

Written evidence from Macmillan Cancer Support (HAB0094)

- Macmillan Cancer Support is a registered charity providing information and support to people with cancer, including specialist support to people with cancer accessing the welfare system.
- Macmillan has face-to-face services embedded locally across the UK. In 2019, we reached an estimated 161,000 people through our national network of face-to-face welfare advisors. Around 129,000 individual people affected by cancer were supported through specialist casework, identifying around £247m in benefits. The Macmillan Support Line also offers confidential support to people living with cancer over the telephone. In 2019, we supported a total of nearly 93,000 people through all Macmillan Support Line teams, including our Welfare Rights advisors.
- Around 27% of people receive some type of benefit after a cancer diagnosis. Those people who are severely financially impacted by cancer are more likely to be receiving benefits. Almost half of people who are severely financially impacted receive some type of benefit after a cancer diagnosis.

Summary of Recommendations

- The criteria and process assessors use to make recommendations for health-related benefits should be clearly and proactively explained to claimants. Assessors should also indicate in their report which evidence they've used to assess somebody's claim and how much weight they've applied to this.
- The DWP should acknowledge the detrimental impact informal observations can have on both the experience and the outcomes of assessments and remove them from future assessments.
- The DWP should explore how assessments could better capture the barriers disabled people and people with health conditions such as cancer face in their daily lives and in relation to the labour market.
- The DWP also should consider whether other types of evidence, such as witness statements from people who support someone with their health condition, should also be considered.
- The DWP should ensure that multiple modes of assessment are available to all claimants. It should also be made clear that claimants have the option to have the assessment recorded.
- The DWP should review and address the barriers third party organisations like Macmillan face in providing advice and advocacy support for people with a disability or health condition, including urgently reforming the system of explicit consent in UC and ensuring that its helplines are sufficiently resourced to provide timely and adequate guidance and support.
- The Government must urgently address any delays in the benefits system to ensure people with cancer get their benefit entitlements within a reasonable time frame. The DWP should make sure that the PIP assessment process takes no more than 11 weeks.

1. How could DWP improve the quality of assessments for health-related benefits?

1.1 People who are awaiting, undergoing, or recovering from cancer treatment are automatically placed in the Support Group or treated as having limited capability for work, without the need for a face-to-face assessment within UC or Employment Support Allowance (ESA) which is based on the presumption that they are too ill to work. In comparison, many people with cancer who make a claim for Personal Independence Payment (PIP) undergo a full capability assessment unless they have a terminal illness.

1.2 A common theme that emerges when we talk to people with cancer about their experience of assessments is a lack of trust in the benefits system to treat people fairly and deliver a good outcome. People with cancer often feel like they aren't trusted, supported or respected by the benefits system. The most common touchpoint where individuals feel the system is not on their side is during assessments.

1.3 Our research with people living with cancer found that most respondents felt like they had to fight for support.¹ With regards to a PIP assessment, respondents felt they were not listened to in their assessment, or they were frustrated by the assessor's manner, or that assessors did not have a basic understanding of their cancer or that their background was not medical enough. Some respondents felt that there were inconsistencies across what was said in the assessment and what was recorded in the report.

Jolene felt lots of the questions she was asked were 'investigative' and designed to encourage inconsistency and contradiction. This 'game' of interpretation caused her significant anxiety. "Questions were phrased in a certain way... [I felt my] responses were being spun. It's a lot to deal with when you're already at the end of your tether." The atmosphere of distrust meant that when Jolene's assessor left her scarf behind, she questioned whether or not this was part of the test. "I did think, if I try and catch up to her will she think I can walk easily?" (Case study: Jolene, 42, bowel cancer)

1.4 When people feel the system is on their side it can significantly improve their experience of claiming benefits. While improving transparency in the assessment process may not necessarily lead to a better assessment outcome, it can put claimants in a more informed position when deciding whether to appeal a decision given that a challenge could see them lose an existing award.

1.5 Recommendation: The criteria and process for assessors use to make recommendations for health-related benefits should be clearly and proactively explained to claimants. Assessors should also indicate in their report which evidence they've used to assess somebody's claim and how much weight they've applied to this.

1.6 The culture around assessments also needs to be more understanding of, and sensitive and sympathetic to, claimant circumstances. Too often we hear from people who say they felt their assessor 'viewed them with suspicion' and was 'trying to catch them out'.

