

November 2013



## **Life and employment opportunities of young people with chronic conditions**

Stephen Bevan  
Ksenia Zheltoukhova  
Kate Summers  
Zofia Bajorek  
Lisa O'Dea  
Jenny Gulliford

## Acknowledgements

We hugely appreciate the time that the participants took to respond to the survey and share their experiences of living with a chronic condition. We are particularly grateful to those who shared their stories during interviews.

This report would not have been possible without the support of the patient organisations from all over the UK who have facilitated data collection.

The authors would like to thank the experts who have reviewed the first drafts of this report, namely Jamie Hewitt, Government Affairs Manager at National Rheumatoid Arthritis Society, and Jenny Christensson, Patient Relations Manager at AbbVie AB. The report has benefited from the feedback of our colleagues at The Work Foundation – especially Krishma Tailor.

This piece of work was supported by a grant from AbbVie UK.

## Foreword

It is a mark of how far medical care has advanced that such a high proportion of young people with chronic ill-health are not only surviving to adulthood but can look forward with optimism to fulfilling lives. However, many young people living with chronic conditions still struggle to meet some of the challenges of becoming independent adults in modern society.

This report takes a new look at this challenge at a time when youth unemployment in the UK are at worryingly high levels. It captures very well the scale of the obstacles faced by young people with long-term, chronic or fluctuating conditions as they seek to make the transition from education and employment – and then to develop and thrive in the workplace. The stories they tell in their responses to the survey and in the testimony they gave The Work Foundation's researchers provide, I think, an authentic and ultimately inspiring picture of the asset that these young people represent to employers and to the wider UK workforce. The resilience, persistence and resourcefulness they have had to demonstrate at such a young age is remarkable – all qualities which all employers say they value highly.

Adolescence and young adulthood are the key ages for developing life skills, for gaining autonomy and self-confidence and increasing social participation. Only with the right access to healthcare, rehabilitation support and vocational guidance can young people living with chronic illness make a successful transition to adulthood and the world of work. My hope is that this report will add to the now overwhelming evidence that timely, work-focused, interventions by clinicians, other health professionals, career advisors, teachers and employers can mean that good quality jobs and fulfilling working lives are within the grasp of all young people living with chronic illness.

A handwritten signature in black ink, reading 'Carol Black', with a stylized, cursive script.

Dame Carol Black DBE MD FRCP MACP FMedSci

## Contents

Life and employment opportunities of young people with chronic conditions .....	1
Executive summary .....	6
The impact of long-term conditions on young people's ability to prepare for and seek employment.....	7
The implications of living with a chronic condition on young people's productivity and work.....	7
Barriers and enablers to employment .....	8
Recommendations.....	9
1. Introduction .....	13
1.1. Research Objectives.....	15
1.2. Methodology .....	15
2. The impact of long-term conditions on young people's ability to prepare for and seek employment .....	17
2.1. Educational attainment and career aspirations.....	17
2.2. Obtaining employment and employability .....	20
2.3. Summary .....	23
3. The implications of living with a chronic condition on young people's productivity and work .....	24
4. Barriers and enablers to employment.....	27
4.1. Control over the course of disease.....	27
4.2. Work-related guidance and advice.....	30
4.3. Workplace support and culture .....	33
4.4. Confidence and self-efficacy .....	36
4.5. Summary .....	38
5. Conclusions and recommendations.....	40
References.....	47
Appendix 1. Sample .....	50
Appendix 2. List of participating patient organisations .....	53

Appendix 3. Questionnaire .....	54
Appendix 4. Interview guide .....	56

## Executive summary

This report looks at the ways in which employment outcomes can be improved for young people living with chronic health conditions. Transitioning successfully from education into employment is a challenge for all young people, but is heightened for young people living with a long term health condition. Experiencing a spell of youth unemployment means that a young person is at greater risk of future unemployment, reduced earnings, and reduced psychological wellbeing; excluding young people with chronic conditions from the labour market can have a significant and long lasting effect on their lives.

This report employed a mixed method approach to understand the extent to which educational, healthcare and workplace settings contributed to positive or negative work outcomes for young people with chronic conditions, and identify ways in which employment outcomes could be improved. The fieldwork consisted of an online survey and in-depth interviews, both of which were conducted with young people living with chronic conditions. **The authors argue that the effects of the physical and psychological symptoms of chronic conditions, combined with stigmatic societal attitudes, create significant barriers to young people with chronic conditions successfully entering the workforce. By supporting young people with chronic conditions from school onwards to understand and manage their condition in the context of work, by educating others about chronic conditions, and by creating accommodating, appropriate work environments, positive work outcomes can be achieved.**

The findings are divided into three main sections:

1. The first section looks at young people's experiences of preparing for and seeking employment, including their time in education.
2. The second section explores how living with a chronic condition affects young people once they have entered the workforce.
3. The third section looks more closely at the specific barriers and enablers to employment for young people with chronic conditions.

## **The impact of long-term conditions on young people's ability to prepare for and seek employment**

This section looks at young people with chronic conditions' experiences in the context of educational settings, their career plans and aspirations, and their experiences of job seeking.

Many of the study participants reported that their condition had disrupted their schooling and affected their attendance rates. This in turn had led to delays in their education or training, and meant that the majority of the respondents felt that they had not reached their full educational potential. Many of the study participants had reviewed and lowered their career plans and aspirations because of their condition.

Worryingly, our findings suggested that one of the central reasons for compromised experiences of education was that educational institutions were unwilling or unable to make adjustments to accommodate young people with chronic conditions.

The study then explored young people's experiences of seeking work. The study found that the physical symptoms of chronic conditions were an impediment to seeking work, as young people were still learning how best to cope with and manage their condition.

However, negative societal attitudes towards young people with chronic conditions also played an important role in how they looked for work. The study participants reported being unwilling to disclose their condition when applying for a job for fear that this would discount them from the selection process. Some participants had specific examples of encountering negative employer attitudes, but moreover participants cited the *expectation* of discrimination and stigma as affecting their job applications. This suggests that self-stigma played a significant part in young people with chronic conditions' experiences of transitioning into the labour market.

## **The implications of living with a chronic condition on young people's productivity and work**

The participants reported experiencing problems with maintaining employment, receiving adequate support, and negative employer attitudes.

A significant proportion of the respondents highlighted the negative impact that their condition had on their job opportunities and careers:

- 68% believed their chronic condition affected their job satisfaction.
- 27% thought their chronic condition inhibited access to training and development.
- 61% said their condition stopped them reaching their full potential in the workplace.
- 57% had their career progression impacted by their chronic condition.
- 50% of the respondents said their condition prevented them from looking for a different job.

93% of survey respondents indicated that the condition affected their confidence and self-esteem. Participants spoke of being fearful that negative employer attitudes towards them would affect their chances of being successfully employed. The majority of participants also felt that they were more vulnerable to job loss than people without a long term condition. These fears meant that almost every single one of the participants continued to go to work even when they were experiencing negative side-effects of their condition (presenteeism). Tackling negative attitudes (both among employers and among young people with chronic conditions themselves) is a crucial component of working towards supportive working environments.

## **Barriers and enablers to employment**

One of the major barriers to young people with chronic conditions successfully entering work was the fluctuating nature of both the physical and psychological symptoms of their condition. The study respondents explained that their chronic condition could be unpredictable, and their employment had to be sufficiently flexible to accommodate these fluctuations.

The study also found that participants often experienced significant gaps in time between experiencing symptoms, receiving a diagnosis of their condition, and then receiving treatment. The delays in receiving a correct medical diagnosis and appropriate treatment has implications for young people successfully entering the workforce, as it took them longer to learn how to live and cope with their condition.



This research also explored where young people with chronic conditions currently received support and guidance. A minority of respondents were receiving formal support to help them to find or maintain employment. The young people in the study heavily relied on peer support, and in particular the support offered by online forums.

The majority of respondents' who were in work had managers that were supportive of their condition when they disclosed it, and many also provided workplace adjustments. However, just under half of the respondents had not discussed workplace adjustments with their employer suggesting that there is still progress to be made in terms of how employers support young people with chronic conditions.

Finally, self-stigma emerged as a major barrier to successful employment which affected young people with chronic conditions' career aspirations, job seeking activities, and help seeking behaviours.

## **Recommendations**

A summary of the report's recommendations follows. For the recommendations in full, please see page 40.

### **Support needs to be provided from the earliest opportunity**

- **The Department for Education should provide improved education to young people about chronic conditions.**
- **Tailor careers advice for young people with chronic conditions.**
- **Information about chronic conditions, careers guidance and out-of-work support should be made available via a one-stop online portal in an accessible format, including access through social media platforms.<sup>1</sup>**

---

<sup>1</sup> See, for example, the Health and Safety Executive <http://www.hse.gov.uk/youngpeople/resources.htm>

## **Unemployment support for young people with chronic conditions**

- The government needs to seriously **consider how the various programmes that offer support for young people with chronic conditions work alongside each other.**
- There needs to be an **investigation into how, and to what extent, people with disabilities are being served by the Work Programme** might be a useful first step in beginning to understand how employment programmes can best serve people with chronic conditions.

## **In-work support recommendations**

- The government needs to raise **awareness of and enforce existing disability** employment legislation.
- **Improve how in-work support services are advertised.**
- **The new Health and Work Service should be prepared to help young people with chronic conditions.**

## **Recommendations for Healthcare Services**

**Healthcare professionals** should consider how a chronic condition may have an impact on a young person's ability to study and work.

- **Healthcare professionals at all levels of care should consider current and future work outcomes as part of young individual's clinical treatment plan.**
- **Look into ways health care professionals can be incentivised to consider their role in the employment outcomes of young people with long-term conditions.**

- **NICE should consider wider societal costs and benefits, such as employment and lifelong opportunities** when evaluating the cost-effectiveness of health technologies.

## **Employer recommendations**

**Employers** need to recognise that many young people with a chronic condition have a great deal to contribute to a workplace, but that they may also often feel anxious about whether their condition can be accommodated at work. Employers should also make themselves aware of practical adjustments that can be made to the workplace to allow for greater employment possibilities for young people with chronic conditions.

- **Employers should play a greater role in shaping the skills of young people graduating from schools and universities**, through organising career fairs, offering traineeships, apprenticeships, internships and mentoring schemes. an environment with their condition, and to begin to learn what they can do to best manage it.
- **Crucially, employers must address the stigma and discrimination both at the recruitment stage and in relation to employees disclosing their health conditions.**
- **Employers need to be supportive in identifying and establishing appropriate workplace adjustments.**
- **Training should be provided to line managers, senior managers and employees in organisations to raise awareness of the impact that chronic conditions can have on an individual, and how they can be managed** in the workplace.

