

# **Consultation on Guidance from the Office of the Chief Medical Officer for Scotland: Definition of Terminal Illness for the Purpose of Disability Assistance**

## **Consultation Analysis**

July 2021

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# Introduction

## Background

The Scottish Government included provision in the Social Security (Scotland) Act 2018 to introduce a new definition of terminal illness that differs from the current UK Government definition. Therefore, when making Disability Assistance Regulations under the Act, the definition is:

“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 a Registered Medical Practitioner that the individual has a progressive disease that can reasonably be expected to cause the individual's death.”

This differs from the current UK DWP Social Security legislation where a person is deemed terminally ill if they suffer from "a progressive disease and their death as a consequence of that disease can be reasonably expected within 6 months".

If diagnosed as terminally ill under the new Scottish definition, an individual becomes eligible for special rules, and their application for Disability Assistance will be processed differently by Social Security Scotland. This means that:

- there is no qualifying period. An individual is not required to have the condition for any length of time before they are eligible under special rules;
- once verification has been given that the person is considered to have a terminal illness, for the purpose of entitlement to Disability Assistance, there is no requirement for an individual to undergo any further assessment to establish that a person has a terminal illness;
- awards will be calculated, at the latest, from the date of application by the patient; and
- individuals who qualify under special rules will be automatically entitled to the highest rate of the component part(s) (care and mobility) of whichever benefit they are entitled to.

This may also enable the person's carer to access Carer's Allowance quicker, as this is a 'passported' benefit, dependent on the person receiving one of the disability benefits.

## The Guidance

To support clinicians' critical decision making, the CMO, in consultation with Registered Medical Practitioners, set the framework in guidance. A Short-Life Working Group on Terminal Illness for Disability Assistance was established, responsible for developing the CMO's Guidance for registered medical professionals to make clinical judgements about 'terminal illness'. They were

supported by a Stakeholder Reference Group (SHRG), who provided the perspective of users and their carers during the development of the Guidance.

The Guidance - which was the focus of the consultation discussed in this report - is concerned with establishing whether a person has terminal illness for the purposes of determining eligibility for disability assistance on the basis of special rules. Its starting point is to determine whether it is the clinical judgement of a Registered Medical Practitioner involved that the person has a progressive condition, which can reasonably be expected to cause the person's death. In addition, it considers whether the individual requires expedited access to Disability Assistance arising from that condition.

Produced in January 2019, the Guidance is around 50 pages in length. It contains a section on eligibility for Benefits Assessment under Special Rules in Scotland (BASRiS), including an example flowchart for assessing eligibility. It also covers broader operational points such as communications, responsibilities, data management, etc., as well as various copies of resources to aid implementation as an Annex (e.g. an example application form).

## **The Consultation**

The purpose of the managed (non-public) consultation was to gather views of relevant professionals on the content, structure, and implementation of the Guidance. Letters were issued to relevant stakeholders by the CMO in February 2019 inviting contributions to ensure that the Guidance, when finalised, meets the needs of medical practitioners and others, and enables them to support the delivery of fair and person-centred outcomes.

The consultation asked nine substantive questions and all but one contained both a closed response option (i.e. respondents were asked to indicate if they agreed or disagreed with the various statements/proposals using a 'yes' or 'no' option) as well as an open-ended component, inviting respondents to explain their answer in more detail. The only question that did not contain a closed response component was the final question, which invited additional comments.

The survey was administered directly by the Scottish Government using the Questback survey facility. Emailed and written responses were also invited.

The consultation opened on 12 February 2019 and closed on 19 April 2019.

## **Responses Received**

A total of 54 responses were received. There was an even split between responses from organisations (35%), Registered Medical Practitioners (31.5%) and Other Healthcare Professionals (31.5%). The one 'other' response came from an individual.

Response received from	Number	Percentage
Organisations	19	35%
Registered Medical Practitioners	17	31.5%
Other Healthcare Professionals	17	31.5%
Other	1	2%
<b>Total</b>	<b>54</b>	<b>100%</b>

The majority of organisational responses came from professional bodies that represent medical professionals or from the third sector (i.e. those who provide support or assistance to individuals who may be eligible for the relevant benefits). Annex A provides a full list of organisations that responded.

## Approach to Analysis

Most responses (n=44; 81%) were submitted directly via Questback, with the remaining nine responses being submitted either by email or letter, directly to the Scottish Government.

All responses were read and logged into a database, and all were screened to ensure that they were appropriate/valid. None were removed for analysis purposes.

Closed question responses were quantified and the number and percentage of respondents who said 'yes' or 'no', were 'unsure' or who provided 'no response' to each question is shown below<sup>1</sup>.

While the length and level of detail provided in response to open questions varied considerably, most gave full responses to support their closed answers. Some respondents did not answer every question, and responses also varied in how closely they answered the specific questions asked.

Similarly, for some questions, although only those who did not agree or said 'no' to closed questions were asked to provide additional information to support their response, many who either did not provide a closed response or who said 'yes' went on to provide additional narrative. This was analysed and is reported below.

The main reasons presented by respondents both for and against the content included in the consultation were reviewed, alongside specific examples or explanations, alternative suggestions, caveats to support and other related comments. Verbatim quotes were extracted in some cases to highlight the main

<sup>1</sup> Where respondents gave no closed response, but provided an open response, these were independently reviewed by two analysts and assigned to categories of 'yes', 'no' or 'unsure' for quantitative reporting purposes. Where there was 'no response' it was coded as such.

themes that emerged. All extracts from responses have been anonymised as no formal consent was sought to publish material alongside respondents' identities.

## **Report Presentation and Research Caveats**

It is important to note that many who took part in the consultation did not answer the questions that were asked directly and, instead, provided more general comments on the new approach to BASRiS. There was also much repetition in some responses, with similar answers being given in response to multiple different questions. Given that this occurred in response to several of the posed questions and was characteristic of a large volume of the data returned, the material was included in the analysis. In some cases, however, material that was provided in response to one question is presented elsewhere in the report, where the fit was considered more appropriate. Findings are presented as they relate to each question in the consultation, in turn.

Another feature of the data was that open-ended explanations were more often submitted by those who gave negative responses, rather than those who supported different aspects of BASRiS. While the findings presented below may, therefore, have some inherent negative bias, it is important to note that all but one question attracted more positive than negative responses when considering the closed data only.

The tables below show the difference in views expressed by the respondent group as a whole. Where there was a difference in view expressed by respondent type (e.g. organisations of individual medical professionals), this is picked up narratively in the report. As a guide, where reference is made in the report to 'few' respondents, this relates to three or fewer respondents. The term 'several' refers to four or more, but typically less than ten. Any views expressed by large numbers of respondents (i.e. ten or more) are highlighted throughout.

Finally, although a reasonably large number of responses were received overall (n=53), it is worth stressing that the views presented here should not be taken as representative of the wide range of stakeholders invited to respond to this consultation, nor should they be generalised too broadly. They simply reflect the views of those individuals and organisations who chose to respond.

This final report on the analysis of the managed consultation was concluded in June 2019. It was determined appropriate to await publication in order that it aligned with the publication of the CMO Guidance itself.

# The Process for Accessing BASRiS

Under the new system, Registered Medical Practitioners, who certify that their patient is terminally ill and is eligible for benefits under special rules will complete the Benefits Assessment under Special Rules in Scotland (BASRiS) form and submit it to Social Security Scotland. The Guidance includes a flowchart for eligibility for BASRiS form completion, designed to be a useful reference in assisting the process. A copy of the draft form was also provided as well as case study examples showing how different types of cases should be managed.

Importantly, the Guidance makes clear that, while Registered Medical Professionals may need to seek advice of specialist nurses or others involved with the patient's care (professionally or non-professionally) to inform the decision, the new form can be completed only by Registered Medical Practitioners. This is in contrast to the DS1500 form used for accessing benefits under UK Social Security legislation, which can also be completed by specialist nurses.

The first part of the consultation sought views on whether the Guidance was clear about the process for accessing BASRiS.

Q1. Is the Guidance clear about the process for accessing benefit assistance under special rules in Scotland (BASRiS)?

Response	Number	Percentage
Yes	36	66%
No	15	28%
No response	3	6%
<b>Total</b>	<b>54</b>	<b>100%</b>

Two thirds of respondents (66%) indicated that the Guidance was clear on process.

The flowchart and case study examples and other annexes were mentioned as being particularly helpful:

“There are clear explanations around the process and the examples are useful to assist with clarify[ing] the process. The flow chart is also useful in supporting the process.” [Other Healthcare Professional]

“...good easy to follow guidance with helpful worked examples.” [Royal College of Occupational Therapists]

There was also a sense that providing guidance of this nature, with a clear definition that removed the specified timescale would (in principle) enable medical

professionals to focus on the patient without being expected to predict a time to death (although this was caveated by some in response to later questions).

Some who said that the Guidance was clear on process overall did, however, caveat their response by suggesting that it was quite lengthy and perhaps unnecessarily so. Some changes may be needed to maximise clarity:

“Overall, we do believe the document can work and the guidelines will support medical practitioners to make clinical decisions around who is terminally ill for the purposes of accessing social security, but a number of key changes need to be made.” [Marie Curie]

Specific comments were made that the Guidance was complex when describing legal implications and that this type of information may be unnecessary:

“I think this is unlikely to be abused in the hands of doctors so removing some of the legal issues from the main body of the text and emphasising trust in clinical expertise would be appropriate.” [Registered Medical Practitioner]

Others who said ‘no’ to this question also suggested that the document was generally too wordy, unstructured, too long and contradictory and perceived that this could be problematic:

“...we are concerned that the Guidance as a whole is not as clear and direct as it could be. We believe that the document should be restructured and edited in order to make sure that it is as easy as possible for busy clinicians to follow. Overly complicated Guidance could act as a barrier to people who need access to benefits under special rules from being able to do so.” [Parkinson's UK Scotland]

While concerns about the length and structure of the document are discussed in more detail below (see Question 3), the more specific concerns regarding understanding of process are presented under themed headings below.

## **Reserved and Devolved Benefits**

While one respondent noted that the document was clear on the difference between devolved and reserved benefits and the different processes for accessing both under special rules, several others suggested that this was one of the main areas of the Guidance (and policy change) which may cause confusion.

Indeed, several respondents commented that greater clarity was specifically required in relation to the need for BASRiS to operate alongside the DS1500<sup>2</sup>. Having the two parallel processes and forms could, it was felt, lead to confusion going forward and may also lead to some repetition of processes:

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<sup>2</sup> The DS1500 form is used for reserved UK benefits in cases of a progressive disease where death as a consequence of that disease can reasonably be expected within 6 months.

