Scottish
Partnership
for Palliative Care

Submission to Scottish Government Consultation on Benefits Assistance Under Special Rules in Scotland (BASRiS)

Introduction

This submission is structured using the questions posed in the SG online consultation document.

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. Discussions about access to benefits provide a potential opportunity to lead into other issues such as ACP and the identification of carers and their needs.

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

SPPC acknowledges the challenge in drafting clear Guidance which covers a complex area of clinical practice and which also needs to make necessary links to the wider landscape of benefits reform (including the use of different definitions of terminal illness for devolved benefits and UK benefits).

However, there is scope for improving the clarity of the Guidance.

It could be a bit clearer (for example in a revised Executive Summary) that different definitions are in play for different benefits.

SPPC is supportive of the new definition of terminal illness for use as part of BASRiS and the way in which the Guidance seeks to operationalise it. However the approach could do with further clarification because it is somewhat counterintuitive and contrary to common ways of thinking about terminal illness. Because the approach is counterintuitive we believe that without further clarification there is scope for confusion and hence avoidable inconsistency in the clinical judgements reached about eligibility.

Specifically the Guidance should be very clear that:-

- The definition and Guidance require that doctors **should not** introduce timescales into their prognostic judgements

- 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.

We make more general comments about the structure and readability of the Guidance in a subsequent section.

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

The heading for Section 9 should include babies - Babies, Children and Young People.

The bullets in Section 8 should reflect that a formal diagnosis may not have been made, as the BASRiS from itself does. Not all progressive diseases in paediatric palliative care have a formal diagnosis.

Do you find the Guidance easy to navigate and understand? If No, please explain why, and suggest what might be helpful:

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. The Guidance needs to be clear about the key questions it is designed to answer. Although the document has a section titled *Executive Summary* this is not easy to read or clearly structured. 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 eg

- 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?

Once orientated at the outset by clear answers to these questions the reader is better equipped to wade through the unavoidable complexities.

The document is very long. Annexes G and H are extracts from primary legislation and it seems possible that these will not be avidly read. They could be reduced to links within footnotes.

Having firmed up the content of the Guidance after this consultation it is suggested that a fresh pair of eyes be brought to bear on the structure and overall readability with some re-working prior to publication.

Does the Guidance make clear how clinical judgements should be made? (Particular attention should be paid to Section 2 and Section 7 of the Guidance)

The flowchart in section 2 and the contents of section 7 are clear and helpful. However, SPPC has some concerns about the relationship between Section 7 and Annex B.

Section 7 is the heart of Guidance to clinicians about how to apply the definition of terminal illness contained in the Act, and SPPC is supportive of the content and approach in this section. However, the key terms in the bulleted indicators are necessarily imprecise (eg "advanced", "rapid/erratic", "unstable", "worsening") and therefore capable of widely varying interpretation, either singly or when considered collectively. This has two consequences. Firstly, there is likely to be wide variation in the judgements made by clinicians, with consequent inconsistency. Secondly, the use of imprecise terms means that the basis of the judgement lacks transparency. Sections B and C of Annex B contain some more precise and objectively verifiable indicators (both general and condition-specific). They can provide a means to increase the consistency and transparency of decision making. SPPC suggests that 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 directively eg *"in reaching your judgement you are expected to use the indicators in Annex B as well as the indicators in this section [7]."*

The BASRiS Form itself (Annex A) should more closely mirror the parameters and requirements of Section 7. Part 1 asks for diagnoses. Part 2 doesn't clearly relate to Section 7, emphasises treat/interventions and places a particular emphasis on "coping with activities of daily living" even though this is not one of the indicators in Section 7. Tick boxes linking to the indicators in section would be one way to align content (see below also under **Any Further Comments**).

The signposting to Annex C (worked examples) could be expanded and made more descriptive so that readers are made aware that it contains worked examples based on a variety of people and conditions, and covering a range of issues which may arise. It might be helpful if the worked examples more explicitly illustrated how the tools can been 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 MDT in the BASRiS process.

4 of the last 5 paragraphs in Section 7 are not about clinical judgment and would sit better elsewhere (the exception is the para referring to Annex C (Worked Examples).