## **Role of the Third Sector**

**Third sector organisations** should create communities for young people to share their experiences and seek advice in a safe environment.

- **Patient groups should include modules on working with chronic conditions online as well as in printed resources.**
- **Patient groups should consider holding career workshops** where young people with chronic conditions can discuss their aspirations and receive advice and support on how they can achieve their goals.
- Patient groups should **offer resources on employment rights** in an accessible manner and provide forums for consultation with employment law specialists.

## 1. Introduction

Young people have been one of the largest casualties of the latest labour market downturn: the most recent Department for Education figures show that 15.5% of people aged 16 to 24 in England are not in education, employment or training (NEET) (Department for Education, 2013). Having to now compete with more mature workers for entry level jobs, it appears that many young people tend to lack the all important 'previous experience' that most employers deem essential (Lee et al., 2012).

Achieving the desired labour market outcomes is even more complicated for individuals with chronic conditions. In addition to the general challenges associated with entering and sustaining a job, they may face further barriers to employment because of their health, including: fluctuations in their performance; the need to attend medical appointments; lack of understanding and the negative attitudes of others; self-stigma; and discrimination from colleagues and potential employers (The ACEVO Commission on Youth Unemployment, 2012; Long-Term Conditions Alliance Scotland, 2011). The proportion of people with a limiting long-term condition in work remains a third lower than those who do not have a long-term condition (Gay et al., 2011). The UK Commission for Employment and Skills found that 24% of 16 – 24 year olds with a work-limiting disability are unemployed, compared to 14% among those without a disability (UK Commission for Employment and Skills, 2011). Furthermore, people with learning difficulties and/or disabilities account for 7% of the 16-24 population but make up 16% of the population who have been NEET for six or more months (The ACEVO Commission on Youth Unemployment, 2012; Long-Term Conditions Alliance Scotland, 2011).

Young adults with childhood onset chronic illnesses are reported to be at risk of worse educational and vocational outcomes regardless of the specific condition (Naylor et al., 2012). Common symptoms such as fatigue, pain and sickness characterise a range of chronic conditions (for example multiple sclerosis, rheumatoid arthritis, ankylosing spondylitis, Crohn's disease, ulcerative colitis, schizophrenia or type 1 diabetes) and are likely to impact individual work outcomes,

in part through disruptions to the course of education and training (Bevan et al., 2011; Gay et al., 2011; Michaud, Suris and Viner, 2007).

Longitudinal data confirms the negative consequences that living with a chronic condition can have on employment outcomes. Work using data from the British 1958 Birth Cohort showed that chronic illness in childhood and/or adolescence results in poorer educational and vocational outcomes, especially in males (Michaud, Suris and Viner, 2007). Similarly, analysis conducted using the National Longitudinal Study of Adolescent Health showed that, when compared with those without childhood chronic illness, respondents with a history of chronic disease have lower odds of graduating from college, being employed, and achieving higher earnings (Maslow et al., 2011).

The consequences of a young person experiencing unemployment stretch far beyond contemporary loss of earnings. Experiencing unemployment when young heightens the chances that someone will be unemployed when they are older. The 2012 ACEVO Commission on Youth Unemployment found that individuals who had experienced unemployment at a young age would spend on average an additional two months per year out of work between the ages of 26 and 29 compared to someone who had been employed (The ACEVO Commission on Youth Unemployment, 2012). There is also evidence to support the notion that those who go through a period of unemployment when young will suffer from deflated wages in the future (Gregg and Tominey, 2005), and that youth unemployment can cause serious psychological scarring (Lee et al., 2012). The negative consequences of youth unemployment are far reaching, which is why it is important that young people with chronic conditions are successfully integrated into the labour market.

Evidence shows that young people with chronic conditions are at a greater risk of being excluded from the labour market. Therefore, it is of greater importance that young people with chronic conditions are successfully integrated into the workforce. This report aims to identify the barriers to employment that young people with chronic conditions face, and offer solutions as to how they can be surmounted.

## 1.1. Research Objectives

Looking at the unemployment rates among young people with chronic conditions, we believe that more could be done to prepare them for tackling the barriers to employment as they make the transition into adult life. The aim of this study is to examine the extent to which work outcomes of young people with chronic conditions are managed in educational, healthcare and workplace settings, identify specific support available for young people with chronic conditions and identify factors that may improve the employment outcomes of these individuals.

This study plans to:

1. Collect data on the general experiences of individuals aged 18-25 living with a chronic condition.
2. Collect data on their experiences of obtaining education, entering and remaining in the labour market, and describe the impact of their chronic conditions on work outcomes.
3. Collect data on young people's expectations about work outcomes and their perceptions of these expectations being met.
4. Collect data on the support available to young people living with chronic conditions to help them to realise their labour market ambitions.
5. Make recommendations for policy and practical support to achieve positive work outcomes for young people living with chronic conditions.

## 1.2. Methodology

To explore labour market experiences of young individuals living with long-term conditions we have applied a two-stage mixed method approach.

The first stage of the research involved collecting 247 valid quantitative survey responses on individuals' experiences of obtaining and maintaining employment. The research was conducted through the use of an online questionnaire, which was circulated to members of selected patient groups aged 18-25 and living with a range of doctor-diagnosed long-term conditions in the UK. (See Appendix 1 for the basic profile of the sample including, respondents' gender, age and employment status and the number of survey respondents with no formal qualifications. Refer to

Appendix 2 for the list of patient organisations that supported this study and Appendix 3 for a description of the questionnaire.)

Social media tools (for example Twitter and Facebook) were used to further circulate the link to the survey. As the questionnaire could be accessed freely, response rates cannot be calculated. Although the questionnaire was accessible, easy to use and targeting the right individuals, the population of patient groups appears to be skewed towards better educated and female participants. While this may be representative of the total population of people with certain long-term conditions, concerns around the representativeness of the sample remain. Therefore, the findings presented in this report should only be considered as indicative of trends among young people with chronic conditions more generally.

Following the survey, 16 face-to-face interviews with individuals diagnosed with long-term conditions were undertaken, aiming to gather more detailed qualitative data on their experiences in accessing support for their labour market ambitions. The participants had previously agreed that they were willing to be contacted for interview, and were chosen on the basis of their employment status (employed/unemployed), gender and health condition. The sample was aged between 17 and 25 years of age, and their chronic conditions included IBD, diabetes and mental health disorders. Interviews were recorded with the participants' consent and thematically analysed. (See Appendix 4 for the interview guide used.)



## **2. The impact of long-term conditions on young people's ability to prepare for and seek employment**

The findings presented in this section report on how young people's chronic conditions can affect their ability to prepare for and seek employment. It was clear from the results that the challenges faced by young people with chronic conditions in terms of finding, entering and maintaining meaningful employment begin well before they enter their first job and include education and careers advice as well as actual job seeking.

Most notably, the physical and psychological symptoms associated with study participants' health conditions were shown to have both an immediate impact on young people's performance in education and work, but also present a cumulative long-term effect on employment status, job quality and earning potential (Ben-Shlomo and Kuh, 2002). Whilst a single spell of sickness could affect school grades or work attendance, an ongoing, chronic condition can significantly alter an individual's life course by negatively affecting educational attainment, career choices and in-work advancement opportunities.

This following section begins by looking at young people with chronic conditions' experiences in the context of educational settings, their career plans and aspirations, and their experiences of job seeking.

### **2.1. Educational attainment and career aspirations**

The onset of long-term conditions at an early age may be disruptive to the education process, potentially damaging a young person's chance of achieving the desired qualifications. For example, the onset of mental health problems in childhood, adolescence or early adulthood has been shown to lead to poor social and economic achievements in adulthood, including lower educational attainment and lower occupational status and income (George, 2007). Research from the Department for Education suggests that poor attendance at school is linked to lower educational achievement and an increased risk of being NEET (Department for Education, 2012). Many of the study participants, regardless of their current

employment status, reported that ill health affected their experience of schooling; 54% of respondents said that they had to delay their education or training, while 63% reported that their condition had prevented them from reaching their full educational potential. In the interview data, several participants described how their condition led to reduced school attendance, which in turn had a negative effect on their grades and eventually on opportunities for entering higher education. According to one interviewee,

*“I probably missed at least 50% of my GCSE year; I was off 2-3 days a week. In the end my A-Levels weren’t as good as I wanted. I think if I had gotten what I was predicted, which was straight As, I probably would have tried to apply for Oxford and Cambridge.”*

Whilst much of the immediate impact of chronic conditions on school attendance was linked to physical symptoms, interviewees suggested that some of the effects resulted from poor psychological wellbeing, whether associated with a mental health diagnosis or psychological comorbidities of other chronic conditions. Research conducted by The King’s Fund found that 30% of people with a long-term condition also had a mental health problem and 46% of people with a mental health problem also reported a physical health problem (Naylor et al., 2012). The results suggest that co-morbid mental health problems can lead to poorer clinical outcomes for the physical conditions.

The presence of co-morbid mental health conditions can affect a broad range of outcomes. The mental state of individuals living with a chronic condition can depend on the severity of the condition and is likely to affect the motivational levels of individuals and the effectiveness of disease management in clinical settings, which has implications for school attendance and grades. A study by Krein et al. (2005) also suggests that people who have co-morbid mental health problems tend to have poorer self-care and are prone to adverse health behaviours, which can lead to lower quality of life. One participant said,

*“I really, really struggled during secondary school. It got to the stage where I missed about half of year 10 because I just couldn’t come in. I was physically weak from being sick, [but the condition] also makes you withdraw socially. Because I was depressed as well I could barely get out of bed.”*

The data suggests that one of the factors hindering progress with secondary and further education was the unwillingness of educational institutions to adjust the educational environment to the young person's needs. This indicates that stigmas still exist in secondary and higher education institutions towards these students. Young people with a chronic condition are more likely than their peers without a condition to report experiencing problems at school with members of staff, other students or difficulty maintaining motivation (The ACEVO Commission on Youth Unemployment, 2012). One participant commented:

*"Due to my condition I couldn't always attend [tutorials] but your grades would suffer if you were marked down for missing more than 3 tutorials and I missed 5 of 11. Some of the more understanding [teachers] said to me I could come to them outside of school hours, or I could email them. A few of them were more like, "It's your illness, you should know how to deal with it by now so you need to catch up with the work and get on with it.""*

Whilst catastrophising the condition is not conducive to the individual's ability to cope with it physically and psychologically, the major concern is that a lack of consistent support at the early stages of their illness discourages young people from seeking and accessing appropriate support, contributes to delays in referral times and has a knock-on effect on young people's ability to work in the longer term.

