

February 2017

## Arthritis Research UK response to Improving Lives: The Work, Health and Disability Green Paper

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- 1 Arthritis Research UK welcomes the opportunity to respond to Improving Lives: The Work, Health and Disability Green Paper from the Department of Work and Pensions and the Department of Health.<sup>1</sup>
- 2 Arthritis Research UK invests in breakthrough treatments, the best information and vital support for everyone affected by arthritis. We combine cutting edge research and the expertise of people with arthritis to make everyday life better for all 10 million people with these conditions in the UK.<sup>2</sup>
- 3 This response addresses consultation questions relevant to people with musculoskeletal conditions and contains the following sections:
  - Summary of direct responses from people with musculoskeletal conditions
  - Supporting employment through the NHS (Chapter 5)
  - Tackling a significant inequality (Chapter 1)
  - Supporting people into work (Chapter 2) and benefits assessments (Chapter 3)
  - Supporting employers (Chapter 4)
- 4 We are members of:
  - The Fit For Work UK Coalition and support their response to this consultation.<sup>3</sup>
  - The Disability Benefits Consortium (DBC) which has provided a detailed response in to Chapters 2 and 3 of the Green Paper.<sup>4</sup>
  - The Arthritis and Musculoskeletal Alliance (ARMA). We have provided input into their response to this consultation.<sup>5</sup>
- 5 **Summary points:**
  - Arthritis and other musculoskeletal affect around 10 million people in the UK. These are mainly long-term conditions with symptoms that fluctuate over time. The pain and functional limitations caused by musculoskeletal conditions can significantly impact people's quality of life, limiting independence and the ability to participate in family, social and working life. In response to the Green Paper, we recommend that:
    - **Healthcare commissioners including NHS England should ensure that care planning is available to people with musculoskeletal conditions (see section 10).**
    - **The Work and Health Unit should investigate what supporting tools and resources can be provided to Clinical Commissioning Groups and employers to enhance their understanding of the role that self-referral to physiotherapy can play in tackling work place absences (see section 11).**
    - **The review of the Health and Work Innovation fund pilots underway in the West Midlands Combined Authority and Sheffield City Regions must consider the effectiveness of interventions for people with musculoskeletal conditions (see section 12)**
    - **Work with NHS England 'to identify opportunities for regular collection of data about incidence, prevalence, clinical activity and outcomes of musculoskeletal patients and services in England' should be prioritised (see section 13).**
- 6 Arthritis Research UK's policy report 'Working with arthritis' was published in June 2016.<sup>6</sup> This report describes the impact of musculoskeletal conditions on the UK workforce and gives the perspectives of people with musculoskeletal conditions about working life.

## Summary of direct responses from people with musculoskeletal conditions

- 7 Arthritis Research UK is committed to ensuring that the views of people with musculoskeletal conditions inform our policy work. To inform this response, we invited people with arthritis and other musculoskeletal conditions to directly share their stories of living and working with arthritis on-line through our campaign website 'Work matters to me'.<sup>7</sup> We have focused on understanding how people with arthritis can be supported to remain in work, return to work and to have access to a fair and timely access to a benefits and assessment system.
- 8 We received 260 responses between 16 December 2016 and 7 February 2017. From an initial analysis, three major themes within these responses are:
- **Flexibility of support provided by employers:** The importance of flexibility on the part of the employer to support people with arthritis was an important issue raised in many responses.
  - **Challenges with the benefit system:** Many respondents indicated that they felt inadequately supported to stay in, or return to work. Some respondents said that the challenges of accessing benefits and support worsened their health condition.
  - **Change of employment status:** Many respondents who had become unemployed or who had retired indicated that they would have stayed in work had they been able to make adjustments to their working hours or way of working. Many people indicated that they had become self-employed as the only way to remain in work.

Three individual responses are included as Annex A. Further information can be provided.