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

Most of the annexes are providing background or context and so are not really relevant to supporting the clinical judgement process.

Annex B is the key section supporting the clinical judgement process. The introductory paragraph could helpfully be re-phrased.

The "Surprise question" in Annex B ('*Would you be surprised if this patient were to die very soon?*') should be removed. The word "soon" is so imprecise and subjective as to be meaningless and likely to result in inconsistency. For many doctors "very soon" may potentially be interpreted as being in less than 6 months and this could cause a reduction in eligibility for some patients compared to current rules. SPPC is also concerned that this formulation of the surprise question has never been tested or validated as a tool.

The content in sections B and C of Annex B is helpful (see above). It should be regularly reviewed to take account of developing evidence and understanding (for example around the definition and recognition of advanced dementia). SPPC supports the detailed comments submitted to the consultation by Dr Kirsty Boyd relating to the bullets in Section B, and condition specific indicators in section 3.

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

SPPC considers that the Guidance will lead to people with a wider range of diagnosis gaining access to benefits under special rules, and this is welcome.

Changes suggested elsewhere in this submission will help to reduce unwanted variability (and inconsistency) in how this Guidance is interpreted and implemented.

Can you think of any support that may need to be in place for professionals the public and others to help the implementation? If yes, please explain:

Sensitivity of Communications

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. Sensitive conversations towards the end of life would often not include the word "terminal". For many people the word "terminal" carries overtones of certainty, finality and very short life expectancy. Sensitive conversations will often make use of phrases which reflect uncertainty such as "we don't know exactly what will happen or when" and "it's possible you might not get better because….".

SPPC has a concern that, 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.

This risk of harm is likely to be bigger for people with some non-malignant conditions, and so greater under this Guidance. Research shows that people's narratives and understanding of cancer more commonly include an appreciation of mortality at an earlier stage. There is evidence that people with conditions such as heart failure or COPD commonly do not fully understand how poor their prognosis may be, even when their disease is advanced.

Easy-Read Leaflets

It would be helpful if an easy-read version of the Guidance were produced targeting staff who maybe involved in decision making (for example nurse practitioners) or who may have a role in informing or advising people about benefits.

There should be separate leaflets for public and for professionals.

Are you generally content with the title of the Guidance?

Yes

Do you have any further comments?

Road-testing

SPPC believes it is important that the draft Guidance should be "road tested" prior to nation-wide 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.

Role of Nurses

SPPC is concerned that the draft Guidance, unlike the current system, doesn't permit nurses to sign off the form, and that this may in practice have a negative effect on ease and timeliness of access. Also, it will frequently be the case that a nurse may be the person best informed to reach the required clinical judgement. The Guidance should go as far as possible (within the limits of the legislation, which effectively states that responsibility for the judgement must be taken by a registered medical practitioner) to enable nurses to continue to play an important role. Nurses should be permitted to populate the form pending sign off by an appropriate doctor. To support this the BASRiS form should be re-worded so that the doctor is not required to state that they have personally sought the consent of the patient – instead there should be wording stating confirmation that consent has been obtained (and perhaps stating by whom).

Currently nurses, including specialist nurses and advance practitioners, can complete and sign DS1500 forms. This supports timely application and award of Attendance Allowance and Personal Independence Payment and, as these are passport benefits, also timely access to additional benefits and vital support such as a Blue Badge. DS15000 forms may be completed from post diagnosis onwards and at key prognostic transitions e.g. for people with metastatic cancer, MND, progressive heart failure and in hospital, out-patient clinics and by nurses who work across primary and secondary care. Nurses play a key role in addressing the impact of a terminal illness, including financial, social needs, in completing Holistic Needs Assessments carer support plans and in anticipatory care planning. Within a multi professional context, nurses may be leading discussions and decision-making with people in relation to realistic medicine and appropriate treatment decisions and goals for people who fulfil the criteria for terminal illness. The nursing role in relation to identifying and leading care planning for terminal illness is recognised within national policy for example, in relation to Do Not Attempt Resuscitation decision-making and completion of DNACPR forms.

