

Findings from the Evaluation of the Special Rules for Terminal Illness process

Introduction

- The Department for Work and Pensions (DWP) provides fast-tracked support through the benefits system for people who are nearing the end of their lives. The mechanism for this is the Special Rules for Terminal Illness (the 'Special Rules').¹ The Special Rules ensure that the people who need it most, are able to receive financial support quickly and easily.
- Under the Special Rules, claims are fast-tracked and a face-to-face assessment is not required. No waiting period is applied, and in the majority of cases the highest level of benefit is awarded.² A Special Rules claim is normally supported by a short form completed by a clinician, called a DS1500.
- 3. The Special Rules were first introduced in Attendance Allowance (AA) in 1990, following a recommendation by the Social Security Advisory Committee. Attendance Allowance claims are subject to a six month waiting period, and the Committee were concerned that some terminally ill people were dying before this period had been completed.³ Eligibility for the Special Rules was therefore limited to people diagnosed with a condition that meant they were unlikely to live for more than six months.
- 4. The Special Rules have subsequently been extended to Disability Living Allowance, Employment and Support Allowance, Personal Independence Payment and Universal Credit, with the same eligibility criteria.
- 5. The Special Rules have become an important way to ensure that financial support is provided quickly and simply for people nearing the end of their lives. They are intended to recognise the challenges that an individual, their family and friends face when a terminal diagnosis is made, and to ensure that the time that remains to people nearing the end of life is not taken up with completing benefit assessments.
- 6. The Special Rules in their current form have been in place without alteration by successive governments since 1990. In 2019, the Secretary of State for Work and Pensions announced that DWP would undertake an evaluation into how the benefits system in Great Britain supports those nearing the end of their lives.
- 7. The launch of the evaluation recognised that there have been considerable medical advances in the 30 years since the Special Rules were first implemented. This includes how people nearing the end of their lives are treated, cared for and their conditions managed. In addition, changes have been made to how clinicians identify people nearing the end of their lives. New approaches have been developed including the Gold Standards Framework, Daffodil Standards and the work led by the Ambitions

Partnership for Palliative and End of Life Care to improve the identification of people nearing the end of their lives.⁴

- 8. The purpose of the evaluation was to consider the policy and implementation of the Special Rules. The evaluation sought the views of individuals and organisations involved in the administration of the rules as well as those of people nearing the end of their lives and the organisations who support and represent them. In this way, the evaluation was able to take a holistic view of the support currently provided and how it could be changed or improved.
- 9. Some improvements to the delivery of the Special Rules were made in the course of the evaluation as a result of early feedback. The DWP published updated guidance for clinicians on completing DS1500s for Special Rules claims and introduced a dedicated GOV.UK page with information on claiming benefits for those nearing the end of their lives.⁵

The Evaluation

- 10. Through the evaluation, the DWP received contributions from a wide range of people and organisations across Great Britain. There were direct contributions from people nearing the end of their life who shared their first-hand experiences of accessing support via the Special Rules, as well as from charities and organisations supporting them. As well as receiving written evidence, the evaluation team held engagement sessions, including an event for people living with or affected by Motor Neurone Disease, conducted telephone interviews with people nearing the end of their lives and met with charities who provide support for people nearing the end of their lives.
- 11. The evaluation team also sought the view of healthcare professionals who work with and support people approaching the end of their lives, through National Expert Palliative and End of Life Care clinical groups and nearly 1,000 clinicians from a range of professions in England, Scotland, Wales and Northern Ireland, provided their views in response to a survey.⁶
- 12. We also considered international evidence, hearing from 22 countries about the support they provide and its effectiveness. Finally, we looked at current DWP performance to critically evaluate our existing processes, using the insight we had gathered throughout the evaluation.

Evaluation Findings

- 13. The evaluation findings can be grouped into six areas:
 - definition of who should be eligible for the Special Rules;

- awareness and communication of the Special Rules;
- consistency in the approach to end of life;
- the process of making a claim under the Special Rules;
- international comparisons; and,
- the Devolved Administrations, including the findings from the engagement that the Department for Communities (DfC) undertook in Northern Ireland which has been considered as part of this Evaluation (See Annex 1).

