Chief Medical Officer for Scotland

E: CMO@gov.scot

Dear Colleague

Updated Guidance on the Implementation of Benefits Assessment under Special Rules in Scotland (BASRiS) Guidance and form for Terminal Illness, for Disability Benefits devolved to Scotland

Purpose

1. This letter is to inform you about updates to the BASRiS Guidance following changes resulting from the phased transfer of disability benefits to Scotland and legislative changes to the DWP processes.
This guidance supercedes the previous CMO Letter - SGHD/CMO(2021)15. The CMO guidance required by legislation has been endorsed by the CNO, and both Registered Medical Practitioners (RMPs) and Registered Nurses (RNs) are required by legislation to take account of the guidance while making a clinical judgement about terminal illness (**Appendix C**).

2. A phased introduction of Scotland's disability benefits is in progress. **Appendix B** sets out the timeline for the transfer as well as where the DWP SR1 forms (previously DS1500) will continue to be required.

3. This letter also advises you of the further support available to clinicians aimed at helping with the implementation of the Scottish terminal illness provisions. Additional information and background is in **Appendix A**.

4. It also provides you with information about the Outline Framework, a scoping document which will be used to aiming to analyse the implementation of the CMO guidance **(Annex J in the Guidance)**.

Key Objectives

5. Scottish Government took responsibility for disability assistance in Scotland in April 2020. Three new benefits - Child Disability Payment, Adult Disability Payment and Pension Age Disability Payment - are being transferred to Scotland in a phased manner. It is hoped transfer will be complete by 2025. The Scottish disability benefits

From the Chief Medical Officer for Scotland
Professor Sir Gregor Smith
Chief Nursing Officer
Professor Alex McMahon

19 December 2023

SGHD/CMO(2023)20

Addresses

For action
All Registered Medical Practitioners and Registered Nurses

For information
Medical Directors, NHS Boards
Directors of Nursing, NHS Boards
Directors of Public Health, NHS Boards
Primary Care Leads, NHS Boards
COPFS
Chairs, NHS Boards and Special Boards
Chief Executives, NHS Boards and Special Boards
Chief Officers of Integration Joint Boards
COSLA and SOLACE
British Medical Association
Royal College of Nursing
General Medical Council
Nursing and Midwifery Council
Medical and Dental Defence Union of Scotland
Medical Protection Society
Medical Defence Union
Academy of Medical Royal Colleges and Faculties in Scotland
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replace the Department for Work and Pension's (DWP's) DLA (Child), Personal Independence Payment (PIP) and Attendance Allowance (AA).

Legislation

6. The devolution of disability benefits has brought about some significant changes to the Scottish benefits system. For people who are terminally ill, Scottish disability assistance is designed to ensure they are able to receive the support they require, as soon as possible and for as long as it is needed.

7. **The Scottish terminal illness definition moves away from the 12 month life expectancy that DWP currently uses.** This is an important step change; the Scottish definition does not require an explicit time frame, within which death is reasonably expected to occur. It is set out in the Social Security (Scotland) Act 2018, (as amended by the Social Security Administration and Tribunal Membership Act 2020):

> "*An individual is to be regarded as having a terminal illness for the purpose of determining entitlement to disability assistance if, having had regard to the (Chief Medical Officer's (CMO)) guidance, it is the clinical judgement of an appropriate healthcare professional that the individual has a progressive disease that can reasonably be expected to cause the individual's death."*

8. The BASRiS guidance, required by the 2018 Act, was developed with the help of clinicians and third sector organisations with an interest in this area. **It is a legal requirement that, when making your clinical judgement, you pay regard to this guidance.** In the best interests of patients, RMPs and RNs will be expected to promptly complete the Benefits Assessment under Special Rules in Scotland (BASRiS) form for relevant patients. **Section 7 - 'CLINICAL ASSESSMENT OF TERMINAL ILLNESS' and bullet points 5 to 8 (highlighted in bold) in section 8 - 'FACTUAL INFORMATION THAT MUST BE INCLUDED'**, provides further detail on applying the definition.

9. The BASRiS form provides Social Security Scotland with confirmation that it is the clinical judgement of the clinician completing the form, that the named individual is terminally ill. Social Security Scotland is responsible for deciding whether an individual is entitled to disability assistance and will use the BASRiS accordingly.

Implementation

10. Several additional sources of support have been developed to ensure that clinicians are well-prepared to implement the Scottish definition. These have been developed in conjunction with clinicians, the GMC and the NMC to ensure relevance to professional regulatory requirements.
These include :

- 'frequently asked questions'
- guidance for clinicians completing a BASRiS form outlining how the definition has changed
- flyer for patients and those who support them
- Clinical Helpline managed by Social Security Scotland

All supportive information will be available in a single place, providing a 'hub' of information on the guidance section of Social Security Scotland's website.

11. The DWP's terminal illness definition will continue to be required for Scottish individuals accessing those benefits which continue to be the responsibility of the UK Government, such as Employment Support Allowance and Universal Credit. Where a BASRiS has already been submitted for an individual, an SR1 form (replacement for DS1500) would also be required if they subsequently went on to apply for a reserved benefit – DWP require their own form for their benefits due to their different terminal illness definition.

Action

12. We would be grateful if you could familiarise yourself with the updates to the BASRiS processes as the BASRiS is now required for disability assistance delivered in Scotland. We would urge you to take full advantage of the supporting advice and information on offer via links.

13. Your professional and timely support will be very valuable to your patients when they need it most.

We greatly appreciate your valuable assistance in this important matter.

With kind regards

Yours sincerely,

Gregor Smith

Professor Sir Gregor Smith
Chief Medical Officer

Alex McMahon

Professor Alex McMahon
Chief Nursing Officer

APPENDIX A

Additional Information and Background

CMO Guidance

The CMO Guidance, required by legislation, is intended as a practical document and a tool to support clinicians, in reaching their clinical judgement to complete the Benefits Assessment under Special Rules in Scotland (BASRiS) form for terminal Illness. It includes the necessary processes to follow and the required legal, ethical, professional and other important factors to take into account while completing the BASRiS form.

This guidance supports clinicians to interpret and apply this definition consistently. To meet the definition the individual should have an illness:

a) that is advanced and progressive or with risk of sudden death, AND;
b) that is not amenable to curative treatment, or treatment is refused or declined by the patient for any reason, AND;
c) that is leading to an increased need for additional care and support.

The guidance also contains information to facilitate clinical decision making e.g.:

- criteria to be considered (sections 7, 8 and 9 in the guidance),
- detailed condition specific indicators (Annex B in the guidance),
- a number of worked examples, (Annex C in the guidance) and
- practical information relating to the new process (Annex A in the guidance).

The guidance will also be useful to others with an interest in this area.

Eligibility to complete the BASRiS form (Section 10 in the guidance)

RMPs and RNs who are involved in the diagnosis of terminal illness for the purpose of accessing disability assistance and thus those able to complete a BASRiS form must meet **all** of the following criteria:

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

Overlap between the DWP system and the Scottish BASRiS system (Annex E in the guidance)

As Scotland's disability benefits are launching in a rolling programme, the definition only applies to individuals where the relevant new Scottish disability benefit has been implemented in Scotland. Additionally, the DWP definition will continue to apply for

access to reserved benefits such as Employment Support Allowance and Universal Credit.

Child Disability Payment

Child Disability Payment launched nationally on 22 November 2021. The terminal illness definition has been applied since the pilot launch date of 26 July 2021.

For children (birth to age 16) diagnosed as terminally ill a BASRiS form, completed by a RMP/RN, supports their special rules application for Child Disability Payment. The BASRiS provides Social Security Scotland with confirmation of the date the individual met the Scottish terminal illness definition.

Adult Disability Payment

Adult Disability Payment launched nationally on 29 August 2022. The terminal illness definition has been applied since the earliest pilot launch date of 21 March 2022.

For adults (aged 16 to state pension age) diagnosed as terminally ill a BASRiS form, completed by a RMP/RN, supports their special rules application for Adult Disability Payment. The BASRiS provides Social Security Scotland with confirmation of the date the individual met the Scottish terminal illness definition.

Pension Age Disability Payment

Pension Age Disability Payment, replacing DWP's Attendance Allowance, will launch in pilot areas from autumn 2024 and nationally in 2025.

For adults aged state pension age and over who have been diagnosed as terminally ill a BASRiS form, completed by a RMP/RN, will support their application for Pension Age Disability Payment under the special rules. The BASRiS will provide Social Security Scotland with confirmation of the date the individual met the Scottish terminal illness definition.

Until Pension Age Disability Payment has been launched, individuals who are state pension age or over and who may have less than 12 months to live, should continue to use the SR1 and send this to the Department for Work and Pensions to support an application for Attendance Allowance.

Special Rules for Terminal Illness (SRTI) route to receiving disability assistance (Annex G in the Guidance)

Individuals who meet the terminal illness definition will be able to receive disability assistance through the fast tracked SRTI route. This will allow the patient's application for disability assistance to be processed differently, under special rules, resulting in the fast tracking of their application and entitlement to the highest rates of the components (care and/or mobility) relevant to the benefit.

Support for Clinicians - The Clinical Helpline

Social Security Scotland 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. Where appropriate this will include speaking with one of Social Security

Scotland's clinical practitioners. Social Security Scotland cannot comment on individual cases as this might prejudice subsequent decision making.

Importantly, while the support of the clinical helpline can provide help and advice to clinicians, the decision (judgement of whether someone is terminally ill according to the new definition) remains the responsibility of the clinician.

Information on contacting the helpline can be found here[1].

The BASRiS form (Annex D in the Guidance)

The BASRiS form has replaced the SR1 form and DS1500 form for disability assistance delivered in Scotland.

The BASRiS form provides Social Security Scotland with relevant clinical information that is required for terminally ill individuals who are applying for Scotland's disability assistance benefits.

The information the BASRiS form requires is similar to that on the SR1 form or DS1500 form. The form asks about the condition, requests details of the indicators supporting the clinical judgement and asks about any planned treatment. It also asks if the individual is aware of their terminal prognosis and asks for the date of the clinical judgement of terminal illness. This is the date of the clinical judgement when the individual met the Scottish terminal illness definition.

A new version of the BASRiS form was released on 15 December 2022. RMPs/RNs should ensure they are using the most up to date version of the form. The new form asks for the date of clinical judgement (of terminal illness). Older versions of the form – which should no longer be used – did not explicitly ask for the date of clinical judgement.

For RMPs/RNs using an NHS device and accessing the Scottish Wide Area Network (SWAN), a BASRiS web form should be completed and submitted directly to Social Security Scotland online: Fill out an online BASRiS web form[2]. This is the quickest and most efficient way for clinicians to complete and submit a BASRiS form. RMPs/RNs should download and save a copy of the submitted web form for their records. After submitting the BASRiS web form, there is an option to fill out a fee claim form for those who are eligible.