## Supporting employment through the NHS (Chapter 5)

### *Consultation questions:*

- *How should access to services, assessment, treatment and employment support change for people with mental health or musculoskeletal conditions so that their health and employment needs are met in the best possible way?*

- 9 Musculoskeletal conditions are the UK's leading cause of sickness absence, resulting in 32.4 million working days lost in 2015.<sup>8</sup> Only two thirds of working age people with a musculoskeletal condition are in work.<sup>9</sup> However, many people with musculoskeletal conditions want to work and can do with the right support. They must be supported to work in roles which are meaningful, fulfilling, flexible and adapted to their skills and capabilities. We welcome recognition in the Green Paper that the right health and care support can make a difference to an individual's employment needs and opportunities. It is essential that people with musculoskeletal conditions can access healthcare services which also consider their employment needs.
- 10 **Care and support planning** is an important approach which enables people with long-term conditions to focus on the personal outcomes which matter most to them, including ability to work. Currently only 12% of people with a musculoskeletal condition have a care plan, but many more people could benefit.<sup>10</sup> We welcome recognition in the Green Paper that this level of support is 'unacceptable'.<sup>11</sup>
- 11 Arthritis Research UK is working to ensure that musculoskeletal health is included in all care planning discussions and that the benefits of care planning are realised by people with musculoskeletal conditions, including those with multimorbidity. Our policy report 'Care planning and musculoskeletal health' (2013) includes recommendations for change, including that **healthcare commissioners including NHS England should ensure that care planning is available to people with musculoskeletal conditions.**<sup>12</sup> Arthritis Research UK is currently supporting a feasibility study to develop and test collaborative care and support planning within general practice for people living with musculoskeletal conditions. We are also members of the Coalition for Collaborative Care (C4CC) which is working to implement care and support planning and other approaches which support people with long-term conditions.<sup>13</sup>

- 12 There are important opportunities to improve and align healthcare services for people with musculoskeletal conditions so they support both health and work. We welcome the focus in the Green Paper on innovative ways of providing musculoskeletal care, including physiotherapists working from general practice surgeries and **self-referral to musculoskeletal services**.
- 13 Self-referral to physiotherapy is a system which enables a person to refer themselves directly to a NHS physiotherapist without requiring a referral from their GP. Self-referral to physiotherapy for people with musculoskeletal conditions is currently available in Scotland, the majority of Wales and in a third of Clinical Commissioning Groups in England. **The Work and Health Unit should investigate what supporting tools and resources can be provided to Clinical Commissioning Groups and employers to enhance their understanding of the role self-referral to physiotherapy can play in tackling work place absences.**<sup>14</sup> **The STarT Back Screening Tool** is a simple questionnaire that helps clinicians identify modifiable risk factors for back pain disability and can be used as an effective triage tool in general practice.<sup>15</sup>
- 14 The Green Paper indicated the Government's intention to trial **new kinds of approach for musculoskeletal services** so that people's health and employment needs are met in the best possible way, including the further development of community based pathways and developing better links between treatment and employment support. **Review of the Health and Work Innovation fund pilots underway in the West Midlands Combined Authority and Sheffield City Regions must consider the effectiveness of interventions for people with musculoskeletal conditions.**<sup>16</sup>
- 15 We welcome recognition that there is 'a lack of detailed information about what kinds of musculoskeletal services are currently commissioned, and the extent to which the services meet local need.' **Work with NHS England 'to identify opportunities for regular collection of data about incidence, prevalence, clinical activity and outcomes of musculoskeletal patients and services in England' should be prioritised.**<sup>17</sup> There is a need for urgent improvement in the quality and availability of data about musculoskeletal conditions and the health and care services needed to address them. NHS England, NHS Digital, Public Health England (PHE) and NHS Improvement should collaborate to ensure systematic collection and publication of musculoskeletal healthcare data and its use to continuously drive improvement in outcomes for people with these conditions.
- Arthritis Research UK hosts the **National Musculoskeletal Health Data Group** bringing together stakeholders to discuss data about musculoskeletal health, health and care services and this group can collaborate in this work.<sup>18</sup> In partnership with the musculoskeletal community, Arthritis Research UK has also developed the **MSK Recommended Indicator Set**, a standard set of indicators for musculoskeletal health services.<sup>19</sup> The set is freely available on-line for consideration and use by people with arthritis, commissioners and providers.
- 16 The Green Paper states that the Government has put in place preventative measures (including the 'One You' campaign) and funded local authorities to commission public health services to improve the health of their populations.<sup>20</sup> The Government must continue to ensure **local authority support for facilities and services that promote physical activity and weight management**. These services support people with musculoskeletal conditions to self-manage their health, however, they are non-prescribed functions. As we highlighted in our response to the recent consultation (Self-sufficient local government: 100% business rate retention) we are concerned that local authorities challenged to make savings may cut spending in these areas.<sup>21</sup>
- 17 The Green Paper states that the Government has encouraged the development of **Sustainability and Transformation Plans (STPs)** to support the delivery of improved health and care based on the needs of local populations. However, we are concerned that musculoskeletal conditions are not being systematically included in STPs. This is also the case for other strategic planning documents including Joint Strategic Needs Assessments (JSNAs) and Joint Health and Wellbeing Strategies (JHWBs).<sup>22</sup> Musculoskeletal health should

be considered in the future development of all STPs. Arthritis Research UK has developed datasets containing prevalence estimates for four common musculoskeletal conditions (the **Musculoskeletal Calculator**) to support local understanding of the burden of musculoskeletal disease.<sup>23</sup>