1.7 One of the elements of assessments that people with cancer report causing them the most distress are informal observations, which contribute to distrust and a perception of unfairness in the

¹ Macmillan Cancer Support. 2021. [Cancer and Social Security: What people with cancer need from the benefits system and what they get](#)

system. We hear regularly from advisers that while many people provide additional evidence about their condition when submitting PIP applications, this is often disregarded based on observations made during face-to-face assessments.

1.8 This issue can be compounded by the fact that some people with cancer report a lack of clarity around what information is being taken into account during an assessment and rely on support from advice services to gather and provide evidence that will be relevant.²

During his assessments, Tom was unsure what they were assessing, and felt he was on the back foot. On many occasions, he struggled to understand why certain decisions had been made about his ability to work. He felt that the assessment hadn't taken into account his inability to speak well and had only assessed his ability to "make a cup of tea". (Case study: Tom, 64, throat cancer)³

1.9 Macmillan Cancer Support also has anecdotal evidence from our welfare advisors that informal observations are being used during telephone assessments.

"My client needed to use the lavatory during the assessment - she explained that her assessor was very friendly, but she still felt awkward having to leave the call to use the lavatory. The client specifically hurried because of this. When the result of the assessment came through the assessor had timed the lavatory visit and it was commented that the client was not out of breath after the lavatory visit and she was therefore not awarded anything for mobility (which is very poor) and standard for daily living." (Macmillan welfare advisor)

1.10 Recommendation: The DWP should acknowledge the detrimental impact informal observations can have on both the experience and the outcomes of assessments and remove them from future assessments.

3. Do the descriptors for PIP accurately assess functional impairment? If not, how should they be changed?/ Do the descriptors for ESA accurately assess claimants' ability to work? If not, how should they be changed?

3.1 People who have cancer may find that their health and wellbeing can fluctuate daily or weekly. They may also move between cancer stages, especially where people have recurrent cancers, or where curative treatment does not work or leaves them with long-term side effects. As such, assessments may not always effectively capture individual's needs and the impact of their condition on their day-to-day lives.

3.2 Macmillan's research into people's experience of the benefits system found that some respondents felt the assessment criteria did not properly capture their experience of living with cancer.⁴ For example, one respondent expected the PIP assessment to be a chance to discuss openly her physical and mental health challenges, but found the questions were very specific and closed. Many also expressed concerns that, because their cancer was not a 'visible' illness, they would not receive the support they needed. As one individual put it, "you can be seriously ill on the inside but look fine on the outside. They don't take that into account, especially if you are young and look fit."

² Ibid

³ Ibid

⁴ Ibid

3.3 These issues can be exacerbated where assessors lack specialist knowledge of cancer and the range of ways that a cancer diagnosis can impact someone's ability to work or their daily life.

3.4 The challenges with PIP descriptors can lead to incorrect decisions and people with cancer needing to challenge these, resulting in delays in accessing much-needed financial support.

3.5 Recommendation: The DWP should explore how assessments could better capture the barriers disabled people and people with health conditions such as cancer face in their daily lives and in relation to the labour market.

6. How practical would it be for DWP's decision makers to rely on clinician input, without a separate assessment, to make decisions on benefit entitlement? What are the benefits and the drawbacks of such an approach?

6.1 While an assessment can give people an opportunity to describe how their condition affects their ability to live and work, it is vital that other types of evidence are given greater weight in the decision-making process to give a fuller picture of the impact cancer has on them and to avoid unnecessary assessments.

6.2 The regulations within UC and ESA which mean that anyone awaiting, undergoing or recovering from cancer treatment is automatically placed in Limited Capability for Work Group or Support Group. This is an excellent example of clinical input being used to avoid unnecessary assessments.

6.3 In order to support the gathering of clinical evidence, DWP should ensure that clinicians are provided with clear, understandable guidance as to what they are required to submit. Macmillan welfare advisors have reported that healthcare professionals can sometimes provide unsuitable information, such as print outs of recent consultations, which evidences that the individual has cancer but does not demonstrate the daily impact of this.

6.4 Recommendation: The DWP also should consider whether other types of evidence, such as witness statements from people who support someone with their health condition, should also be considered.