Many young people, whose long-term conditions are not managed well, may already be reviewing their career plans while still attending secondary school. Almost 93% of survey respondents indicated that the condition affected their confidence and self-esteem; and just under three-quarters reviewed their career choices. Most of the interviewees believed that certain jobs were not an option for them because building a career in those sectors would require more energy than they had. One interviewee said:

*"I was considering going into law but it has dawned on me that it is just not going to be a possibility because you have to get funding for it. Even studying will be too much because you have to work part-time whilst studying and get pupillages and work experience. So the amount of energy required to get qualified to the extent that you actually get hired...it's just not going to happen. I need to know that I have at least 2-3 years where I am*

*going to be stable and [even if I became a lawyer] there is too much competition. It's just too much I think."*

Whilst certain occupations (for example, the military and paramedic services) indeed require a certain level of physical and mental fitness to perform those jobs, our findings suggest that some young people with chronic conditions may be dismissing career options that they could perform, if they had the right support. This is confirmed by other studies, which have shown that young people with chronic conditions often downgrade their educational and employment aspirations (Shahnasarian, 2001). Such beliefs may influence self-esteem and undermine the chances of young people in securing competitive and meaningful jobs.

## **2.2. Obtaining employment and employability**

Finding a first job and entering employment has additional challenges for young people with chronic conditions, as they have to adjust their management of the condition in order to meet the demands of particular jobs. A study looking at employment outcomes for people with Juvenile Idiopathic Arthritis, for example, found that their sample had lower than average employment rates, but higher than average GCSE and A level results (Packham and Hall, 2002).

The findings of this study indicate that such challenges may be associated with the fluctuating nature of disease, but also – worryingly too often – with the negative perceptions of disability in society. For example, a common worry among the participants in the study was that they would be screened out by employers during the application process. As the onset of the condition often arrived before individuals could build up a history of career experience, participants in this study were concerned with how their applications – with a history of unfavourable grades or breaks in the study process – would fare in the currently competitive labour market. One individual said,

*"I am concerned that when you have re-sits – whether they are out of special circumstances – they would be on your record/CV, and it might look like you didn't work very hard."*

Equally young people in the study reported concern that their performance in the face-to-face selection stages would be affected by the symptoms of the condition, making them reluctant to attend. One participant explained how their condition has an impact on their ability to go to interviews:

*“Colitis affects your bowels. Mine is quite tricky right now so I have got to watch where I go. If I don’t know where I am going I won’t know where the toilets are. So it’s like do I go or not go?”*

Several participants suggested that the stressful interview situation might in itself contribute to the symptoms. Simultaneously, most individuals preferred not to inform their potential employer about their condition, fearing that disclosure would lead to a negative perception of their application and undermine their chances to get the job, when compared to individuals without apparent health issues (Packham and Hall, 2002).

*“Why I don’t declare the disability – because people will be like, “We don’t want someone who has to take a week off at a time.”*

More than a third of young people in the survey said they were unlikely to talk to their future employers about their condition. One participant described their negative experience of an employer finding out about their condition shortly after being accepted for the job:

*“When I told them about it and all the information – no holds barred, their attitude changed completely and it was more negative than it had been before. It felt that once I told them they started to compile a list of what they could use against me to get rid of me.”*

However, even positive workplace experiences did not appear to dissipate fears of the discrimination that young people could be facing in their future jobs. Notably, the perceptions of young people around employers’ stigma were often based on individuals’ anticipation of negative treatment rather than personal experience of discriminating attitudes. One interviewee said:

*“I don’t know whether it is directly or if it is me anticipating it but I am scared to declare my condition on application forms. Because you’re not necessarily told*

*but you are aware that if someone has exactly the same qualifications as you they're just not ill they will just go to that person."*

These concerns may influence young people's job seeking behaviours and their beliefs around the type of jobs available to people with disabilities. The fact that many interviewees did not report personal experiences of negative treatment suggests that self-stigma plays an important role in individuals' expecting negative experiences as jobseekers. Eventually deteriorating self-efficacy can have a cumulative negative impact on young people's ability to reach their full career potential. For example, young people with a chronic condition may believe that they have to opt for less secure and lower-paid jobs (Long-Term Conditions Alliance Scotland, 2011). One participant said:

*"I worry that people might just think that I am lazy and a bad employee. But I'm not just slacking off. My worry was that as I'm only a uni student they wouldn't take me [for a permanent job] if I told them about the condition."*

Whilst lack of initial experience may be compensated by gaining some sort of work experience prior to entering paid jobs, several respondents believed that having a chronic condition would undermine such a transition. One participant described these concerns:

*"I am on internship at the moment so I am unpaid, however, when I go full-time and permanent, I am unsure if I will be able to get time off so easily to attend appointments. I will have to bring it up before I sign the contract."*

Research from the Department for Work and Pensions and the Equality and Human Rights Commission suggests that employers favour the employment of non-disabled people compared to disabled people (Needels and Schmitz, 2006), believing that disabled people will be less productive and that they will impose additional costs on the employer (Hogarth et al., 2009). This could account for the concentration of disabled people and those with work-limiting conditions in low-paid and low-skilled work, as employers' attitudes are a major barrier for these groups seeking meaningful employment.

Many of those in the study had chosen not to declare their condition until they had a chance to prove themselves to their employer, or until their illness became apparent to managers or colleagues. One person commented:

*“I said it to them two weeks after starting, so they could see what my quality of work is like, what my value is. When you speak to someone who wants to work with you everything gets a lot easier.”*

Unwillingness to disclose a condition may cause anxiety over being found out, which in turn can lead to worse psychological outcomes and an increase in work disability (Stuart, 2004). The fear is that non-disclosure of a chronic condition may delay the referral process and access to interventions that would be able to support individuals in employment.

### **2.3. Summary**

This section highlights how long-term conditions begin to have an impact on life decisions and the opportunities of young people, even before the start of their careers, by affecting their school attendance and limiting their job choices. These issues were associated with the fluctuating symptoms of chronic conditions, which when combined with unaccommodating educational and work environments, affected the individuals' ability to train for jobs, go through the application process and maintain employment.

Self-stigma, associated with an individual's beliefs about their ability to perform certain jobs or to compete with healthy individuals in the labour market, may have a substantial and unnecessary added effect on employment opportunities of young people with chronic conditions. Worryingly, such self-stigma often arises from the expectation of, as opposed to actual negative experiences in the workplace, and may result in behaviours that undermine young people's chances to secure employment. Tackling stigma and self-stigma will be crucial for improving the employment outcomes of young people with chronic conditions.

### 3. The implications of living with a chronic condition on young people's productivity and work

This section looks at how the participants' conditions currently affected their working lives. Many participants reported problems with maintaining employment, receiving adequate support, and negative employer attitudes.

Participants reported that they struggled to maintain employment as a result of the lack of control over their condition. In the survey 29% of individuals had difficulty remaining employed, and 57% said their condition had prevented them from pursuing their preferred career. Fluctuations in the course of the condition were often cited as the reason for not being able to manage at work:

*"I worked in retail a few months ago but at the time I was going through a rough patch with my diabetes, it wasn't very well controlled so I found it quite difficult to manage at work."*

It appears that many were struggling to receive appropriate workplace adjustments, as a significant proportion of the respondents highlighted the impact of the condition on their job opportunities and careers:

- 68% believed their chronic condition affected their job satisfaction.
- 27% thought their chronic condition inhibited access to training and development.
- 61% said their condition stopped them reaching their full potential in the workplace.
- 57% had their career progression impacted by their chronic condition.
- 50% of the respondents said their condition prevented them from looking for a different job.

Whilst the participants could do little to stop the negative effect of the condition's symptoms, supportive work environments had the potential to reduce the extent to which the condition interfered with work responsibilities. One participant said:



*"I cannot be in a structured environment unless they have got that understanding. Because my condition changes day to day, one day I love the organisation and I thrive on it, but the next day I can't keep it with myself."*

As a result of feeling particularly vulnerable to negative employer attitudes and job loss, many participants reported going into work despite experiencing symptoms of their conditions. Presenteeism (going to work when sick) could suggest feelings of anxiety about losing one's job (Centre for Mental Health, 2011). Our survey reported that 97% of respondents continued to go into work even when they were experiencing negative side-effects of their condition, often because they were not fully aware of their rights at work. The interviews further illustrated this finding. For example, one participant said:

*"If I get hit with pain I can be out for 4 days really intense pain... you cannot just ring up work and say "I am in pain I cannot come in". I would get fired."*

The survey respondents reported to have lost an average of 6.22 hours of work in the week preceding data collection, which equates to almost one full working day per week. One participant explained the consequences of having a flare up in their condition:

*"It slows me down a bit so I am not as interested in the customers. I won't have the five, ten minute conversations that I usually have. I just won't be able to."*

It appeared that even where employers attempted to accommodate the effects of the condition in the workplace, the competitiveness of the labour market worked against young people with long-term conditions. Overall, 72% felt their condition made them more vulnerable to job loss during the recession than people without a long term condition. One interviewee said:

*"They did try to accommodate me but they had very good graduates working for them, they pushed you quite hard...I had just been going on for too long."*

Worryingly our findings showed that the young people in our study had seriously compromised their career choices and felt that they were not reaching their full potential in the workplace. Many found remaining in employment difficult and felt that they were more vulnerable to job loss than their peers without a chronic

condition. Our respondents cited negative employer attitudes (whether they be actual or perceived) as a major factor contributing to these limited employment outcomes, highlighting the importance of ensuring supportive working environments.

## 4. Barriers and enablers to employment

Whilst all cases of illness may differ in their course, our research identified common barriers and enablers specific to the employment of young people with chronic conditions. It was clear from the study that most young people diagnosed with a chronic condition wanted to work, and appreciated work environments that gave them an opportunity to engage in meaningful employment:

*“Work...gave me the sense of doing something worthwhile. It gave me sense of routine as I had to get up in the morning.”*

The following section discusses the key barriers to employment identified in our research and suggests ways of addressing them.

### 4.1. Control over the course of disease

Unsurprisingly, the extent to which young people could prevent and manage fluctuations in their physical and psychological wellbeing was one of the most common factors cited as hindering employment outcomes. The fluctuating nature of most long-term conditions means that people can have periods of feeling normal, but then have “flare-ups”, which can cause acute episodes of illness. Fluctuations may affect productivity at work, and have an impact on an individual’s ability to stay in a job for long periods of time. As a result, many young people with fluctuating conditions may only be able to take up employment if it is sufficiently flexible (The ACEVO Commission on Youth Unemployment, 2012):

*“If you get into a bad relapse it can take quite a long time to get better. So it just didn’t make sense to stay [in the job].”*

When only recently diagnosed, young people with chronic conditions are still trying to find the right treatment plans to gain better control over their conditions. For example, one interview participant had only been on a new treatment plan for two months, and could not predict if they would be well enough to pursue their chosen

career. Young people frequently relied on monitoring the changes in their condition and learning from their own experience in order to cope: at least 32% were self-managing their condition in addition to receiving treatment from their GP.

