The Self-Advocacy Process
Arthritis Canada

Identify Your Issue
• know and understand your issue

Do Background Research
• know core facts about your issue

Set Your Goal
• know clearly what you want to achieve

Get to Know Your Audience
• identify your "audience" and communicate your goal effectively with them

Frame Your Issue and Develop Your Key Messages
• Understand your audience's interests and where your issue fits in. Develop an 2-3 key messages that explain the key points of your issue and position them into your audience's interest and concerns.

Develop a Plan of Action
• Ensure your goals are achievable, measurable, practical and timely.

Put Your Plan into Action!
• Build relationships, communicate and follow-up.
THE ADVOCACY CYCLE

1. Identify issue
2. Analyse the issue and set objectives
3. Stakeholder analysis
4. Decide your activities
5. Design your advocacy action plan
6. Implement advocacy plan
7. Monitor and evaluate
8. Revise advocacy plan
3. Key messages analysis

Source: Adapted from Ian Chandler, Introduction to Advocacy course 2002

Keep people moving
| Step 1 | Identify the issue | The stakeholders need to consider the range of issues on which they can undertake advocacy, and follow a process to identify an appropriate one. |
| Step 2 | Analyse the issues and set objectives | Determine what the causes and effects of the issue are, and see what specific changes need to be brought about. |
| Step 3 | Decide the specific messages and audience | Decide on the solutions or recommendations that need to be implemented to resolve the issue, and refine these into specific messages to use when engaging with target audiences. |
| Step 4 | Decide the activities (policy and campaigns) | Decide how to influence the audiences you want to engage with – what are the most appropriate activities to draw attention to the issue? (possibilities include publishing research; media work; public campaigning; coalition building; lobbying and insider influencing - depends on the issue and objectives). |
| Step 5 | Design the advocacy action plan | The written advocacy plan will set out the aims and objectives, the strategies and activities, the timeline and budgets to achieve the agreed solutions or recommendations. |
| Step 6 | Implement the advocacy plan | Carry out the advocacy strategy. |
| Step 7 | Monitor and evaluate | Agree indicators of success and assess at baseline and monitor. |
| Step 8 | Revise the advocacy plan | Approaches to advocacy are either an ‘insider’ (strategically work within the system, forming working relationships and partnerships with decision-makers and policy implementers) or an ‘outsider’ (more oppositional / confrontational) approach. |
Step 1

- Identify the issues
Musculoskeletal conditions - the unmet need

• Musculoskeletal disorders are common in all countries and cultures
• Second largest cause of disability worldwide
• Most common cause of severe long-term pain and physical disability
• Major burden on health and social care
• There are effective ways of preventing and controlling musculoskeletal conditions but these are not being implemented with equity
• There is a lack of policies and priorities for musculoskeletal conditions

➤ There is enormous unmet need and avoidable disability
Musculoskeletal conditions - the unmet need

- Musculoskeletal disorders are common in all countries and cultures
  - include joint diseases, spinal disorders, back and regional pain problems, osteoporosis and fragility fractures, and consequences of injuries and trauma
  - worst impact on quality of life of many chronic diseases
  - most common cause of severe long-term pain and physical disability
  - hundreds of millions of people are affected around the world
- They are a major burden on health and social care
- There are effective ways of preventing and controlling musculoskeletal conditions but these are not being implemented with equity
- There is a lack of policies and priorities for musculoskeletal conditions

There is enormous unmet need and avoidable disability
Step 2

• Analyse the issues and set objectives
Musculoskeletal conditions - some reasons for lack of priorities and policies

• Lack of awareness by policy makers, non-expert health workers and public about
  • the impact of musculoskeletal conditions (incidence, prevalence, morbidity, costs etc.)
  • what can be achieved by prevention and treatment
  • how to implement evidence to optimise prevention and management of musculoskeletal conditions
We do not work together

• wide range of musculoskeletal diseases and conditions encompassed within “MSC” including trauma
• wide range of professions that manage musculoskeletal diseases and conditions
• historically there has been a lack of unity in the stated goals and priorities of primary stakeholders
• advocacy groups are often focused on one disease or condition and commonly professional groups do not have a tradition of working together
• patient organisations lack strength in many of the disease areas or do not exist in many countries.
Step 2

- Analyse the issues and set objectives
Form partnerships with other stakeholders
Physicians, health professionals, patients organisations

Scientists

Orthopaedics
Our objectives: What do we want?

