Summary

The Improving Lives: The Work, Health and Disability Green Paper is the opportune moment for the Government to strengthen the foundations it has already begun to lay by recognising that:

- Employers require confidence to recruit those with health conditions
- Employees require ongoing support throughout their career path
- Local models which are already in place and proving to be successful should become models for a nationwide strategy

Setting the Scene

Despite the fact that the exact cost of chronic pain is unknown, according to the Working with Arthritis (2016) report by Arthritis Research UK, the annual cost to the economy of back pain alone is £10 billion¹, with 33% of the UK population experiencing back pain at any one time². The British Pain Society also notes that, “British businesses lose an estimated 4.9 million days to employee absenteeism through work related back pain.”³ Based on this data, the economic case for aiding those that live with chronic pain to enter, remain and return to the workforce after a period of absence is clear. It is clear from both the recent patient research that the CPPC has conducted alongside evidence collected from work and health experts, as is gathered here in this summary, that there is scope to build on the current successes of a number of programmes across the country set in place by government.

¹ “Working with Arthritis” report (2016), Arthritis Research UK
³ Media resources, British Pain Society, https://www.britishpainsociety.org/media-resources/

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About the Chronic Pain Policy Coalition

The Chronic Pain Policy Coalition (CPPC) brings together a wide range of professional bodies, patient organisations, parliamentarians and industry representatives, with one purpose - to work together to improve the lives of people living with pain and their families.

Organisations include academic institutions, commercial organisations, employers and healthcare companies that specialise in pain management, government and quasi government bodies, parliamentarians, professional and NHS representative bodies, Royal Colleges of Medicine, Nursing and other health professions, trade unions and employee representatives as well as voluntary and patient organisations.

The Chronic Pain Policy Coalition has been working closely on the issue of employment for people living with chronic pain for some time, taking a particular interest in the Fit for Work scheme. Parliamentary Champion, Lord Luce, initiated a debate on this issue in the House of Lords in October⁴. After consulting with Coalition stakeholders, it became apparent that there were several areas where it was felt changes could be made to help improve inclusion and outcomes. Lord Luce’s debate highlighted these areas⁵.

The CPPC would like to:

1. Highlight the importance of work for the everyday lives of those with chronic pain⁶
2. Stress the importance of empowerment and integration of chronic pain sufferers to enable them back into work⁷
3. Support work for cultural change through policy⁸
4. Encourage provision of information and support for those living with chronic pain in order to aid GPs to better support their patients into work⁹,¹⁰,¹¹

⁴ Lord Luce, Fit for Work Debate, House of Lords Hansard, 19th October 2016: https://hansard.parliament.uk/lords/2016-10-19/debates/C77930A2-F723-4E99-AD2D-A5CEB174A451/FitForWorkScheme
⁵ Lord Luce, Fit for Work Debate, House of Lords Hansard, 19th October 2016: https://hansard.parliament.uk/lords/2016-10-19/debates/C77930A2-F723-4E99-AD2D-A5CEB174A451/FitForWorkScheme
⁷ Lord Luce, Fit for Work Debate, House of Lords Hansard, 19th October 2016: https://hansard.parliament.uk/lords/2016-10-19/debates/C77930A2-F723-4E99-AD2D-A5CEB174A451/FitForWorkScheme
⁸ Ibid

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Methodology

The Chronic Pain Policy Coalition conducted two roundtable sessions, both Chaired by Lord Luce, in order to deliver evidence from CPPC stakeholders directly to the Green Paper. The first roundtable involved a wide discussion of the key areas of interest in the Green Paper ahead of the second roundtable, which involved briefing civil servants on the results of the previous discussion. The process included representatives from the Department of Health the Joint Work and Health Unit.

Panel Members

This summary from the roundtable discussion led by the Chronic Pain Policy Coalition roundtables held on the 1st February included the following panel members:

- The Rt Hon. Lord Luce; Parliamentary Champion for the Chronic Pain Policy Coalition
- Neil Betteridge; Co-Chair for the Chronic Pain Policy Coalition, patient representative
- Dr Martin Johnson; Co-Chair for the Chronic Pain Policy Coalition, clinical representative and ex-GP
- Dr John Chisholm; Chair, Health and Work Lead of the Royal College of General Practitioners, Chair of Medical Ethics Committee of the British Medical Association, member of the Fit for Work Coalition UK and the Council for Work and Health, former GP
- Sarah Winstone; Secretariat to the Fit for Work UK Coalition, a coalition of organisations including charities, patient representatives, clinicians and employers
- Karin Bishop, Assistant Director, Professional Practice, College of Occupational Therapist
- Ollie Har; GP and Commissioner, National Centre Sport and Exercise Medicine Sheffield
- Jonathan Shaw; CEO, Policy Connect, former Minister for Disabled People
- Katherine Perry, Manager, Chronic Pain Policy Coalition


11 Chronic Pain and Opioids, Early Day Motion 555, UK Parliament, 18th October 2016: https://www.parliament.uk/edm/2016-17/555

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Key Points

1. For the provision of impartial support, advice and information, DH and DWP should encourage a combination of local health services and third parties external to government in order to increase trust and local understanding of health information, for example, utilisation of the local voluntary sector, self-help groups and health coaches or ‘case managers’.