For those without access to SWAN, an editable pdf of the BASRiS form can be downloaded: editable pdf of the BASRiS form[3]. This pdf version must be emailed to Social Security Scotland from an approved domain name/email address on the 'allow list' e.g. nhs.net; scot.nhs.uk. An organisation on The Scottish Charity Register (OSCR) can apply to be on the approved 'allow list' by emailing: DigitalBASRiSGeneralEnquiries@socialsecurity.gov.scot

Stocks of the updated paper forms can be ordered by emailing: Glasgow.mailroom@socialsecurity.gov.scot. Paper forms need to be posted to the address on the form. Forms need to reach Social Security Scotland in the right way

[1] Social Security Scotland - Special Rules for Terminal Illness: Contacting the clinicians helpline
[2] Social Security Scotland - Special Rules for Terminal Illness: Requesting a BASRiS form
[3] BASRiS medical form (socialsecurity.gov.scot)

in order to land in the priority terminal illness work queue. RMPs/RNs should keep a copy of the PDF/paper BASRiS for their records. Please use the 'hub' of information[4] for details on how to request BASRiS forms for your organisation. The 'hub'[5] on Social Security Scotland's website provides Special Rules for Terminal Illness information and resources.

APPENDIX B

Table detailing when Scotland's definition applies by age group

<table>
<tr><td rowspan="2">Children and Young People (aged 0 -16)</td><td colspan="2">Disability benefits:
Child Disability Payment (Social Security Scotland)</td></tr>
<tr><td colspan="2">Use definition and CMO Guidance.
Complete a BASRiS form and send to Social Security Scotland to support Child Disability Payment application.</td></tr>
<tr><td>Young People aged 16-18 already in receipt of Child Disability Payment[6]</td><td colspan="2">Use definition and CMO Guidance.
Complete a BASRiS form and send to Social Security Scotland to ensure young person receives highest rates of Child Disability Payment.</td></tr>
<tr><td rowspan="2">Adults aged 16 to State Pension Age[7]</td><td colspan="2">Disability benefits:
Adult Disability Payment (Social Security Scotland)</td></tr>
<tr><td colspan="2">Use definition and CMO Guidance.
Complete a BASRiS form and send to Social Security Scotland to support Adult Disability Payment application.</td></tr>
<tr><td rowspan="4">Adults State Pension Age and Older</td><td colspan="2">Disability benefits:
Attendance Allowance (DWP) – send form SR1 to DWP in support of an application

Until launch of:
Pension Age Disability Payment (Social Security Scotland) – launching in pilot area Autumn 2024. BASRiS required.</td></tr>
<tr><td>Autumn 2024 onwards: in pilot area only (Local Authorities not yet announced).</td><td>Use new definition and CMO Guidance.
Complete a BASRiS form and send to Social Security Scotland to support Pension Age Disability Payment application.</td></tr>
<tr><td>Autumn 2024 onwards: for all areas outwith the pilot area.</td><td>Continue to use SR1 (replacement for DS1500) and send to DWP to support Attendance Allowance application.</td></tr>
<tr><td>Early 2025 onwards: all of Scotland</td><td>Use new definition and CMO Guidance. Complete a BASRiS form and send to Social Security Scotland to support Pension Age Disability Payment application.</td></tr>
</table>

[4] Social Security Scotland
[5] Social Security Scotland
[6] Children and young people up to the age of 16 are eligible to apply for Child Disability Payment. For those who are already in receipt of Child Disability Payment the award can continue until the child is 18 years old.
[7] Adults (including young people) aged 16 to state pension age are eligible to apply for Adult Disability Payment.

APPENDIX C

CMO Guidance

GUIDANCE FOR DOCTORS AND NURSES COMPLETING BENEFITS ASSESSMENT UNDER SPECIAL RULES IN SCOTLAND (BASRiS) FORM FOR TERMINAL ILLNESS v1.2

ADVICE FROM THE CHIEF MEDICAL OFFICER

THE SCOTTISH GOVERNMENT

Updated December 2023

GUIDANCE FOR DOCTORS AND NURSES COMPLETING BENEFITS ASSESSMENT UNDER SPECIAL RULES IN SCOTLAND (BASRiS) FORM FOR TERMINAL ILLNESS

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1. EXECUTIVE SUMMARY

Following the Scotland Act 2016, three disability benefits have been devolved to Scotland and will become the responsibility of Scottish Ministers. These benefits are Child Disability Living Allowance (DLA Child), Personal Independence Payment (PIP) and Attendance Allowance (AA). The new Scottish replacements of these 3 benefits are administered by Social Security Scotland with different rules. They are called Child Disability Payment, Adult Disability Payment and Pension Age Disability Payment. Other benefits, such as Universal Credit, have not been devolved and continue to be administered on a UK basis, by the Department for Work and Pensions (DWP), following existing rules and definitions.

People of all ages who live in Scotland with terminal illness are able to apply for disability benefits under special rules resulting in the fast tracking of their application and higher rates of assistance. This guidance sets out the new rules for accessing those Scottish replacements of the 3 disability benefits where the potential recipient is terminally ill (Benefits Assessment under Special Rules in Scotland (BASRiS)) using a new definition of terminal illness for social security purposes.

This guidance provides a framework to support those making a clinical judgement about terminal illness i.e. doctors and nurses who provide care, in a professional capacity, for people towards the end of life. The guidance is also relevant to others with an interest or involvement in the care of people who may be approaching the end of life and/or who are involved in advising on social security benefits. It will also be of interest and relevance to people who are themselves approaching the end of life, plus their family and carers.

New Scottish legislation changes the definitions and rules surrounding terminal illness for the purpose of access to the devolved benefits. This means that there will be no limit set on how long a patient has left to live before their condition is considered “terminal”.

The terminal illness definition that the Scottish Ministers use when making Disability Assistance Regulations under the Social Security (Scotland) Act 2018 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 an appropriate healthcare professional that the individual has a progressive disease that can reasonably be expected to cause the individual’s death.*

An appropriate healthcare professional is defined as a registered medical practitioner or registered nurse who meets the requirements set out in the regulations.

This guidance supports clinicians to interpret and apply this definition consistently. To meet the definition the individual should have an illness:

> a) that is advanced and progressive or with risk of sudden death, AND;
> b) that is not amenable to curative treatment, or treatment is refused or declined by the patient for any reason, AND;
> c) that is leading to an increased need for additional care and support.

Notable features of this definition of terminal illness, which are different from some other existing definitions, are:

- It is based on a clinical judgement, using a range of largely clinical indicators.
- There is no requirement to make a prognostic judgement about how long somebody will live.
- There is no requirement to assess individual care needs.
- It goes beyond cancer to include all diseases and conditions that are judged to be terminal. Examples include: organ failure (respiratory disease, heart and vascular diseases, kidney disease, liver disease); neurological diseases (Parkinson's disease, Huntington's Disease, Motor Neurone Disease, Multiple Sclerosis); Stroke; Frailty with one or more co-morbid diseases; Dementia; rare diseases; combinations of diseases with conditions.
- It applies to all irrespective of criteria such as age and residency status, provided they live in Scotland or fall into one of the statutory exceptions from the requirement to live in Scotland.

There are many diseases, which may lead to a patient's death in the future such as diabetes or COPD but where the diseases are not at a stage that means the patient requires fast tracked benefits. This guidance is not intended for such cases.

The BASRiS form, confirming that a patient is terminally ill according to the Scottish definition and enabling them to apply for benefits under special rules, is included in this guidance. This form replaces the DS1500 or SR1 forms for the Scottish replacement of benefits listed above that have been devolved to Scotland. Those already on a DS1500 or SR1 for a reserved benefit do not additionally require a BASRiS form to be completed for a devolved benefit. Their entitlement will be automatically recognised and transferred to the benefits under the Scottish system.

Where someone applies for a devolved benefit first and then applies for a reserved benefit eg Universal Credit or Employment and Support, DWP will require the SR1 (or DS1500 which it has replaced) as the person has to meet their 12-month terminal illness definition.

Section 2 is a flowchart illustrating the different processes through which an individual presenting with progressive disease may pass, depending on their circumstances and whether or not they meet the new definition. It should be remembered that a patient who is not eligible under the special rules is still able to apply for benefits and undergo assessment in the usual way.

Section 3 is a table summarising the differences between the current UK rules for terminal illness benefits (SR1/DS1500) and the new approach to disability benefits which have been devolved (Benefits Assessment under Special Rules in Scotland (BASRiS)).

Sections 4-6 provide more detail on the aim, purpose and principles of BASRiS. Section 7 is a key section providing more detail on how doctors and nurses must approach the clinical assessment of terminal illness.

Section 8 lists the factual information which will be required when documenting a clinical assessment of terminal illness on a BASRiS form.

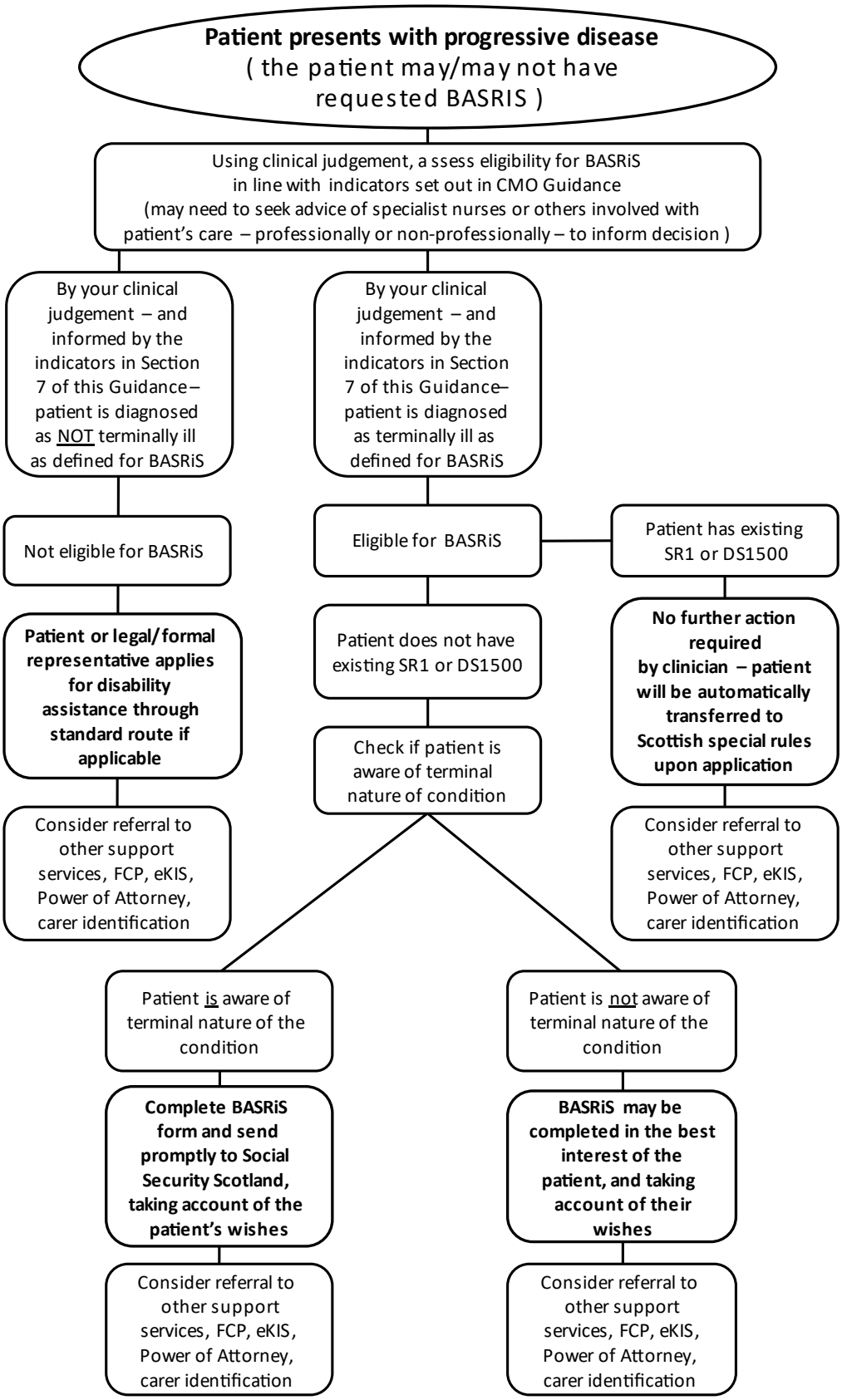
Section 9 provides information on how to apply this guidance in the case of babies, children and young people.