“It seems unfortunate that this is an addition to a DS1500, rather than replacement, this surely makes things more, not less, complex?” [National Advisory Committee for Neurological Conditions]

The notion of automatic eligibility also seemed unclear to several respondents:

“It is not clearly enough explained what happens if someone is applying for disability assistance or for a higher rate of disability assistance on the basis of terminal illness and: they already have entitlement to a reserved benefit on the basis of a DS1500; they are also applying for a higher rate of a reserved benefit on the basis of a DS1500; they are also making a new claim for a reserved benefit as well as disability assistance. The aim must be to ensure that having two parallel processes to evidence terminal illness is no hindrance to people being fast-tracked to their entitlements. The surest way to achieve this would be that in any circumstances a DS1500 would be accepted instead of a BASRiS form. The Guidance, including the flowchart (and the disability assistance regulations) should reflect this.” [Child Poverty Action Group in Scotland]

One respondent stressed that, while the Guidance may be clear for medical staff accessing forms, it could be confusing to patients, especially if applying for benefits under both the devolved and reserved systems at the same time. The fact that this may entail communication with two separate healthcare professionals was also seen as potentially confusing for some:

“I think the Guidance is clear for medical staff accessing forms but will be confusing for patients as they will need two forms if they are applying for disability benefits and other benefits not devolved to Scotland. They may also have two health professionals completing two forms as GP/Medical staff will be completing BASRiS form and Specialist nurses will be completing the DS1500s as previously.” [Other Healthcare Professional]

Another indicated that the two parallel processes needed to be more clearly signposted in the title of the document:

“The fact that BASRiS replaces DS1500 for benefits devolved to Scotland is mentioned, but not clearly enough in the title of the document. There was confusion during discussions with clinicians about the implications of this legislation, and accompanying Guidance, and a lack of awareness that DS1500 is being replaced by BASRiS in certain circumstances.” [RCGP Scotland]

While the concurrent operation of the two processes is explored throughout the draft Guidance document, it is perhaps not explicit enough and this may lead to confusion among medical practitioners, it was suggested, especially if they fail to read the Guidance in detail, due to time pressures.

## **The Role of Clinical Nurse Specialists**

A second dominant concern regarding process was linked to the role of clinical nurse specialists (CNS). Several used this question (as well as later questions in the consultation) to make a point that, as nurses will not be allowed to complete the BASRiS form, it may mean that many patients will not receive their benefits in as timely a manner as they do at present:

“The process will now be less efficient as the nurse specialists who know the patients well, will be unable to complete the form. It is a step backwards, where nurses fill in a form and then bring it to a doctor to sign. A process to make it less complicated and more accessible to those in need, just became less efficient.”  
[Other Healthcare Professional]

Others commented that they simply did not understand the rationale for excluding nurses from being able to sign the BASRiS form and argued strongly against their exclusion, especially in general practice. This was on the grounds that it would be too time consuming for medical professionals, especially since the broadening of eligibility criteria may result in more requests to access such benefits:

“It is not clear why nurse specialists can no longer fill out the form. Nurse specialists who have contact with patients eligible under special rules, are well positioned to know such patients. My concern is that medical staff due to other commitments will not fill out the form in a timely manner for patients and many patients will miss out. It will also take away a process that is already working by meaning that nurse specialists/other health professionals will be chasing medical staff to fill out the forms. This will make the process itself very inefficient on a day-to-day basis.” [Other Healthcare Professional]

There was also concern that having two forms to access reserved and devolved benefits would compound pressure on doctors' time, unless the intention was that responsibility for decision making only applied in cases where a patient was ineligible for a DS1500 (as specialist nurses are able to complete these forms).

The same respondent also indicated that the decision to exclude nurses had, perhaps, been rushed and not fully considered:

“More generally, the amendment that limited decisions to Registered Medical Practitioners was published less than a week before the Social Security (Scotland) Bill passed at stage 3. This meant there was simply not enough time for the wording limiting completion of these forms to medical practitioners to be fully considered or scrutinised. While we acknowledge that it would require further primary legislation, we believe there is a strong case for a future amendment to the Social Security (Scotland) Act to allow specialist nurses to complete BASRiS forms on the same basis as they can currently complete DS1500 forms.” [British Medical Association (BMA)]

Indeed, the exclusion of nurses and the perceived absence of rationale for this was a cross-cutting theme for the consultation and is discussed in relation to some of the other questions below.

## **Clarity Regarding Eligibility**

While some again welcomed the aspirations of the Guidance, and respondents agreed that having a workable definition of 'terminal illness' was key, several commented that the Guidance could be clearer in this respect, as well as being clearer with regard to eligibility:

"I think that currently there would be variable interpretation of the definition."  
[Registered Medical Practitioner]

"As it is currently drafted, this Guidance does not provide anything approaching clear definitions of when conditions should or should not be considered terminal for the purposes of this Act and is therefore wholly inadequate. While having sufficient flexibility in the system for doctors to use their professional judgement is important, there needs to be a credible set of criteria against which this judgement can be applied. Without robust definitions, doctors will be left in the impossible situation of not knowing what should or should not trigger eligibility for BASRiS forms." [British Medical Association (BMA)]

"This new proposal by using the word 'terminal' is not clear enough in my opinion." [Registered Medical Practitioner]

Suggestions were made that more information may be needed in particular around assessments involving some cancers and lymphoma with long survival times as well as secondary cancer and some other progressive conditions (e.g. diabetes, Chronic Obstructive Pulmonary Disease (COPD), ischaemic heart disease, cancer, cerebrovascular disease, dementia, chronic lung conditions, multiple sclerosis, cystic fibrosis and potentially even alcohol or opiate dependency). One respondent specifically suggested that reference to 'cancer' should be replaced with reference to 'advanced, incurable cancer' with some other qualifiers (where this appears in Annex B).

The main concern around having a 'loose' definition was that it could lead to a significant increase in applications for the benefit as well as place too much responsibility on medical professionals for something which respondents felt should be clearly set out in legislation. Doctors should not be expected to be the ones to set limits on what conditions are or are not eligible for assistance, it was suggested and these could be more clearly stipulated by government in the Guidance. While several did support the matrix in Annex B, and the indicators were largely welcomed, refinements may be needed to provide a more workable and definitive way of determining eligibility, it was suggested.

Several respondents also commented later in the consultation that Annex B could be reworked and strengthened, or moved to the main body of the report if it was to be used to determine eligibility.

## **Clarity Regarding Timescales**

On a related note, several respondents raised the issue of timescales and whether it was appropriate to require medical professionals to make subjective assessments in this regard or to raise the issue of life trajectories in discussions with patients:

“The Guidance should not ask Registered Medical Practitioners if they would expect their patient to die ‘very soon’. This is completely contradictory to the content and purpose of the legislation. Regular reference in Section 7 of the Guidance to Annex B is therefore highly problematic. Instead, the Guidance should highlight that Registered Medical Practitioners should not introduce timescales, in any way, into their prognostic judgements.” [MND Scotland]

“...we consider there is further scope to clarify the Guidance particularly around the requirement of not introducing timescales into their prognostic judgements as per the definition of terminal illness in the act.” [Children's Hospices Across Scotland (CHAS)]

Several respondents also stressed that they perceived it wholly inappropriate that doctors be asked to make functional assessments:

“...the Guidance should be very clear that: the definition and Guidance require that doctors should not introduce timescales into their prognostic judgements; and the definition and Guidance mean that doctors should not base their judgement on particular needs of a patient, nor is there a requirement that patient needs or functional impairments should be assessed.” [Scottish Partnership for Palliative Care]

Greater clarity or tightening up of the definition for patients with life-limiting illness and where treatments may prolong life but not cure was needed, it was felt. Some comments were made that the case studies could be tightened-up to add clarity in this regard too (and this was also discussed in relation to Question 5, discussed below). Some stressed that it could be clearer and more ‘up front’ that different definitions are in play for different benefits.

## **Other Suggestions for Adding Clarity**

Other suggestions for making the process clearer still, and which were mentioned in response to this question rather than later on, included:

- adding more indicators of progressive illness in the Guidance, for consideration (e.g. ability to cope with activities of daily living and other generic markers of declining health);

- that occupational therapists be specifically named as professionals who could be consulted for advice at Section 10, as well as Welfare Rights Officers;
- moving some of the bullets listed under the subheading 'Principles' to elsewhere in the document (i.e. those that may be better described as 'facts');
- including more detail about where to find the form on the Social Security Website (and possibly a web link) and highlighting in the Executive Summary that further information on the form can be found in Section 21; and
- avoiding use of the term 'passport benefit' as this may be jargonistic and unclear (alternatively, expanding on the meaning of this phrase the first time it is used in the document may add clarity).

One respondent proposed using the term 'Registered Medical Practitioner' throughout the document so as to avoid confusion, removing references to GPs. The same respondent suggested that it should be made clear throughout the document that, while Registered Medical Practitioners can make a 'judgement', it is Social Security Scotland that will make the final benefits award 'decision':

"The clinician makes a 'judgement' on terminal illness, BASRiS form is submitted on which Social Security Scotland makes a 'decision'. The clinician is therefore not the 'decision-maker'." [Children's Hospices Across Scotland (CHAS)]

Other more general comments included that more advice or guidance on process would be welcomed, especially for non-specialist service providers, and which could be easily shared among professional networks.

Overall, however, while there was scope for the Guidance to be clearer, responses also indicate that Guidance was nonetheless welcomed to assist patients and families in accessing the benefits to which they are entitled:

"SPPC welcomes the intention of the Act and Guidance to broaden access to benefits under special rules. The Guidance has the potential to enable more people with medical conditions other than cancer to get access to benefits under special rules. We welcome the potential for this Guidance to support dignity and wellbeing towards the end of life." [Scottish Partnership for Palliative Care]

# The Process for Children and Young People

The second question in the consultation sought views on the process set out in the Guidance as it relates specifically to children and young people. Section 9 of the draft Guidance offers specific advice around how such cases should be managed as well as highlighting the need to consider the views of children and young people in the decision-making process, and how to approach discussions sensitively with this group.

Q2. Do you feel that the Guidance clearly outlines the process as it relates to children and young people?

Response	Number	Percentage
Yes	34	63%
No	8	15%
No response	12	22%
<b>Total</b>	<b>54</b>	<b>100%</b>

The majority of respondents (63%) expressed that the Guidance clearly outlined the process as it relates to children and young people.

Importantly, however, several respondents, including those who either said ‘yes’, ‘no’ or gave no closed response to this question indicated that, as they did not work with children or young people, they felt unable to comment further.

Particular praise was given to the reference to Getting it Right for Every Child (GiRFEC)<sup>3</sup> within the Guidance, as well as reference to the need for appropriate communication strategies to be employed:

“It is reassuring to see acknowledgement of the need for different forms of verbal and non-verbal communication to meet the needs of children and young people. Inclusive communication is key to delivering this and respecting their rights as individuals.” [RCGP Scotland]

Among those who agreed that the Guidance was clear in this regard, however, some caveats were put forward, including that information in relation to processes for children and young people could be included as an annex to the main document, since cases would be quite rare.

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<sup>3</sup> GiRFEC is the Scottish Government's approach to supporting children and young people. More information is available at: <https://www.gov.scot/policies/girfec/>

Comments made by those who felt that the Guidance was not clear as it relates to children and young people included that the section was unnecessary since the BASRiS process is fundamentally the same for children as it is for adults and that information on appropriate communication strategies may also be unnecessary, given that professionals' working in the medical field would already be adept at communicating sensitively with children and young people:

“...there seems little value in having separate sections on children and young people, particularly as it creates an expectation that there will be different requirements or processes involved. Doctors are already well aware of the need to communicate appropriately with and respect the rights of children and young people and it serves little purpose to reiterate this in Guidance that is already lengthy.” [British Medical Association (BMA)]

Conversely, one organisation suggested that more could be included to signpost medical professionals to specialists working with younger patients, to ensure that assessments are robust:

“While there is an outline stating that children and young people are also eligible, it would be helpful to suggest that a doctor making the assessment consult a colleague with expertise in care of children and young people with progressive conditions as the progressive conditions are different in this group and take a different course from adults.” [Registered Medical Practitioner]

One organisation and one Registered Medical Practitioner noted that they perceived the examples were helpful, as this was a complex area. However, a different organisation suggested that greater clarity could be achieved if the bullets in Section 8 of the document reflect that a formal diagnosis may not be able to be recorded as this may not have been made. This was because not all progressive diseases in paediatric palliative care have a formal diagnosis. This individual highlighted that this lack of formal diagnosis was recognised as an option in the BASRiS form.