Definition of who should be eligible for the Special Rules

- 14. Strong evidence was received throughout the evaluation that the current sixmonth rule is not fit for purpose and should be changed. This was a consensus across all the groups we consulted.
- 15. We received evidence that the six-month rule made it difficult for people with fluctuating conditions or uncertain life expectancy to access benefits under the Special Rules. This was a particular issue for people with Motor Neurone Disease. We also heard that in some situations the six-month rule was forcing conversations between clinicians and patients about their life expectancy at a time they would not have chosen to do so, which could be difficult and distressing for individuals and their families.
- 16. There was less consensus on the best way to replace the six-month rule. Contributors to the evaluation mainly favoured one of two alternative approaches:
 - a 12-month rule, mirroring the "end of life" approach used by NHS England (with similar definitions used elsewhere in Great Britain);
 - a clinical recommendation supported by guidance, without an explicit time frame.
- 17. The was significant support for a 12-month rule, mirroring the 'end of life model' used by NHS England (with similar definitions used elsewhere in GB). Contributors felt that this approach would align the welfare system with the approach and work of the NHS and other organisations that support people nearing the end of their lives across Great Britain.
- 18. This would potentially support a holistic approach to providing support to people nearing the end of their life. For example, it would align the process of accessing benefits under the Special Rules with existing interactions that people nearing the end of their lives have with clinicians, reducing the number of difficult conversations. Contributors told us that having similar

definitions of "end of life" across the health and welfare systems would make it easier for clinicians and people nearing the end of their lives to understand and access the Special Rules. However, contributors also told us that any time-bound rule would retain problems associated with the current six-month rule and would therefore be imperfect.

- 19. Contributors who preferred an open-ended time period with eligibility based solely on a clinical recommendation supported by guidance felt that this would give access to people with health conditions who currently find it difficult to claim under the Special Rules, particularly those with an uncertain prognosis.⁷ However, we also heard that there would be risks with this approach, as a broad definition would make it difficult for clinicians to make decisions about who is eligible.
- 20. The survey of clinicians found that when asked what they thought the time criteria for receiving benefits under the Special Rules should be, 38 per cent of respondents preferred a 12-month model, 34 per cent preferred a model without reference to a time limit and only 10 per cent supported the existing six-month model.
- 21. On balance, our view is that the evaluation supports a move to a 12-month, end of life approach that mirrors the existing NHS England practice on end of life care. This will provide clarity for both claimants and clinicians and ensure that people approaching the end of life do not get conflicting messages from the health and welfare systems. It also maximises the opportunity to improve awareness of the Special Rules and consistency in their application. This should make it easier for people nearing the end of their lives to access the benefits system through the Special Rules.

Awareness and Communication

- 22. The evaluation showed there are areas where more could be done to improve awareness of the Special Rules. Respondents felt that improving the information and guidance available would help people to access the Special Rules.
- 23. Charities and clinicians play a crucial role in helping people to make a Special Rules claim. People are often unaware of the financial support available from DWP and of the Special Rules when informed that they are nearing the end of their lives. They told us they find the support provided by welfare benefits advisors from supporting charities and local authority teams to be invaluable. We also heard that there are clinicians who are not aware or have limited knowledge of the Special Rules.

- 24. As a result of these contributions, as indicated above, DWP made some immediate improvements to guidance for clinicians, and we will make further improvements to the information and support we provide. By aligning to the 12-month end of life approach we expect to be able to improve awareness among clinicians by taking advantage of existing training and educational resources.
- 25. People also told us that the language and terminology DWP uses could be improved to make it easier for people to understand whether they are able to make a Special Rules claim. Clinicians told us that language has changed within the field of palliative care and the phrase 'terminally ill' is being used less now than it was previously. Therefore, by using more commonly used terms such as "end of life", the DWP could help to improve awareness and understanding of the Special Rules.

Consistency

- 26. Throughout the evaluation consistency in the approach to defining when someone is nearing the end of their life was raised as a key issue. We heard that improving consistency within the benefits system would support people to make a successful Special Rules claim.
- 27. We heard that it would be helpful to have similar definitions across the health and welfare systems, to reduce confusion and make the Special Rules clearer to understand for clinicians and people nearing the end of their life. At engagement sessions with two clinical expert groups, (the Palliative and End of Life Care Strategic Network and the Ambitions Partnership for Palliative and End of Life Care), attendees were supportive of an approach that aligns more closely with that used in the NHS. They thought that this would have the potential to simplify the process for both clinicians and people nearing the end of their lives.

Making a claim under the special rules

28. The evaluation also considered the process of making a claim under the Special Rules. Feedback fell into two broad categories; providing medical evidence and making a special rules claim.