Section 10 sets out which doctors and nurses are eligible to make a clinical assessment of terminal illness for the purpose of BASRiS.

Section 11 provides guidance on handling the sensitive communications with individuals and their families/carers which is required throughout the BASRiS process.

There are nine annexes (A to I) which provide a range of background information and practical resources. These are signposted at relevant points in the body of the guidance. Annex B contains resources designed to help in reaching a clinical judgement as to whether an individual meets the definition of terminal illness. Annex C contains some case-based worked examples involving adults and children of how the definition would apply to different individuals.

2. FLOW CHART FOR ELIGIBILITY FOR BASRiS FORM COMPLETION



DIFFERENCES BETWEEN THE REQUIREMENTS FOR BASRiS AND SR1 (REPLACING DS1500) FORMS

The Table below provides the differences between the 2 systems

Requirements	**BASRiS For Social Security Scotland (devolved benefits)**	**SR1 (which has replaced DS1500) For DWP (reserved benefits)**
Definition of terminal Illness	It is the **clinical judgement** of an appropriate healthcare professional that the individual has a progressive disease that can reasonably be expected to cause the individual's death.	A progressive disease where death as a consequence of that disease can reasonably be expected within 12 months.
Time limit	No time limit	Likely to die within 12 months
Qualifying period	None	None
Review period	No review period	Review after 3 years
Benefits	Child Disability Payment (CDP) Adult Disability Payment (ADP) *and* Pension Age Disability Payment (PADP) Automatic award to the highest rate of assistance that they are entitled to.	Personal Independence Payment (PIP); Disability Living Allowance (DLA) for children; Attendance Allowance (AA); Universal Credit (UC); Employment and Support Allowance (ESA) May get benefits at a higher rate or get extra money
Completed by	Registered Medical Practitioners and Registered Nurses	Medical Practitioners or specified Specialist Nurses
Interaction between BASRiS and SR1 (replacement for DS1500)	Individuals in receipt of BASRiS will need to meet the DWP terminal illness definition if claiming reserved benefits such as Universal Credit. Where a patient already has a BASRiS form, an SR1 form (replacement for DS1500) would also be required if they subsequently went on to apply for a reserved benefit – DWP require their own form for their benefits due to their different terminal illness definition under the DWP rules.	Individuals already in receipt of SR1 (replacement for DS1500) will be automatically eligible under BASRiS if applying for Child Disability Payment, Adult Disability Payment or Pension Age Disability Payment

Definitions

BASRiS
For the purposes of the BASRiS, the terminal illness definition under the Social Security (Scotland) Act 2018 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 an appropriate healthcare professional that the individual has a progressive disease that can reasonably be expected to cause the individual's death."*

SR1 form (replacement for DS1500)
Terminal illness for the purposes of SR1 (replacement for DS1500) is defined in UK Social Security legislation as:

> *"a progressive disease where death as a consequence of that disease can reasonably be expected within 12 months".*

3. BACKGROUND

The Scotland Act 2016 gave Scotland new powers relating to social security, including responsibility over certain benefits (**Annex E**).

These powers have been used to create a Scottish Social Security system based on dignity, fairness and respect, which will help to support those who need it, when they need it. This includes improving benefits for disabled people and people with ill health, as well as confirming that on the infrequent occasions that assessments are required, they will not be carried out by the private sector.

The Social Security (Scotland) Act 2018 confirms that there will be no limit set on how long a patient has left to live before their condition is considered "terminal" (**Annex G**). It is for Registered Medical Practitioners (RMPs) and Registered Nurses (RNs) to use their clinical judgement to decide whether the illness is terminal, enabling their patient to apply for disability assistance under special rules, where appropriate. This will allow the patient's claim for disability assistance to be processed differently, under special rules, resulting in the fast tracking of their application and entitlement to the highest rates of the components (care and/or mobility) relevant to the benefit.

In this context, it is expected that the RMPs and RNs involved in the diagnosis of terminal illness:

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

(More information can be found in the online Frequently Asked Questions https://www.socialsecurity.gov.scot/guidance-resources/guidance/special-rules-for-terminal-illness-frequently-asked-questions[8])

The evidence you provide through BASRiS will support Social Security Scotland to make a decision about entitlement to disability benefits under special rules.

Your responsibility is to use your clinical judgement to diagnose whether you consider the individual's condition to be terminal, according to the new definition, i.e. *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 this CMO guidance), it is the clinical judgement of an appropriate healthcare professional that the individual has a progressive disease that can reasonably be expected to cause the individual's death.*

4. LEGISLATION

Special Rules in Scotland has 4 components:

- 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 earlier of: the date of application or the date of the clinical judgement of terminal illness by the RMP or RN, subject to it not being earlier than 26 weeks if being calculated retrospectively; or when Scottish Ministers first become aware of the terminal illness (as a result of the individual notifying a change in circumstances or otherwise)
- Patients who qualify under special rules will be automatically entitled to the maximum amount of award of the benefit they are entitled to

The Social Security Principles, with the underpinning legislation for the special rules are set out in (**Annex G**).

5. AIM

The aim of this guidance is to enable RMPs and RNs to use their clinical judgement to determine whether their patient is terminally ill, for the purpose of entitlement to disability assistance under special rules. Through the completion of a BASRiS form, your evidence will support your patient's application for disability assistance to be processed differently, so that the final decision can be made under special rules by Social Security Scotland. Social Security Scotland may require further information from RMPs and RNs signing the BASRiS form, where the content is not explicit or legible enough, before making the decision on the application e.g. a Social Security Scotland practitioner will contact a clinician who has not yet provided a completed BASRiS form, in this time critical situation, where a patient believes that they are terminally ill and applies for expedited disability assistance on the advice of the clinician; or if an individual approaches Social Security Scotland first, in which case

[8] https://www.socialsecurity.gov.scot/guidance-resources/guidance/special-rules-for-terminal-illness-frequently-asked-questions

Social Security Scotland will contact the clinician for a clinical judgement on their patient via a completed BASRiS form. In these circumstances, Social Security Scotland will have the **individual's or their legal representative's consent to contact their preferred named clinician**.

With this in mind, this document provides guidance to support and assist you in making these difficult decisions. It will also enable you to explain and provide a clear rationale for making those decisions made on clinical grounds if a patient, carers, family, or others have any queries.

The process for diagnosing terminal illness for the purposes of applying for Scottish equivalents of disability assistance, as laid out in this Guidance, applies to all – irrespective of criteria such as age and residency status, provided they live in Scotland (or fall into one of the statutory exceptions from the requirement to live in Scotland). This includes people with no fixed address or who are homeless. The only exception is those who are subject to immigration status. However, there is no requirement for RMPs and RNs to determine these factors, as these checks will be undertaken by Social Security Scotland.

6. BASRiS PURPOSE AND PRINCIPLES

The purpose of the BASRiS form is to provide supporting information and clinical evidence about whether, in your clinical judgement, the condition is "terminal" and therefore the individual requires expedited access to disability assistance. This will provide evidence of eligibility to disability assistance under special rules. It is not for you to assess the type of disability benefit that your patient is eligible for or undertake a formal functional assessment. In addition, the purpose of the clinical assessment for these benefits, in this instance, is not to provide care. However, those patients who are eligible for these benefits could also be in receipt of other care and support services or signposted to these services where appropriate.

By recording your clinical judgement and the date the judgement was made (which may not be the same as the date the form was signed) on the BASRiS form, your patient will be able to access much needed additional support at the time of their greatest need. The disability benefits are likely to enable them to have the quality of life that they seek, for example: meeting additional costs of care or travel, and providing the ability to visit places or people that they hold dear.

Principles:

- The process should be fair and seen to be fair and transparent to the RMPs RNs, other professionals and the public.
- The process should support an individual when they are terminally ill (see definition set out in **Section 7**), reducing unnecessary distress wherever possible. It may also improve the quality of life of carers and those close to the individual.
- Receipt of the new Scottish benefits Child Disability Payment, Adult Disability Payment and Pension Age Disability Payment, may enable access to relevant housing, and health and social care support for the individual. The benefits may assist in the access to benefits for the patient's carers.
- The process may also require an application by the individual or a third party acting on their behalf for the relevant disability assistance, if this is not already in place.

- The clinical judgement of terminal illness enables the provision of assistance for the added costs of the disability. The benefit is not “income support” and is not means tested.
- The process of making the clinical judgement should be consistent with this guidance, despite the decisions varying according to individual circumstances.
- Social Security Scotland may require further information from RMPs and RNs signing the BASRiS form, where the content is not explicit or legible enough to process the application.
- A Social Security Scotland practitioner will contact a clinician who has not yet provided a completed BASRiS form to support their patient’s application for disability assistance under special rules; Social Security Scotland will have an individual’s or their legal representative’s consent to contact their preferred named clinician.
- Even if the decision is that the patient is not deemed eligible for the fast tracking of benefits assistance under special rules, they can be assessed by Social Security Scotland using the usual standard application route.

7. CLINICAL ASSESSMENT OF TERMINAL ILLNESS

The Social Security (Scotland) Act 2018 states that regulations are to make clear that: *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 CMO guidance), it is the clinical judgement of an appropriate healthcare professional that the individual has a progressive disease that can reasonably be expected to cause the individual’s death.*

It is important to note that this definition goes beyond cancer to include all diseases, including those associated with other conditions, that are judged to be terminal by an RMP and RN. Examples include: organ failure (such as respiratory disease, heart and vascular diseases, kidney disease, liver disease); neurological diseases (such as Parkinson’s disease, Motor Neurone Disease, Multiple Sclerosis, Huntington’s Disease); Stroke; Frailty with one or more co-morbid diseases/conditions; Dementia; and rare conditions or diseases. This list is not exhaustive. In addition, individuals’ eligibility for BASRiS also could be established based on a combination of diseases with conditions.