A more general comment was made that the wider confusion of Scotland having two forms (with a DS1500 still being operational alongside BASRiS) may be confounded when considering how children and young people fit into the process.

A different respondent suggested that more emphasis should/could be made earlier in the document that the Guidance was for all potential recipients, rather than mentioning children and young people later in the document.

There was also a suggestion from one organisation that reference to Children's Hospices Across Scotland (CHAS) within the Guidance may usefully include a link to the referral page on their website: [www.chas.org.uk/referral](http://www.chas.org.uk/referral)

Only one other final comment was made that the heading for Section 9 of the Guidance should include babies, i.e. Babies, Children and Young People.

# Understanding and Navigation

The Guidance was designed to be accessible and succinct, whilst still providing reference to additional support, where necessary, to aid practitioners in their decision-making process. As well as including a flowchart for eligibility for BASRiS form completion, the Guidance outlines the purpose and principles of BASRiS, provides legislative context, sets out the aims of BASRiS and addresses components of professional practice (i.e. how clinical assessments should be made, factual information that should be included in the assessment, consideration of children and young people as patients, details on who can complete the form, communication, professional responsibilities, timescales, consent and access to/release of information).

Q3. Do you find the Guidance easy to navigate and understand?

Response	Number	Percentage
Yes	30	56%
No	21	39%
No response	3	5%
<b>Total</b>	<b>54</b>	<b>100%</b>

More than half of respondents (56%) said that they found the Guidance easy to navigate and understand.

Some again mentioned the flowchart as being particularly helpful, welcoming its prominence in the Guidance, and others said that they found it helpful to have supporting information contained in annexes:

“The flow chart in Section 2, and Section 7 are likely to be the most read parts of the document by clinicians and we believe that these are the main strengths of the document.” [Marie Curie]

The table highlighting the differences between the reserved and devolved systems was again welcomed.

## Length of the Document

Similar to responses to the earlier questions, however, even those who gave a positive response to this question noted that the Guidance was perhaps too long. Suggestions were made that even more of the main content could be moved to annexes, and/or that some of the paragraphs could be broken up a little to help the reader:

“While much of it is formed of annexes, it is unrealistic to expect already overstretched doctors to refer to over 50 pages of guidance when presented with a BASRiS form to complete. A very short ‘at a glance’ guide is required with signposting to further details for those who wish them. This should be limited primarily to the criteria against which decisions should be made that are currently absent from this guidance and the process for completing BASRiS forms.”  
[British Medical Association (BMA)]

There were some suggestions that the length of the document may be prohibitive and result in some practitioners not finding time to read it thoroughly, potentially leading to mistakes in implementation.

“Document too lengthy and has too much information contained within it. Busy Health Care Professionals (HCPs) won't have time to go through all the sections and I fear that errors will be made, resulting in people affected by cancer losing out on valuable benefits at a time when they most need them.” [Individual]

Specific suggestions for making the document easier to navigate and understand included:

- including an index page of content at the beginning of the document (noting, however, that a table of contents is already provided);
- shortening the Executive Summary; and
- removing repeated references to the annexes.

Things which could potentially be removed, moved to an annex or required greater explanation included:

- moving the section on ‘patients interests to disclose’ to an annex;
- moving four of the last five paragraphs in Section 7 elsewhere in the document, as they do not explicitly cover clinical assessment (the exception being the paragraph that refers to the worked examples in Annex C); and
- deleting or providing more explanation for the need to discuss the number of patients a GP will spend time with, on average (Section 7).

## **Structure of the Document**

The layout was also seen as problematic, for some. One medical organisation reported that they found it difficult to navigate as it was fragmented with too many references and cross-references to the 12 Annexes, various websites and to the other sections within the document. The same respondent also suggested that different parts of the document were directed to the reader i.e. Registered Medical Practitioners, and others to a more general audience. This organisation, and another, suggested changes to the structure to make the document more succinct:

“The Guidance is not easy to navigate or understand. There is a need to improve the structure of the document so that key information is prominent and it is easier for clinicians to pick up and use.” [Scottish Partnership for Palliative Care]

Highlighting more clearly the key steps in the process, e.g. by putting them into boxes throughout the document, was suggested.

As well as being perceived as being too long, the Executive Summary, in particular, was criticised for being too wordy and potentially off-putting to readers:

“We believe that as it currently stands the Executive Summary feels too ‘busy’ and doesn’t flow when reading it. It is a key element of the Guidance which professionals may concentrate on reading alongside Section 7 of the document. Greater thought needs to be given to making the Executive Summary shorter and sharper. The main body of the document extends to nineteen pages yet the Summary runs into three pages.” [MS Society Scotland]

“The final paragraph on page 5-6 in the Executive Summary talks about complexity, and confusion. “Complex” appears twice, “confusing” and “challenging” once each. The word “different” is used six times in a single paragraph. While we acknowledge that this is a complex area of policy, there is a risk that what is intended as a description has the effect of becoming a self-fulfilling prophecy, and being told how difficult it is going to be could act as a major disincentive for doctors to continue the process.” [Parkinson's UK Scotland]

One respondent strongly supported a redrafting of the document to simplify language, shorten sentences and paragraphs where possible, to distill the key information into the main document. This, they suggested, would better help meet the policy aim, to make sure that everyone who can benefit from access to benefits under special rules can do so.

One organisation and one Registered Medical Practitioner suggested that an online version with links between sections may be easier to navigate. Another organisation suggested that it may be helpful to hyperlink the contents page to allow people to navigate more easily to particular sections within the Guidance (including hyperlinks to relevant annexes within the text):

“Having to go back and forward to the annexes made it difficult to read this Guidance. This may be easier online but the text is too dense and needs broken up to make it easier to read.” [Registered Medical Practitioner]

## **Target Audience and Purpose of the Document**

A further issue raised by just a few respondents was that the document did not make clear who the target audience/reader group was.

One organisation suggested that the purpose of the document needed to be more clearly communicated at the start and should set out the key questions it is designed to answer:

“The Executive Summary or an Introduction should give clear and succinct answers to some basic questions which any reader is likely to have when picking up this document for the first time...Once orientated at the outset by clear answers to these questions the reader is better equipped to wade through the unavoidable complexities.” [Scottish Partnership for Palliative Care]

The suggested questions that should be covered were:

- Who is the document for?
- What is the document aiming to do?
- Why is this important for the reader and the people they provide care for?
- How will the document go about its aim?

## **Eligibility Criteria**

A final point (mentioned here and elsewhere in the consultation) was that the Guidance should focus more ‘up front’ and more clearly on the definition of terminal illness and eligibility criteria for BASRiS. One medical organisation noted that, while the new definition of terminal illness was repeated several times within the document, there was no clear heading to direct the reader to it.

Again, there was a suggestion from one respondent that the material and eligibility criteria outlined in Annex B would be better positioned in the main body of the Guidance.

Another individual noted that, while they accepted that it was professionally very difficult to predict the timing of a person’s death from a condition (and that this is a key reason behind the new definition), they anticipated some difficulties with the new approach and felt that making objective and subjective criteria more explicit in the Guidance maybe helpful.

One organisation also specifically suggested removing the final bullet point in Section 6 (which discussed eligibility without obtaining BASRiS nor DS1500), as this may be contradictory and potentially confusing.

Overall, it seems that there was support to make the Guidance more concise with some restructuring to make eligibility criteria and the definition of terminal illness more prevalent within the main body of the document. On the whole, the substantive content of the document was not questioned, rather the focus seemed to be on reducing the length and improving the structure:

“The Guidance would benefit from further work to really think about what the audience’s requirements are and how best to guide them through it. There is also a need to be mindful of the length of the Guidance. Where possible plain English

should be used and with as succinct wording as possible.” [Children's Hospices Across Scotland (CHAS)]

One suggestion was made that, once the content of the Guidance has been revised (following the consultation) an independent review be undertaken to ensure that the structure and overall readability is acceptable, prior to publication.

# Clinical Judgements

The definition of terminal illness for the purpose of disability assistance will be based on the clinical judgement of a Registered Medical Professional, and will not be based on any time-restriction in relation to prognosis of the condition/s. A number of relevant indicators were provided in the Guidance and it is made clear that it is not necessary for all of the indicators to be present for eligibility to apply, but that several in combination would be expected. The Guidance also explains that decisions should be made on clinical grounds as well as based on suitable clinical expertise and opinion (including experience of the patient and their carers or family, and information gathered from colleagues). It also sets out that certainty is not required.

Q4. Does the Guidance make clear how clinical judgements should be made?

Response	Number	Percentage
Yes	35	65%
No	13	24%
Unsure	1	2%
No response	5	9%
<b>Total</b>	<b>54</b>	<b>100%</b>

Two thirds of respondents (65%) agreed that the Guidance makes clear how clinical judgements should be made.

Again, supportive comments were made that the Guidance contained a lot of information to guide judgements, that the worked examples were helpful and that the list of indicators provided in Section 7 were a useful summary of the more detailed content in Annex B.

One respondent welcomed the statement that it is not necessary for all of the indicators to be present and two commented that removing the length of the qualifying period and removing the need for certainty was welcomed<sup>4</sup>:

“...it is to be welcomed that the focus is on the patient’s clinical status, prognostic factors, underlying disease and that the, for some, confusing issue around the length of qualifying period is removed from the process.” [RCGP Scotland]

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<sup>4</sup> One respondent suggested that ‘Certainty is not required’ should be a paragraph on its own in Section 12, as it is in Section 7.

“...it is made clear to clinicians that there are difficulties that surround prognosticating the exact time in which someone will die and that therefore certainty of death is not required from a clinician.” [Macmillan Cancer Support]

Again, several commented here and elsewhere that the flowchart was particularly helpful.

## **Contradictions Confounding Judgements**

The main emerging issue for this question was concern that some parts of the Guidance may provide contradictory advice on how judgements should be made and the role of the clinician in making those judgements.

In particular, one organisation noted that the Disability Assistance Regulation (DAR) and Section 3 of the Guidance both state that illnesses must be ‘terminal’ in order for a patient to be eligible whereas Sections 1 and 7 provide guidance that eligibility for BASRiS is not defined solely by the diagnosis of a terminal condition, and that clinicians should make an additional assessment on the person’s need and functionality. While some may therefore interpret that a diagnosis of a terminal disease is not the sole qualifier for access to the BASRiS system, others may not. This was confounded by the inclusion of Annex B and the indicators in Section 7 which may also be interpreted differently:

“We are concerned that conflicting guidance for clinicians may have a negative impact on access to BASRiS. We would like to see stronger engagement with clinicians about how easy they find the Guidance to understand, particularly in relation to what requirements they expected to meet in terms of defining a person’s eligibility. We are keen to ensure is that this lack of clear instruction to clinicians does not create the environment for inequitable application of eligibility criteria on applicants.” [Macmillan Cancer Support]

This same organisation said that they would like to see the Guidance amended to give clinicians clear guidance as to whether they are: (a) defining eligibility based on the diagnosis of a terminal illness that will likely be the cause of their death (b) defining eligibility based on both a diagnosis of a terminal illness that will likely be the cause of their death and based on their clinical judgement that a patient fits a range of indicators that the CMO has defined as symptomatic of nearing the end of life.