6.5 This could include giving more weight to oral testimonies and evidence from carers to illustrate the impact of someone's health condition or disability. Such individuals are well placed to give evidence on the day-to-day challenges people with cancer face.

10. What lessons should the Department learn from the way that it handled claims for health-related benefit claims during the pandemic: for example, relying to a greater extent on paper-based assessments, or using remote/telephone assessments?

10.1 The pandemic demonstrated how the system can be flexible and adapt to the changing and diverse needs of claimants, including people with cancer. It is important that the DWP maintains the flexibilities brought in during the pandemic, such as verifying claims remotely and access to telephone assessments, where claimants have a preference.

10.2 However, there is no 'one size fits all' solution. While changes made in response to the pandemic worked well for some and should be integrated into the system long term, there also needs to be an acknowledgement that they may not suit everyone. In the case of remote

assessments, claimants should be empowered to choose the method of assessment that is right for them and the DWP should ensure that multiple modes of assessment are available to all claimants.

10.3 In 2020 we surveyed Macmillan’s welfare advisors to understand the financial impact of the pandemic on people with cancer and the support available from the welfare system, including the roll-out of telephone-based assessments.

10.4 Overall, claimants we supported reported a mixed experience of telephone assessments. Around 36% of welfare advisors who responded to our question on telephone assessments said the claimant experience has generally been better than for face-to-face assessments, 29% said it has generally been worse and 35% said the experience is about the same.⁵

“Many cancer patients struggle to leave home during treatment and so more telephone assessments, or video assessments, could be a positive move. For Work Capability Assessments it used to be very difficult to get a home visit. Having said this, I know it is sometimes preferable for some claimants to meet the assessor face-to-face for them to fully appreciate their functional difficulties.” (Macmillan welfare advisor)

“Claimants worry that they cannot show the assessor visible signs of illness. They worry that they will not be listened to and cannot be physically assessed and without the information gleaned from physical assessments they will be wrongfully turned down. They worry that anxiety about using the phone will cause them to accidentally give incorrect information or not convey how much they struggle, or that they will panic and say they are fine.” (Macmillan welfare advisor)

10.5 Telephone assessments can help individuals feel more comfortable in their own home. They can also mean it is easier to schedule the assessment around cancer treatment, without the need to travel to an assessment centre. This is especially important for people who experience reduced immunity and fatigue because of treatment, which can mean they are unable to safely use public transport. Being appropriately signposted to, and being able to access, assessments carried out through a home visit, or in other locations outside of the assessment centre setting, for example in hospital, is important.

10.6 Macmillan welfare advisors report that some people with cancer find it difficult to access home visits, even where evidence for the need for a home assessment is provided. Home visits are not consistently signposted to and many claimants do not know they exist. The Disability Benefits Consortium commissioned a survey of PIP claimants which found that 79% of respondents were not told about the opportunity to request a home visit.⁶ The DWP should proactively offer home assessments and provide a guarantee that enables people to understand that a home visit is part of their entitlement, so that everyone who wants one can have the option to do so.

10.7 We’ve also heard about some inconsistency in the length of telephone assessments. Lengthy calls are a concern as they are very tiring for people with cancer (and this not always being taken into consideration).

10.8 The DWP is right to open up more choice of assessment methods for claimants, but claimants need to be empowered to choose the method of assessment that is right for them.

⁵ Macmillan Cancer Support. 2020. 137 Macmillan Welfare Rights advisers completed the survey from a range of settings, including hospitals, local authorities, Citizens Advice offices, SLS and GP surgeries. 56% were based in England, 4% in Northern Ireland, 38% in Scotland and 2% in Wales.

⁶ The Disability Benefits Consortium. 2017. [Supporting those who need it most? Evaluating PIP](#)

10.9 Recommendation: The DWP should ensure that multiple modes of assessment are available to all claimants. It should also be made clear that claimants have the option to have the assessment recorded.

10.10 It should also be acknowledged that delivering assessments over the telephone or video does not necessarily resolve the issues people experienced with the face-to-face assessments. For example, Macmillan welfare advisors continued to report an over-reliance on the indicators used in the assessment, with little consideration given to other evidence provided by the claimant and that this could result in a decision being made on a 'snapshot' of someone's condition.