Your patient should display all of the following indicators:

a) an illness that is advanced and progressive, or with risk of sudden death, AND;
b) that is not amenable to curative treatment, or treatment is refused or declined by the patient for any reason, AND;
c) that is leading to an increased need for additional care and support.

There are a number of tools, which can be used to assist you in the process of making your clinical assessment of terminal illness, and these are given in **Annex B**.

There are many diseases, which may lead to a patient’s death in the future such as diabetes or COPD but where the diseases are not at a stage that means the patient requires access to disability assistance under special rules for terminal illness. This guidance is not intended for such cases because expedited access to benefits is unnecessary.

Accurately predicting when someone may die is known to be difficult and imprecise. Estimating prognosis is also recognised to be challenging. The clinical judgement becomes more challenging the further ahead you are asked to predict a patient's death.

Certainty is not required.

A GP on average will be involved in approximately 20 deaths/2000 patients/year. Of these, 2 are likely to be Sudden Unexpected deaths; around 5 deaths will be due to Cancer; around 6 deaths will be due to Organ Failure; and around 7 deaths will be due to Dementia, Frailty, and Decline (Murray SA & Sheikh A. Palliative Care Beyond Cancer: Care for all at the end of life. BMJ 2008;336:958-9).[9] The clinical judgement that you are being asked to make is about the patient's overall condition, and from a basket of indicators. At the time of making the decision, in addition to the diagnosis of the terminal disease, you should also take account of the wider circumstances affecting their ability to cope with undertaking activities of daily living, without making a formal functional assessment.

The assessment and judgement should be made on clinical grounds and be based on suitable clinical expertise and opinion, as well as the experience of your patient and their carers or family. Any additional information gathered about the patient's condition and circumstances, may be of assistance to you and other colleagues in assessing and planning to meet other health and care needs. The information you gather may also help you to provide a clear rationale for making the decision for or against eligibility for BASRiS, in the event of any queries or disagreement from the patient, carers, family, and/or others.

Some tools to help you to improve the consistency in the process of making the clinical judgement of terminal illness are attached in **Annex B.**

Social Security Scotland may seek information from the RMP and RN signing the BASRiS form, depending on explicitness, legibility and clarity of the content.

Some worked examples are included in **Annex C**.

An information leaflet for professionals and a similar leaflet for individuals who are terminally ill and those who support them have been developed by Social Security Scotland with input from stakeholders, which can be shared widely. Links to these can be found in **Annex H.**

The differences between DWP criteria for SR1 (replacement for the DS1500) and the BASRiS will require to be handled sensitively, particularly if a patient is accessing both devolved and reserved benefits. The differences between the BASRiS and SR1(replacement for the DS1500) are laid out in **Section 2**.

It is important that you are aware that there are other legislative definitions of terminal illness (e.g. Carers (Scotland) Act 2016.). However, these should not be used to assess eligibility for BASRiS.

8. FACTUAL INFORMATION THAT MUST BE INCLUDED

[9] https://www.bmj.com/content/336/7650/958.1.short

The BASRiS form is based on factual information, and should contain details of:

- Community Health Index (CHI) number of the individual
- Your General Medical Council (GMC) or Nursing and Midwifery Council (NMC) number and official work contact details including telephone number (not your personal number)
- Affirmation that you are providing the information to the best of your knowledge and belief and that you have been professionally involved in the diagnosis and/ or care of the patient and had access to the relevant records. This includes doctors or nurses taking over the care of the patient.
- Diagnosis of the main disease/s and other relevant associated conditions (in some cases there may be no formal explicit diagnosis e.g. you may have to record the diagnosis as "neurological disease" without specifying which neurological disease in babies, children, young people or adults)
- **Clinical features of the disease (causing the terminal illness) which indicate a severe progressive condition (examination findings and results of investigations including staging if appropriate)**
- **Relevant treatment including response and planned treatment/interventions that may significantly alter the prognosis**
- **Whether the patient is aware of their condition and/or prognosis**
- **If unaware, the name and address of the patient's legal representative requesting the form or aware of the form being completed**
- **Date of the clinical judgement regarding terminal illness (not the date when the form was signed as these may not be the same)**
- Consent from the patient and/or their representative to share the information with Social Security Scotland, or taken by Social Security Scotland and notified to the clinician, to be recorded in the patient's clinical records
- Whether carers' views have been taken into account

9. BABIES, CHILDREN AND YOUNG PEOPLE

This guidance is equally applicable to babies, children and young people with life threatening or life limiting diseases or illness.

Children and young people may have particular needs. Their views, if they have mental capacity, need to be considered alongside those of their parents, carers and family, in accordance with the Getting it Right for Every Child (GIRFEC)[10] approach.

Children and young people have rights, which should be respected. This includes taking into account their views and respecting their confidentiality.

Appropriate language and forms of non-verbal communication should be employed, noting that conversations with children and young people may be very challenging when considering issues related to likely end of life care, not least, as many professionals do not undertake these on a regular basis.

The Social Security (Scotland) Act 2018 recognises the importance of inclusive communication. It states that:

[10] https://www2.gov.scot/Topics/People/Young-People/gettingitright

"'communicating in an inclusive way' means communicating in a way that ensures individuals who have difficulty communicating (in relation to speech, language or otherwise) can receive information and express themselves in ways that best meet each individual's needs."

http://www.legislation.gov.uk/asp/2018/9/enacted[11]

Identifying the best interests of babies, children and young people is often not easy**,** and may be complicated by legal and ethical issues, as well as issues of consent and capacity.

Child protection issues also need to be considered in the usual way, as some individuals may be a danger to the child or young person.

The trajectory of diseases and illness in babies, children and young people, may be different to that in adults.

Specific issues related to neonatal conditions need to be considered, such as, following premature birth, birth injuries, the diagnoses of congenital abnormalities and metabolic diseases.

Children and Young People may have different support mechanisms e.g. young people may relate more to their peers.

You may wish to discuss the completion of a BASRiS form with the specialist involved in the care of the child or young person, or another specialist in this area. A reference point may be through discussion with colleagues at Children's Hospices across Scotland (CHAS): https://www.chas.org.uk/.

10. ELIGIBILITY TO COMPLETE THE FORM

An RMP or RN who meets all 5 criteria can complete the BASRiS form. The RMP or RN:

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

This is in contrast to the SR1 (replacement for the DS1500) which can be completed by certain types of specialist nurses. Currently, the Scottish legislation only allows Registered Medical Practitioners (RMPs) and Registered Nurses (RNs) to take responsibility for signing the BASRiS form for devolved benefits. Other professional groups are not eligible to sign the BASRiS form at this stage. However, RMPs and RNs may wish to consult and seek the advice of the wider healthcare and non-healthcare staff involved in the care and support of the patient where relevant, in addition to seeking the views of the patient's informal carers, when completing the form.

[11] http://www.legislation.gov.uk/asp/2018/9/enacted

This may include nurses and other clinical professionals, social workers, care workers, housing officers and others.

On some occasions, Social Security Scotland may receive a completed application form from an applicant or their representative without an accompanying BASRiS, stating that the application is under Special Rules for Terminal Illness. In this instance, a Social Security Scotland (clinical) Practitioner may make contact with the RMP or RN nominated on the form by the applicant and check the eligibility of their patient to receive a BASRiS certificate. If the answer is “yes”, then the consideration of the application will be fast-tracked and payment made to the applicant. Following this the RMP or RN will complete and send a BASRiS form for their patient and keep a copy for the patient record. Social Security Scotland would expect to receive the form within a month; if it has not been received they could follow this up. The RMP or RN will only receive a payment, if eligible to claim fees for completion of the form, when Social Security Scotland receive a completed and signed BASRiS form and the Fee Payment Form. If the answer is “no”, then the applicant can choose whether to agree to Social Security Scotland processing the application under normal rules or to contact the RMP or RN to discuss their clinical condition.

Where the individual who is terminally ill meets the residence and presence conditions for disability assistance but is currently living in an EEA state, Switzerland or Gibraltar then the appropriate healthcare professional includes a doctor or nurse who has equivalent qualifications to a registered medical practitioner or registered nurse, in an EEA state, Switzerland or Gibraltar. They must meet the 5 criteria set out above with the exception of the fifth. Instead the doctor or nurse must be a member of the professional body equivalent to the General Medical Council or Nursing and Midwifery Council in that EEA state, Switzerland or Gibraltar.

11. COMMUNICATION AND CONSULTATION WITH OTHERS (INCLUDING CARERS)

Communication with other healthcare professionals

You may wish to take the opportunity to seek the views of other professional colleagues involved in the care of the individual. You may also wish to share the information that a BASRiS form has been completed with other relevant professional colleagues, once completed.

Communication with your patient, carers, and family

You should raise the issue of BASRiS when appropriate, rather than wait for the patient, their carer or family to raise it with you e.g. it would be beneficial to consider the provision of a BASRiS form at relevant interactions, such as when agreeing an electronic Key Information Summary (eKIS) and a Future Care Plan (FCP) recommended by the Healthcare Improvement Scotland’s Scottish Future Care Programme.

In some cases a patient may already be aware of BASRiS and may approach the RMP or RN, asking them for a BASRiS form.

You should have a conversation with informal and formal carers, wherever possible and relevant e.g. where the individual or their legal representative has given

permission, and where this will assist a clinical judgement to be made without resulting in additional unnecessary delays. Your approach should be sensitive to their needs and beliefs. Carers and family members may be able to provide evidence and examples of the rapidity of deterioration of the condition, which may help you to make a decision.

Depending on what the patient already knows, it can be a difficult conversation for clinicians and their patients, and/or family and carers. An imprecise prediction of prognosis may cause distress to the patient, their carers or family.

There may not be the opportunity to have several conversations over time with patients and those close to them.

Be mindful that some patients may wish to know everything about the prognosis of their condition and others may not want to have the conversation at all. In addition, some patients may not be aware of their condition. Your approach can have a long lasting effect on the individual and their carers and families.