Medical Evidence

29. People nearing the end of their lives, or those that support them, provide the DWP with medical evidence that provides details of their clinical condition, treatment and response to treatment. This is most commonly done by the clinician completing a DS1500 form. The DS1500 form can be completed by

GPs, hospital doctors and registered nurses (where they are working in a role such as advanced nurse practitioner, Macmillan nurse, clinical specialist nurse or a practice nurse with expertise in long term conditions management).

- 30. The DS1500 can be submitted either as a paper copy or an electronic copy and in England by NHS staff, using an online tool. The DS1500 is the preferred and simplest route for providing medical evidence, but is not compulsory, other medical evidence can be considered where a DS1500 isn't available.
- 31. We heard that the clinicians who provide DS1500s don't always fully understand the Special Rules, and that this meant some patients found getting a DS1500 or other medical evidence challenging. Of the clinicians who took part in the survey and had completed a DS1500, the majority believed it was of value: 73 per cent of respondents agreed or strongly agreed with the statement 'the DS1500 is an effective way of providing evidence to support a patient's benefit claim under the Special Rules criteria', while only 12 per cent disagreed or strongly disagreed.⁸ Respondents were asked to explain the reasons for their views. For the majority it was perceived as easy and clear to use. However, some considered that the DS1500 failed to capture certain information they felt was important – particularly where the patient meets the definition but is receiving active treatment, or where it is necessary to explain the details of a condition other than cancer.
- 32. There was consensus that there should be more join up between the DWP, clinicians and people nearing the end of their lives to ensure that the right people can make a Special Rules claim. During the evaluation DWP clinicians conducted two audits of DS1500s that both found high levels of accuracy. The audits found that in many cases, the presence of a 'palliative phrase' helped make it clear that the person was nearing the end of their life.⁹
- 33. There was support during the evaluation for encouraging the use of 'palliative phrases', where appropriate when clinicians are completing a DS1500 and providing training for DWP staff to recognise these phrases. It was felt that this would improve the consistency and accuracy of the DS1500 process. Other improvements were suggested, including to the questions on the DS1500, to make it easier for clinicians to complete the form. Some respondents suggested that the DWP should be able to get medical evidence directly from clinicians rather than asking the individual, when it was needed for a Special Rules claim.

The Claim Process

- 34. We heard that it can be challenging to understand the support available through the benefits system, in particular where different DWP benefits have different requirements and ways to claim. We heard that more information and support to make a claim would improve the process for people nearing the end of their lives, and that once a Special Rules claim is made it would be helpful to have access to information on the progress of the claim, either through a single Special Rules helpline or digitally.
- 35. We discussed the Special Rules process with a group of staff from across the DWP, in a variety of roles. DWP staff who process Special Rules claims felt highly motivated to deliver the best service they could, and handle special rules claims as quickly as possible. While they felt the benefits system allowed them to process Special Rules claims quickly, they also highlighted some areas that could be improved. For example, they identified that the DWP definition of a 'Terminal Condition' is not fully understood by people making a benefits claim and leads to challenges processing Special Rules claims. DWP staff felt that improving how medical evidence is provided to support Special Rules claims would make the process simpler and quicker. Finally, they identified that there were different internal processes in place for processing Special Rules cases in each of the eligible DWP benefits. Staff felt that the DWP should look to align processes across benefits. In particular, they felt that better sharing of information across DWP systems would support Special Rules claims to be handled quickly and efficiently.
- 36. We will consider the feedback received about making a claim under the Special Rules and work to make improvements to the process to better support people nearing the end of their lives in making a Special Rules claim. For example, DWP will begin to implement the 'palliative phrases' approach, this is where the DS1500 includes terms that reference end of life or palliative care to improve accuracy and consistency of DS1500s. This will support both DWP staff and clinicians who are completing medical evidence. We will also continue to make improvements to the DS1500 form and the process of providing medical evidence.

International Comparisons

- 37. In 2020 we sent a questionnaire to a range of countries to ask how they supported people nearing the end of their lives. The questionnaire asked whether they had any processes in place in their welfare systems to support those with a terminal illness, whether they used a definitions of terminal illness and if so, what that definition was.
- 38. Replies were received from 22 countries. In 11 of these countries, a specific route exists for those with a terminal illness to access support from the benefit

system. In others there is not a specific system but support tends to be provided via different avenues for example, through health services provided by hospitals.