2. It is therefore of utmost importance that the information made available by DH and DWP is widely available and inclusive in terms of terminology in order to encourage people affected by chronic pain conditions to access all support options they are in reality entitled to and can help them to stay in work.

3. More can be done throughout different stages of life – including schools and further education – to teach people about long term conditions including chronic pain and calls on the national curriculum to expand to include health literacy skills in order for all people to be able to make appropriate choices in the healthcare system.

4. Employer flexibility is an important aspect to give confidence to employees affected by a disability or chronic pain condition.

5. Amongst DH and DWP enabled programmes, the Fit for Work (FfW) scheme and contained Occupational Therapies (OTs), should become more flexible in order to ensure full utilisation of the OT skillset. To this end, FfW should be linked into local communities.

6. DH and DWP should accredit and publicise ‘Disability Confident’ employers in order to create an impetus for organisations to get involved themselves.

7. While the programme ‘Access to Work’ has been proven to work, its reach is currently too small. As well as increasing awareness of the scheme amongst those with disabilities, there should be an expansion of the programme’s eligibility rules in order to overcome its current limitation that prevents some people from accessing the support they need to attain a job.

8. The government should consider supporting this through subsidies, particularly for Small and Medium-Sized Enterprises (SMEs) who may find it logistically difficult to employ someone with a disability or long-term condition.

9. The establishment of a portal for employer information, possibly provided by government, to provide legal and HR support around work and health issues would help to ensure consistent messaging, disprove myths and support employers find an entry point to managing conversations about their employee’s support needs.

10. Targeted education and information for young people is needed in order for them to confidently move through to adult health services and pursue a successful work life.

11. Tax incentives for employers that encourage inclusive employment strategies and pro-actively support members of staff that are disabled or have long-term conditions are very welcome, however there appears to be a lack of awareness of these schemes, particularly amongst small employers.
12. A substantial growth in workload over the last decade means that many GPs do not have the spare capacity to go beyond brief interventions with their patients.

13. The former national education programme for GPs on health and work, focused on how to negotiate around the discrepancy between patient and doctor expectations to achieve better outcomes should be revisited.

14. The Fit Note should involve a three-way negotiation between employers, employees and an expert in occupational health. Consideration should be given to moving away from only letting GPs assess and issue Fit Notes and, through adequate training, enable professions such as OTs and physiotherapists or mental health workers to issue Fit Notes.

15. There should be a change in narrative and a slight ‘de-medicalising’ of conversations about health and work in order to make them more relatable for patients and to enable the inclusion of non-medical issues in these discussions, that might be just as important for a person’s continuation or way back into work.

16. The quality of the Fit Note determines what kind of conversation employers are able to have with their employees and, in many cases, the absence of information can create a barrier to conversations and positive changes in the work place or specific task.

17. There is potential to build on existing community network programs, such as the use of health trainers/health champions, community development programmes and asset-based community development programmes to trial co-location around employment assessments.
Supporting people into work

Empowerment and Integration

- In order to help people who are already ‘in work’ to stay in work and progress, the CPPC would like to draw attention to the important connection between patient empowerment and the integration of care services. Devolution models such as ‘Devo Manc’, in the context of which Greater Manchester is taking control of its health and social care budget, aim to cluster the health and social care services people closer to individuals. These need to incorporate patient- or user-centred models of care in order for people to have access to the support they need to enable them to remain in work despite having acquired a painful disability. Building individuals’ confidence in self-management so they can continue to work on their own terms requires the empowerment that comes through such patient-focused approaches.

Localism and Devolution

- While much of the information and support people with chronic pain need is already in existence, affected people are often either not aware of it or they have little trust in the information available to them. Localised messaging and information are crucial to increasing patients’ accessibility to and trust in information. Structures developed at the national level, such as the joint unit straddling the Department for Health (DH) and the Department for Work and Pensions (DWP) are rarely replicated locally across the UK. Therefore, for the provision of impartial support, advice and information DH and DWP should encourage local health services to work with third parties external to government, for example, the local voluntary sector, self-help groups and health coaches or ‘case managers’ which can help to build trust.