A different organisation suggested that, while they welcomed the content of the approach to clinical assessment set out in Section 7, they felt that the language used to describe the indicators was necessarily imprecise (e.g. “advanced”, “rapid/erratic”, “unstable”, “worsening”) and therefore capable of widely varying interpretation, either singly or when considered collectively. This may lead to variation in the judgements made by clinicians, with consequent inconsistency. Secondly, the use of imprecise terms may mean that the basis of the judgement lacks transparency. For this reason, they and another respondent suggested that Section 7 could be further improved by linking it more explicitly to Annex B or

bringing it into the main body of the text. Both respondents recommended stating that the tools in Annex B are to be used as part of the clinical assessment to inform the clinician's judgement, to help reduce variability in implementation:

"... this content should be brought into the body of Section 7 so that they are clearly and unambiguously part of the required clinical judgement process. Currently the content of Annex B is framed as "some tools which you may wish to use" - this means that some doctors may use Annex B content and some may not, further increasing inconsistency and lack of transparency in decision-making. An alternative to including the content of Annex B (sections B and C) in the body of Section 7 would be to frame the link to the Annex more directly e.g. "in reaching your judgement you are expected to use the indicators in Annex B as well as the indicators in this section [7]." [Scottish Partnership for Palliative Care]

Another respondent noted that there was contradiction between Sections 7 and 6 with the former suggesting that Registered Medical Practitioners should consider the wider circumstances of their (terminally ill patient's) ability to cope with undertaking activities of daily living (the same as on the draft BASRiS form) while the latter states that it is not for practitioners to undertake a formal functional assessment. This paragraph should, therefore, be taken out of the Guidance, they suggested as it was both contradictory and superfluous (and may lead to confusion and considerable variation in application of the guidelines, another suggested):

"This is not relevant to the fundamental objective of the Guidance which is to assist a Registered Medical Practitioner to make a judgement on whether or not a patient is terminally ill, as defined by the Social Security (Scotland) Act." [MND Scotland]

Again, there was a feeling that the eligibility criteria were too loose and there was insufficient guidance around progressive but potentially curable illnesses:

"With regards to patients with malignant disease I think further guidance is necessary on definition of a terminal condition. With increasing treatment options many patients live for a reasonable time with advanced incurable disease. Does progressive illness mean currently progressive or highly likely to progress in future and is it expected that progression is accompanied by decline? I think the looser a definition the more likely it is that there will be inconsistencies in interpretation." [Registered Medical Practitioner]

Redrafting of Section 2 and Section 7 would assist with this, it was suggested.

## **The Surprise Question**

Several other organisations highlighted what they perceived to be contradictions or problems about the relationship between Section 2 (the flowchart), Section 7 and Annex B. Specifically, Annex B makes reference to the 'surprise question' which was perceived to introduce the concept of timeframe, and therefore was seen as

being in direct opposition to the legislation which very deliberately removes the need for a clinician to be able to estimate time to death:

“The subjective term “very soon” could be argued to be even more restrictive than the six-month timeframe stipulated by DWP. We believe that there is a high risk that some clinicians may understand it as limiting eligibility for special rules to those who they identify are in the last weeks of life... We believe that it is extremely unhelpful for this question to be included in the light of the emerging evidence that it is not useful, and acts as a barrier to some, and in particular those with non-malignant and neurological conditions from being identified.”  
[Parkinson's UK Scotland]

A different respondent suggested that it should be removed not only because it contradicts text in other parts of the Guidance, but because it contradicts the legislation:

“The whole purpose of this part of the legislation was to remove the matter of life expectancy from diagnosing someone as terminally ill.” [MND Scotland]

One individual also suggested that the ‘surprise question’ could lead to confusion and that the form should only be completed if the patient were expected to die 'very soon':

“As a former Specialist Palliative Care Lead CNS I feel that this gives the impression that patients who may be expected to survive for months to years might be excluded. These patients can suffer from progressive, constant deterioration and will need their benefits in place as will their carers. This patient group is increasing and require intervention from a range of practitioners throughout their trajectory and have increasingly complex needs. Just because they are not expected to die 'very soon' should not mean that they are unable to have a BASRiS or DS1500 completed.” [Individual]

One Registered Medical Practitioner suggested that it may be better to rephrase this closer to the original question formulated for this purpose, which asks professionals to decide if the person is sick enough to die and ‘Would you be surprised if this person were to die in the next weeks, months or years?’ (rather than ‘very soon.’)

If the ‘surprise question’ is to be retained in the Guidance, the Guidance should acknowledge that it is problematic as an identification tool, based on research evidence, it was suggested.

## **Consultation with Nurses**

While one respondent noted that the document made clear that medical professionals can consult nurse specialists who know the patient best, if needed, five different respondents who said ‘yes’ to this question did go on to stress that they remained unclear as to why nurses would not be able to complete the forms

(but could nonetheless be consulted in the decision-making process). This was also raised by some who said 'no':

"I think the Guidance is clear but don't quite understand why the specialist nurses' clinical judgement can't be used for the BASRiS forms as it can be for DS1500. I feel that this is a retrograde step of about 20 years as we have been completing the DS1500 forms for this time and make the judgements without a problem. I feel the patients may lose out some times if they are waiting for busy medical staff/GP to complete the form." [Other Healthcare Professional]

"The CNSs in our team are highly skilled and experienced and are in a unique position to complete the form, and given they see the patient at the start of their cancer journey, are able to access this benefit rapidly. This is clearly very important in a group of patients who can deteriorate very quickly. Although the forms are fairly brief, if I had to complete them for my relevant patients, it would certainly reduce my time spent interacting with patients. If the CNSs are uncertain if a patient is appropriate for a BASRiS form, they would discuss with medical colleagues and occasionally do." [Registered Medical Practitioner]

"...my concern is around who completes the BASRiS form as now specialist nurses are not able to complete. This will result in patients not receiving benefits." [Other Healthcare Professional]

One respondent suggested that the flowchart be edited and that Registered Medical Practitioners should be actively encouraged to seek the advice of specialist nurses and others.

One final comment was made that there was perhaps "too much" information and that this may not be helpful in assisting decisions and another was made that the consent requirements may add an additional burden to already overstretched clinic appointments.

## Annexes to the Guidance

Twelve separate annexes were attached to the Guidance to provide additional support and information for practitioners making BASRiS assessments, as follows:

- Annex A: draft BASRiS application form;
- Annex B: a matrix to support the clinical judgement process (including links to additional tools to support clinical judgement);
- Annex C: worked examples or 'case studies' showing how different types of cases may be managed;
- Annex D: a summary of current benefits devolved to Scotland by recipient group;
- Annex E: a copy of the DS1500 form;
- Annex F: a summary of the differences between the requirements for BASRiS and DS1500 forms;
- Annex G: the Scottish Social Security Principles;
- Annex H: a copy of the Social Security (Scotland) Act 2018;
- Annex J: definitions for different types of residency status;
- Annex K: suggested areas for inclusion in an information leaflet (to be completed);
- Annex L: a draft BASRiS fee claim form for General Practitioners; and
- Annex M: legislative definitions of 'a child'.

Views were sought on whether the information presented in the annexes would likely support the clinical judgement process.

Q5. Do you think that information presented in the annexes are likely to support the clinical judgement process?

Response	Number	Percentage
Yes	38	70%
No	13	24%
No response	3	6%
<b>Total</b>	<b>54</b>	<b>100%</b>

This question attracted a strong, positive response, with nearly three quarters of respondents (70%) agreeing that the annexes would be supportive.

## **The BASRiS Form**

A few suggestions were put forward for changing the BASRiS form in Annex A to better assist clinical judgements, including that the form should directly refer to the legislation and the Guidance and that essential components of the Guidance could be moved to the form itself (e.g. listing the indicators from Section 7 on the form):

“We believe the form should better reflect the guidance and make more direct reference to the definition used in the legislation.” [Marie Curie]

“The essential components of the Guidance need to be contained on the actual form as not all doctors will read the 51-page Guidance document every time they complete one of these.” [Registered Medical Practitioner]

One other respondent also suggested that the BASRiS form should more closely mirror the parameters and requirements of Section 7, with tick boxes linking to the indicators to align the content. Again, the form should not ask the Registered Medical Practitioner to make a functional assessment of their patient, it was suggested.

One individual and one medical organisation suggested that reference to ‘terminal illness’ in the form be replaced with ‘has progressive conditions leading to death.’

A different organisation suggested that a clearer justification was needed for the information being requested on the BASRiS form, which was more than is required in the DS1500, and which will require more time to complete.

One respondent suggested that a form for doctors to complete on the Scottish Care Information (SCI) gateway with improved formatting would be more suitable, given pressures of GP workload and another suggested that having an electronic form would avoid risks associated with sensitive data being printed, filled in, scanned and/or emailed to Social Security Scotland<sup>5</sup>.

## **Matrix to Support Clinical Judgement**

Annex B was seen as particularly helpful in guiding practitioners:

“We welcome the addition of annexes as a way to guide clinicians into taking a broader view about which of their patients may be eligible for BASRiS and see the matrix in Annex B as a useful tool to support clinicians to identify whether an individual has a progressive disease that can reasonably be expected to cause the individual’s death.” [Macmillan Cancer Support]

That being said, there was also some suggestion that Annex B could be reworked (as highlighted earlier), to provide clearer definitions of some of the conditions,

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<sup>5</sup> Another respondent suggested that links to allow BASRiS forms to be submitted online and/or email addresses should be included at Section 13

especially cancer. Other specific suggested changes to Annex B, Section B (mainly presented by one Registered Medical Practitioner) included:

- Bullet 1 - changing the text to ‘Decreasing activity and function - limited self-care, in bed or chair for more than 50% of day, and increasing dependence in most activities of daily living (see: performance status tools below)’ to reference more than one score;
- Bullet 4 - revising to take account loss of muscle mass which happens in people with heart failure and people with a high BMI who research shows have poorer outcomes, e.g. ‘Significant appetite and weight loss over the last few months, remains underweight, loss of muscle mass.’;
- Bullet 8 - clarifying if the statement means the person chooses no treatment or none is available, e.g. ‘No available treatment option that would lead to recovery or the person chooses not to have curative treatment. Dramatic changes in cancer treatment mean it is no longer so likely that the person will decline rapidly in a predictable way so suggest: Cancer (where the decline may be rapid or more predictable)’;
- Bullet 2 under Motor Neurone Disease - changing to ‘aspiration pneumonia’;
- Bullet 7 under Stroke - changing to ‘difficulty with communication’; and
- under the general neurological conditions and frailty sections of Annex B, that recurrent chest or urine infection and labile Blood Pressure be added.

One respondent suggested that the referencing in paragraph 1 of Annex B should refer to the Supportive and Palliative Care Indicators Tool (SPICT) as well as the Gold Standards Framework (GSF), since much of the text was taken from SPICT rather than GSF. The same respondent noted that a new version of SPICT was shortly due to be produced and that the annex could be update to use the new text.

Moving some of the contents of Annex B into Section 7 of the main document was also suggested (as above):

“Parts B) and C) of Annex B contain additional important indicators of decline, which relate to both the person’s overall health and also by disease. We believe that these would be very useful in supporting clinicians to make their judgement. Leaving them in the Annex, entitled ‘some tools which you may wish to use’ could mean that they are not read or referred to. Therefore, we would like to see these elements absorbed into Section 7 of the document.” [Marie Curie]

One respondent also suggested that the content in Sections B and C of Annex B be regularly reviewed to take account of developing evidence and understanding (for example, around the definition and recognition of advanced dementia).

## **Worked Examples**

There were several supportive comments that the worked examples in Annex C were particularly helpful (for both doctors and others) although there may be scope to change some of these for accuracy.

Specifically, more work was needed on the Motor Neurone Disease (MND) example and one organisation offered alternative wording for this case study<sup>6</sup>.

A better worked example for patients with long-term outlook on secondary cancer which could be classed as 'terminal' was also needed.

A different respondent suggested that the colon cancer case study needed to be adjusted to show that they were on palliative chemotherapy and to be absolutely clear that there is not a prospect of cure. The case study for cancer of the intestine should also be revised as it did not make sense, it was suggested (i.e. cancer of the intestine would spread to other organs rather than throughout the intestine unless exceptionally rare).