- Greater priority and resources to reduce the burden and cost of musculoskeletal conditions to individuals, carers and society in all countries through
  - Promotion of a lifestyle that will **optimise musculoskeletal health** at all ages
  - **Identify** and treat those who are **at highest risk**
  - Accessible, timely, safe, appropriate **treatment to control symptoms and prevent unnecessary disability** due to musculoskeletal conditions and injuries
  - Accessible and appropriate **rehabilitation to reduce any disability** due musculoskeletal conditions and injuries
  - **Equity** across and between countries
  - **Research** to advance knowledge and care
Step 3

• Decide on the solutions or recommendations that need to be implemented to resolve the issue
• Refine these into specific messages for engaging with target audiences.
The challenges

• Non-communicable diseases recognised as a major health problem but focus is on high mortality not high morbidity conditions
• Urgency of improving lifestyle recognised but benefits to musculoskeletal health not appreciated
• Need for lifelong economic independence recognised but threat from common disabling musculoskeletal conditions not seen
• Aging of population globally recognised but focus on minds not mobility
Our Key audiences:

- Our target audiences
  - WHO
  - UN
  - Regional policy makers, such as EU
  - National policy makers
  - Non-specialist health care professionals

- Our mobilising audiences
  - Professional, scientific and patient organisations relevant to musculoskeletal health advocating for change

- Our enabling audiences
  - Sponsors
  - Partners

- Our supporting audience
  - Public
Finding solutions

Prioritise what has high impact but is easy to do
Factors that influence health policy

- Needs
- What is achievable
- Cost effectiveness
- Evidence
- Expert opinion
- Public opinion
- Economic climate
- Opportunities
- Lobbying
- NGOs
- Commercial interests
- Contextual factors
- Competing priorities

What is achievable

Cost effectiveness

Needs

What is achievable

Evidence

Expert opinion

Public opinion

Economic climate

Opportunities

Lobbying

NGOs

Commercial interests

Contextual factors

Competing priorities
Evidence to support advocacy

• Identifying and communicating the evidence that policy makers need and understand
  – How many people are affected (voters!)
  – What is the cost to us
  – What can you do about it
  – What savings can be made with what investment (tax payers!)

• Guiding principles
  – Consider ALL musculoskeletal conditions and problems
  – Public health approach not disease based (prevention v treatment, self-management v medical care)
  – Demonstrate value for money
  – Appeal to the public
Impact on the health of the population

DALYs (death+disability), YLLs and YLDs (disability)


Both sexes, all ages, thousands

<table>
<thead>
<tr>
<th>Disorders</th>
<th>YLDs</th>
<th>YLLs</th>
<th>DALYs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiovascular</td>
<td>21,984.9</td>
<td>273,056.1</td>
<td>295,041</td>
</tr>
<tr>
<td>Neoplasms</td>
<td>4,482.9</td>
<td>184,011.1</td>
<td>188,494</td>
</tr>
<tr>
<td>Mental and behavioural</td>
<td>176,625.4</td>
<td>8,564.6</td>
<td>185,190</td>
</tr>
<tr>
<td>Musculoskeletal</td>
<td>165,952.5</td>
<td>3,668.5</td>
<td>169,621</td>
</tr>
<tr>
<td>Chronic respiratory</td>
<td>49,302.7</td>
<td>68,644.3</td>
<td>117,947</td>
</tr>
<tr>
<td>Neurological incl dementia</td>
<td>42,941.7</td>
<td>30,839.3</td>
<td>73,781</td>
</tr>
</tbody>
</table>

*Cardiovascular is the 2nd highest cause of YLDs.*

*Neurological incl dementia is the 4th highest cause of DALYs.*
The future

The burden of musculoskeletal conditions is increasing

Why?