*“I still don’t understand it very well as some days I will be great and some days I will feel rubbish and I don’t want to talk to anyone and then the next day I will be fine. I have made myself a booklet to keep track of what I have been doing, eating, drinking etc. and try to find out triggers.”*

The importance of receiving the correct clinical support and interventions was made clear, and participants who had received appropriate treatments reported being able to carry out day-to-day activities with fewer or no problems:

*“...on daily basis, I have got it quite well under control. I have an insulin pump, which makes it a lot easier... When I was first diagnosed, I was on insulin pens and I was struggling to keep it under control then when I moved onto the pump... things started to improve quite a lot.”*

According to the survey responses, it took an average of 3.42 years to diagnose the condition from the onset of symptoms, although the time of diagnosis differed by condition, for example, results from the survey found it took an average of 2.13 years to diagnose chronic musculoskeletal conditions, and an average of 5.39 years to diagnose endometriosis. Delays in diagnosis had for some caused adverse clinical outcomes, resulting in a significant impact on the young people’s ability to engage in education and employment. One participant said,

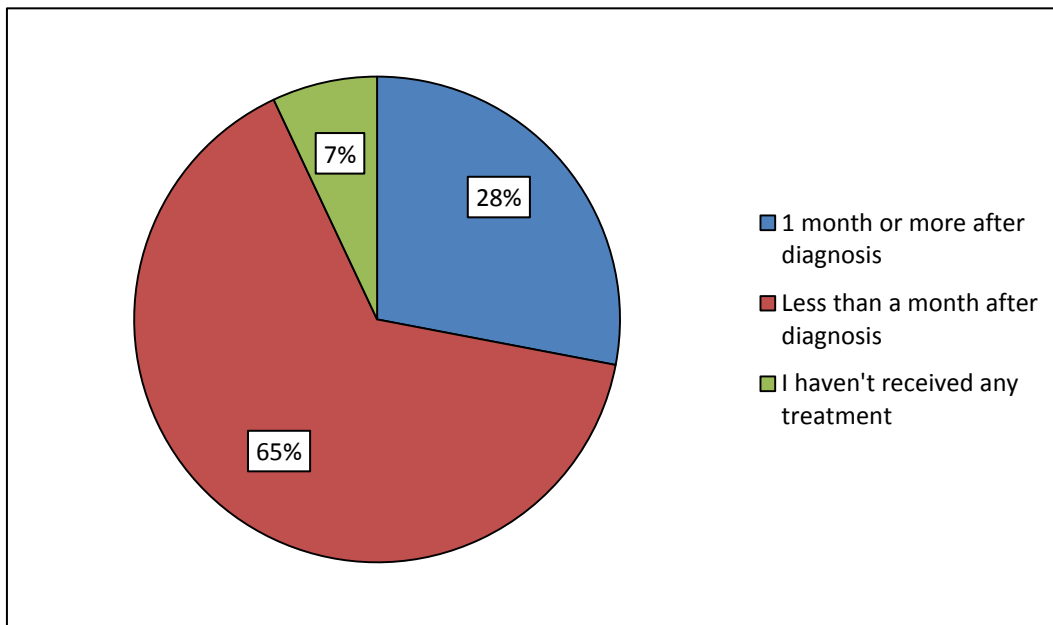
*“I was diagnosed with my illness when I was 20 but I had symptoms from the age of 14. I was in and out of hospital every six months through out my GCSEs and A-Levels, them not finding anything and then sending me home again, filling me up with painkillers to get through every day of my life.”*

Most participants had their diagnosis for less than five years at the time of the survey, but had been experiencing symptoms for an average of 7.22 years. The survey findings suggest that if the diagnosis was made earlier, the impact that the condition has on the individuals’ experiences of, and attitudes to, work could be managed more appropriately. One interviewee appeared to have been relieved to finally receive a diagnosis, which meant their condition was better managed:

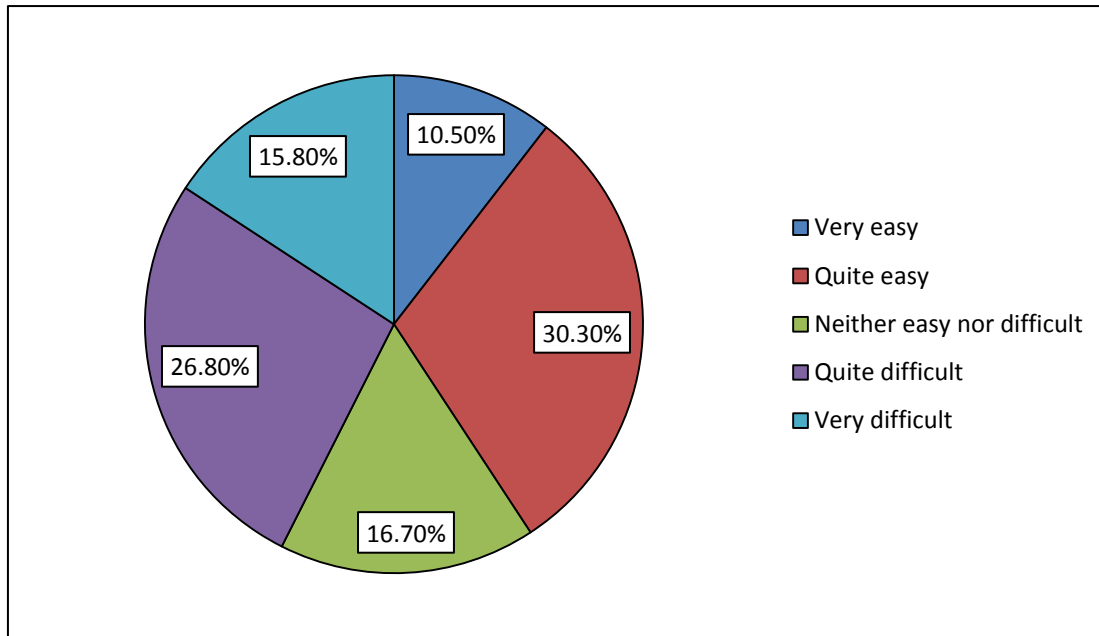
*“Several doctors told me I was imagining it, so when I finally got a diagnosis, I was overjoyed.”*

Even when a diagnosis was received some participants reported delays until they received treatment. Although 65% had received treatment within a month of diagnosis, over a quarter (28%) had not received treatment until one month or more after diagnosis. The remaining 7% of respondents had not received any intervention (see Figures 3.1 and 3.2). Of those receiving interventions, 95% were on drug therapy, 22% were accessing psychological therapy, and only 6% had access to occupational therapy. A further concern is that some young individuals felt the treatment was not explained adequately, and was given without enough attention to its potential impact on their ability to remain in education or to work. Several participants suggested they chose not to receive treatment because they were worried that side effects would have a negative impact on their performance.

**Figure 3.1. Timing of intervention**



**Figure 3.2. Ease of access to treatment**



Alongside the potential exacerbation of an individual's condition following delayed diagnosis and treatment, inadequate healthcare experiences may undermine young people's trust in the competency of healthcare professionals, and discourage help-seeking behaviour when advice about condition management is needed (Michaud et al., 2007).

#### **4.2. Work-related guidance and advice**

Evidence from chapter two suggests that with no solid history of work experience many young people were unsure of how managing their condition – both the symptoms and the perceptions of others – would be different in employment settings. Two-thirds would have liked to have received work-related guidance on managing the condition. One interviewee explained:

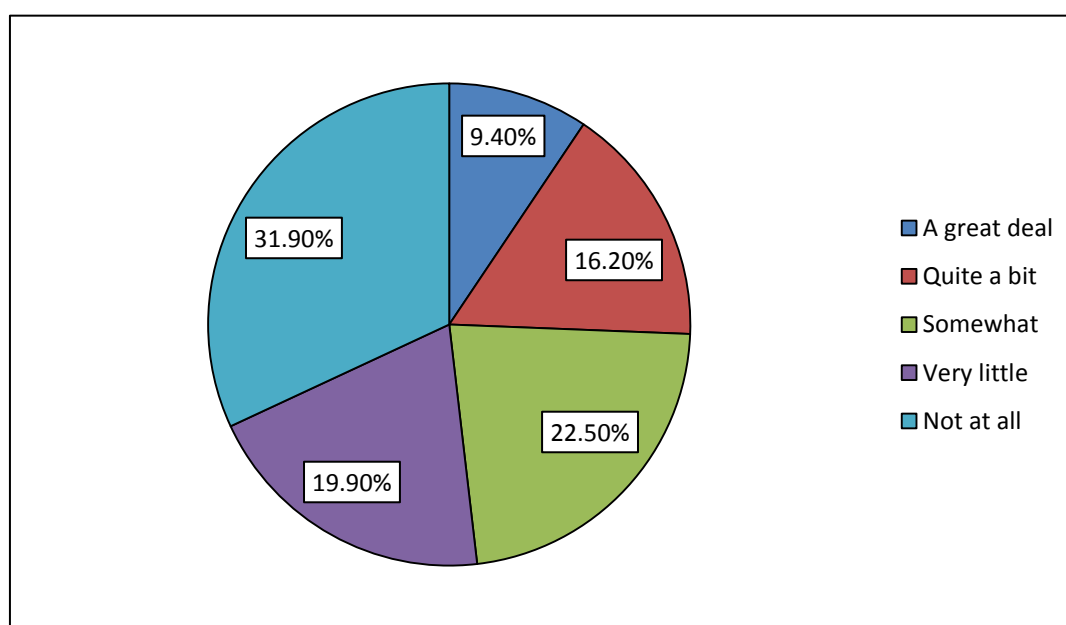
*"I haven't really read anything on managing depression at work, other than how aware employers are and what the law is i.e. discrimination. I haven't talked about it with my GP. I'm not sure if you can take days off sick for it, if it's a recognised illness. I guess I will have to ask my GP, who may not know and then I'll probably end up Googling it."*

More than half of all respondents (55%) had not had a conversation with a GP or another healthcare professional about managing their condition in the workplace.

*“We just discuss diabetes, not anything around the diabetes.”*

The results highlight that work was often not considered in healthcare settings, despite employment being one of the outcomes in the NHS Outcomes Framework. Figure 3.3 shows that nearly a third of the survey respondents did not think their GP or healthcare professional considered work as an outcome of clinical treatment at all. Furthermore, 65% of respondents said that they had not had a return to work conversation with their GP or another healthcare professional.