The case study for terminal lung cancer was also seen to be in need of change, to offer guidance on how to talk with a patient and family about 'hoping for the best and planning just in case'. [Registered Medical Practitioner]

The case study on Glioblastoma should also avoid including a year, it was suggested, as this may date the Guidance too much (suggested by one medical organisation). The same respondent noted that it might also be helpful here to explain the legal position of an 'appointee' as this is less familiar than a welfare guardian, it was suggested.

One children's organisation also requested that the word 'very' be removed from the first sentence of the worked example of a rare brain tumour.

Another medical organisation suggested that, while the worked examples were welcomed, none were especially controversial and more borderline cases may be more helpful (although they noted that all cases would inevitably be unique and need to be dealt with on a case-by-case basis). One children's organisation suggested that it would also be more helpful to have case studies that clearly explain how the DS1500 for reserved benefits interacts with the BASRiS process in various circumstances, to build on GPs' current knowledge.

One respondent suggested that the case studies for adults should be presented before those of children and young people. Another children's organisation suggested that it would be helpful to remove references to the Registered Medical Practitioner's gender throughout the worked examples.

One organisation suggested that there could be better sign-posting to the worked examples or case studies contained in Annex C of the Guidance, as these could be helpful in guiding clinical judgements. Linking the case studies more to decision making may also be welcomed (i.e. explaining how the tools in Annex B were applied to inform clinical judgement):

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<sup>6</sup> Another respondent stated that they would hope that all those with a diagnosis of MND would be eligible for a BASRiS and that the diagnosis alone would be sufficient.

“It might be helpful if the worked examples more explicitly illustrated how the tools can be used to aid consistent decision-making. At least one of the case studies should be used to explore and highlight communication and language issues - where a patient may be approaching the end of life but where “terminal” may not be the best or most useful form of language. Another case study might usefully explore the role of other members of the multidisciplinary team (MDT) in the BASRiS process.” [Scottish Partnership for Palliative Care]

Another organisation that welcomed the inclusion of worked examples in Annex C suggested that these should be tested with clinicians to ensure that they assist real world clinicians in making the decisions about eligibility under special rules.

Only one respondent suggested that medical professionals would be able to make assessments based on their experience/expertise and so such examples may be redundant, and another suggested that they were inappropriate or misleading.

## **Rationalising the Annexes**

Some who rated the annexes positively overall commented that they could be further explained, rationalised or reduced:

“The Guidance is long, and we would question whether all the annexes are necessary in their current form. We believe that material that is likely to have a bearing on decision making should be prioritised.” [Parkinson's UK Scotland]

There were few comments made in relation to annexes D-M, except for the following (each raised by just one or two respondents):

- Annex D - that there was perhaps some inaccuracy with table and that it was not as clear and helpful as it could be. The respondent offered to provide an alternative version, if useful;
- Annexes G and H - providing links/hyperlinks to primary legislation instead of the full text was suggested, as these were unlikely to be routinely read/used;
- Annex J - that it should be removed as it may be inferred that GPs are being asked to make decisions about residency;
- Annex K - respondents would welcome seeing more information in this section in due course; and
- Annex M - that it was unclear why a doctor completing this form would need the legal definition of a child or for background on the Social Security (Scotland) Act to be repeated.

Only one respondent noted that the annexes collectively provided only background or context and so were not relevant to supporting the clinical judgement process.

## Variability in Implementation

Included in the underlying principles of BASRiS are that the process should be fair and seen to be fair and transparent to medical practitioners, other professionals and the public. The decision-making process should be consistent, despite the decisions varying according to individual circumstances. The Guidance seeks to assist practitioners in realising each of these and views were sought on whether it would, as drafted, lead to reduced variability in implementation.

Q6. Do you think the Guidance is likely to lead to reduced variability in implementation?

Response	Number	Percentage
Yes	17	31%
No	30	56%
Unsure	4	7%
No response	3	6%
<b>Total</b>	<b>54</b>	<b>100%</b>

This question attracted the least positive response overall, with more than half of respondents (56%) expressing that they did not agree that the Guidance would likely lead to reduced variability in the clinical judgement process, unless it was changed.

### Variability Due to Time Constraints

Consistent with other areas of the consultation, comment was again made that limiting the form-filling to Registered Medical Practitioners may lead to variability, largely because those authorised to complete the forms are the least likely to have time to do so. This, in turn, may lead to delays in patients receiving benefits when they needed them most, it was perceived:

“I am concerned that the need for medics to complete the form will lead to delay for patients receiving benefits. Often it is clinical nurse specialist who is best placed to complete form as they have completed a holistic assessment. With the new form, as there is often not a medic within the team, I will have to ask a medical practitioner who may not know the patient as well as I and who may be busy with other tasks leading to delay in completing form.” [Other Healthcare Professional]

Limited time and other pressures already faced by practitioners may also mean that they are unable to complete the forms at the most appropriate junctures:

“In order to ensure it is implemented at the right time this form should be able to be completed at the appropriate time by whichever Health Care Professional knows the patient best. This could be a nurse or a doctor.” [Forth Valley Local Medical Committee]

“Under the proposed Guidance I believe that there will be an increase in variability in implementation. Clinical nurse specialists and advanced nurse practitioners who currently complete DS1500s on a daily basis are excluded from doing so with the proposed system and I do not believe that a consultant or GP will be able to commit to implementing benefits assistance in a timely manner. This could potentially have a detrimental effect on the care and wellbeing of individuals who are living with a life limiting illness.” [Other Healthcare Professional]

Concerns were raised that the completion of BASRiS may not be prioritised with the same urgency as the DS1500 currently receives and that this may, inevitably, disadvantage patients. Indeed, one respondent suggested that the numbers of referrals may be reduced as a consequence of removing nurses from a position of responsibility.

‘Fear of change’ and a need for practitioners to become familiar with the process may also lead to some variability in practice, it was suggested. One respondent also suggested that variability may be more likely to occur as a result of differences in the relationships held between GPs and their patients/families, and the varying levels of input that different clinicians have with their patients and families. Less variability in relationships was seen to exist for nurses:

“Making it doctors only sadly will mean significant delays in patients getting the funding they are entitled to as clinical nurse specialists largely complete these at present. They often have better knowledge of patients and their social situation, level of functioning too, so are often better placed anyway.” [Registered Medical Practitioner]

“In many situations the person who knows the individual best will be a District Nurse, Advanced Nurse Practitioner, Hospice Nurse or Clinical Nurse Specialist. It is essential that the person who knows the individual best is the person who signs the form.” [Registered Medical Practitioner]

One respondent suggested that medical practitioners simply would not complete the forms.

## **Variability Due to Eligibility Interpretations**

Again, similar to responses received elsewhere, variability was also seen as possible due to differences in how individuals interpret what is a progressive disease and what is ‘terminal’:

“Despite the attempt at thorough guidance, defining who is terminally ill and appropriate for this benefit will still be open to a huge amount of interpretation.”  
[Registered Medical Practitioner]

“...we are concerned by the inconsistencies within the Guidance, and the resulting lack of clarity in for clinicians as to their responsibilities when defining a patient as eligible for BASRiS...Any revised definition of special rules, or criteria for qualification, should provide the clinicians who are expected to implement it with clear, understandable guidance against with they can make judgments.”  
[Macmillan Cancer Support]

Loosening of the definition was seen by one as inevitably having the opposite effect of reducing variability and, indeed, two organisations suggested that this may be a positive feature if it meant that more people who could benefit from the assistance were reached (albeit not necessarily in a consistent way):

“...the Guidance will lead to people with a wider range of diagnosis gaining access to benefits under special rules, and this is welcome.” [Scottish Partnership for Palliative Care]

“While we believe and welcome that the Guidance will lead to people with a wider range of diagnosis (or undiagnosed conditions) gaining access to benefits under special rules, we are not convinced that it will reduce unwanted variation as currently drafted.” [Children's Hospices Across Scotland (CHAS)]

## **Variability Due to Cost**

In addition to concerns about how eligibility may be differently understood between practitioners, one respondent suggested that there may be variability due to cost concerns, i.e. that some practitioners may be concerned that they are applying the rules too broadly and curtail applications as a result:

“As it stands, this Guidance is likely to create substantial and undesirable levels of variation in how doctors assess eligibility for BASRiS forms. Some will take the absence of any robust guidance as enabling them to apply the broadest possible definition of terminal illness while others will feel they are expected to police the system in order to ensure costs do not spiral out of control so that support remains there for those who clearly need it. While there will always be some degree of variation in a system that relies on an individual’s judgement, the Guidance as it currently stands means that this variability will be far more extensive than it needs to be.” [British Medical Association (BMA)]

This may be exacerbated by concerns among practitioners that eligibility for BASRiS may be perceived as a gateway to other benefits. One respondent suggested that workloads and associated costs may increase due to more people considering themselves to be eligible for assistance:

“...the removal of qualifying time period may encourage the public to present at the GP on the basis of self-belief of having something ‘terminal’ and this could cause an increase in workload and pressure on the GP, especially when nursing staff are not afforded the authority to make a decision around BASRiS.” [RCGP Scotland]

Also linked to cost was the issue that Registered Medical Practitioners would charge for BASRiS form completion, whereas completion of the existing DS1500 by nurses incurred no such charge:

“Nurse specialists under current legislation can complete a DS1500 for patients who have a life expectancy less than six months. This document is completed efficiently by nurse specialists, to the benefit of patients and at no charge, which is of benefit to the government and the Scottish public. Registered Medical Practitioners charge a fee, which will also generate additional administration costs.” [Other Healthcare Professional]

Concerns around the costs of administration may, therefore, lead to variability.

## **Possible Reductions**

Those who felt that the Guidance (if followed) may reduce variability primarily agreed on the basis that it would reduce risk of delay due to removing professional worries about making prognostic judgements:

“This is a major step to avoid inequity as it reduces risk of delay due to professional worries about making prognostic judgements and prioritises people with progressively increasing care and support needs.” [Registered Medical Practitioner]

“This will make the DS1500 process better for patients - prognosis can be extremely difficult to predict and can disadvantage patients and their families who may live with an incurable, progressive illness for some time and endure significant financial hardship and related anxiety while dealing with the effects of treatment on their lives that preclude from working.” [Registered Medical Practitioner]

These were, however, minority views.

## **Evidencing and Monitoring Variability**

Several respondents indicated that they were unsure if variability would be reduced, mainly because this would be difficult to evidence. Three organisations suggested that data on decision-making consistency and how long it takes to make a determination should be collected and published. This would demonstrate variability in implementation which could then be addressed, it was felt. Another organisation suggested that it may be helpful to track and publish condition-specific data about which groups of people are accessing benefits under special rules (so that Guidance could be modified if inequalities in access become apparent):

“So that we are fully aware of any variability in implementation, detailed data on BASRiS awards by Registered Medical Practitioners should be collated and publicly reported. Any variation should be analysed and addressed.” [MND Scotland]

“...we believe that there needs to be robust data collection and analysis of awards by practitioner to help ensure consistency of application. There should be regular review of the data and the guidelines to ensure that indicators and support for clinicians allows for consistent application of the legislation to ensure that terminally ill people get the support they need.” [Marie Curie]

One respondent also suggested that some facilitated learning be put in place once the process was introduced to promote equity and ensure that people do not miss out due to differences between practitioners in interpreting the Guidance.

Overall, there was a strong sense that, while the Guidance could or should support clinicians to feel more confident, implementation would always be subjective and be at the discretion of medical professionals.

