Thank you for your letter dated 25th April 2019 regarding the revised DS1500 guidance the Department has recently issued to clinicians.

I am pleased to hear that the Committee believes the recent changes made to the DS1500 guidance will be helpful. As I stated in my previous response, I firmly believe that it is a fundamental right that people who have been diagnosed with a terminal illness should receive the support they need, when they need it and in a way that minimises any potential stress.

However, I feel it is important to clarify that the work carried out by Professor Radford and the subsequent revisions to the guidance, do not represent a change in policy regarding the Special Rules for Terminal Illness (SRTI). Professor Radford’s initial informal discussions allowed us to identify where certain areas of the process could be improved to ensure the SRTI operate as intended.

I will now look to address the specific questions raised in your response:

1. How the findings from Professor Radford’s group were used to inform this wording change;

2. Whether the Department:
   a. consulted with claimants and stakeholder groups on the guidance change;
b. what the findings of those discussions were; and
c. how findings fed into the wording change.

As I made clear in my previous letter, one of the key issues that emerged from Professor Radford's meeting was that the language we use around terminal illness could be improved, to allow clinicians to better understand and more effectively engage with the SRTI process.

Following this initial informal meeting a number of my officials, alongside Professor Radford, held workshops with leading clinicians and disability charities (including Marie Curie and Motor Neurone Disease Association) to discuss how the wording of the guidance for the DS1500 could be revised. We held two events, in December 2018 and January 2019, with the main findings being:

- We needed to make it clearer to clinicians what the DWP means by the term 'terminal illness';
- Determining life expectancy is not an exact science;
- We needed to reiterate that the SRTI do not only apply to claimants who have cancer;
- The wording was unclear around who should complete a DS1500, and when clinicians should be completing it for their patients.

The workshops discussed these findings, as well as how we could revise the wording to address these issues. We ensured that all stakeholders involved were consulted on the final version of the revised wording.

3. How the Department will monitor whether the rule change is leading to a more flexible approach to the SRTI amongst clinicians.

The Department has supported the release of the revised guidance with communications to key stakeholders, such as the British Medical Association and NHS England, in order to ensure as many clinicians as possible are made aware of the changes.

In regards to monitoring the effect of the change, the Department can monitor the volume of cases awarded benefits under the SRTI over time to examine longer term trends in claims that result from the DS1500. In the future we may also look to engage with clinicians directly for feedback on the revised wording. However, as some clinicians may only complete DS1500s on an infrequent basis it is important to allow time for them to engage with the new wording.

Finally, I would like to thank the Committee for sharing the letter from the National Association of Welfare Rights Advisers and I am sorry to hear that they have had negative experiences whilst supporting claimants through the SRTI process. I appreciate that this is a sensitive and important issue and I hope that the information provided in this response has highlighted to the
Committee that our recent work carried out to revise the DS1500 guidance aims to address many of the issues raised in their letter.


Justin Tomlinson
Minister for Disabled People, Health & Work