- 18 The Government has indicated an intention to double the number of **employment advisers** in mental health services. The Government should clarify the level of provision of employment advisers in services used by people with musculoskeletal conditions and work towards establishing equal provision in these settings.<sup>24</sup>
- 19 The Green Paper refers to evidence that **waiting times for musculoskeletal services** can vary from 4 to 27 weeks, across the country.<sup>25</sup> As part of an overall improvement in data collection relevant to musculoskeletal health (see section 13), NHS England should examine access to services used by people with musculoskeletal conditions and subsequently work to improve access where this would improve health outcomes.

### Tackling a significant inequality (Chapter 1)

*Consultation questions:*

- *What evidence gaps have you identified in your local area in relation to supporting disabled people or people with long-term health conditions?*
- *How should we develop, structure and communicate the evidence base to influence commissioning decisions?*

- 20 The Green Paper acknowledges that there are gaps in the evidence base, including ‘how musculoskeletal treatment and occupational health interventions improve employment outcomes’.<sup>26</sup> The **National Centre of Excellence for Musculoskeletal Health and Work** is a multidisciplinary collaboration funded by Arthritis Research UK and the Medical Research Council. Established in 2014, the aim of the centre is to identify cost-effective ways to minimise the substantial adverse impacts of musculoskeletal disorders in the workplace.<sup>27</sup> It should be routinely consulted as a potential collaborator in new research programmes and initiatives to address evidence gaps in this field.
- 21 The Green Paper sets out the intention to ‘develop a set of work and health indicators’ and to identify how to share evidence with local commissioners and delivery partners.<sup>28</sup> Arthritis Research UK has developed the **MSK Recommended Indicator Set** which includes an indicator on the use of employment support allowance (ESA) (see section 13).<sup>29</sup>
- 22 Arthritis Research UK has developed the **Musculoskeletal Calculator** which can be used to support local commissioning decisions (see section 15).<sup>30</sup>

### Supporting people into work (Chapter 2)

*Consultation questions:*

- *What specialist tools or support should we provide to work coaches to help them work with disabled people and people with health conditions?*
- *What support should we offer to help those ‘in work’ stay in work and progress?*

- 23 The new **Personal Support Package (PSP)** for people with health condition includes increased funding for the **Access to Work Mental Health Support Service** to support new claimants in the ESA WRAG and the equivalent Universal Credit Limited Capability for Work (UC LCW) Groups.<sup>31</sup> Consideration should be given to providing a comparable dedicated support service accessible to people with musculoskeletal conditions. The PSP should provide personalised support for people with musculoskeletal conditions which can be tailored to individual needs. Musculoskeletal and mental health are common co-morbidities, and the relationship between physical and mental health is considered by many to be bi-directional.<sup>32</sup> Consideration should also be given to ensure the PSP effectively supports people with both mental and musculoskeletal health needs, and other long-term conditions.

- 24 The Green Paper outlines the Government's intention to build and develop the **capacity of work coaches** so that they can better support people with complex and fluctuating health conditions.<sup>33</sup> From 2017, an enhanced training offer will be introduced into the accredited learning journey for work coaches, so that they can better support people with mental health conditions and engage with employers about mental health. Work coaches should also receive adequate training in musculoskeletal conditions. Arthritis Research UK developed the '**Core Musculoskeletal Skills for GPs**' programme in association with the Royal College of General Practitioners. This is a mixed-format education programme drawing on the latest evidence and consensus thinking on the skills required to manage patients with musculoskeletal problems in primary care. Its content may be useful for the development of skills training for work coaches.<sup>34</sup>
- 25 The Green Paper notes the intention of recruiting up to more **Disability Employment Advisers** to work alongside work coaches, and around 200 **Community Partners** to work with Jobcentre Plus staff providing insight into the issue individuals with a health condition face in securing and sustaining employment.<sup>35</sup> People with expertise in musculoskeletal conditions must be included in these appointments. Disability Employment Advisers and Community Partners should receive adequate training in musculoskeletal conditions.
- 26 The proposed **trial of access to specialist advice**, based on a conversation between a work coach, a healthcare professional and a person in the ESA Work-Related Activity Group (WRAG) should include people with a range of musculoskeletal conditions. There should be a robust evaluation of whether this intervention improves outcomes and experience among people with musculoskeletal and other fluctuating conditions, and which healthcare and allied healthcare professionals may be best placed to provide this advice (e.g. physiotherapists, general practitioners, specialists).<sup>36</sup>