Please consider the following links, which provide advice and guidance on initiating sensitive and difficult conversations:

https://gmcuk.wordpress.com/2016/05/13/handling-difficult-conversations-ten-top-tips/ [12]
http://www.sad.scot.nhs.uk/media/16017/transcript-of-discussing-dying.pdf[13]
http://www.sad.scot.nhs.uk/before-death/end-of-life-care/[14]
https://www.bhf.org.uk/informationsupport/publications/living-with-a-heart-condition/difficult-conversations---talking-to-people-with-heart-failure-about-the-end-of-life[15]
https://ihub.scot/project-toolkits/future-care-planning-toolkit/future-care-planning-toolkit/[16]
Meaningful conversations - Meaningful conversations (ihub.scot)[17]
Healthcare professionals | Marie Curie[18]
Bereavement support | Grief support (mariecurie.org.uk)[19]

[12] https://gmcuk.wordpress.com/2016/05/13/handling-difficult-conversations-ten-top-tips/
[13] http://www.sad.scot.nhs.uk/media/16017/transcript-of-discussing-dying.pdf
[14] http://www.sad.scot.nhs.uk/before-death/end-of-life-care/
[15] Difficult Conversations | BHF
[16] https://ihub.scot/project-toolkits/future-care-planning-toolkit/future-care-planning-toolkit/
[17] Meaningful conversations - Meaningful conversations (ihub.scot)
[18] Healthcare professionals | Marie Curie
[19] Bereavement support | Grief support (mariecurie.org.uk)

ANNEX A

ADDITIONAL INFORMATION (INCLUDING PARTICULAR CIRCUMSTANCES)

1. PROFESSIONAL RESPONSIBILITIES

For RMs, your actions should be in line with your professionalism required in the GMC's Good Medical Practice[20] e.g. you are competent, keep your knowledge and skills up to date, you establish and maintain good relationships with patients and colleagues, are honest and trustworthy, and act with integrity and within the law. RN actions should be in line with the NMC Code[21] e.g. you maintain the knowledge and skills required for safe and effective practice, communicate effectively and clearly and show integrity in your practice. You should be alert to and address unwarranted variation in your assessments and decisions.

You should provide the report to the best of your knowledge and belief, on the balance of probabilities. The clinical judgement should be made by you, and supported by as much relevant information that is available to do so. Certainty is not required. Reflection on previous decisions may be able to support you to make the appropriate decisions in the future.

GMC does caution doctors, that the legal requirements should not be construed in such terms that they prevent doctors from exercising appropriate clinical judgement, or give rise to conflicts of interest, when it comes to diagnosing and managing a patient's condition. For example, any interpretations likely to incentivise doctors and/or patients to take a particular approach to the diagnosis and management of a patient's condition, which might not otherwise be seen as clinically appropriate, or of no overall benefit to the wellbeing of the patient, should be avoided. NMC requires nurses to exercise their judgement in any decision making and to uphold the values set out in the Code and in line with the laws of the country of practice.

BMA ethical guidance[22] and NMC principles[23] and RCN ethical guidance [24] can also help with the consideration of relevant legal and ethical principles.

2. TIME TO RESPOND AND RETURN THE FORM TO SOCIAL SECURITY SCOTLAND

Once you have determined that a BASRiS form should be completed, including the date when the clinical judgement of terminal illness was made (not the date the form was signed, as these may not be the same), you should complete the form promptly, with the expectation that it will be done as quickly as possible. This may be following your own knowledge of the condition and decision, or an assessment of the situation following a request by the individual, their carer, another healthcare professional involved in their care, or Social Security Scotland. This does not have to be via a face-to-face appointment.

3. CONSENT

[20] https://www.gmc-uk.org/-/media/documents/good-medical-practice---english-20200128_pdf-51527435.pdf?la=en&hash=DA1263358CCA88F298785FE2BD7610EB4EE9A530
[21] https://www.nmc.org.uk/globalassets/sitedocuments/nmc-publications/nmc-code.pdf
[22] https://www.bma.org.uk/advice/employment/ethics/ethics-a-to-z
[23] https://www.rcn.org.uk/professional-development/publications/pub-006499
[24] https://www.rcn.org.uk/professional-development/principles-of-nursing-practice

Since the introduction of GDPR in 2018 (now UK GDPR), an inherent change to the lawful basis for processing health data occurred now falling under the term 'special category' data. In alignment with current data protection laws and organisations in the wider NHS Scotland, the updated lawful basis for processing health data, changes from "requiring consent" to that of "public task" under UK GDPR, with supported articles in the Data Protection Act 2018.

As with any lawful basis, Health Boards and GP Practices-should ensure that they are adhering to UK GDPR principles, especially when ensuring the right to be informed e. g. Privacy Notices, which are legally required under UK GDPR.

Processing of personal data in NHS Scotland uses the UK GDPR articles 6 and 9[25] (see below):

6(1)(e) Public task: the processing is necessary for you to perform a task in the public interest or for your official functions, and the task or function has a clear basis in law.

Health data is also categorised as a special category under UK GDPR, the processing of which is subject to the following further conditions under Art. 9:

Art. 9 (h) processing is necessary for the purposes of preventive or occupational medicine, for the assessment of the working capacity of the employee, medical diagnosis, the provision of health or social care or treatment or the management of health or social care systems and services with the corresponding and required section 10(1)(c) and Schedule 1(2) of the Data Protection Act 2018.

Art. 9 (i) for archiving, research and statistics, with the corresponding required section 10(1)(c) and Schedule 1(2) of the Data Protection Act 2018.

The UK GDPR is the supporting framework that further enhances the protections afforded to patients in their health and care journey. Where this legislation may conflict with other provisions found in other legislation pre UK GDPR implementation and while understanding their Common Law Duty of Confidentiality (which may require informed and explicit consent) e.g. Gender Recognition Act 2004[26], Human Fertility and Embryology Act 2008[27], Venereal Diseases Regulations 1974[28], etc., where, a balanced view must be considered and appropriately documented. Information Governance frameworks found in NHS Scotland organisations that support such decisions should be utilised to gain the upmost clarity and assurance in decisions made, and just as importantly, not made.

With this understanding, there are 3 possible processes for the consideration of the completion of the BASRiS form:

- Consideration of the completion of the BASRiS form if the patient or their representative requests a BASRiS form

[25] A guide to lawful basis | ICO
[26] Gender Recognition Act 2004
[27] Human Fertility and Embryology Act 2008
[28] Venereal Diseases Regulations 1974

- You make a decision that it is appropriate to consider the completion of a BASRiS form on eligibility without a prior request from anyone else
- A request from a Social Security Scotland practitioner to complete a BASRiS form. This will occur when a patient who believes they are terminally ill applies for disability assistance first, without requesting you to provide a completed BASRiS form. In these time critical circumstances, Social Security Scotland will have the **individual's or their legal representative's consent to contact their preferred named clinician to request a completed BASRiS form**.

In some cases, such as in the absence of the patient's legal representative, you may need to send the BASRiS form to Social Security Scotland without the knowledge of the patient. This would be necessary, if you believe that it is in the best interests of the patient, as disclosing the clinical information to the patient, in your view would be harmful to the patient (see section - 7 Harmful Information). If the BASRiS form has been completed and sent under these circumstances, detailed records need to be kept of the reasoning and analysis to comply with the Common Law Duty of Confidentiality and UK GDPR principles e.g. it is necessary to support the mental and emotional wellbeing of the patient. You must also be aware that the European Convention on Human Rights[29],states you cannot override the express wishes of the patient, where the patient has capacity to express them. In other words, where such a patient has stated that they do not wish the BASRiS form to be completed and submitted to Social Security Scotland, the BASRiS form must not be completed.

The Social Security (Scotland) Act 2018 ('the 2018 Act') makes provision for formal and legal representatives to act on behalf of adults with incapacity such as:

Appointees;
Guardians;
Personal Acting Bodies;
Corporate Acting Bodies; and
Power of Attorney

However, there may be individuals who do not lack capacity but could benefit from an appointee in certain circumstances. Some individuals may prefer and agree to another person becoming their appointee during a very difficult time in their lives. Where harmful information has been withheld, Social Security Scotland will inform the individual of the many ways they could be supported in their interactions with the agency and this will include the option of having an appointee to act on their behalf.

Third Party Representative

Many adults who do not fall within the definition of an adult with incapacity[30] and who need or want help or advice can also access it from another person or organisation (Third Party Representative) to engage with Social Security Scotland. In the majority of circumstances it will be possible for individuals to rely on common law agency arrangements to appoint another person to act on their behalf in their interactions with Social Security Scotland. This policy is specific to third party representatives and does **not apply to** formal representatives as listed above. This is particularly important for patients with disabilities or conditions that make it difficult for them to

[29] https://www.equalityhumanrights.com/en/what-european-convention-human-rights
[30] As defined in the Adults with Incapacity (Scotland) Act 2000 section 1 para 6

express themselves but who are not deemed to be an adult with incapacity, or patients for whom English is not their first language and find it difficult to communicate without an interpreter. It is important that patients who wish to do so are able to ask a third party representative to help them conduct their business with the Social Security Scotland, but that this is balanced with Social Security Scotland's obligations to protect personal information as set out in the Data Protection Act 2018.

GMC's Guidance on Confidentiality (10c)[31] also states that you must *"get the patient's explicit consent if identifiable information is to be disclosed for purposes other than their **own** care or local clinical audit, unless the disclosure is required by law or can be justified in the public interest."* The NMC Code[32] *states that 'a person's right to privacy must be respected in all aspects of their care and that information may be shared about ongoing care or treatment as far as the law allows'.*

Occasionally consent may be provided by a third party appointed to act on the patient's behalf, for example:

- If the patient is incapable within the meaning of the Adults with Incapacity (Scotland) Act 2000[33], and where the individual's estate is not being administered by a judicial factor or other person who has authority to act on behalf of the individual and is willing to do so e.g. an Appointee, a welfare or financial guardian or someone with a power of attorney.

The Adult Support and Protection (Scotland) Act 2007[34] may also be relevant in certain situations.

Children and Young People

In Scotland, the general position is that a young person 16 years and above is presumed to have the capacity to enter into a transaction - Age of Legal Capacity (Scotland) Act 1991[35]. However, the Act makes clear that a person under the age of 16 years will have capacity to consent to a surgical, mental or dental procedure, on his or her own behalf, providing that the medical practitioner providing care is satisfied that the person is capable of understanding the nature and possible consequences of the procedure or treatment. No minimum age is set down, as the matter is based simply on what the medical practitioner believes to be the level of understanding of the young person. This is reflected in guidelines related to Gillick/Fraser competence[36]

Under UK GDPR, children have the same rights as adults over their personal data. - Children and the GDPR - ICO[37]. A child may exercise the above rights on their own behalf as long as they are competent to do so. In Scotland, a person aged 12 or over is presumed to be of sufficient age and maturity to be able to exercise their data protection rights, unless the contrary is shown.

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[31] https://www.gmc-uk.org/-/media/documents/gmc-guidance-for-doctors---confidentiality-good-practice-in-handling-patient-information----70080105.pdf?la=en&hash=08E96AC70CEE25912CE2EA98E5AA3303EADB5D88

[32] https://www.nmc.org.uk/globalassets/sitedocuments/nmc-publications/nmc-code.pdf

[33] https://www.legislation.gov.uk/asp/2000/4/contents

[34] https://www.legislation.gov.uk/asp/2007/10/contents

[35] https://www.legislation.gov.uk/ukpga/1991/50/contents

[36] https://learning.nspcc.org.uk/research-resources/briefings/gillick-competency-and-fraser-guidelines/

[37] https://ico.org.uk/media/for-organisations/guide-to-the-general-data-protection-regulation-gdpr/children-and-the-gdpr-1-0.pdf

You need to have a lawful basis for processing a child's personal data e.g. UK GDPR Articles 6 and (as above).