**Figure 3.3. Extent to which participant perceived their GP or healthcare professional considers work as an outcome of clinical treatment**



The respondents also highlighted the importance of receiving careers advice and support prior to reaching adulthood. A report from the Education Select Committee (House of Commons Education Committee, 2013) and our own research (Balaram and Crowley, 2012) suggests that access to careers advice is problematic for all young people, however, adequate careers advice is of heightened importance for those with a long term condition. One interviewee told us:

*“Part way through my A-levels I said, “I don’t think I’m going to get into uni, I’m not confident of my ability now, I’m in and out and I don’t know what is going on.” If they hadn’t sat down with me and been understanding I would have kept floundering.”*

Only 29% of the survey respondents had access to a support service that provided information about employment. From the interview data it appeared that participants had never heard of, nor accessed any of the Government programmes available to support youth employment, and were not provided with this information through their disability advisors. One interviewee described how they experienced unsatisfactory and disjointed encounters with multiple organisations:

*“Jobcentre Plus tried to push me back into work when I wasn’t ready. But the recruitment agency discharged me because they said I wasn’t well enough to work. They said, “There is no point in you coming back and wasting our time because you’re not well enough to work.””*

As a consequence of being unable to access guidance and support from more ‘official’ avenues, young people with chronic conditions heavily relied on their peers to access advice and help. Some participants found patient groups were a way for them to access support and to talk to others who were in the same situation:

*“I think the idea of me going into it was to see what the other people are about and see what their situations are and see how they manage it and just get to know some people who have the same diagnosis as me, so if I am having a really bad day and I don’t want to talk to anybody who doesn’t know about it, I can speak to one of them from the experience side.”*

If the patient group had a social media presence, the participants reported this as a very useful resource for gaining knowledge about how to manage conditions on a day-to-day basis. Studies that have investigated the benefits of using online support groups for individuals’ suffering from cancer and musculoskeletal disorders have found that patients who use these groups are considered to be more successful in managing their condition, collaborating with their health providers, maintaining their health functioning and accessing appropriate and high quality care (van Uden-Kraan et al., 2009). One interviewee said:



*“I quite frequently post things on the Diabetes UK’s Facebook page, as not only do Diabetes UK actually respond but so do other people who have diabetes, who have been through a similar situation and suggest tips for managing and coping. With GP and specialist nurses it is usually quite a medical point of view so they will say, “Don’t do this as it can affect you in this way.” But if other people with diabetes have done it and they were ok, then I don’t see why it should affect me and restrict me from doing anything.”*

The findings indicate that most of the participants agreed that speaking with someone with direct experience of living with the disease was most helpful in understanding their own condition. This peer-type support often came in the form of patient support groups. However, they also saw value in professional advice, and suggested that medical professionals and employment specialists form part of patient communities to moderate the advice given by patients themselves. One participant explained how the lived experience combined with the professional knowledge of his doctor helped manage the condition:

*“I found out the consultant I see at my local hospital has been diabetic since he was a small child so he has a lot more experience than me. He is quite active into cycling and mountaineering, so I have been able to talk with him about the strategies he has used and put some of his experience into practice. I can’t say that all consultants would do that, I think I have just been quite lucky with who I have been referred to.”*

### **4.3. Workplace support and culture**

A major factor contributing to the participants’ success of managing their work outcomes and careers was the extent to which their employers and colleagues were supportive in accommodating the effect of the disease on workplace attendance and productivity. There was a great deal of variation amongst the participants’ experiences of workplace support. The majority of employed respondents had told their line manager (87%) and their co-workers (81%) about their condition, and almost half of them also felt comfortable discussing their condition at work. The main reasons for non-disclosure (13% of respondents had not disclosed their

condition at work) were fear of losing their job and disbelief that managers or co-workers could help manage the condition better.

It is important to create a supportive work environment for employees with chronic conditions, for example, by introducing work adjustment policies, making provisions for practical and social support, and encouraging disclosure. Research has shown that this might help individuals to effectively manage their illness at work, and also minimise the extent to which their condition may affect work itself. For example, a study into job retention and work characteristics amongst people suffering from depression and anxiety, found that high job support, high job control and reduced working hours may be especially helpful to prevent poor work functioning amongst people with a mental health condition (Plaisier et al., 2012). One interviewee described the changes she observed following a discussion regarding her condition with her employer and colleagues:

*“A lot of them had no experience of diabetes, so I let them know what to look out for if I am going low, what to do, what happens. They have put hypo kits in place in each area of the building that I work in, so there is always a cupboard with a can of coke, a packet of biscuits, something to put my sugars up if I do drop low.”*

Just over 76% of the survey respondents said their manager was supportive of their condition when they disclosed it, and in 88% of these cases respondents received some form of adjustment to their work which improved the management of their condition. For 23% of respondents this meant an adaptation to their working patterns, and for 24% it meant a change to their working hours.

However, slightly less than half (49%) of respondents reported that they had not discussed or been offered any workplace adjustments by their employer. Young people are not disproportionately represented in occupations with inflexible working conditions that are unable to accommodate requests for adjustments (Office for National Statistics, 2012). The instances of lack of support identified in the study can moreover be linked to the employers' apparent unwillingness to make even the simplest adjustments to help individuals manage their condition:

*“They were absolutely flabbergasted that I would go home [during lunchtime] each time, and eventually they terminated my employment using that as one of the reasons.”*

Many employers lack understanding of the effects of specific conditions on the employee. This can contribute to workplace stigmatisation around the condition and the individual living with it, and complicate disclosure of symptoms and their management. For example, one interviewee described how the effects that the fluctuations in their chronic condition had on their performance were poorly understood by colleagues:

*“When I was phoning in sick I was getting lots of snarky comments like “Are you sure you’re not just wanting a day off?” And “You were fine yesterday.” Or “I saw you this morning and you looked fine.” They didn’t really believe that I was ill.”*

Poor awareness about the condition among line managers is particularly concerning, as it can hinder access to workplace adjustments:

*“It should have been all over my notes because they sent me to the occupational health and they agreed that I had it and they had to make changes for me so they put the headset in but didn’t change the chairs, which made me even worse because they were half way down my back and didn’t support my shoulders and by that point I hadn’t even had an operation to solve the main problem. So after a while, I remember them putting this on the occupational health form, my line manager wrote that he thought I was milking my condition to get away with doing things.”*

The results of our survey highlight a need for employers to improve the way they treat young people with chronic conditions at all stages of employment, from providing assistance to job candidates to making workplace adjustments to enable people to continue in their jobs. The Responsibility Deal initiated by the Department of Health provides guidance for employers on supporting young people’s health in the workplace (Department for Health, 2013). An interviewee described their experience of an example of good employer practice:

*“I sat down and chatted with my supervisor about my depression. They said I should have told them, as they are quite flexible with mornings. They said, “We would rather you felt you could come in late and not be judged, than worry and not come in at all.”*

Reports have suggested that while work is generally good for our health (Waddell and Burton, 2006), jobs of poor *psychosocial* quality (e.g. low levels of control, high demands and complexity, job insecurity, and unfair pay) may have a detrimental impact on overall physical and mental health and wellbeing (Butterworth et al., 2011). It is only *good* work – or work that offers meaning and purpose– that is likely to improve an individuals’ health status. The data from this study suggests that job quality was important to the respondents, even where practical workplace adjustments were not required:

*“The social side is important to me, and I have been lucky to work for [a company] that is understanding, and no one is the boss. Divvyng up responsibilities is based on what you know.”*

#### **4.4. Confidence and self-efficacy**

Another overarching factor undermining employment opportunities of young individuals with chronic conditions is the affected sense of ‘normality’ or ‘being like everyone else’. Evidence suggests that young adults may experience additional limitations such as physical and psychological symptoms as a result of their chronic condition, which negatively affects their self-confidence and self-efficacy (Woodgate, 1998). One participant said:

*“I want to wake up and for it all to be a dream so I can go back to work and feel normal again.”*

As highlighted above, some of the effects of chronic conditions on young people’s long-term career plans occurred as a result of loss of confidence. This was particularly salient among survey respondents who had never been in paid employment. Young people with chronic conditions worry about being able to manage their symptoms in the workplace, and the discrimination they may face. Research has also shown that young people fear their condition will affect their

ability to be productive at work and that their need for workplace adjustments or time off for hospital appointments will make them more vulnerable in times of job insecurity (NASS, 2010).

As a consequence of these concerns these individuals might give up on looking for jobs altogether – a phenomenon nicknamed the ‘why try’ effect. For example, research (Corrigan, Larson and Rusch, 2009) suggests that individuals with a mental illness may internalise the societal perception that life opportunities are damaged by chronic illness, and apply those beliefs to themselves, resulting in individuals reviewing their behaviours and the extent to which they feel they can pursue their life goals. In relation to the labour market, one participant interviewed believed that:

*“With my condition, and the requirements I would need, [and the fact that] there are hardly any jobs up here at the moment, I just won’t get anywhere even though I am very qualified. They don’t even bother to reply.”*

Self-stigma is known to impact help-seeking behaviours among individuals with a chronic illness, as these people may perceive support as ‘pity’ rather than genuine concern (Munir, Leka and Griffiths, 2005). One participant said:

*“I don’t know why I didn’t go to my GP. I only went when it got to crisis stage. I feel bad for taking extra”*

This may also have an impact on the extent to which these individuals accept adjustments in educational settings and the workplace:

*“I don’t think I wanted to admit [the impact] to myself...because I really wanted to work. I was kind of brushing it under the rug and hoping it would be ok.”*

An important dimension linked to perceptions of disability is the individuals’ willingness to register themselves as disabled, as they do not want to have such a label attached to them:

*“I don’t like identifying myself as ill. I know I am ill but when I am well I don’t want to talk about it; and when I’m ill I’m too tired to go to a support group.”*

At the same time, the primary Government employment support programme exclusively aimed at people with disabilities, Work Choice, is only accessible to people recognised as disabled under the Equality Act 2010. One interviewee reflected on receiving a disability status:

*“It wasn’t until the second year that the doctor suggested I should register with the disability service at uni, because I didn’t realise that it is a disability. I always thought a disability was something really obvious like people who couldn’t function physically or who had learning difficulties.”*

The nature of many of our participants’ conditions meant that, as well as being unwilling to register themselves as disabled, many young people felt that others who did not have any experience of a long term condition, were not able to understand what it is like to live with a long-term condition and what support they needed. For example, one interviewee reported feeling out of touch with their friends:

*“I don’t talk about it that much with my friends, because, unless they have been ill themselves, a lot of them find it quite hard to relate to and they don’t really understand. So when I am ill I tend to drop off the radar.”*

## 4.5. Summary

The results from this study have indicated there are multiple structural and attitudinal barriers to employment experienced by young people living with chronic conditions.