Provision of impartial support, advice and information

- People with chronic pain conditions, such as arthritis, do not always identify as 'disabled'. Yet, an officially declared disability status is often necessary in order to qualify for support necessary for them to stay in work, including relevant benefits and the provision of in-work adaptations. Information made available by DH and DWP needs to be mindful and inclusive in terms of terminology in order to encourage people affected by chronic pain conditions to access all support options they are in reality entitled to and which can help them stay in work.

- DH and DWP should consider the importance of health literacy in the context of messages concerning health and its relation to work. For patients, being able to understand, contextualise and apply information available to themselves as an individual is highly important for successful outcomes. More can be done throughout different stages of life – including schools and further education – to teach people about health and work and calls on the national curriculum to expand to include health literacy skills in order for all people to be able to make appropriate choices in the healthcare system.
Flexibility

- **Employer openness and flexibility is essential in giving confidence to employees affected by a disability or chronic pain condition that they can talk about their condition and discuss the adjustments that they may need to continue to work.** This can range from flexibility in working hours, enabling part-time work patterns, the ability to move around during the day and vary between seated and standing positions, access to work place supports and adaptions.

Extending the programmes that are already in existence

- **Amongst DH and DWP enabled programmes, the Fit for Work (FfW) scheme and contained Occupational Therapies (OTs), should become more flexible in order to ensure full utilisation of the OT skillset.** To this end, FfW should be linked into local communities. This could, for example, be done through implementing walking groups whose benefits are not limited to just the results of physical activity. Such programmes also further social and coping skills that can be beneficial to a person’s relationship with their employment.

- **DH and DWP should improve ‘Disability Confident’ and ‘Access to Work’.** Currently, ‘Disability Confident’ employers are required to consider recruitment and employment through a ‘disability lens’. While this might help the individual employer to improve, DH and DWP should accredit and publicise ‘Disability Confident’ employers in order to create an impetus for organisations to get involved themselves. Further, the scheme should be extended in order to connect small businesses better with the local services available and thereby contribute to their capacity to meet affected employees’ needs better.

- **While the programme ‘Access to Work’ has been proven to work, its reach is currently too small.** As well as increasing awareness of the scheme amongst those with disabilities, expansion of the programme’s eligibility rules is needed in order to overcome its current limitation that prevents some people from accessing the support they need to attain a job. For example the programme’s current form requires a person to already have an offer of an interview before being able to access the available grant. However, in many cases, being able to access a grant and consequently being able to make the necessary adaptions may only make it possible for a person to secure an interview.

Supporting employers to recruit with confidence and create healthy workplaces. Embedding good practices and supportive cultures

Cultural Change

- **The prevalent “one size fits all” culture that favours fast delivery and long working hours is a problem and discourages employers to consider and become more aware of the benefits of employing disabled people.** The government should consider supporting this through
subsidies, particularly for Small and Medium-Sized Enterprises (SMEs) who may find it logistically difficult to employ someone with a disability or long-term condition.

- There is also a requirement to change the narrative; focusing on what employees can do rather than what they are unable to do. Employer and employee should identify areas of individual employees’ skills and capabilities that are currently untapped. This might also help the employer to adjust the roles that are being offered, how tasks and responsibilities are distributed, and where workloads have the potential to be personalised.

- Young adults with painful or complex conditions are often not spoken to about career ambitions, education or how their skills may be applied to a work setting and can be discouraged from entering the work force altogether. Targeted education and information needs to be available to these young people in order for them to confidently move through to adult health services and pursue a successful work life.

- In order to tackle barriers that are currently preventing employers to recruit and retain the talent of disabled people and people with health conditions, consistency of messages across employment, health and welfare systems is crucially important.

Incentives

- There is a lack of awareness of available tax incentive schemes, particularly amongst small employers, that encourage inclusive employment strategies and pro-actively support members of disabled staff or those with long-term conditions. Accountants and financial advisors could play a significant role in signposting employers to relevant schemes and could be a new channel through which to reach particularly smaller businesses (which may not have an occupational health service in-house). It is crucial that necessary information is accessible.

Overcoming Fear

- Many SMEs do not have dedicated HR or occupational health departments and therefore may lack the expertise or confidence to adequately engage with employees that are living with a long-term condition or disability. As a result, such employers may avoid engaging in conversations about work and health for fear of legal consequences or implications for the relationship with the employee. A portal could be developed for employers by government, to provide legal and HR support guidance around health and work, ensuring consistent messaging, dispelling myths and helping employers find an entry point to managing conversations around health and work.