- Growing and ageing population
- Changes in lifestyle
Impact on the health of the world population

Years Lived with Disability (YLDs)

Musculoskeletal conditions  (both sexes, all ages)

<table>
<thead>
<tr>
<th>Year</th>
<th>YLDs</th>
</tr>
</thead>
<tbody>
<tr>
<td>1990</td>
<td>114,718.0 YLDs</td>
</tr>
<tr>
<td>2010</td>
<td>165,952.5 YLDs</td>
</tr>
</tbody>
</table>

• An increase of 45% over 20 years
  (v 33% for all conditions, 36.5% for mental & behavioural conditions)

• What will happen in the next 20 years!
The problem

• Musculoskeletal conditions are
  – the single biggest cause of physical disability in developed countries and rapidly increasing in developing countries
  – major cause of healthcare and social support costs
  – a major reason for people to not be economically independent throughout their lives
  – a major cause of lost work productivity

• The burden will increase unless actions are taken
Interventions for musculoskeletal conditions are effective

- Trauma and injuries related to road traffic, work and sports are preventable
- Osteoarthritis
  - exercise, pain control and self management
  - joint prostheses
- Rheumatoid arthritis
  - effective disease modifying therapy eg methotrexate, biologics
- Osteoporosis and Fractures
  - fracture prevention strategies using anti-resorptive agents for those at highest risk
- Back Pain
  - early rehabilitation
In spite of this enormous and increasing burden and what can NOW be achieved by prevention and treatment, this is not reflected in:

- Public awareness
- Health care provision
- Medical education for undergraduates and primary care
- Research expenditure
- Political priorities

There is enormous unmet need and avoidable disability
What do we want?

- We call for explicit plans by governments, health policy makers at regional level and the WHO to deal with the large and growing burden of musculoskeletal conditions on individuals and society through
  - improving musculoskeletal health
  - preventing musculoskeletal disorders and injuries
  - equitable access to cost-effective management
  - research to close our gaps in knowledge
Step 4

• Decide how to influence the audiences you want to engage with – what are the most appropriate activities to draw attention to the issue?

Step 5

• Design the advocacy action plan that sets out the aims and objectives, the strategies and activities, the timeline and budgets to achieve the agreed solutions or recommendations.
Factors that influence health policy

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- Needs
- Cost effectiveness
- What is achievable
- Contextual factors
Influencing the decision makers - changing public and political opinion

David & Goliath
1 Samuel 17:1–58
What is needed to close the gap?

- Health promotion
  - inclusion of musculoskeletal health as a benefit for healthy lifestyles
- Prevention
  - accidents related to road traffic, workplace and sports
- Case-finding strategies
  - early onset polyarthritis
  - previous fragility fracture
- Access to appropriate management at the right time
  - disease modifying drugs with monitoring eg methotrexate
  - surgery eg fracture management, arthroplasty, trauma
  - rehabilitation to restore function
- Resources
  - trained health professionals / health workers
  - availability of interventions – drugs, prostheses……
- Surveillance
  - measurable quality indicators
Worldwide endorsement

UN
The Vatican
Germany
WHO
USA
Japan
BJD Advocacy Toolkit - Main Elements

- What is advocacy and how to run a campaign
- Supportive materials – data on burden, evidence-based standards of care, audit tools, educational and promotional materials
- Dialogue – case studies, story lines, political events….to generate momentum

- Phase 1 funded by a grant from Roche
Working Together

The Bone and Joint Decade
The Global Alliance Promoting Musculoskeletal Health

“Keep people moving”