In this section we identified four groups of barriers that prevented young individuals with chronic conditions from entering and staying in the labour market. These were: control over the course of the disease, work-related guidance and advice, workplace support and culture, and confidence and self-efficacy. Some of these barriers result from the lack of support that individuals can access in clinical and employment settings, diagnosis and treatment often came too late and there was little scope for workplace adjustment in a significant proportion of workplaces.

Other barriers to meaningful employment are attitudinal and associated with a lack of awareness of the ways to manage chronic conditions among employers and the individuals with chronic conditions themselves. Some healthcare professionals, line managers and co-workers may overlook the fact that ability to work is an important

part of a young person's life ambition and that simple workplace adjustments and individualised treatment plans can make that ambition realistic. Unfortunately, young people with insufficient support may internalise negative beliefs and refrain from seeking help to manage their condition.

If more young individuals with long-term conditions were given equal opportunities at the start of their career, some of the longer term problems that have been reported throughout this research could be prevented.

## 5. Conclusions and recommendations

Whilst chronic conditions may have a direct impact on the physical and psychosocial development of young people, our research finds that some of the key barriers to their work outcomes arise from the fact that chronic conditions are often viewed to be disabling, rather than manageable in a workplace context. For example, work is not always considered to be an outcome of clinical treatment, with few doctors giving young people advice and guidance on managing a chronic condition in the workplace. Despite employment being considered an outcome in the National Outcomes Framework it is not in the Clinical Commissioning Outcome Indicator Set, which sets the agenda for all commissioned services.

Stigma and discrimination against individuals with chronic conditions is still prevalent among employers and other employees, contributing to job inequality, delays in referrals and interventions, and instability of employment for a high proportion of young people. An equally important concern is that young people living with chronic conditions internalise negative societal perceptions of their disability and gradually lose confidence in their ability to enter and maintain meaningful employment.

By appreciating the intersectional challenges that young people with chronic conditions face, and delivering services that respond to these challenges, more members of this group could enter and remain in employment, reducing the number of people claiming out of work benefits, and allowing employers to benefit from the commitment and effort of talented young people.

Various groups of stakeholders play a part in supporting the work outcomes of young people with chronic conditions. Our recommendations are addressed to these groups individually. We have identified several key methods through which young people with chronic conditions can be supported:

### **Support needs to be provided from the earliest opportunity**

- **The Department for Education should provide improved education to young people about chronic conditions.** Improved education will begin to



reduce the stigma that exists towards chronic conditions. Secondary school programmes would benefit from a module on major groups of chronic diseases, including musculoskeletal conditions, mental health, diabetes, IBD, cancer and others. This module could be included in the 'Personal Wellbeing' section of the current Personal, social, health and economic education (PSHEE) curriculum for Key Stages 3 and 4, and/or could be included in the 'Organisms and health' section of the Key Stage 4 Science curriculum.

- **Tailor careers advice for young people with chronic conditions.** Recent changes to the way in which careers advice and guidance is organised means that schools, rather than local authorities, have responsibility for careers advice and guidance but with no increases in budget. Previous research published by The Work Foundation indicates that this may result in a decrease in the quality of careers advice provided (Balaram and Crowley, 2012). Young people with chronic conditions are likely to be particularly affected by this. Schools should be encouraged and supported (informationally and financially) to work in partnership with local employers to facilitate young people's access to job training and apprenticeships. The government should ensure that schools have the necessary funds and capacity to provide specialised careers advice for students with chronic conditions, so they can successfully transition from school to work.
- The results from this research show that young people rely on online resources for information about their chronic conditions. **Information about chronic conditions, careers guidance and out-of-work support should be made available via a one-stop online portal in an accessible format, including access through social media platforms.**<sup>2</sup> Many young people with chronic conditions self-manage their health with the help of online tools. Evidence based online resources should also be made available to a larger proportion of young people, for example, through GPs, social services and in collaboration with youth groups.

---

<sup>2</sup> See, for example, the Health and Safety Executive <http://www.hse.gov.uk/youngpeople/resources.htm>

## Unemployment support for young people with chronic conditions

- The government needs to seriously **consider how the various programmes that offer support for young people with chronic conditions work alongside each other**. Young people with chronic conditions can often be overlooked in the design of both unemployment and youth support programmes. From the results of this research, we would argue that the government needs to take a holistic view of education, unemployment support and in-work support in order to provide improved employment opportunities for young people with chronic conditions.
- The job outcome rate for Employment Support Allowance (ESA) claimants and young people with disabilities in the Work Programme remains low. Since the Work Programme was launched throughout Great Britain in June 2011, 17.9% of non-disabled people aged 18-24 who were referred to the programme have moved into sustained employment lasting either 3 or 6 months. In comparison, only 9.6% of people aged 18-24 who self-identify as disabled have moved into sustained employment.<sup>3</sup> Properly **investigating how, and to what extent, people with disabilities are being served by the Work Programme** might be a useful first step in beginning to understand how employment programmes can best serve people with chronic conditions.

## In-work support recommendations

- The government needs to raise **awareness of and enforce existing disability** employment legislation.
- **Improve how in-work support services are advertised**. Schemes like Access to Work can be used to fund workplace adjustments, for people with both physical and mental health conditions, that some employers – particularly small businesses – cannot afford. We cannot understate how

---

<sup>3</sup> Calculated using the DWP Tabulation Tool ([http://tabulation-tool.dwp.gov.uk/WorkProg/wp\\_cuml\\_jo/tabtool\\_wp\\_cuml\\_jo.html](http://tabulation-tool.dwp.gov.uk/WorkProg/wp_cuml_jo/tabtool_wp_cuml_jo.html))

much potential this service has, and we would argue that more should be done to promote the service among employers and make young people with chronic conditions aware of it.

- **The new Health and Work Service should be prepared to help young people with chronic conditions.** The Health and Work Service (HWS), expected to be launched in 2014, will help people who have been absent from work for four weeks as the result of sickness create a 'back to work' plan. HWS should ensure that it has access to specialised expertise for young people. This is especially important given the unique issues we have highlighted in this report that young people with chronic conditions may experience- such as the relative newness of their condition and their inexperience in managing its effects.

## **Recommendations for Healthcare Services**

**Healthcare professionals** should consider how a chronic condition may have an impact on a young person's ability to study and work.

- **Healthcare professionals at all levels of care should consider current and future work outcomes as part of young individual's clinical treatment plan.** Both child and adult care services should work to minimise disruptions to study and work caused by fluctuations in the health condition. Whilst the NHS Outcomes Framework measures employment as an outcome, it is not in the Clinical Commissioning Group Outcome Indicator Set (CCG OIS), or in the Quality and Outcomes Framework. We recommend that the government reconsider this, and **look into ways health care professionals can be incentivised to consider their role in the employment outcomes of young people with long-term conditions.**
- **NICE should consider wider societal costs and benefits, such as employment and lifelong opportunities** when evaluating the cost-effectiveness of health technologies.

## Employer recommendations

**Employers** need to recognise that many young people with a chronic condition have a great deal to contribute to a workplace, but that they may also often feel anxious about whether their condition can be accommodated at work. Employers should also make themselves aware of practical adjustments that can be made to the workplace to allow for greater employment possibilities for young people with chronic conditions.

- **Employers should play a greater role in shaping the skills of young people graduating from schools and universities**, through organising career fairs, offering traineeships, apprenticeships, internships and mentoring schemes. This will help employees understand the needs of young people with chronic conditions in the workplace, and what adjustments to the work environment may be necessary. It may also be beneficial for the young person to experience what it is like to work in such an environment with their condition, and to begin to learn what they can do to best manage it.
- **Crucially, employers must address the stigma and discrimination both at the recruitment stage and in relation to employees disclosing their health conditions.** In this study young people with chronic conditions often reported that they expected or perceived others would stigmatise their condition. With increased awareness of such conditions, and a 'safe culture' where people feel they are able to disclose their condition, individuals with chronic conditions can begin to have the confidence to participate in the work environment. It is important that HR and line managers ensure that the Disability Equality Act is understood, to reduce the effects and outcomes of discrimination.
- **Employers need to be supportive in identifying and establishing appropriate workplace adjustments.** By implementing flexible working hours and adjustments to the workplace environment, young people with chronic conditions will have greater opportunities to remain in employment. For example, providing an employee with the option to work from home, or

simple adjustments in the workplace for administering medication if needed. Employers should draw on existing support schemes such as Access to Work, highlighting reasonable adjustments that are possible for young individuals with chronic conditions.

- **Training should be provided to line managers, senior managers and employees in organisations to raise awareness of the impact that chronic conditions can have on an individual, and how they can be managed** in the workplace. Providing case studies of lived experiences of living with a chronic condition will help tackle the stigma around individuals with chronic conditions, and hopefully the condition itself. This will improve team of awareness of the condition and support job quality for these workers.

### **Role of the Third Sector**

**Third sector organisations** should create communities for young people to share their experiences and seek advice in a safe environment.

- **Patient groups should include modules on working with chronic conditions online as well as in printed resources.** This would encourage self-management of chronic conditions and offer practical advice to young people seeking work or struggling to hold down a job, in a forum that young people regularly use.
- **Patient groups should consider holding career workshops** where young people with chronic conditions can discuss their aspirations and receive advice and support on how they can achieve their goals. These groups could be an important additional source of peer support and advice, and provide a forum where young people can discuss the problems of working with their chronic conditions.
- Many young people are still unaware of their rights with regard to fair employment. Considering that patient groups are often their main source of

advice, they should **offer resources on employment rights** in an accessible manner and provide forums for consultation with employment law specialists.

Many young people with chronic conditions want to work, and receive social and psychological, as well as remunerative, benefits from doing so. This study found that the physical and psychological symptoms of chronic conditions, combined with stigmatic societal attitudes and gaps in the provision of support services, meant that young people with chronic conditions experienced significant barriers to entering the workforce. These barriers presented themselves in educational, healthcare, and workplace settings. It is hoped that the preceding recommendations highlight some of the ways in which these barriers can begin to be broken down, and young people with chronic conditions can be empowered to engage in fulfilling employment where their condition is understood and accommodated.

## References

Balaram, B. and Crowley L. (2012) *Raising aspirations and smoothing transitions*. London: The Work Foundation

Ben-Shlomo, Y. and Kuh, D. (2002). A life course approach to chronic disease epidemiology: Conceptual models, empirical challenges and interdisciplinary perspectives. *International Journal of Epidemiology*, 31(2), 285-293.

Bevan, S., Zheltoukhova, K., McGee, R. and Blazey, L. (2011). *Ready to Work? Meeting the employment and career aspirations of people with multiple sclerosis*. London: The Work Foundation.