# Support to Help Implementation

While the Guidance is primarily aimed at doctors, it also needs to be accessible to a wider audience, including those who are eligible for assistance, their families/supporters and other members of the general public. Respondent were asked what, if any, support may need to be in place to assist in implementation, for both professionals and non-professionals alike.

Q7. Can you think of any support that may need to be in place for professionals, the public and others to help the implementation?

Response	Number	Percentage
Yes	46	85%
No	5	9%
No response	3	6%
<b>Total</b>	<b>54</b>	<b>100%</b>

A large majority of respondents (85%) provided suggestions for support that may need to be put in place for professionals, the public and others to help implementation (those who did not, provided no justification for their responses).

## Support for Professionals

A range of supports were mentioned for professionals, and these included:

- training and awareness raising for health care professionals on the new BASRiS rules;
- an easy-read version of the Guidance;
- a health care professional helpline for BASRiS questions during the implementation phase; and
- short video guides.

If training is to be developed and delivered, a range of suggestions were put forward for what this should cover, including:

- more information on how the new process will be rolled out;
- support for medics to understand the new BASRiS system including a clear understanding of the benefits system (including how to support patients with financial issues as this has traditionally been the role of nurse specialists who, it was suggested, have a clearer understanding of the benefits system);
- training on the nuances of specific illnesses/conditions, such as motor neurone disease;

- the time implications for medical staff completing the new BASRiS forms; and
- communication skills training for GPs/Hospital doctors having difficult conversations.

Indeed, several respondents highlighted the importance of supporting or equipping health professionals in having sensitive discussions, particularly when the conversation involves babies, children and young people and their families/carers:

“Equipping health care professionals and the public to have challenging conversations about death and dying will be fundamental to ensuring both professionals and patient have these conversations about access to this benefit...We would welcome reassurance that the Social Security Agency and the Scottish Government that will continue to engage with professionals and claimants to develop information and support tools that ensure professionals are equipped to clearly communicate the differences between the two systems, as well as clearly written information for applicants.” [Macmillan Cancer Support]

One organisation stressed the particular need to avoid use of reference to ‘terminal’ in such discussions, and for all involved in administration of BASRiS to be cognisant of this:

“The Guidance identifies the need for practitioners to engage in sensitive communications when engaging with people who may be eligible for BASRiS. It is not the role of the Guidance to equip practitioners with the communications skills required to undertake these conversations, though we welcome the fact that the Guidance signposts to helpful communications resources...despite excellent sensitive communication by clinicians, distress may be caused to people and their families if the word “terminal” is inadvertently and inappropriately used as part of the wider benefits process. Examples could include words used in written communication from the Benefits Agency, or used as part of verbal communication by Benefits Agency staff.” [Scottish Partnership for Palliative Care]

The risk of such harm was also described (by the same respondent) as being potentially greater for people with some non-malignant conditions, and so of particular relevance to the Guidance<sup>7</sup>. Importantly, support around sensitivity of communications was seen as necessary not only for professionals, but also for the public and other non-medical support organisations.

Several respondents indicated that training and awareness raising for professionals needed to be wide-reaching to cover as many appropriate medical staff as possible, with specific suggestions including clinical nurse specialists, palliative care staff,

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<sup>7</sup> Another organisation noted that guidance in Section 11 on communication mainly links to resources on talking about dying. As the new benefit is available to people with deteriorating health who may not consider themselves to be ‘dying’ a suggested link to the HIS Scottish Anticipatory Care programme was made: <https://ihub.scot/project-toolkits/anticipatory-care-planning-toolkit/anticipatory-care-planning-toolkit/> as well as a link to information on talking about anticipatory care planning on the NHS Scotland Effective Communication for Healthcare programme site <https://www.ec4h.org.uk/resources/>

occupational therapists and primary care teams. These training and awareness raising opportunities should also be available for Social Security Scotland staff, benefits advisors, information agencies and advocacy organisations, to ensure that they are aware of the changes and understand what they mean in practice.

Suggestions for other more practical supports which may need to be in place included:

- additional government funding to support the fees medical practitioners may claim for completing the forms; and
- additional doctors (as the Guidance indicates that nurses cannot lead on this assessment).

“GP's are already stretched within their caseloads and now to ask for them to complete more paper work, additional staff will be required.” [Other Healthcare Professional]

On a related note, one respondent suggested that clarification was required on whether only GPs would be permitted to submit the fee payment form (as indicated on the example given) and the same respondent suggested that the payment process may also need to be simplified to support implementation:

“There needs to be a mechanism that makes payment easier - either a code for practitioners is the case for DS1500 forms and an easy way to opt out of fees - many hospital practitioners do not charge a fee for completing forms (you do list GMC registered consultants on the suggested payment form) whereas my impression is that this is less of the case in primary care so BASRiS may cost more in terms of fees.” [Registered Medical Practitioner]

Although additional training and awareness raising activities would be welcomed for professionals, one respondent mentioned that time/availability of busy medical staff to attend such training may be limited. This may provide a barrier to future understanding of the new process.

As with many other areas of the consultation, this question also attracted a number of comments regarding the importance of including nurses in the decision-making process for BASRiS (and calls that specialist nurses should be able to fill in the new form). Although the Guidance sets out that medical professionals can seek information from other colleagues, including specialist nurses to aid the decision-making process and gather evidence to support their thinking, some suggested that this level of input or support from specialist nurses was not enough and that preventing nurses from having direct responsibility may lead to reduced efficiency and increased costs:

“By changing the legislation to only allow medical practitioners to complete these forms sets prompt decision-making back at least fifteen years. CNSs have been completing DS1500 forms for patients for decades now, which reduces delays in

claims and ensures that people have support when they need it....The CNSs will result in delays as it will not be prioritised. It will create further anxiety for the patient and carer and add further stress to the CNSs workload as he/she will no doubt spend a great deal of time chasing these up.” [Individual]

Finally, one respondent suggested considering asking professional subgroups to produce tailored guidance for their individual specialties.

## **Support for the Public**

Specific supports which were mentioned for members of the public (including patients and their families or other supporters) included:

- an awareness raising campaign to support its roll out<sup>8</sup>;
- information leaflets for patients, families and carers (including social care practitioners and third sector agency staff so that they can advocate on behalf of people in need);
- distribution of leaflets, etc. at educational events; and
- a simple/pictorial chart to help the public understand who to go to complete the forms and what they are entitled to.

Importantly, many respondents mentioned that the resources/supports that they would like to see put in place for professionals may be equally relevant for members of the public, e.g. if awareness raising campaigns are to be created, alternative versions may be needed for professionals and the public alike. Similarly, if printed educational materials/information videos, etc. are to be developed, equivalent versions should be made available to GPs, patients and their families:

“It will be important to have a good patient information leaflet so people know what to expect and what the language used means.” [The Royal College of Physicians of Edinburgh]

Providing separate, equivalent documents for the public was seen as necessary not only as a means of ensuring that they understand and that information is available in an accessible way, but also because it may help reduce the time/demands placed on medical professionals in having to help explain the new processes to patients and their families, etc. It may also reduce the likelihood of claims from those who are not eligible:

“A supporting document for members of the public to explain clearly who is entitled to BASRiS would be helpful. This will help reduce workload for GPs

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<sup>8</sup> Only one respondent noted that, as a small percentage of the general population will be affected by this change, a wider public information campaign may perhaps be less prescient.

which might otherwise result from people who are clearly not eligible requesting a form.” [Registered Medical Practitioner]

“Would be concerned about high numbers of patients seeking one of these forms inappropriately and leading to significant increased GP workload. Good public information may support this as well as clear knowledge amongst other health care professionals who may be advising patients to seek these forms.” [Forth Valley Local Medical Committee]

Indeed, the main focus of any public focused support materials were seen to be clear definitions around eligibility, qualifying periods, automatic eligibility and signposting to wider support services:

“The public needs to understand that there is no longer any qualifying period, but also needs to be made more explicitly aware of the difference between a chronic condition, and a terminal illness, to mitigate against the risk of large numbers of the public presenting to their GP, requesting help to access benefits which they may not be eligible for.” [RCGP Scotland]

“...it will be very important to make clear in any public-facing materials that it is not expected that people will automatically qualify under special rules from diagnosis. When the rules around benefits are not made very clear, it can cause great confusion.” [Parkinson's UK Scotland]

“While frontline services have an important role in increasing take up of benefits, it is crucial that independent and expert welfare rights advice is always available for individuals. Having robust referral systems in place could prove hugely beneficial as they can actively help people find the right advice. For complex areas of advice, such as social security, an active referral system can be more effective than signposting to advice.” [Child Poverty Action Group in Scotland]

Providing better signposting for patients to additional support services may help to reduce inequity of access, it was suggested, and this could be referenced in the flowchart for eligibility as a way of standardising referral/signposting practices.

## **General Support and Information**

Having an “expert point of contact” was suggested, as well as a ‘helpline’ and a poster with a short explanation and the key steps required to implement (although it was not specified for whom). Similarly, workshops were posited, but it was not made clear who these should be directed at.

Another specific concern was that the existing Guidance did not make clear how patients, family and other professionals can check if form has been completed. More information may be needed in this regard.

Finally, consistent with comments made elsewhere in the consultation, suggestions were put forward that the document should be made shorter and more readable

with relevant information contained in an annex. Any support information or materials produced should also be in Easy Read format, it was stressed and be available in public areas and in workplaces.

Overall, there was support for what one respondent described as “a dual-track campaign in which an accessible, public-friendly resource is promoted alongside clinician-focused information.” [RCGP Scotland]

## Title of the Guidance

The draft Guidance was titled ‘Guidance for Doctors Completing Benefits Assessment under Special Rules in Scotland (BASRiS) Form for Terminal Illness.’ The Executive Summary of the document also makes clear that the Guidance is for all Registered Medical Practitioners and licensed to practice, who certify that their patient is terminally ill and is eligible for benefits under special rules by completing the Benefits Assistance under Special Rules in Scotland (BASRiS) form (replacement of DS1500 for benefits devolved to Scotland). The penultimate question in the consultation sought views on whether respondents were generally content with the title of the Guidance.

Q8. Are you generally content with the title of the Guidance?

Response	Number	Percentage
Yes	35	65%
No	14	26%
No response	5	9%
<b>Total</b>	<b>54</b>	<b>100%</b>

The majority of respondents (65%) expressed that they were content with the title of the Guidance.

Importantly, while a quarter of respondents said ‘no’ to this question, the qualitative comments given in support were unrelated to the question in a number of cases. Specifically, five respondents (a mix of individuals and organisations) used this question to express dissatisfaction about the exclusion of clinical nurse specialists being able to complete the BASRiS form, which they perceived would make the process more timing consuming for GPs and less cost effective (as above).

Where comments were made by those who were not content and which did relate specifically to the title of the Guidance, these included that it was “clunky” and perhaps “a bit long”.

One individual and two organisations suggested that the title should ideally avoid using the word ‘terminal illness’ except where it is essential to fit with the law as it is enacted. This was because they perceived that many people who may be eligible would not identify themselves this way:

“Many people with multimorbidity or frailty do not view themselves as ‘terminally ill’ and it could be a barrier to implementation similar to the 6-month life expectancy if not explained well.” [The Royal College of Physicians of Edinburgh]

One national support organisation also explained that additional problems may exist with a lack of understanding of the word ‘terminal’ in the wider population:

“In addition to situations where the person may not be informed of their prognosis because of risk of harm, there are people with progressive and incurable conditions who would consider the use of terminal to suggest that they are reaching the end of their life imminently. They may not consider this to be the case, while still clearly meeting the criteria for an application under special rules. If people who do not consider that their condition is terminal [are] aware that the Guidance is titled terminal illness, it may cause harm. There is a specific issue around the way in which the word terminal is used and applied.” [Parkinson's UK Scotland]

The same organisation noted that including this term in the title may also result in some medical professionals not considering all relevant patients as eligible:

“...uncertainty involved in assessing someone on a protracted trajectory of frailty makes doctors more reluctant to identify that someone may be reaching the end of their life. It is possible that the insertion of the word terminal in the Guidance title may mean that doctors do not consider that people with Parkinson’s and other non-malignant diseases would be eligible, even though the Guidance makes clear that people with advanced illness would meet the criteria. [Parkinson's UK Scotland]

A suggested alternative was to replace ‘terminal illness’ with ‘progressive illness’. Another organisation noted that the title did not have any reference to terminal illness and questioned if this was intentional. They also suggested that the term ‘special rules’ may serve up some unwelcome connotations.