Consent is one possible lawful basis for processing, but it is not the only option. Sometimes using an alternative basis is more appropriate and provides better protection for the child.

However, only children aged 13 years and over may lawfully provide their own consent for the processing of their personal data if consent is the legal basis for processing the data.

Parental responsibility – The British Medical Association and RCN offer advice on this, but considerations also need to be made if both parents do not agree and specific considerations need to be made when a baby, child or young person has a legal guardian. Individuals who are "looked after and accommodated" have special considerations and 'parental responsibility' may be devolved to their local authority up to the age of 25 years.
Parental responsibility – BMA[38] Parental Responsibility p10 - RCN[39]

Children and young people may have particular communication needs and may need help to make decisions.

4. ACCESS TO THE COMPLETED FORM BY INDIVIDUAL (PATIENT) OR LEGAL REPRESENTATIVE

The Access to Medical Reports Act 1988[40] only applies to access to reports for insurance and employment purposes. It does not apply to the completed BASRiS form.

However, patients have a right to request access to their clinical records, under the Access to Health Records Act 1990[41].

5. RELEASE OF INFORMATION TO SOCIAL SECURITY SCOTLAND - WHO USES THE INFORMATION? HOW WILL THE INFORMATION BE USED? WHO IS RESPONSIBLE FOR THE FINAL DECISION?

The information should only be released to Social Security Scotland, with the knowledge and consent of the individual or their Appointee, Legal Guardian or Power of Attorney, except where information has been withheld (see Section 7 – Harmful Information).

Social Security Scotland Case Managers are required to consider all the available evidence before making a decision about eligibility for disability assistance.

[38] https://www.bma.org.uk/advice-and-support/ethics/seeking-consent/parental-responsibility-and-consent
[39] https://www.rcn.org.uk/professional-development/publications/rcn-caring-for-cyp-uk-pub-009405
[40] https://www.legislation.gov.uk/ukpga/1988/28/section/1
[41] https://www.legislation.gov.uk/ukpga/1990/23/contents

The medical information you provide will be considered as part of this evidence gathering.

Decisions on disability assistance are made usually by a team in Social Security Scotland, which include non-medical/non-clinical decision-makers. One of Social Security Scotland's Clinical Practitioners may contact you for clarification if your report is not explicit enough for a decision to be made. They will not challenge your clinical judgement in relation to the terminal nature of the disease or condition but may need to clarify and confirm other details provided by the you (for example, in cases of illegibility).

6. APPEALS BY APPLICANT REGARDING DECISION MADE BY SOCIAL SECURITY SCOTLAND

Social Security Scotland is responsible for the decision to make an award following receipt of the BASRiS and therefore an appeal can be made against the decision of the Case Manager on the eligibility of components of the disability assistance but not against your clinical judgement. However, Social Security Scotland may contact you for further information about the content of the BASRiS form to process the application. This could be where it appears that the form has been completed by someone who is unauthorised to do so or where it is clear that the form has been completed without having regard to this guidance. Case Managers in Social Security Scotland have access to advice from a senior medical or other clinical professionals to review the information provided in the BASRiS where needed. The intention is to audit the data collected on the various aspects of the process in this area e.g. to monitor unwarranted variation in the application of this guidance.

However, you need to be aware that the individual and/or their legal guardian may not agree with your views and may ask for a second opinion from another RMP/RN. You should follow the usual processes for requests for a second opinion, including advice by the GMC or NMC. You should also follow the usual processes for any issues of indemnity cover and professional advice and support.

Where a patient is not deemed eligible for disability assistance under the special rules i.e. BASRiS, the patient will be able to apply for disability assistance through the standard application route, and they should be supported to do so e.g. referral to Social Security Scotland or welfare advisers.

7. HARMFUL INFORMATION

Harmful information is anything that would be considered to cause serious harm to an individual's mental and/or physical health (see GMC's Guidance on Consent [42]), if they were to become aware of it (e.g. a diagnosis of malignancy). In practice, while addressing the needs of a patient holistically, it is understood that in most circumstances, serious harm to mental health may not be able to be separated from harm to physical health and vice versa. According to GMC guidance there is a limited exception of "serious harm" where it may be appropriate to withhold the information form the patient. "Serious harm" means more than that the patient might become upset. GMC guidance also states that, "if you delay sharing information necessary for making a decision, you should let the patient know there is more to discuss and make sure arrangements are made to share the information as soon as

[42] https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/decision-making-and-consent

it's appropriate to do so. You must make a record of the information you still need to share, your reasons for not sharing it now, and when it can be shared." The information on the BASRiS form may be withheld from a patient at that time, where that is thought to be in the patient's best interests, but GMC Guidance advises that arrangements should be made to share the information as soon as it is appropriate to do so.

In the context of the BASRiS form withholding harmful information is relevant if there may be "serious harm to the physical and / or mental health of the patient or the parent/individual with legal parental responsibilities for a child". This information will then not be released to the recipient by Social Security Scotland in accordance with the Data Protection Act 2018 [43] (see below) and the Social Security Administration and Tribunal Membership Act 2020[44].

In the highly unlikely scenario that you have withheld information from your patient's legal representative/appointee, it is important that you indicate this on the BASRiS form. You are not being asked to make any additional assessment of serious mental and / or physical harm to a legal representative. It is only where you have withheld the information on the BASRiS form from a legal representative/appointee of the patient that you need to inform Social Security Scotland of this.

This will also need to be considered where a patient or their legal representative may make a request to Social Security Scotland to access the patient's medical records.

Social Security Scotland can only withhold information from the patient when the exemption in the Data Protection Act 2018 [45] and the corresponding exemption in the Social Security Administration and Tribunal Membership Act 2020[46] applies. This allows information to be withheld where it is 'likely to cause serious harm to the physical and / or mental health of the data subject'. If you have withheld information it is important that this is clearly noted on the BASRiS form itself.

Where Social Security Scotland has been informed on a BASRiS form that harmful information has been withheld they will follow this up, after 3 months, by contacting the clinician and asking them to confirm whether the information continues to be withheld. If Social Security Scotland is given reason to believe harmful information is no longer withheld before the 12 weeks, they will contact the clinician earlier. This is to ensure that Social Security Scotland retains an accurate record of when harmful information is withheld.

If your reason does not fit the criteria of "serious harm to the physical and / or mental health of the patient, or parent/individual with legal parental responsibilities for a child", and they are not subject to Adults with Incapacity legislation, you will need to seek the consent of your patient before completing and sending the BASRiS form to Social Security Scotland. However, if an individual approaches Social Security Scotland first, Social Security Scotland will contact the clinician for a clinical judgement on their patient via a completed BASRiS form. In these circumstances, Social Security Scotland will have the **individual's or their legal representative's consent to contact their preferred named clinician**.

[43] https://www.legislation.gov.uk/ukpga/2018/12/schedule/3
[44] Social Security Administration and Tribunal Membership (Scotland) Act 2020 (legislation.gov.uk)
[45] https://www.legislation.gov.uk/ukpga/2018/12/schedule/3
[46] Social Security Administration and Tribunal Membership (Scotland) Act 2020 (legislation.gov.uk)

8. EMBARRASSING INFORMATION

Under data protection legislation, the Data Protection Act 2018[47], the fact that information would simply embarrass the author, or someone else, is not taken into account in determining whether it should be processed. Any certificates, which you provide, should not contain inappropriate personal remarks, which cannot be substantiated, and which you would not want your patient to see e.g. suspicions of exaggerating or feigning.

9. REHABILITATION OF OFFENDERS ACT

To ensure compliance with the Rehabilitation of Offenders Act 1974 (Exclusions and Exceptions) (Scotland) Order 2013 (SI 2013/50)[48], your report should not contain any reference to criminal convictions whether spent or not unless the information is directly relevant to the individual's condition. This may be relevant where, for example, a person is due to be released/liberated from prison on compassionate grounds, because of having a terminal illness.

10. PROCESS FOR OBTAINING BLANK BASRiS FORMS AND SENDING COMPLETED FORMS TO SOCIAL SECURITY SCOTLAND

If using an NHS device and accessing the Scottish Wide Area Network (SWAN), you should complete a BASRiS web form online: Fill out an online BASRiS web form. For those without access to SWAN, use an editable pdf BASRiS form and email this to Social Security Scotland (email addresses for children and adults are on the pdf): editable pdf of the BASRiS form. Only paper based BASRiS forms, if used, are to be posted. Whatever the method, completed forms need to be submitted to Social Security Scotland in the right way, so they can be identified quickly for fast-tracked processing.

Please use the Information Hub[49] for up to date details on how to request more BASRiS forms for your organisation. To note, BASRiS forms are numbered to prevent misuse.

Stocks of the updated paper forms can be ordered by emailing: Glasgow.mailroom@socialsecurity.gov.scot. Where a paper BASRiS form has been completed, this should be sent as quickly as possible to Social Security Scotland at this address:

BASRiS Form
PO Box 27165
Glasgow
G4 7BR

[47] http://www.legislation.gov.uk/ukpga/2018/12/contents/enacted
[48] https://www.legislation.gov.uk/ssi/2013/50/contents/made
[49] https://www.socialsecurity.gov.scot/terminal-illness

11. CLAIMING FOR A FEE FOR COMPLETION OF A BASRiS FORM

Eligibility to claim a Fee

Independent GP contractors and private GPs, as well as GPs and RNs employed by the independent contractor and private GP practices, can submit a claim on behalf of the GP practice.

RMPs and RNs who are employed by a third sector organisation (for example a charity) can submit a claim on behalf of that organisation.

Details of when a fee can be claimed by other medical staff are contained in the Terms and Conditions for Medical Staff in Scotland.

Process for claiming a Fee

Please use the Information Hub[50] for up to date details on how to request more fee payment forms.

You should include the relevant payment details on the BASRiS fee payment form **(example in Annex I)**, in order for Social Security Scotland to process your payment.

Completed fee payment forms should be submitted online at the same time as the BASRiS form or posted to this address:

BASRiS Fee Payment Form
PO Box 27165
Glasgow
G4 7BR

The BASRiS fee will be processed upon receipt of the BASRiS form and BASRiS Fee Form within 30 days.

The fee for completion of the BASRiS form is: £17

[50] https://www.socialsecurity.gov.scot/guidance-resources/guidance/requesting-a-basris-form

ANNEX B

MATRIX TO SUPPORT THE CLINICAL JUDGEMENT PROCESS

Decision of whether the individual has (having had regard to the CMO guidance), a progressive disease that can reasonably be expected to cause the individual's death, can be helped by any one or a combination of the additional criteria and indicators below. This could also take account of the carer's own experience of his/her worsening circumstances or distress, which is affecting the care of the individual.

Some additional criteria and indicators which may suggest that a patient is terminally ill

Making a clinical judgement of terminal illness is an extremely complex professional clinical process, which can be an intuitive one, pulling together a range of clinical, co-morbid, social and other factors that give a whole picture of deterioration.