Reliance on only medical practitioner access to and completion of BASRiS has resource implications for already stretched medical teams, specialty consultants and GPs. This carries risk for people who are terminally ill in relation to timely completion, also with potential via non completion to restrict rather than widen access to benefits. Whilst the intention of the Act and guidance is to widen access to people with terminal illness for any diagnosis, there is the potential to adversely impact on cancer patients given the number of specialist nurses in cancer care who currently complete significant numbers of DS1500 forms on a daily basis.

Medical Practitioners will now be required to complete forms previously completed by their senior nursing colleagues and cope with an increasing requirement for forms due to the revised definition of terminal illness. Nurses are commonly first point of contact for Benefits Services in attempting to access a DS1500, due to difficulties in accessing this directly from time pressured medical staff. Changes to allowing nurses to complete the DS1500 were previously made in relation to this issue.

There is a focus on GPs in the guidance but completion only in primary care may result in further delays in applications for patients moving from hospital in / out-patient settings to home and pending transfer of relevant information to GPs to make eligibility judgements. Of consideration also is the learning from restricting the completion of Key Information Summaries to a single professional and already pressured group, with work underway to extend access to other professionals and care settings necessary to support timely completion.
Whilst acknowledging the Act is clear regarding the decision re terminal illness definition is via a medical practitioner, allowing nurses to support the process is an important consideration for people who are terminally ill, families and

important others. As suggested nurses could complete the form for final medical staff sign off. A further option may be to amend the form to include confirmation that the decision the patient was terminally ill had been agreed with the responsible medical practitioner, with relevant details provided. This would provide an option for continued multi professional team working where teams decide this and whilst acknowledging restriction in claiming medical fees.

Inconsistent Use of Terms "decision" and "decision-maker"
Section 5 (Aims) refers to "decisions" being made by the registered medical practitioner. Section 13 refers to the doctor having "*made a decision on eligibility*". Section 17 (Appeals) refers to "the decision-maker" and "appeal may be made against the conclusions of the decision-maker". However in this instance the decision-maker is someone in a role at the Social Security Scotland. It might be clearer if throughout the document the task of the registered medical practitioner is described as "judgement", "reaching a clinical judgement" and "making a judgement that the person meets the definition of terminal illness". It is Social Security Scotland who make decisions about eligibility and it is their decision which may be appealed.

Section 6 (Purpose and Principles)
Many of the bullets listed under the subheading *Principles* are really just facts and would sit better elsewhere.

Section 11 (Communication)
The second para (about proactively raising the issue of BASRiS with patients, carers and families) should be moved under the subheading which follows (Communication with your patient, carers, and family). As well as being a communication issue this is also a key process issue, so perhaps it should also be mentioned in a side box parallel to the top level of the flowchart.

The list of conversation resources could usefully link to this page of the EC4H site which has some very relevant, practical and useful content
http://www.ec4h.org.uk/resources/anticipatory-care-planning-in-scotland/

Annex A (BASRiS Form)

The text and thrust of the form should be better aligned to the indicators and approach in Section 7. For example the Box in section 2 of the form seems to be asking for diagnoses. It would be better if health professionals completing the form were asked: 1. Does this individual have a progressive disease that can reasonably be expected to cause the individual's death. Yes/NO 2. Are several of the factors *(lifted from section 7)* listed below present YES/NO (*or alternatively tick which ones are present*).

The form also asks doctors to use their "clinical judgement about the ability of your patient to cope with activities of daily living", but there is nothing in Section 7 which requires or suggests judging or assessing activities of daily living. The final worked example about Harry (Annex C) also makes reference to judgements about coping with activities of daily living. "Limited self-care" is one of the indicators in Section B of Annex B. If the BASRiS Form and the case studies are making reference to activities of daily living then the Section B should be within Section 7 or more directively linked from Section 7 (as we have suggested earlier in this response.

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?

Annex B

The referencing in para 1 should refer to SPICT as well as GSF – much of the text is SPICT rather than GSF. A new version of SPICT is due soon and it would make sense to update the annex using that text.

Consistent use of "Registered Medical Practitioner"

In places the term GP is used alone and this may cause confusion.

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