39. Several countries provided information about the definition of 'terminal illness' that they use for welfare purposes, these are included in Table 1 below.

Definitions of 'terminally ill'	
Belgium	palliative status: expected survival of a maximum of two months, due to one or more irreversible disorders and with the intention of dying at home
Netherlands	with an expectation to die within 12 months
Australia	average life expectancy of less than two years
New Zealand	average life expectancy of less than two years
Canada	a terminal medical condition is a disease state that cannot be cured or adequately treated and is reasonably expected to result in death within six months
Ireland	end of life means a prognosis of less than 12 months to live
Spain	that they will benefit from palliative care e.g. those with an incurable, advanced and progressive disease; limited life forecast; low possibility of response to specific treatments; evolution of oscillating character and frequent crisis of needs; intense emotional and family impact; impact on the care structure; high demand and use of resources

Table 1. Definition of 'terminally ill' used internationally

40. It is clear that there is no international consensus among the 22 countries which responded regarding the definition of terminal illness within the welfare system.

Conclusions and Next steps

41. The Minister for Disabled People has announced the Department's intention to make changes as a result of the evaluation.¹⁰ We will legislate to introduce a 12-month, end of life eligibility definition for the Special Rules. When implemented, where a clinician considers someone to be in their final year of life, they will be able to make fast-tracked claims to the benefits system.

- 42. The 12-month definition of the 'end of life' period was originally developed by a group of 21 organisations including the General Medical Council (GMC), the Department for Health and Social Care and national charities. Aligning with this approach will enable the DWP to align with existing standards and approaches used in the Health and Care sector. GPs are encouraged to identify who among their patients is likely to be in their final year of life, and in the survey of clinicians moving to a 12-month prognosis period as the eligibility criteria for accessing benefits via the Special Rules was the option with the highest level of support. Our conversations with clinicians also demonstrated significant support for aligning the definition used in the welfare system with the 12-month definition of 'end of life' used in the NHS and by the GMC. It is fair and compassionate to frame the fast-tracked procedure for all individuals who are approaching the end of their lives in a way that reflects current clinical practice. There are a number of benefits to aligning with the NHS, including reducing the need for clinicians to have multiple difficult conversations with people nearing the end of their lives. It also provides opportunities to take advantage of existing NHS initiatives to identify people in their final year of life and for clinicians to consider whether financial support is required and to support the person to make a Special Rules claim to benefits.
- 43.We will also address other findings from evaluation. We will bring forward proposals to improve:
 - awareness of the Special Rules;
 - the process for making a Special Rules claim and; and,
 - obtaining / providing medical evidence for a Special Rules claim.
- 44. These will build on the changes that have already been made during the evaluation period. In 2019, we published updated guidance to support clinicians with completing DS1500s for Special Rules claims. We also introduced a dedicated GOV.UK page with information on claiming benefits for those nearing the end of their lives. The DWP is committed to continuing to work with those that contributed to the evaluation to ensure that further improvements are made.
- 45. The Special Rules are part of the wider support the DWP provides people with severe health conditions and disabilities. The Health & Disability Green Paper explores where and how we can make further improvements to the benefit application and assessment processes for people with the most severe health conditions and disabilities. The proposals in this paper should be considered alongside those in the Green Paper, in particular, for those people with the most severe health conditions and disabilities and disabilities but who would not meet the

eligibility Criteria for the Special Rules, where we intend to test the introduction of a Severe Disability Group.

Annex 1: Devolved Administrations

<u>Scotland</u>

- 1. The Scottish Parliament have legislated to determine who can receive Disability Assistance under terminal illness rules. The Social Security (Scotland) Act 2018, slightly amended by the Social Security Administration and Tribunal Membership Act 2020, introduced the Scottish definition of terminal illness; "An individual is to be regarded as having a terminal illness for the purpose of determining entitlement to disability assistance if, having had regard to the (Chief Medical Officer's (CMO) guidance), it is the clinical judgement of an appropriate healthcare professional that the individual has a progressive disease that can reasonably be expected to cause the individual's death." The 2020 Act included that 'appropriate healthcare professional' must include registered medical practitioner and registered nurse.
- 2. The Scottish Government's definition will apply to new benefits which will replace Disability Living Allowance, Personal Independence Payment and Attendance Allowance. The Scottish Government has not yet introduced replacement Disability Assistance benefits and the DWP continues to administer disability benefits in Scotland on their behalf under Agency Agreements. While these arrangements are in place, the UK rules and definitions regarding terminal illness for the purposes of social security will be applied to Scottish residents in the same way as in England and Wales.
- 3. To support clinicians in Scotland, the Chief Medical Officer for Scotland has produced guidance in advance of the introduction of the Child Disability Payment. This will be the first of the replacement benefits and will replace Disability Living Allowance for children in Scotland. Child Disability Payment will be introduced in Summer 2021 as part of a pilot, with full rollout by Autumn 2021.