Criteria

Below are some of the criteria, which may be considered. It is not necessary for all the indicators to be present but several in combination would be expected. For example:

- The disease is advanced
- The disease is progressive with decreasing reversibility
- There will be deterioration of an incurable condition
- Increasing need for input of health and social care providers
- The terminal condition is not amenable to further curative treatment, or alternative treatment which is not tolerated or chosen by the patient or their legal representative
- Where death will be an inevitable consequence of the condition
- Any significant events that are likely to impact on function and life e.g. fall with significant harm
- Rapid/erratic decline, unstable
- A deteriorating condition carrying a high risk of sudden death
- Worsening or anticipated worsening of symptoms despite optimal management

General indicators of decline and specific clinical indicators of terminal illness

A) Are there general indicators of decline – deterioration and increasing assistance for care and mobility required (it is <u>not</u> necessary for all the indicators to be present)?

- Decreasing activity and function – (functional performance status declining e.g. Barthel score) limited self-care, in bed or chair for more than 50% of day, and increasing dependence in most activities of daily living
- Increasing dependence on others for unstable or deteriorating physical and mental health
- The individual's carer needs more help and support

- Significant appetite and weight loss over the last few months, or remains underweight (although some patients may gain weight – such as those with heart failure), or loss of muscle mass
- Persistent or worsening symptoms or complex symptoms despite optimal treatment of underlying condition/s
- Repeated unplanned/crisis admissions
- Sentinel Event e.g. fall with significant harm
- No available treatment option that would lead to recovery or the person chooses not to have curative treatment for the disease causing the terminal illness

Functional Indicators

- Barthel Index describes basic Activities of Daily Living (ADL) as 'core' to the functional assessment e.g. feeding, bathing, grooming, dressing, continence, toileting, transfers, mobility, coping with stairs, etc. https://www.physio-pedia.com/Barthel_Index[51] https://www.mdcalc.com/barthel-index-activities-daily-living-adl#use-cases[52]
- PULSE 'screening' assessment - P (physical condition); U (upper limb function); L (lower limb function); S (sensory); E (environment).
- Australia Modified Karnofksy Performance Status Score 0-100 ADL scale. https://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow129188.pdf[53]
- WHO/ECOG Performance Status 0-5 scale of activity. https://ecog-acrin.org/resources/ecog-performance-status[54]

B) Are there specific clinical indicators of terminal illness related to certain conditions?

Cancer (where decline may be rapid or more predictable)

- Functional ability deteriorating due to progressive cancer
- Too frail for cancer treatment or treatment is only for symptom control
- Where any anti-cancer treatment is not aimed at eradicating disease

Organ Failure (where decline is erratic)

Respiratory Disease

- Severe chronic lung disease, with breathlessness at rest or on minimal effort, between exacerbations (e.g. FEV1 <30% predicted in COPD, more than 6 weeks of systemic steroids for COPD in preceding 6 months)
- Persistent hypoxia requiring long term oxygen therapy
- Has needed ventilation for respiratory failure or ventilation is contraindicated
- Recurrent hospital admissions (more than 3 in last 12 months due to COPD)
- Signs and symptoms of right heart failure
- Combination of other factors – i.e. anorexia, previous Intensive Care Unit/Non Invasive Ventilation (ITU/NIV) resistant organisms

[51] https://www.physio-pedia.com/Barthel_Index
[52] https://www.mdcalc.com/barthel-index-activities-daily-living-adl#use-cases
[53] https://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow129188.pdf
[54] https://ecog-acrin.org/resources/ecog-performance-status

Heart/Vascular Disease

- Heart failure or extensive untreatable coronary artery disease; with breathlessness or chest pain at rest or on minimal exertion
- Severe inoperable peripheral artery disease
- Repeated hospital admissions with heart failure symptoms

Kidney Disease

- Stage 4 or 5 Chronic Kidney Disease (CKD) – eGFR<30ml/min, with deteriorating health
- Kidney failure complicating other life limiting conditions e.g. symptoms of nausea and vomiting, anorexia, pruritus, reduced functional status and intractable fluid overload
- Stopping or not starting dialysis, even following transplant failure

Liver Disease

- Cirrhosis with one or more complications in the past year – diuretic resistant ascites; hepatic encephalopathy; hepatorenal syndrome bacterial peritonitis; recurrent variceal bleeds
- Liver transplant is not possible.

General Neurological Diseases

- Progressive deterioration in physical and/or cognitive function despite optimal therapy
- Speech problems with increasing difficulties in communicating
- Swallowing problems (dysphagia) leading to recurrent aspiration pneumonia, sepsis
- Breathlessness or respiratory failure
- Labile blood pressure
- Speech problems with increasing difficulty in communications (progressive dysphasia).

Specific Neurological Diseases

Parkinson's Disease

- Reduced independence, needs increasing help with activities of daily living
- Dyskinesias, mobility problems and falls
- Psychiatric signs (depression, anxiety, hallucinations, psychosis)
- Increased cognitive difficulties/significant cognitive deterioration
- Similar pattern to frailty with one or more co-morbid diseases/conditions - see "Frailty with one or more co-morbid diseases/conditions" section below.

Motor Neurone Disease

- Marked rapid decline in physical status
- Difficulty in swallowing, first episode of aspiration pneumonia
- Low vital capacity (below 70% of predicted using standard spirometry)
- Weight Loss
- Increased cognitive difficulties
- Significant complex symptoms and medical complications
- Communication difficulties.

Multiple Sclerosis

- Significant complex symptoms and medical complications

- Dysphagia, poor nutritional status
- Communication difficulties e.g. Dysarthria, fatigue
- Cognitive impairment e.g. dementia – see “Dementia” section below.

Stroke

- Dense paralysis
- Minimal conscious state
- Progressive deterioration in physical and/or cognitive function despite optimal therapy
- Swallowing problems (dysphagia) leading to recurrent aspiration pneumonia, sepsis,
- Breathlessness or respiratory failure
- Speech problems with increasing difficulty with communication (progressive dysphasia)
- Frailty with stroke and post stroke dementia – see “Dementia” section below.

Frailty with one or more co-morbid diseases/conditions and Advanced Dementia (where there is gradual decline)

Dementia - There are many underlying conditions, which may lead to degrees of dementia, and these should be taken into account. Triggers to consider that indicate that someone is entering a later stage are:

- Unable to walk, dress or eat without assistance,
- Eating and drinking less, difficulty in swallowing
- Weight loss
- Urinary and faecal incontinence
- Not able to communicate by speaking i.e. no meaningful conversation, little social interaction
- Frequent falls, with or without fractures
- Recurrent febrile episodes or infections, aspiration pneumonia
- Severe pressure sores e.g. ulcers with deeper involvement of underlying tissue with more extensive destruction, such as extending into the muscle, tendon or even bone.

TOOLS TO SUPPORT CLINICAL JUDGEMENT

University of Edinburgh Supportive and Palliative Care Indicators Tool (SPICT™)

THE UNIVERSITY of EDINBURGH

Supportive and Palliative Care Indicators Tool (SPICT-4ALL™)

The SPICT™ helps us to look for people who are less well with one or more health problems. These people need more help and care now, and a plan for care in the future. Ask these questions:

Does this person have signs of poor health or health problems that are getting worse?

- Unplanned (emergency) admission(s) to hospital.
- General health is poor or getting worse; the person never quite recovers from being more unwell. (This means the person is less able to manage day to day life and often stays in bed or in a chair for more than half the day).
- Needs help from others for care due to increasing physical and/ or mental health problems.
- The person's carer needs more help and support.
- Has clearly lost weight over the last few months; or stays too thin.
- Has troublesome symptoms most of the time despite good treatment of their health problems.
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

Does this person have any of these health problems?

Cancer

Less able to manage usual activities; health getting poorer.

Not well enough for cancer treatment or treatment is to help with symptoms.

Dementia/frailty

Unable to dress, walk or eat without help.

Eating and drinking less; difficulty with swallowing.

Has poor control of bladder and bowels.

Not able to communicate by speaking; not responding much to other people.

Frequent falls; fractured hip.

Frequent infections; pneumonia.

Nervous system problems

(eg Parkinson's disease, MS, stroke, motor neurone disease)

Physical and mental health are getting worse.

More problems with speaking and communicating; swallowing is getting worse.

Chest infections or pneumonia; breathing problems.

Severe stroke with loss of movement and ongoing disability.

Heart or circulation problems

Heart failure or has bad attacks of chest pain. Short of breath when resting, moving or walking a few steps.

Very poor circulation in the legs; surgery is not possible.

Lung problems

Unwell with long term lung problems. Short of breath when resting, moving or walking a few steps even when the chest is at its best.

Needs to use oxygen for most of the day and night.

Has needed treatment with a breathing machine in the hospital.

Other conditions

People who are less well and may die from other health problems or complications. There is no treatment available or it will not work well.

Kidney problems

Kidneys not working well; general health is getting poorer.

Stopping kidney dialysis or choosing supportive care instead of starting dialysis.

Liver problems

Worsening liver problems in the past year with complications like:

- fluid building up in the belly
- being confused at times
- kidneys not working well
- infections
- bleeding from the gullet

A liver transplant is not possible.

What we can do to help this person and their family.

- Start talking with the person and their family about any help needed now and why making plans for care is important in case things change.
- Ask for help and advice from a nurse, doctor or other professional who can assess the person and their family and help plan care.
- We can look at the person's medicines and other treatments to make sure we are giving them the best care or get advice from a specialist if problems are complicated or hard to manage.
- We need to plan early if the person might not be able to decide things in the future.
- We make a record of the care plan and share it with people who need to see it.