### Benefits assessments (Chapter 3)

*Consultation questions:*

- *Should the assessment for the financial support an individual receives from the system be separate from the discussion a claimant has about employment or health support?*
- *How might we share evidence between assessments, including between Employment and Support Allowance/Universal Credit and Personal Independence Payments to help the Department for Work and Pensions benefit decision makers and reduce burdens on claimants?*
- *Building on our plans to exempt people with the most severe health conditions and disabilities from reassessment, how can we further improve the process for assessing financial support for this group?*

- 27 People with musculoskeletal conditions may qualify for specific benefits or support payments to help them with the additional costs of living with a long-term health condition or disability, or to provide them with support when they are unable to work because of their health condition or disability. Arthritis Research UK believes that people with musculoskeletal conditions should have **fair and timely access to benefits**. We welcome the commitment in the Green Paper that the Government does not seek any further welfare savings beyond those already legislated for.<sup>37</sup>
- 28 Arthritis Research UK believes that the Government should not seek to reduce support for disabled people when they are seeking to return to work and regain health.<sup>38</sup> Together with the DBC, we continue to oppose the forthcoming 30% reduction to the **Employment and Support Allowance Work-Related Activity Group (ESA-WRAG)** rate and its equivalent for the 'Limited Capability for Work' group within Universal Credit from 1 April 2017.<sup>39</sup>
- 29 The Green Paper recognises that concerns have been raised about the effectiveness of the **Work Capability Assessment (WCA)** and it questions whether assessment for financial support should be separated from discussions people have about access to employment or health support.<sup>40</sup> We support the broader view of the DBC, that beyond (or rather than) considerations of whether to split assessment, the Government should undertake fundamental reform of the WCA including its underlying principles.<sup>41</sup> We believe that the

WCA should better take into account the needs of people with musculoskeletal and fluctuating long-term conditions. Any proposals to reform WCA should be developed in consultation with individuals with these conditions as well as with professionals with expertise in this area.

- 30 The Green Paper indicates that people expect public services to work together, and that there are **opportunities to share information** across processes and systems. We share the view of the DBC, that collection of evidence has been a serious failing of the current WCA system and a source of severe frustration for many disabled people. There are likely to be opportunities to reduce the burden on individuals of providing the same information several times. It is evident, however, that some data – particularly data originating from healthcare records – may be collected and used only with appropriate consent and that good governance in data handling is essential. As part of wider work on data, the Government should improve consistency in recording of health conditions and work status in national data sets.
- 31 The Green Paper states the Government’s intention to exempt people with the most **severe health conditions and disabilities** from reassessment, noting that these groups represent a small proportion of those receiving Employment and Support Allowance (ESA).<sup>42</sup> It suggests that a simpler assessment process could be developed for these groups. Together with the DBC we welcome the Government’s intention to ‘switch off’ reassessments for those with severe, life-long conditions in the ESA Support Group. The case review exercise being conducted to inform decisions in this area must be adequate in scale and robustly evaluated.

#### Supporting employers (Chapter 4)

*Consultation questions:*

- *Which measures would best support employers to recruit and retain the talent of disabled people and people with health conditions?*