Northern Ireland

- 1. Whilst social security is a devolved matter in Northern Ireland, parity has long been a guiding principle.¹¹ This means that in practice, a single system of social security is maintained across the two jurisdictions by the UK Government and Northern Ireland.
- 2. The Department for Communities (DfC) has worked closely with DWP officials from the outset to ensure that the experiences of people in Northern Ireland were captured and considered as part of this wider review of the provision currently in place. DfC has ensured that local input was gathered from clinicians, charities, people nearing the end of their lives and those that

support them and fed into this evaluation work. This included holding an expert stakeholder event in December 2019. DfC issued the online survey to clinicians in January 2020 and gathered the views of people who have first-hand experience of the special rules process in June 2020.

The Eligibility Definition

- 3. As in Great Britain, there was a general consensus from attendees at these sessions that the six-month rule should be changed. Overall, the Special Rules were thought to be important and any changes needed to ensure that DfC were able to continue to fast-track claims.
- 4. DfC heard that the six-month rule was outdated and has no clinical meaning. They were told that the need to obtain evidence showing you are eligible under the Special Rules can be distressing for people. DfC heard that the 6month rule can make it challenging for clinicians to determine life-expectancy for non-cancer conditions with difficult to predict trajectories.
- 5. The 12-month approach, used in the health system, was thought to be an improvement on the current six-month rule. In particular, it was thought that it would allow more people to access the special rules and would be easier for clinicians to use and understand than the current six-month rule. Some felt this definition would give more scope to clinicians to make a judgement call and would potentially work for cancer patients but there were some concerns expressed that it may not necessarily work for those with other terminal conditions.
- 6. While there were a range of views, attendees at the focused stakeholder event hosted by DfC preferred the clinical judgement model. It was thought that it would be more flexible and supportive for people nearing the end of their lives. Attendees cited the support from specialists and experts in Scotland for the clinical judgement model adopted in that jurisdiction for devolved disability benefits. However, some were concerned that such a clinical approach could potentially open up the special rules process to many more people, which could slow the process down. This would be counterproductive to the purpose of the Special Rules. They indicated that there would need to be clear guidance in this model to address this risk.

Awareness

7. DfC also heard that awareness among clinicians of the Special Rules and the DS1500 could be improved. To improve this, they heard that they should promote the revised guidance that supports the completion of DS1500s that was published in 2019. They were advised that they could use existing

clinical networks like the Regional Palliative and End of Life Care group in Northern Ireland.

- 8. It was also highlighted that some clinicians misunderstand the Special Rules and so can be 'nervous' about providing DS1500s. For example, some clinicians mistakenly believe that there would be repercussions if the person lived beyond six-months and so will not complete a DS1500.¹²
- 9. They also heard that people are often unaware of the support available from the benefits system or the Special Rules. Feedback indicated that help from advice groups and independent organisations like Macmillan and support from DfC's Make the Call service is invaluable.¹³

Making a Claim to the Special Rules

10. DfC also heard similar concerns to DWP about making a claim under the Special Rules and obtaining medical evidence.

The DS1500

- 11. They were told that getting a DS1500 can be distressing and inconsistent. One solution that was presented was to allow different types of health professionals to be able to complete DS1500s. In particular, those who are more closely involved in the person's care. It was thought this would improve consistency and make the process easier for people nearing the end of their lives and those that support them. It was suggested that there should be specialised decision makers to deal with Special Rules claims to ensure consistency of decision making.
- 12. It was felt that people nearing the end of their lives should only have to provide medical evidence once. New medical evidence should not be needed when Special Rules claims are reassessed or reviewed.¹⁴ It was also thought the reassessments for Special Rules claims should be replaced by the approach implemented in Personal Independence Payment for people over State Pension age.¹⁵

Making a Special Rules claim

13. DfC also spoke to their own staff from across the different benefits they deliver. Overall, it was thought that the Special Rules work well but some improvements could improve their operation further. They said that generally the DS1500 works well but some misunderstandings can cause problems, in particular they would like to communicate more easily with clinicians when information needs to be checked. DfC also found that communication could be improved and clearer information could be provided on claim forms and in information pages. Finally, it was suggested that some improvements could

be made to the referral process to the Department's 'Make the Call' service for people nearing the end of their lives.