Localised Employer Support

- Localised charities and organisations can be particularly helpful for SMEs. By working closely with health and social care teams in the patient’s geographical proximity they help build confidence, skills and knowledge in their cooperation with SMEs. Such localised employer support can be particularly useful for employers that are presented with the need for different levels of support, as they can draw on universal (information for everyone),
targeted (signposting towards a particular service such as cognitive behavioural therapy (CBT)) and specialist information or services.

Improving discussions about fitness to work and sickness certification

Better Conversations

- At present it is unrealistic to expect General Practitioners (GPs) to have a meaningful conversation about fitness for work and what people affected by a long term condition or disability require to be able to stay in work within a 10 minute appointment. A substantial growth in workload over the last decade means that many GPs do not have the spare capacity to go beyond brief interventions with their patients. The lack of more in-depth conversations can also lead to a potential mismatch between the patients’ and doctors’ expectations about whether time off work is in patients’ best interest or not. The past DWP-funded national education programme for GPs on health and work, focused on how to negotiate around the discrepancy between patient and doctor expectations to achieve better outcomes.

- Leading conversations about health and work should be a shared responsibility between GPs and secondary health care professionals and thereby prevent patients, having been unable to have a conversation with their primary care provider, from falling through the cracks.

- A change in narrative and ‘de-medicalising’ of conversations about health and work can make the topic more relatable for patients and can help include non-medical issues in these discussions that might be just as important for a person’s continuation or way back into work.

Extra Support in the GP surgery and Referrals

- Additional resources for GP surgeries will be needed in order to improve the duration and quality of conversations about health and work. Further, occupational therapists can be better suited to primary care rather than hospitals and other secondary care settings. Examples in which occupational therapy services within GP surgeries working in conjunction with GPs have proven to be effective as they provide the opportunity to develop targets for patients, explore underlying problems of their condition and absence from work and develop strategies for returning to work. However, the costs for these services currently needs to be paid for by the surgery, which represents a barrier to this good practice being implemented more widely.
The Fit Note

- Confidence in the employer can often be more important for patients than the actual diagnosis when deciding whether and how to stay or return to work. While a diagnosis might help to determine broad implications, it often cannot portray how well an individual can cope with the condition in question. In order to aid the process of communicating with employers, organisations should make clear what their areas of concern are in order to simplify the process of capturing relevant information for issuing a Fit Note. **The Fit Note could involve a three-way negotiation between employers, employees and an expert in occupational health.** Further, we should move away from only letting GPs assess and issue Fit Notes and, through adequate training, enable professions such as physiotherapists, occupational therapists or mental health workers to issue Fit Notes. This could help relieve GPs of some of the associated workload.

- GPs, who are currently the only authority able to issue a Fit Note, are rarely involved in communicating with employers during the consultation process to negotiate the terms of returning to work and exploring how much the employer will be involved with the Fit Note process. This process could be initiated by GPs asking what sort of company the patient works for to enable the right referral.

The quality of General Practice with a special interest

- More specialist information and support at a local level is needed to equip GPs and other health care professionals with the expertise to conduct health and work related assessments. Two possible ways to implement this would be; either through commissioning it as a service by Clinical Commissioning Groups locally or by developing it as a service through a federation of GP practices – essentially a provider organisation of a number of joined up GP practices to be able to develop economies of scale and enable internal referrals within the federation. This could further be complemented by a centralisation of information of GPs with a special interest – an approach the Royal College of General Practitioners has trialled previously. Such a register of skills is vital and could become an extremely valuable resource for GPs that require extra knowledge or guidance in the absence of local information networks.

Expanding Pilots

- The Government needs to revisit and expand previous pilot schemes where health and work advisers were based in GP surgeries. Further, in-depth research should be conducted to assess best practice models already in place and determine whether advisers from job centres are appropriate and how to ensure that an appropriate focus of returning to work and remaining in work, beyond the GP’s capacity can be delivered within the given time frame.

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Creating the right environment to join up work and health

Data

- In order to create the right environment to join up work and health, an increased focus on data input for each patient’s care record is needed. In many cases, patients themselves are better placed to update their records than doctors, provided they are given the right tools and appropriate level of access. Measuring patients’ skills, knowledge and confidence to self-manage is key to introducing a more ‘person-centred’ focus. Further, Key Performance Indicators (KPIs) on Fit Notes are necessary in order to understand how to really encourage behaviour change amongst GPs. Once both of these data sets are developed joining up the metrics across the system will be critical as presently, there are blunt measures for capturing work outcomes and overlaying them with health outcomes. A detailed focus on the interplay between both sides is important to improve this.