- 32 The Government had already announced additional funding through the **Access to work**, and now aims to support over 60,000 people per year by the end of the Parliament through this scheme.<sup>43</sup> (The 2015 Spending Review included a commitment to a real-terms increase in spending on Access to work to help a further 25,000 people each year).<sup>44</sup> Around 35,560 people used Access to Work in 2013-4 and 24% of these (8,650 people) used the scheme due to problems with their ‘arms and hands’, ‘legs or feet’ or ‘back and neck’ - descriptions likely to relate to musculoskeletal conditions.<sup>45</sup> The Access to Work scheme should be supported by a greater than real terms increase in funding. In addition, the Department of Work and Pensions should undertake immediate and ongoing promotion of Access to Work to target people with musculoskeletal conditions and employers to counter low awareness of this scheme.
- 33 The Green Paper indicates that the Government will undertake research to find out what employers would find most useful in a **‘one-stop shop’ on health and work**.<sup>46</sup> We strongly advise that information about musculoskeletal conditions and their impact on people’s ability to work is included. Arthritis Research UK has produced a suite of **on-line materials for people with musculoskeletal conditions** which may be adapted to support employers.<sup>47</sup>
- 34 The Government has indicated that they will work with partners to develop and run **information campaigns on key topics around health and work** to help employers access existing information and adopt good practices.<sup>48</sup> A campaign addressing musculoskeletal health needs in the workplace should be included as a priority.
- 35 We agree that further action is needed to **establish supportive networks** between employers, employees and charities around health and work.<sup>49</sup> To further encourage employers to support the musculoskeletal health of their staff, Public Health England (PHE) should ensure that a musculoskeletal component is added to the **Workforce and Well-being Charter**, and should allocate resource to implement the Charter, to raise awareness among employers of their mandatory duties and of best practice.

- 36 The Green paper questions whether the **Disability Confident scheme** should include an index of employers, indicating how inclusive of disability they are. We suggest that if such index is included it should seek to illustrate inclusivity by different aspects of health, for example by considering accessibility of facilities and measures to promote musculoskeletal health.

## **Annex A: Responses from people with arthritis and musculoskeletal conditions**

### **Helen, North Yorkshire, inflammatory arthritis:**

"My experience of working with arthritis is that it is difficult to get a job that will allow sufficient flexibility for me to carry out my role in and around my flare ups. I am currently very lucky to work for my husband's business. I have flexible working to carry out my role. If I have a flare up I can switch my working days. I am able to work part-time on this basis. My reality is that to do this saps all of my energy. I am not able to commit myself to anything on an evening and have not done so for years. This clearly limits my social life which I have had to give up in order to contribute financially.

Part of living with inflammatory arthritis means having a condition which often is not visible to others which makes life difficult. Prior to working in my husband's business I went into a job with fixed hours which after eight months I found I was unable to continue with as I kept having flare ups which meant I missed days at work. I resigned before I got to the point of being dismissed on health grounds. I know others wouldn't have the luxury and would have to keep going until they were dismissed and then have to deal with the financial and mental stress as well.

One of the biggest consequences of the condition is feeling out of control and isolated. It's hard to maintain friendships/social links. Friends can quickly grow tired of 'I am having a flare and so can't go - or I am just too exhausted at the moment'. I have found the invitations just dry up."

### **Janet, Cheshire, 62, osteoarthritis and inflammatory arthritis:**

"I work as a registered nurse in a care home. I am one of the unfortunate ladies who were expecting to retire at 60 but are no longer allowed to. I am 62 and I have osteoarthritis and rheumatoid arthritis in most of my joints, in particular my hands, feet and knees, degenerative lumbar vertebrae and sciatica in my left buttock and leg, causing severe neuropathic pain. I am prescribed medication for arthritis, back pain and neuropathic pain, including morphine based transdermal patches.

I find work exhausting, painful and stressful and I rarely sleep well. My colleagues and I drown in paperwork, all of which has to be completed by hand with a pen. I find sitting or standing for long periods acutely painful. I often go home in tears as I am in so much pain. At home I can pace myself and even though I continue to need all my medication my pain is more manageable.

I need to retire now not when I'm 66. I will have to keep working though as my private pension won't be enough to pay all my bills. I'm not sure how I will keep working for another 4 years when every year the arthritis and the pain get worse."

### **Joanne, Berkshire, 53, psoriatic arthritis:**

"I have had psoriatic arthritis since 1999 at the age of 35. I managed to continue to work until 2010. I was working for a very understanding company for 17 years, and they allowed me to reduce my hours, which helped me to continue to work. They were understanding when I had time off sick and also for surgeries.

Unfortunately, my condition worsened and I had to give up work 6 years ago. I am not in a position to try to find work just yet, but worry that if my employment support allowance (ESA) was taken away then I would have to and I am not confident that new employers would be as understanding to someone they know nothing about, compared to my old employers who knew me prior to my psoriatic arthritis and saw how my life had changed."

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