Butterworth, P., Leach, L.S., Stradzins, L., Olesen, S.C., Rodgers, B., Broom, D.H. (2011). The psychosocial quality of work determines whether employment has benefits for mental health: results from a longitudinal national household panel survey. *Occupational & Environmental Medicine*, 68(11), 806-812.

Centre for Mental Health. (2011). *Managing presenteeism: A discussion paper*. London: The Centre for Mental Health. Retrieved on 28 November 2012 from [http://www.centreformentalhealth.org.uk/pdfs/managing\\_presenteeism.pdf](http://www.centreformentalhealth.org.uk/pdfs/managing_presenteeism.pdf)

Corrigan, P.W., Larson, J.E., and Rusch, N. (2009). Self-stigma and the “why try” effect: impact on life goals and evidence-based practices. *World Psychiatry*, 8(2), 75-81.

Department for Education (2013), *NEET Statistics - Quarterly Brief – April to June 2013*, London: Department for Education.

Department for Education. (2012). *Reducing absence – ensuring schools intervene earlier. Briefing note*. London: Department for Education. Retrieved on 28 November 2012 from <http://www.education.gov.uk/inthenews/inthenews/a00192057/government-changes-definition-of-persistent-absence-to-deal-with-reality-of-pupil-absenteeism-in-schools>

Department for Health (2013), *Young People in the Workplace pledge: a call for organisations*, Retrieved on 15 May 2013 from <http://www.dh.gov.uk/health/2013/02/young-people-pledge/>

Gay, M. et al. (2011). *Crohn's, Colitis and Employment – from Career Aspirations to Reality*. Hertfordshire: Crohn's and Colitis UK. Retrieved on 28 November 2012 from [http://www.crohnsandcolitis.org.uk/downloads/research/Crohns\\_Colitis\\_Employment.pdf](http://www.crohnsandcolitis.org.uk/downloads/research/Crohns_Colitis_Employment.pdf)

George, L.K. (2007). Life course perspectives on social factors and mental illness. In: Avison, W.R., McLeod, J.D. and Pescosolido, B.A. (Eds.) *Mental Health: Social mirror*. New York: Springer.

Gregg and Tominey (2005), 'The Wage Scar from Youth Unemployment', *Labour Economics*, 12(4): 487-509.

Hogarth, T., Owen, D., Gambin, L., Hasluck, C., Lyonette, C., Casey, B. (2009). *The equality impacts of the current recession*. Manchester: Equality and Human Rights Commission. Retrieved on 4 December 2012 from [http://www.equalityhumanrights.com/uploaded\\_files/research/47\\_the\\_equality\\_impacts\\_of\\_the\\_current\\_recession.pdf](http://www.equalityhumanrights.com/uploaded_files/research/47_the_equality_impacts_of_the_current_recession.pdf)

House of Commons Education Committee. (2013). *Careers guidance for young people: The impact of the new duty on schools*. London: The Stationery Office Limited. Retrieved on 19 March 2013 from <http://www.parliament.uk/business/committees/committees-a-z/commons-select/education-committee/news/substantive-careers-guidance/>

Krein, S.L., Heisler, M., Piette, J.D., Makki, F., Kerr, E.A. (2005). The effect of chronic pain on diabetes patients' self-management. *Diabetes Care*, 28(1), 65-70.

Lee, N., Sissons, P., Balaram, B., Jones, K. and Cominetti, N. (2012). *Short-term crisis - long-term problem? Addressing the youth employment challenge*. London: The Work Foundation.

Lee, Sissons, Balaram, Jones and Cominetti (2012), 'Short term crisis – long-term problem? Addressing the youth unemployment challenge', The Work Foundation.

Long-Term Conditions Alliance Scotland (LTCAS). (2011). *Employability briefing*. Glasgow: The Alliance.

Maslow, G.R., Haydon, A., McRee, A.L., Ford, C.A., Halpern, C.T. (2011). Growing Up With a Chronic Illness: Social Success, Educational/Vocational Distress. *Journal of Adolescent Health*, 49(2), 206-212.

Michaud, P.A., Suris, J.C. and Viner, R. (2007). *The adolescent with a chronic condition: epidemiology, developmental issues and health care provision*. WHO Discussion Papers on Adolescence. Geneva: World Health Organization

Munir, F., Leka, S. and Griffiths, A. (2005). Dealing with self-management of chronic illness at work: predictors for disclosure. *Social Science and Medicine*, 60(6), 1397-1407.

NASS (2010). *National Ankylosing Spondylitis Society Survey 2009: Working with ankylosing spondylitis*. Richmond: NASS

Naylor, C., Galea, A., Parsonage, M., McDaid, D., Knapp, M. Fossey, M. (2012). *Long-term conditions and mental health, the cost of co-morbidities*. London: The King's Fund and the Centre for Mental Health.

Needels, K. and Schmitz, R. (2006). *Economic and social costs and benefits to employers of retaining, recruiting and employing disabled people and/or people with health conditions or an injury. A review of the evidence*. London: Department for Work and Pensions.



Office for National Statistics (2012), *Young People in Work, 2012*, Office for National Statistics.

Packham, J.C. and Hall, M.A. (2002). Long-term follow-up of 246 adults with juvenile idiopathic arthritis: education and employment. *Rheumatology*, 41(12), 1436-1439.

Plaisier, I., de Graaf, R., de Bruijn, J., Smit, J., van Dyck, R. et al. (2012). Depressive and anxiety disorders on-the-job: The importance of job characteristics for good work functioning in persons with depressive and anxiety disorders. *Psychiatry Research*, 200(2-3), 382-388.

Shahnasarian, M. (2001). Career rehabilitation: Integration of vocational rehabilitation and career development in the twenty first century. *The Career Development Quarterly*, 49(3), 275-283.

Stuart, H. (2004). Stigma and Work. *Healthcare Papers*, 5(2), 100-111.

The ACEVO Commission on Youth Unemployment (2012), *Youth unemployment: the crisis we cannot afford*, London: ACEVO.

The Marmot Review. (2010). *Fair Society, Healthy Lives*. Retrieved on 17 October 2011 from <http://www.marmotreview.org/>

UK Commission for Employment and Skills. (2011). *Youth inquiry evidence base*. London: UKCES.

van Uden-Kraan, C.F., Drossaert, C.H., Taal, E., Seydel, E.R., van de Laar, M.A. (2009). Participation in online patient support groups endorses patients' empowerment. *Patient Education and Counseling*, 74(1), 61-69.

Waddell, G. and Burton, K. (2006). *Is work good for your health and well-being?* London: Department for Work and Pensions.

Woodgate, R. L. (1998). Adolescents' perspectives of chronic illness: "it's hard". *Journal of pediatric nursing*, 13(4), 210-223.

## Appendix 1. Sample

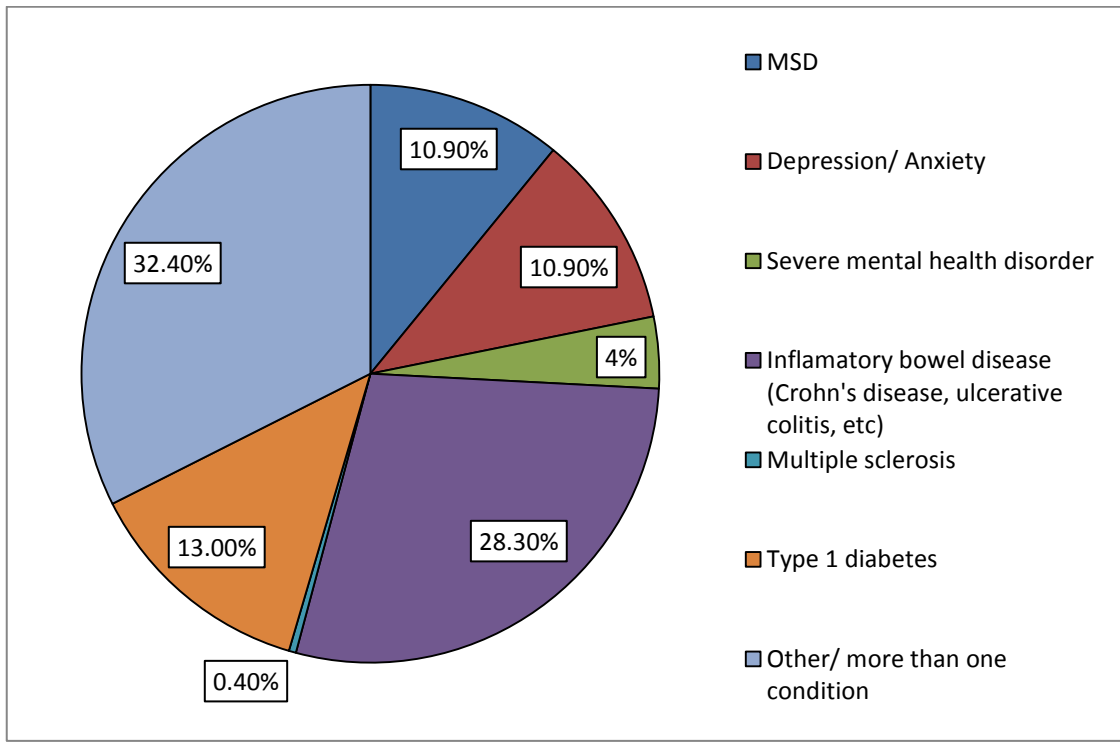
This survey drew on a non-random sample of members of patient groups in the UK, to a specification that was designed by The Work Foundation. It was specified that the respondents were 16 years old or over at the time of the survey, and had been diagnosed with a chronic health condition by a medical doctor. The average age of the sample was 22.6 years old (SD = 2.1).