12. How can the Department best help the third sector to support claimants in their applications?

12.1 Many people access information, advice and advocacy from the third sector to help them navigate the benefits system. Our research found that many respondents rely on outside support to help complete their claim, and they felt they would have been unable to do so without it.⁷ However, Macmillan faces several barriers within the benefits system which can make providing advice and support to benefits claimants difficult and cumbersome.

12.2 We also know from speaking to people with cancer and Macmillan welfare advisors that they often experience long delays on the DWP helplines when trying to get through to a member of staff to discuss a claim. This can be challenging for people with cancer who may be too unwell to spend long periods of time on the phone, as well as taking time away from welfare advisors to deal with other cases.

12.3 Advisors also report that staff on the UC helpline often lack the knowledge and expertise to deal with inquiries related to a disability or health condition. For example, they may not be familiar with guidance designed to support such claimants. Furthermore, requirements around explicit consent in the case of UC mean that helpline staff are often either unable or unwilling to respond to requests from Macmillan advisors on behalf of claimants.

12.4 Macmillan has been calling for the DWP to relax the requirement in UC for explicit consent from claimants for third parties to act on their behalf, as it can create significant barriers to people with cancer accessing support from advice services like Macmillan. A requirement for explicit consent is built into the UC process, requiring claimants to provide verbal or written explicit consent each time a third party accesses their account or acts on their behalf to solve a problem with their application. It can be very difficult for individuals to provide this level of consent, particularly if they are hospitalised, undergoing treatment, or close to the end of life. We would like to see implicit consent reinstated

12.5 Recommendation: The DWP should review and address the barriers third party organisations like Macmillan face in providing advice and advocacy support for people with a disability or health condition, including urgently reforming the system of explicit consent in UC and ensuring that its helplines are sufficiently resourced to provide timely and adequate guidance and support.

14. What could the Department do to shorten waits for health-related benefit assessments—especially for ESA/UC?

⁷ Macmillan Cancer Support. 2021. [Cancer and Social Security: What people with cancer need from the benefits system and what they get](#)

14.1 The financial impact of cancer quickly hits when treatment begins and escalates for those who do not recover.⁸ People can face often unexpected costs after a diagnosis which can quickly begin to accumulate, frequently coupled with having to leave or cut down on work during cancer treatment. As such, it's critical people with cancer receive their benefits in a timely manner.

14.2 People with cancer often tell us they rely on income from other sources to get by in the early stages of their diagnosis. Many of those affected do not have emergency funds to draw on when cancer hits. Around 23% of people who claim benefits after a cancer diagnosis report that they don't have access to savings or emergency funds.⁹ Gaps in support can lead some people to take on problem debt and risk further financial uncertainty. Around 1 in 3 of the most financially impacted had to take out a loan or go into credit card debt to cover increased costs.¹⁰ They are also significantly more likely to use riskier loan options such as loan sharks, payday lenders and unsecured loans.¹¹

14.3 Waiting times for PIP are currently excessively long. Government statistics for PIP for the quarter ending October 2021 show clearance times are currently 24 weeks "end to end" (from registration to a decision being made).¹² This mirrors what we have been hearing from our benefits advice services, with reports of people waiting up to 7 months to receive their benefit. As a result, those affected often do not get the extra money when they need it most.

14.4 Evidence from our benefits advice services also indicates that people with cancer are regularly experiencing prolonged delays in referrals to a Work Capability Assessment. This includes cases of people waiting longer than four weeks to receive a UC50, the questionnaire where claimants register a cancer diagnosis, resulting in delays to protection entitlements.

14.5 We acknowledge that the COVID-19 pandemic has put the system under considerable strain because of an increase in the number of people claiming benefits. However, it is critical that the Government prioritise bringing down waiting times and are open and transparent about how they plan on addressing delays.

14.6 Recommendation: The Government must urgently address any delays in the benefits system to ensure people with cancer get their benefit entitlements within a reasonable time frame. The DWP should make sure that the PIP assessment process takes no more than 11 weeks.

December 2021

⁸ Macmillan Cancer Support and Truth survey of 1,329 adults who have received a cancer diagnosis. Fieldwork was undertaken between 13th January and 7th February 2020.

⁹ Ibid

¹⁰ Ibid

¹¹ Ibid

¹² Department for Work and Pensions. 2021. [Personal Independence Payment: Official Statistics to October 2021](#)