One Registered Medical Practitioner noted that they felt the title should be less formal and more patient-friendly:

“Needs to sound more human and patient centered rather than a piece of legislation. The title should be friendly and something patient can remember without strain.” [Registered Medical Practitioner]

The same individual also suggested that the word ‘benefits’ should be removed as it may be perceived as “humiliating and degrading”.

Only three suggestions for alternative titles were put forward, these being:

- Guidance for doctors completing benefits assessment under special rules in Scotland (BASRiS) form for people with a terminal illness;
- Scottish Special Rules Benefits Assessment (SsSBA); or
- Financial Assistance - Special Tier (F.A.S.T)

One respondent suggested that the title should also make explicit reference to the fact that, where appropriate, BASRiS replaces DS1500 in Scotland.

# Additional Comments

To ensure that the consultation was as effective as possible in informing the final Guidance document, respondents were invited to share any additional comments that they had, other than feedback provided in response to direct questions.

Q9. Do you have any further comments?

A large number of respondents (32) provided additional comments on the Guidance, and these are summarised here.

## Specialist Nurse Practitioners

The majority of the additional comments related to the decision to disallow specialist nurse practitioners to complete the BASRiS form.

The main contentions with not permitting nurses to sign the BASRiS form were:

- that most GPs are too busy to complete the administrative work associated with filling in the forms and that nurses may be better placed to complete forms in a timelier manner and at the most appropriate times;
- that nurses often know the patients best, and so may be able to make more rounded decisions, as well as being able to negotiate their working timescales to facilitate sensitive discussions with patients, their families and carers/supporters in a more relaxed fashion;
- as a consequence of the above, not engaging nurses may mean that eligible patients do not receive the benefits they are entitled to and/or not receive them in a timely manner;
- that nurses currently do not charge for completing the DS1500 and the same rule would presumably apply to the BASRiS (as opposed to General Medical Practitioners who would charge for their time), thus making it more cost effective to employ nurses in completing the process; and
- not permitting nurses to sign the forms in Scotland may place benefit recipients in Scotland in a worse position than those elsewhere in the UK:

“That only Registered Medical Practitioners, and not specialist nurses, can sign BASRiS forms is a real cause for concern and puts terminally ill people in Scotland in a weaker position, in this regard, to those in the rest of the UK. We would like to see specialist nurses permitted to sign a BASRiS...The vast wealth of knowledge and experience that specialist nurses/clinical specialists have must be effectively utilised.” [MND Scotland]

These more practical issues aside, several comments were made in response to this question that excluding nurses could be perceived as undermining their experience built up in this area over a number of year and as deskilling the profession:

“Our current Primary Care strategy emphasises alternatives to seeing a GP and the important skills that other primary care professionals have. Asking a medical practitioner to sign a form when the assessment has been carefully undertaken by another professional will undermine this.” [Registered Medical Practitioner]

“...we are shocked and disappointed that our role in supporting people with terminal illness, is overlooked and not valued. Very disappointed.” [Other Healthcare Professional]

“I feel that it this decision will be viewed as insulting to the skills, experience and expertise that the CNS/ANP workforce bring to the care of complex patients and will not help plummeting morale. These nurses have often spent years increasing their knowledge through theoretical and experiential learning and this is being completely ignored in this instance.” [Individual]

Other comments included that nurses may be more familiar with information around benefits and other financial supports available, based on their experience built up over time, and that nurses were more likely to be able to provide continuity of care. They may also have better knowledge, awareness and understanding with other local support services that the patients or their family may benefit from accessing (and could advise as part of the BASRiS process).

Importantly, many respondents stressed that they would not wish to see the role moved exclusively to nurses, but rather that the option for them to complete forms alongside and in collaboration with GP colleagues was important.

This was main area of the consultation that respondents wished to be reconsidered:

“We are disappointed that the Scottish Government chose to restrict the ability to sign people off as terminally ill for access to social security in Scotland to medical practitioners. We understand that it is not the preference of the Scottish Government to allow registered nurses to sign off BASRiS forms, but we would ask that this be reconsidered and if there is any scope within the legislation for nurses to be able to sign off BASRiS forms.” [Marie Curie]

## **GP Workloads**

On a related note, additional comments were made at the end of the consultation that the changes being introduced by BASRiS may impact negatively on GP and other medical practitioners' workloads:

“This has potential to cause significant workload and may delay benefit claims for those in most immediate need.” [Registered Medical Practitioner]

“I think it is inappropriate that only doctors will be allowed to complete the forms. This seems to go against the drive from the Scottish Government to have people health care needs delivered by the right person in the right place at the right time. By restricting this to doctors...it will also inevitably lead to increase in doctor

workload which will take the GP away from delivering care as an 'expert medical generalist' as intended. This could lead to harm for other people who will find it harder to get access to their GP. I suggest allowing nurses and suggesting that the form is completed by the doctor or nurse who knows the patient best or who suggests completion of the form both in primary and secondary care.” [Forth Valley Local Medical Committee]

Some again stressed the costs associated with this task for GPs and urged that additional funding would be required to support the change, if implemented:

“It is also essential that General Practice is remunerated with an appropriate fee for this work in order to lessen the strain on GP capacity.” [Forth Valley Local Medical Committee]

One other organisation suggested that an increase in demands brought about by BASRiS may also uncover or make clearer the need for wider support and care planning for people with progressive illness, and that the Scottish Government would need to be alert to this:

“...a significant issue will be the increase in demands on GPs to consider people with progressive illness for BASRiS. This will hopefully emphasise the importance of other aspects of palliative care, especially starting anticipatory care planning and providing easy access to care in and out of hours. This is likely to take considerable time, and primary care policymakers and planners should be alert to this increased area of demand, of early palliative care or looking after people with advanced illnesses at home. Hopefully the early benefits may assist more people to stay at home for longer.” [The Royal College of Physicians of Edinburgh]

## **Overlaps between BASRiS and DS1500**

Some respondents again used the 'additional comments' to stress that they perceived that the parallel operation of BASRiS and DS1500 may be confusing for some (both professionals and non-professionals). If not managed well, it may also lead to additional administrative burdens for both patients and professionals, it was felt. Additional and ongoing clarity was sought in this regard:

“Macmillan would welcome on-going clarity from the Scottish Government and Social Security Agency that those who have an existing DS1500 when the legislation comes into force will automatically qualify under BASRiS. More broadly, while we appreciate that there will now be two distinct processes for determining access to devolved and reserved terminal illness benefits, our understanding of the policy intent is that future claimants who meet the criteria for a DS1500 would also qualify under the BASRiS criteria. We would be concerned about any reduction in access for these claimants, and would welcome reassurance that the Social Security Agency and the Scottish Government will explore how to limit the administrative burden on these individuals of making two separate applications.” [Macmillan Cancer Support]

Another questioned if BASRiS would be used as a form of evidence for patients wishing to access other benefits, as this was not clear:

“[The Guidance] appears to suggest that receiving BASRiS means being treated as being terminally ill for the purposes of disability assistance, and that not receiving BASRiS means being treated as not terminally ill. In contrast, a DS1500 is not required to receive PIP under special rules, it is simply a piece of evidence that can be used. It would be useful to clarify what the intention is as to whether a BASRiS form is required or is a form of evidence. We do not believe that the position in Scotland should be more stringent, therefore it should be clarified that a BASRiS form should not be necessary but sufficient.” [Child Poverty Action Group in Scotland]

Such clarification was particularly important, they stressed, in cases of appeal:

“This is also important to ensure that individuals have a clear right of appeal. Appeals by applicant regarding decision made by Social Security Scotland - it is not clear that an individual will have a meaningful right of appeal against determinations involving BASRiS. If it is the case that a person can only qualify for disability assistance on the basis of terminal illness if they have a BASRiS form, and cannot challenge the clinical judgement, then it would appear that any appeal about whether or not a person qualifies as terminally ill would be bound to fail even if a person had other medical evidence. Appeal rights are a fundamental part of a rights-based system and it should therefore be clearly set out if individuals will have a right of appeal against a determination involving terminal illness.” [Child Poverty Action Group in Scotland]

Ensuring that the appeals process in Scotland was as clear, transparent and equitable as the process for reserved benefits was seen as key.

## **Communication and Consent**

A small number of comments were made that the Guidance could be strengthened in relation to communications. In particular, one respondent noted that a section on inclusive communication was included for children and young people but that there was no equivalent for adults. Some patients who may be eligible for BASRiS may lack capacity and so guidance could usefully be included for clinicians on how to deal with clients with cognitive and communication issues, it was suggested.

Another respondent proposed that the paragraph text which discussed raising the issue of BASRiS with patients, carers and families should be moved under the sub-heading ‘Communication with your patient, carers and family’ and that links to relevant support websites could be included<sup>9</sup>. The same respondent suggested

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<sup>9</sup> The respondent specifically suggested a link to the EC4H site:  
<http://www.ec4h.org.uk/resources/anticipatory-care-planning-in-scotland/>

that communication was also a key process issue and so could be mentioned in a side box parallel to the top level of the flowchart in Section 2 (and one other respondent endorsed including considerations around raising the issue of BASRiS with patients, carers and families in the flowchart).

On the topic of consent, one respondent noted that, currently, claims for PIP under special rules can be made by a third party with or without the consent of the claimant and that they do not have to be an appointee nor a guardian (S 82 (5) of the Welfare Reform Act 2012). This is confirmed by the DWP's Guidance, they noted. The BASRiS Guidance, as currently drafted, suggests there will be no similar provision for disability assistance and the respondent viewed that this was an important provision and there would be less support for terminally ill claimants in Scotland if this provision were not included in Scotland.

A different respondent noted that it could be made more explicit that patient consent would be required before medical practitioners have conversations with carers and family members, and that the Guidance could also be clearer regarding how consent would be taken and how evidence of consent would be stored. Another respondent also sought clarification around such conversations and the time/resource requirements implied:

“The Guidance outlines that a doctor should, where possible, consult family members and seek evidence prior to making a decision...We are concerned that this may create a burden on clinicians and families, as well as cause delays. It should be the role of doctors to make the clinical judgement on the condition, rather than families. It may also be that some family members are not aware of the individual's condition or are experiencing some denial about the terminal nature of it. It would be helpful to clarify what 'where possible' means here. We believe that this process should not cause delays, give rise to confidentiality issues or cause distress. It may be useful to add: 'where this will assist a decision to be made, the patient has given permission and it will not result in additional delays.'” [Child Poverty Action Group in Scotland]

The same respondent also noted that, if an individual is unaware of their prognosis then the name and address of the patients' legal representative must be supplied. This, they suggested, implied that a legal representative may be needed in such cases (which is different from the UK system) which they perceived was overly restrictive. Further guidance on this matter was urged and the same respondent also noted that proof of residence in Scotland should also not be required.