**Table A. Demographic characteristics of the sample**

Employment status	Male	Female	Total
In paid work (employee, self-employed, working for your family)	12	122	134
In education (not paid for by employer)	5	39	44
Unemployed and actively looking for a job	5	18	23
Unemployed, wanting a job but not actively looking for a job	-	11	11
Permanently sick or disabled	6	18	24
In unpaid work (volunteering, home working)	-	6	6
Other	1	3	4
<b>Total</b>	<b>29</b>	<b>217</b>	<b>246</b>

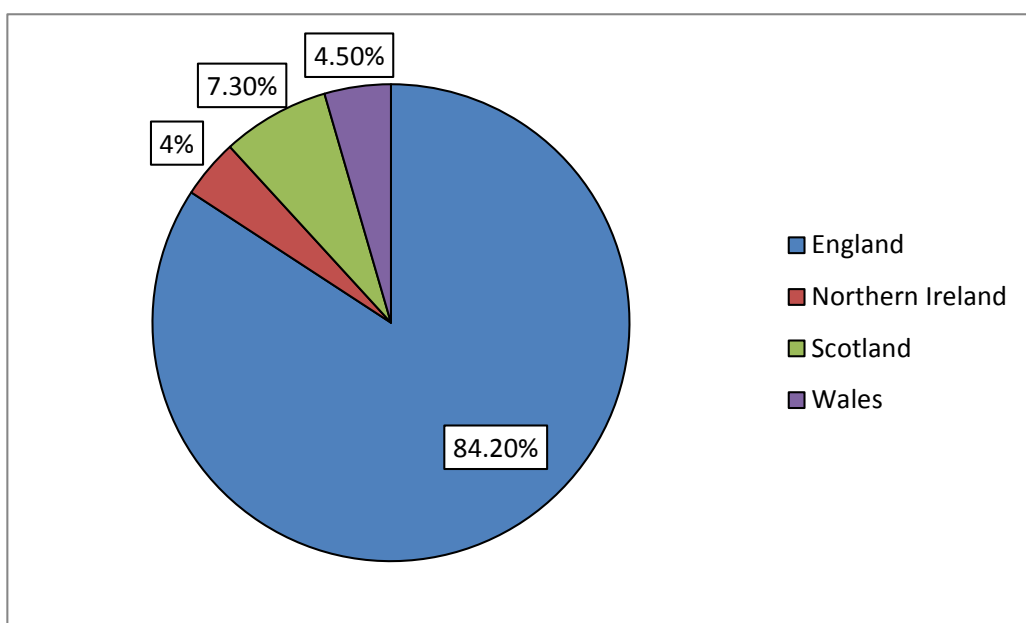
The figure below presents the distribution of the medical diagnoses in the sample.

**Figure B. Type of diagnosis**



The figure below presents the country where the respondents lived. For analysis purposes we treated all the respondents as one sample.

**Figure C. Distribution of the sample by country of residence.**



**Table D. Highest level of qualifications**

Educational attainment	Percentage
No formal qualifications	1.6%
GCSE	22.5%
Vocational qualifications	12.3%
A-levels	36.1%
Bachelor's degree or similar	32.8%
Masters/PhD	7.0%
Other professional	6.1%

Survey respondents were also asked to estimate the severity of their condition, on a scale of 0 (no impact) to 10 (very significant impact). On average, the respondents indicated the severity of their condition at 5.83 (SD = 2.14), which corresponds to above average severity. The severity of the condition did not correlate with the respondents' age, but correlated with the number of years lived with the condition ( $r=0.156$ ,  $p=0.05$ ).

## Appendix 2. List of participating patient organisations

Several patient organisations have participated in the survey. An advance email was circulated to members of each of the participating patient groups. This email introduced the survey and directed respondents to the URL address where the questionnaire could be completed.

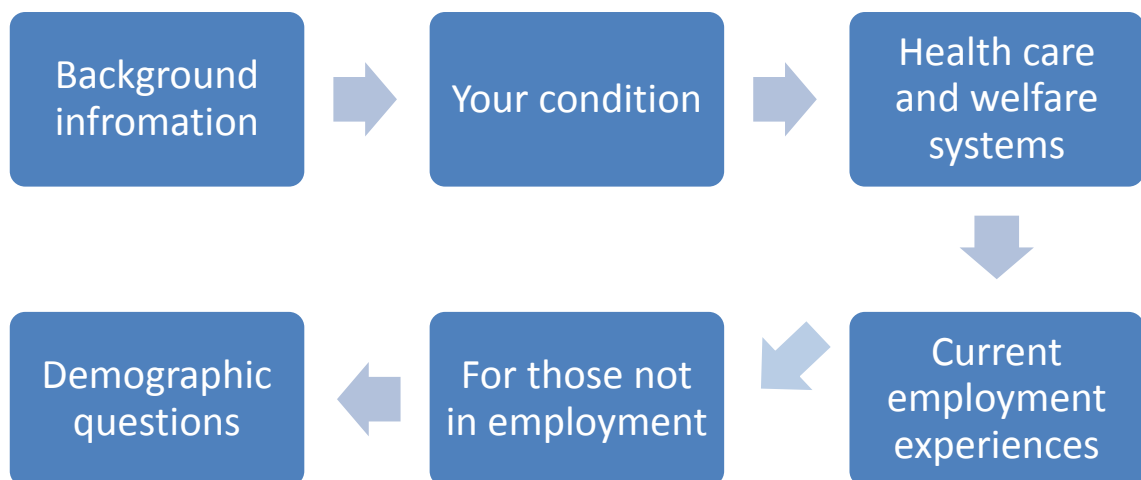
- Arthritis Care
- The Arthritis and Musculoskeletal Alliance
- Centre for Mental Health
- Crohn's and Colitis UK
- Chronic Pain Policy Coalition, which includes:
  - Action on Pain
  - BackCare
  - FMA UK
  - National Osteoporosis Society
  - Pain Alliance Northern Ireland
  - Pain Association Scotland
- Diabetes UK
- Endometriosis UK
- Macmillan Cancer Support
- MIND
- National Ankylosing Spondylitis Society (NASS)
- National Rheumatoid Arthritis Society (NRAS)
- National Voices
- Shift MS
- UK Gout Society

## Appendix 3. Questionnaire

The questionnaire was developed and piloted by the Work Foundation in 2011/2012. The draft of the questionnaire has been peer-reviewed by Professor Anthony Woolf of EUMUSC.net, Prof Ingemar Petersson of Epi-centrum Skåne and Maarten de Wit of Stichting Tools. The questionnaire and the survey method were reviewed and adjusted after the completion of the pilot phase in spring 2012.

The structure of the questionnaire and individual modules were as follows from the chart below.

**Figure E. Questionnaire structure**



Responses were collected between 24 July 2012 and 30 September 2012. The questionnaire length was between 10 and 20 minutes depending on the answers given. Most questions were closed questions, with multiple choice answers. However, there were some open questions available to respondents throughout the questionnaire. These were recoded into a numeric format for the statistical analysis purposes.

All survey responses were automatically forwarded to a designated mailbox, belonging to The Work Foundation. The responses were collected using SNAP

survey software and were consequently exported into SPSS software for statistical analysis purposes.

## Appendix 4. Interview guide

The following interview questions were used to gather more detailed qualitative data regarding the experiences of 16 individuals diagnosed with a long-term condition.

### Generic questions (asked of all respondents)

- 1) Please tell me a little about yourself - what do you do, where do you live, who do you live with.
- 2) How does your condition affect you on a day-to-day basis? How are you coping generally? Are you able to do household work, take part in physical activities?
- 3) How old were you when you first started experiencing symptoms?
- 4) How old were you when you were diagnosed by a medical professional? How did your diagnosis impact on you?
- 5) Were you at school/college/work?
- 6) Did you tell school/college about your condition
  - a. How did your condition impact on your performance at work/school/college?
  - b. Did you receive any careers guidance at school?
  - c. If yes: did they talk to you about managing a long term condition whilst at work?
- 7) If was in work – have they changed jobs since and why?
- 8) Would you say that your condition impacted your education and employment opportunities?

### In work, education

- a. Is this your first job?
- b. Has there been a service or person who has supported you in finding your first job? If yes: tell me more about it?



- c. Does your employer/line manager/colleagues know about your condition? How did you feel about telling them about your condition?
  - a. Have they been supportive? i.e. time off for appointments etc.
- d. If didn't tell – why not?
- e. Do you feel well enough to work? i.e. symptoms under control
- f. Are there good and bad days?
- g. What factors have allowed you to stay in work? Medication, work characteristics
- h. Do you have to take time off due to your condition? Do you come to work when feeling unwell and why?
- i. Do you enjoy your job? What is important to you about work?
- j. What are your aspirations for the future? Are you likely to change employers/career?
- k. What sort of jobs do you consider doing? Have you ruled out certain careers you would have otherwise considered?

## **NEET**

- a. Why are you not in work? Do you feel well enough to work? i.e. symptoms under control
- b. How do you feel about being out of work?
- c. Do you want to work? If Yes:
  - a. Is there anywhere where you are being provided with careers guidance?
  - b. Do you have any concerns about working with your conditions?
  - c. Do you expect to receive any support from employers?
  - d. What is important to you about work?
  - e. What are your aspirations?
- d. What factors do you think would help you enter the work force?
- e. Have you ruled out certain careers you would have otherwise considered?
- f. Has your condition delayed your education and employment opportunities?

### **Questions about family and friends**

- 1) What else do you do/enjoy doing (hobbies/socialising)? Does your condition have an impact on that?
- 2) Does anyone help you manage your condition? How?
- 3) How does living with the condition impact your family life?
- 4) Do your friends know about your condition? How did it impact your social life?

### **Clinical and Vocational Interventions**

*To identify who provides any aspect of vocational rehabilitation or return to work assessments and/or interventions in for people with long term conditions.*

- 1) Are you receiving treatment for your condition and where? How does treatment impact on you? Can you manage your condition without medication?
- 2) Has your GP ever spoken to you about work?
- 3) Has any other healthcare professional eg nurse, specialist spoken to you about work?
- 4) Have you ever been in contact with JobCentre plus?
  - a. If yes: did they speak to you about working with your conditions or any programmes of support?
  - b. Did they ever point you in the direction of vocational services i.e. places where you can receive vocational training? Eg Connexions? Barnardos?
- 5) Educational training and vocational services?
  - a. Has anyone ever spoken to you about educational training and vocational services eg courses and support provided by local colleges, charities such as Barnardos, Prince's Trust, which provide training and qualifications.

Is there anything else you would like to add?

## About The Work Foundation

The Work Foundation aims to be the leading independent, international authority on work and its future, influencing policy and practice for the benefit of society. Through its rigorous research programmes targeting organisations, cities, regions and economies, The Work Foundation is a leading provider of research-based analysis, knowledge exchange and policy advice in the UK and beyond. Organisations from across all industry sectors can sign up as partners to gain access and active involvement in research, thinking and practice emerging from its work. The Work Foundation is part of Lancaster University – an alliance that enables both organisations to further enhance their impact.

## Contact details

The Work Foundation  
21 Palmer Street  
London SW1H 0AD

[info@theworkfoundation.com](mailto:info@theworkfoundation.com)  
[www.theworkfoundation.com](http://www.theworkfoundation.com)

All rights reserved © The Work Foundation (Lancaster University). No part of this publication may be reproduced, stored in a retrieval system or transmitted, in any form without prior written permission of the publishers. For further information please contact [info@theworkfoundation.com](mailto:info@theworkfoundation.com). Trading address: The Work Foundation Alliance Limited, 21 Palmer Street, London, SW1H 0AD, UK. Registered Charity No. 1146813. Registered as a company limited by guarantee No. 7746776. Registered address: Lancaster University, Bailrigg, Lancaster LA1 4YW, UK.