14. During the evaluation, and mirroring the DWP approach from early feedback, DfC also published updated guidance for clinicians on completing DS1500s for Special Rules claims and introduced a dedicated NIDirect page with information on claiming benefits for those nearing the end of their lives.

Annex 2: DWP Evaluation Engagement Events

DWP would like to thank the following organisations and people for their support and input during the evaluation.

The following charities and organisations took part in the evaluation.

- Association of Palliative Medicine
- British Medical Association
- Hospice UK
- Macmillan
- Marie Curie
- Motor Neurone Disease Association
- Queen's Nursing Institute
- Royal College of Nursing
- British Lung Foundation
- Muscular System Atrophy Trust
- National Nurse Consultant Group
- National Bereavement Alliance
- Sue Ryder

The following expert clinical groups also took part in the evaluation. This engagement was facilitated by the National Clinical Director of End of Life Care for NHS England.

- National Strategic Leaders Network for Palliative Care
- The Ambitions Partnership for Palliative and End of Life Care

The evaluation also includes a survey of clinicians from across England, Scotland, Wales and Northern Ireland from a range of professions.

We also heard directly from people nearing the end of their lives through drop-in sessions, telephone interviews and written testimonials organised by Marie Curie and the Motor Neurone Disease Association.

The DWP also discussed the Special Rules with DWP staff and conducted two audits of DS1500s that had been received in support of Special Rules claims.

Finally, we considered the international evidence and heard from 22 countries about their definition and support for people nearing the end of their lives.

DfC Engagement Events

The following charities and organisations took part in the evaluation

- Age Northern Ireland
- Macmillan
- Northern Ireland Motor Neurone Disease Association
- Marie Curie
- British Medical Association Northern Ireland

In addition, DfC heard from people nearing the end of their lives, those that support them and DfC staff. Local clinicians responded to the DWP clinicians survey. ⁶ The clinical survey was live during February 2020, during which time 986 responses were captured (16% consultants, 13% General Practitioners, 6% other doctors, 21% palliative care Clinical Nurse Specialists, 19% Clinical Nurse Specialists, 11% nurses and 14% other)

⁷ The prognosis is the likely outcome of a medical condition.

⁸ These percentages apply to the sub-sample of respondents who had completed a DS1500.

⁹ A Palliative Phrase is a reference to any form of end of life or palliative treatment or palliative care. ¹⁰ https://questions-statements.parliament.uk/written-statements/detail/2021-07-08/hcws166

¹² The guidance for completing a DS1500 states "You will not face any negative consequences from the factual information you supply, for example if your patient lives longer than 6 months"
¹³ In Northern Ireland a service is provided by DfC called Make the Call that supports and advises people applying for benefits

¹⁴ Claims made under the special rules are in most cases given three-year awards.

¹⁵ Most people receiving PIP who have reached State Pension age no longer have their awards regularly reviewed, instead moving to a light touch review at 10 years.

¹ The terminology 'Special Rules' is not used in Universal Credit but the rules relating to terminal illness are comparable to other DWP benefits.

² For example, in Personal Independence Payment when a special rules claim is made, the payment is put in place on average in 4 working days, starting from the point the claim was first made.

³ Social Security Act 1990 - https://www.legislation.gov.uk/ukpga/1990/27/section/1/enacted; Benefits for Disabled People: A Strategy for Change,1988, Social Security Advisory Committee

⁴ https://www.goldstandardsframework.org.uk; https://www.rcgp.org.uk/daffodilstandards; http://endoflifecareambitions.org.uk

⁵ https://www.gov.uk/government/publications/dwp-factual-medical-reports-guidance-for-healthcareprofessionals/dwp-medical-factual-reports-a-guide-to-completion; https://www.gov.uk/terminal-illnessbenefits

¹¹ Social Security and policy on health are wholly transferred in Northern Ireland. On social security matters, Ministers regularly consult one another with a view to maintaining parity in the systems across the UK. In Northern Ireland the social security system is administered by The Department for Communities.