## **Ongoing Engagement**

Finally, several respondents stressed the need for ongoing consultation with relevant stakeholders in finalising the Guidance, as well as engagement during and after implementation:

“We would appreciate seeing the draft Guidance produced for the public and having an opportunity to feed back our views on it, if possible.” [Breast Cancer Care and Breast Cancer Now]

Others suggested that the final draft Guidance should be piloted or ‘road tested’ with a group of Registered Medical Professionals before full roll out:

“...it is important that the draft Guidance should be “road tested” prior to nationwide implementation. This would involve something like a group of “typical” GPs being asked to use the draft Guidance and complete the form based on several different case studies. They would then be asked to reflect on and discuss the experience and the utility of the Guidance. The judgements recorded on the forms could also be compared for consistency. Road testing should also consider hospital teams, as a significant number of DS1500 forms are currently completed in this setting.” [Scottish Partnership for Palliative Care]

“We...would like to see a group of GPs apply the guidelines to a number of case studies. Feedback on the guidelines, the form and how they used their clinical judgement could be used to support the final version of the guidelines.” [Marie Curie]

This would help give an idea of its robustness in supporting clinical judgement and reducing variation of implementation, it was suggested. Given the importance of ongoing monitoring, one respondent also questioned if additional data fields should be added to BASRiS:

“The BASRiS form will be the key document in building a data set which enables implementation to be monitored and evaluated. Are there other fields necessary which would enable the accessibility, reliability, consistency and timeliness of the BASRiS process to be evaluated?” [Scottish Partnership for Palliative Care]

## **Miscellaneous**

Other miscellaneous comments/suggestions included:

- that the government may need additional funds to finance implementation;
- that any reference to doctors being prepared to justify their decisions to ‘members of the public; be removed (as this would be a breach of patient confidentiality);

Others simply commented that they welcomed the Guidance, in principle, and hoped that it would be a useful document, once revised:

“We welcome the Guidance and value the work that has gone into producing it. We are optimistic that it can be refined into a more successful document that will drive more effective identification of people who can - and should - benefit from access to disability benefits under special rules...” [Parkinson's UK Scotland]

“Marie Curie fully supports the Scottish Government’s approach to supporting terminally ill people access social security in a fair and dignified way. In including a definition of terminal illness based on clinical judgement there is now the potential for all those who are terminally ill and need to access social security quickly, in a dignified way and at an amount that will reflect their needs, being able to do so. This is in stark contrast to the previous definition used to support access to disability benefits used by the DWP which defines people as terminally ill if they can prove they have less than six months to live, which sees many people missing out on the support they need.” [Marie Curie]

# Discussion

The consultation attracted a strong response from a large number of individuals and a wide mix of organisations from across different sectors. Responses were detailed and there was much discussion for each of the questions asked, with many organisations in particular providing comprehensive justifications for their views.

## Overview of Responses

The table below shows the proportion of respondents who answered ‘yes’, ‘no’, were unsure or did not provide a response to each of the consultation questions.

Question	Yes	No	Unsure	N/R
Q1. Is the Guidance clear about the process for accessing benefit assistance under special rules in Scotland (BASRiS)	66%	28%	-	6%
Q2. Do you feel that the Guidance clearly outlines the process as it relates to children and young people?	63%	15%	-	22%
Q3. Do you find the Guidance easy to navigate and understand?	56%	39%	-	5%
Q4. Does the Guidance make clear how clinical judgements should be made?	65%	24%	2%	9%
Q5. Do you think that information presented in the annexes are likely to support the clinical judgement process?	70%	24%	-	6%
Q6. Do you think the Guidance is likely to lead to reduced variability in implementation?	31%	56%	7%	6%
Q7. Can you think of any support that may need to be in place for professionals, the public and others to help the implementation?	85%	9%	-	6%
Q8. Are you generally content with the title of the Guidance?	65%	26%	-	9%

Levels of agreement were similar for almost all questions with two exceptions. A large majority of respondents expressed that they did not agree that the Guidance in its current form would likely lead to reduced variability in implementation. Conversely, a large proportion agreed that there were additional supports that could be put in place to help professionals, the public and others to help implementation. There was also some slight disagreement regarding how easy the Guidance was to navigate and understand.

## Cross Cutting Themes

A number of cross-cutting themes emerged across the consultation, including:

- concern and a perceived lack of rationale the removal of responsibilities for specialist nurses to complete the new form, and a perceived need to broaden the scope for who can complete the BASRiS form;
- some confusion regarding overlaps between reserved and devolved benefits and the how BASRiS and the DS1500 would work in parallel (and if this would be sufficiently well understood);
- more clearly defining what is meant by 'terminal' and giving this a stronger presence in the Guidance was also suggested, as well as making eligibility criteria easier to understand, with cross-referencing to the form itself;
- limited time/availability of medical professionals to be able to familiarise themselves with the new Guidance and new process, or to undertake training to ensure that the new process rolls out smoothly;
- potential costs associated with the new process, especially in terms of GP's time and claims for fees;
- while there is some helpful information in the Guidance, there are some perceived issues with the structure and language used that make it more challenging to navigate than it needs to be; and
- ongoing monitoring and evaluation of the new process in practice, and continued engagement with stakeholders during roll-out would be welcomed.

Addressing these key concerns seems to be key as an initial first step to ensure buy-in and understanding of the relevant audiences.

## Next Steps

The report will be used by policy staff, the CMO and the Short-Life Working Group on Terminal Illness for Disability Assistance, to finalise the Guidance and inform the policymaking process.

## Conclusion

Although not a key focus of the consultation, one of the main themes to emerge was a strong level of dissatisfaction with the decision not to allow specialist nurse practitioners to complete the application for BASRiS. While not explicit feedback on the Guidance *per se*, this issue seems to be fundamental to the how well the Guidance (and proposed new practice) is likely to be received by the medical profession. This seems to be the biggest immediate challenge to be addressed.

There may be a need to consider ways in which the Guidance can be shortened to make it even more accessible to a wider audience, and a range of secondary support materials/resources may also be required to aid implementation.

Subject to some changes to the Guidance, including simplification and reduction of text, refinement of annexes and case studies and making the Guidance available in easy to navigate formats, organisations and individuals alike seem to welcome that a document has been developed to aid implementation of the new BASRiS process.

## **Annex A - Organisations that Responded**

Breast Cancer Care and Breast Cancer Now

British Heart Foundation Scotland

British Medical Association (BMA)

Child Poverty Action Group in Scotland (CPAG)

Children's Hospices Across Scotland (CHAS)

Forth Valley Local Medical Committee

Grampian LMC Ltd

Interim Directors of Public Health NHS Ayrshire & Arran

Macmillan Cancer Support

Marie Curie

MND Scotland

MS Society Scotland

National Advisory Committee for Neurological Conditions

Parkinson's UK Scotland

The Royal College of Physicians of Edinburgh

RCGP Scotland

Scottish Partnership for Palliative Care (SPPC)

The Royal College of Occupational Therapists

The Scottish Lung Cancer Nurses' Forum

# **Annex B - Finalisation of the CMO Guidance following the Managed Consultation**

This annex was added in June 2021, prior to publishing.

The overall response was very positive and respondents were largely very supportive of the new guidelines. Below are the key areas identified for improvement in the finalisation of the Guidance and consequent developments.

## **The Role of Clinical Nurse Specialists**

### **You Said**

Respondents used a number of different questions in the consultation to express that they disagreed with completion of BASRiS forms being limited to registered medical practitioners. They gave the following reasons; the process will be less efficient; this could compound the workload pressures which doctors are already experiencing; nurses have the requisite skills required to make a clinical judgement in line with the CMO Guidance.

### **We Did**

Provision was included in the Social Security Administration and Tribunal Membership (Scotland) Act 2020 to amend the Social Security (Scotland) Act 2018 to allow registered nurses to make a clinical judgment of terminal illness.

The CMO Guidance, along with all tools to support clinicians, has been updated throughout to reflect this legislative change.

In making this change, five criteria which the registered medical practitioner or registered nurse must meet in order to complete a BASRiS form were agreed, by the Chief Medical Officer's Directorate (CMO) and the Chief Nursing Officer's Directorate (CNO), in consultation with stakeholders. These are that they:

1. must have appropriate skills, knowledge and experience to undertake the role and;
2. must be involved with the diagnosis and / or care of the patient and;
3. must be acting in their professional capacity and;
4. must work in accordance with a clinical governance framework and the requirements of your employers and/or contractual arrangements and;
5. must hold current registration with the General Medical Council or the Nursing and Midwifery Council.

These criteria, which have been provided for through a combination of legislation and guidance, will ensure that only those with the appropriate skills and experience will be able to undertake this role.

Electronic completion of the BASRiS form is in development, which will make the completion and administration of the form easier for the clinicians.

## **Improvements to the usability of the Guidance**

### **You Said**

Clarity was suggested in a number of areas for example the overlap between the Social Security Scotland BASRiS and Department for Work and Pensions DS1500 systems.

Further development of the executive summary was also suggested to enable the Guidance to be more easily navigated.

Refinement of some of the worked examples included in the Guidance was also recommended.

It was suggested that an on-line version of the Guidance would make it much more user friendly.

### **We Did**

The Short Life working Group and the Stakeholder Reference Group further refined the guidance throughout to improve clarity and ensure consistency.

The executive summary was re-written to ensure it provides a clear overview of the purpose of the Guidance and the content of each section.

Some of the worked examples have been further developed.

When published online, the document will have hyperlinks taking the reader to the section being referenced allowing much easier navigation.

## **Support to help Implementation of the CMO Guidance**

### **You Said**

Responses were clear that supporting materials would be needed to help ensure the smooth implementation of the Guidance. Respondents offered the following suggestions; training and awareness raising on the new rules, easy read documents to support understanding, a professional helpline, short video guides.

## **We Did**

It is vitally important registered medical practitioners and registered nurses have the knowledge and understanding of both the new definition and the CMO Guidance which supports it. To ensure this the following support measures have been developed with the help of the Terminal Illness National Implementation Group:

A frequently asked questions document has been developed to support clinicians using the Guidance. This includes a comprehensive list of questions to support clinicians particularly who may be navigating the new process for the first time.

An easy read leaflet has been developed for patients which provides clear information explaining the BASRiS process and how it will support access to Scotland's new forms of disability assistance.

A comprehensive easy read fact sheet has been developed for clinicians providing a clear overview of the new process.

Social Security Scotland will provide a helpline whereby a clinician completing a BASRiS form can seek assistance regarding how they can access the Guidance, what the process of decision making is and how the Guidance can best be navigated by that clinician.

A hub of information is being established on Social Security Scotland's website where the Guidance will be published alongside a number of supporting materials. This will provide a single location for clinicians to easily access all resources.

Social Security Scotland are developing a video, due to be available before Child Disability Payment launches, highlighting the new process, timelines and support available.

Stakeholder Roadshows are being planned which clinicians will be encouraged to attend

Presentations have been made to Health Board Communication Leads and materials provided for onwards communication.

Communications, including a CMO/CNO letter, will be sent to clinicians and copied to others with an interest, including Chief Officers of Integrated Joint Boards

## **Variability**

### **You Said**

Concern was raised about the potential for inconsistent implementation of the Guidance.

## **We Did**

While decisions based on clinical judgements will consider the individual's particular circumstances, and therefore will be "patient-centred" the guidance is intended to ensure that such judgements are underpinned by a consistent deliberative approach.

We agree on the importance of the efficacy of the guidance and for that reason will undertake a robust audit to review its implementation and inform any future amendments. A framework to analyse the implementation of the Guidance has been developed, which will form part of the comprehensive package of audit activity which will be undertaken once disability assistance is being delivered.



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