- The fact that Fit Notes can now be measured on a computer opens the opportunity for even greater data collection. However, the inaccurate completion of Fit Notes and use of paper Fit Notes could present a problem. The quality of the Fit Note determines what kind of conversation employers are able to have with their employees and, in many cases, the absence of information can create a barrier to conversations and positive changes in the work place.

Encouraging healthcare professionals to promote work as a health outcome

- There is a great potential to build on existing community network programmes, such as the use of health trainers/health champions, community development programmes and asset-based community development programmes to trial co-location around employment assessments.

- Leadership that demonstrates that work as a health outcome is highly important at all levels of the system is of crucial importance.
**Best Practice**

**Training of rheumatology teams in having positive conversations around work and health**¹²

Cardiff University developed and piloted a face-to-face training programme for rheumatology multidisciplinary team (MDT) members (rheumatologists, nurse specialists, occupational therapists and physiotherapists). The purpose was to improve participants’ knowledge and increase their confidence in having early conversations with their patients about work and health. The content was based on material designed for the Royal College of General Practitioners’ National Education Programme for Work and Health training course, in which more than 3,000 GPs across Wales have participated. Piloted across five sites with 99 participants, the training increased participants’ confidence in managing conversations around health and work. 8 out of 10 respondents said it had an impact or considerable impact on their practice¹³.

**Improving shared decision-making in work and health**

Cardiff University is developing a shared decision-making tool to aid and improve conversations around health and work between patients and their healthcare professionals. By facilitating better conversations – for example around the patient’s wants, concerns and need around their ability to work – the project aims to optimise the management of their condition and help them achieve their health and work goals. The tool is currently being piloted in primary and secondary care settings in more than 15 centres across England and Wales, and results of these pilots will be evaluated in 2017. Once evaluated, it is hoped the tool will sit alongside and support the existing 36 therapy-based shared decision-making tools for long-term conditions, and be used by clinicians in multiple health settings.

**Early Intervention Clinic (EIC) in Leeds, led by Dr Stephen Brannan**

Unique in the UK, the Leeds Early Intervention Clinic focuses on early intervention for people with musculoskeletal conditions. The model allows GPs to refer patients signed off work with a musculoskeletal condition to the clinic for assessment within five days – substantially quicker than they might wait for a secondary care appointment. At the clinic, the patient has a longer assessment with a specialist, and is provided with tailored advice and support or if necessary referred on to secondary care. The clinic is based on a model from Spain, which has been shown to improve

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patients’ health, support them to return to work quicker, and save costs to the health service and wider economy\textsuperscript{14}. Results from the Leeds pilot are expected later this year.

**Health and Work Champions**

The College of Occupational Therapists and Public Health England are carrying out a pilot project in which 28 occupational therapists across England have become Health and Work Champions. They are using peer to peer education training sessions to help their NHS colleagues understand the positive links between good work and good health; to be able to use employment status as a measure of functional outcome and to more routinely offer support for patients’ employment aspirations. The pilot will run until June 2017.

**Bromley-by-Bow**

The general practice and the health centre were established in 1997. Labelled one of the first healthy living centres in England, the centre combines a traditional GP surgery with a charity, local authority and public health funded programmes and social care teams to deliver holistic, personalised care for every patient that walks through its doors. One of the main reasons why the Bromley-by-Bow is considered so revolutionary is its work around social prescribing, which recognises that not all health problems have a physical cause\textsuperscript{15}.

**Dr Ollie Hart, Sheffield Pilot**

Dr Ollie Hart has chosen three areas to highlight in regards to the Sheffield pilot:

1. The pilot has been using the Patient Activation Measure (PAM) in clinical settings- this is something NHS England has heavily invested in with 1.8 million licences for 5 years purchased.
2. Sheffield now has wide experience of using Health trainers/ Health Champions and in practice occupational health advisors.
3. The long-term multi-stakeholder “Move More” project, a culture change project, has helped to embed physical activity in normal city life. It is led by the CEOs of all the major stakeholder groups in the city. The pilot has allowed for 3 large co-location centres to be recently opened, where health clinics are co-located in leisure centres. It’s Dr Hart’s opinion that this model would lend itself well to employment capability and support being integrated into systems.

\textsuperscript{14} Juan Jover, Hospital Clinico San Carlos, A cost-effective, evidence-based solution to reduce the burden of MSDs, Presentation to the EU Summit on Chronic Diseases, 2014

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