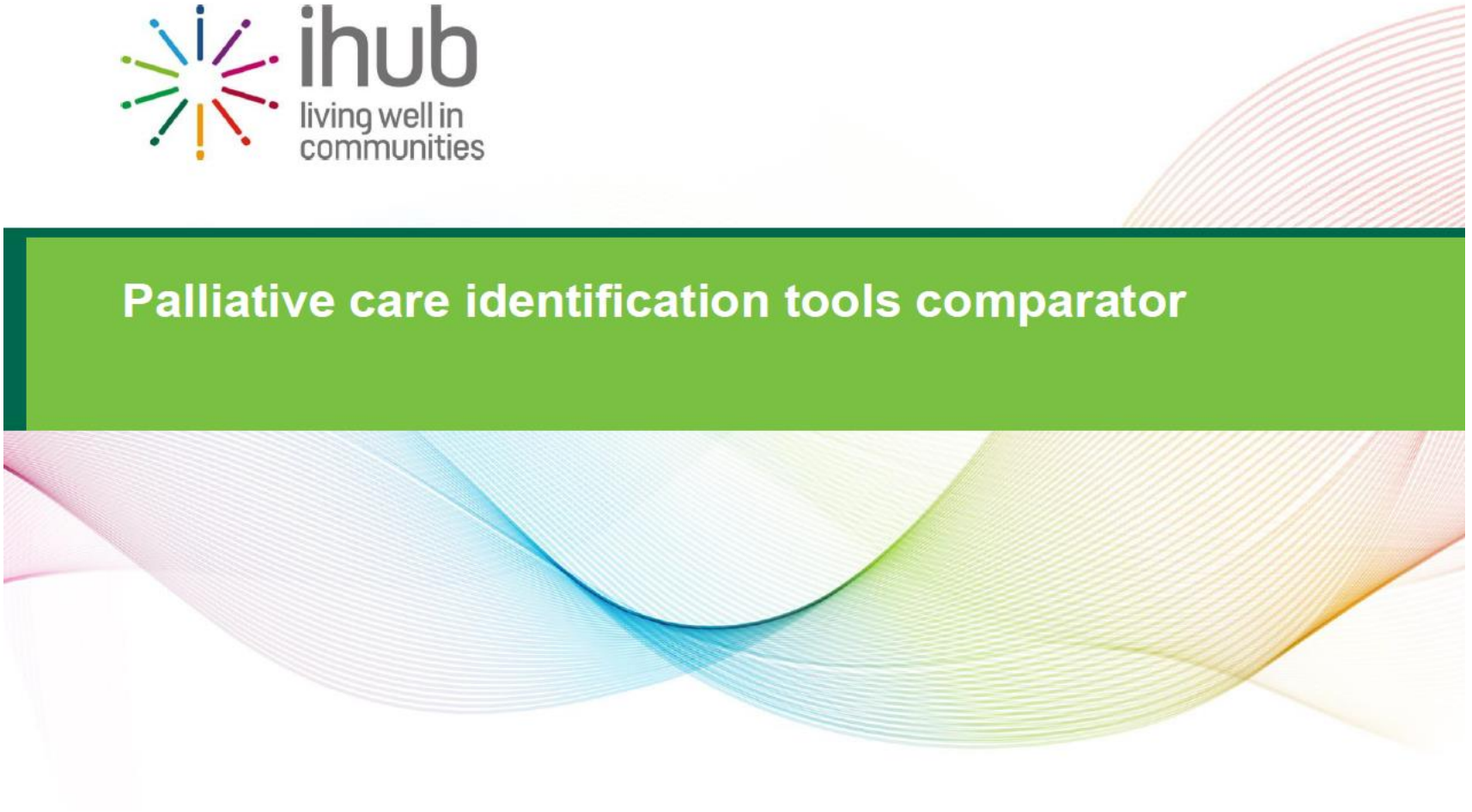
Please register on the SPICT website (www.spict.org.uk) for information and updates.

SPICT™ 2023

https://www.spict.org.uk/[55] SPICT-4ALL[56] https://www.spict.org.uk/red-map/[57]

[55] https://www.spict.org.uk/
[56] SPICT-4ALL
[57] https://www.spict.org.uk/red-map/

ihub Palliative Care Identification Tools Comparator



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Form by Kiryl Sytsko

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Toolbox by lastspark

The Improvement Hub (ihub) is part of Healthcare Improvement Scotland

Published February 2018

http://ihub.scot

Introduction

This tool has been designed to help health and social care professionals identify those who would benefit from a palliative approach to their care. Earlier identification has many advantages. It can allow people to make informed choices about what medical treatments and care they would like to receive, or not receive, and to prioritise things that are important to them when length of life may be short, or when the presence of irreversible illness has altered life for that person.

It can be very difficult to recognise when someone is nearing the end of their life due to a chronic, progressive medical condition, frailty or old age. A number of tools are available to help identify people who could benefit from a palliative care approach at an earlier stage. Some of these assessment tools are listed within this document, alongside a summary of who the tool is aimed at and how it should be used.

Having earlier open and honest conversations with people about palliative care can help them to have improved quality of life and ensure that they receive the care that they want at the end of life, and helps staff to coordinate care and support. This video, produced by the University of Edinburgh, based on research studies with people suffering from various progressive diseases, gives a rationale for early palliative care, and a call for early assessment and care planning.

Resource rationale and limitations

This resource is not intended to be a comprehensive literature review, but rather a visual comparison of some of the main identification tools that are currently used in Scotland. There are brief outlines of all of the tools featured in the comparison table and decision tree, together with links to some key research and further information on these tools. We do not advocate the use of any one tool over another, but rather aim to make it easier for services to compare the features of different tools at a glance, and to select the tools that are most appropriate for their context and requirements.

We have focused on tools that were identified in a literature review by Maas et al, and discussions with palliative care clinicians in Scotland. Some have been validated and others have not. We have tried as far as possible to include information on the limitations of different tools. A selection of additional relevant and emerging research is highlighted at the end of this document, including AnticiPal software.

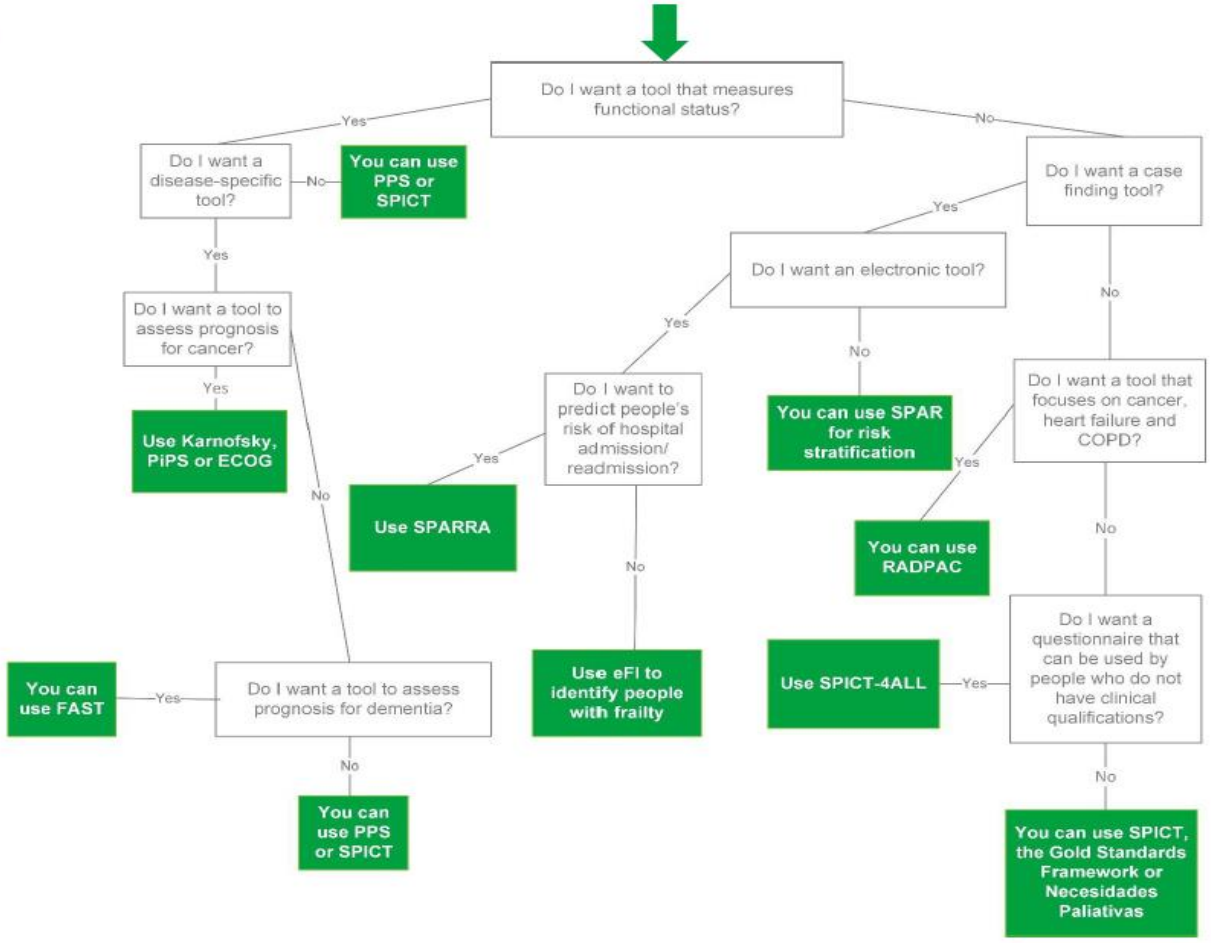
You may wish to use different tools in conjunction with one another, such as the Supportive and Active Palliative Care Register (SPAR) for population risk stratification, and the Palliative Performance Scale for assessing individual prognosis.

Such tools serve to highlight individuals who have advanced illness that is showing signs of advancing. They do not identify specific care needs of individuals, but rather highlight those who may benefit from a palliative care approach being added to their current care and could be assessed for unmet palliative care needs after identification. Some tools make use of the 'surprise question' for estimating prognosis. However a Canadian systematic review published in 2017 does not recommend its use for people with non-cancer illnesses.

Features

Tool	Community Care	Hospital/ Hospice	Cancer	Organ failure	Frailty	Dementia	Neurological	Electronic	Manual
SPICT	✓	✓	✓	✓	✓	✓	✓		✓
PPS	✓	✓							✓
Necesidades Paliativas	✓	✓	✓	✓	✓	✓	✓		✓
eFI	✓				✓			✓	
RADPAC			✓	✓					✓
FAST	✓	✓				✓			✓
Gold Standards	✓	✓	✓	✓	✓	✓	✓		✓
Karnofsky		✓	✓						
ECOG	✓	✓	✓						✓
SPAR	✓	✓							✓
PPP	✓								✓
SPARRA	✓	✓						✓	
PIPS	✓	✓	✓						✓

Decision tree



Supportive & Palliative Care Indicators Tool (SPICT)

Features

Method

Manual individual assessment

The Supportive & Palliative Care Indicators Tool (SPICT) can support the identification of people with advanced health conditions who are at risk of deteriorating and dying. It lists general indicators of deteriorating health to look for, and advises looking for clinical indicators of one or more advanced conditions:

- Cancer
- Dementia/frailty
- Neurological disease
- Heart/vascular disease
- Respiratory disease
- Kidney disease
- Liver disease

It also makes recommendations to review current care and care planning.

SPICT can help to identify people at risk of deterioration or dying at an earlier stage so that they can benefit from well-coordinated, supportive and palliative care, combined with appropriate treatment of their illnesses. In addition to SPICT, SPICT-4ALL can be used by people without clinical qualifications to help to identify signs that an individual's health is deteriorating, and could potentially prevent inappropriate admission to hospital. An electronic SPICT, known as AnticiPal, is in development.

Further reading

SPICT. *SPICT*. Available from: http://www.spict.org.uk/ [Accessed 18th January 2018]

Highet, G. et al. *Identifying patients with advanced conditions for supportive and palliative care using a clinical indicators too: SPICT*. Available from: https://www.palliativecarescotland.org.uk/content/publications/Identifying-SPICT-poster.pdf [Accessed 18th January 2018]

Boyd, K., Murray, S. A. Recognising and managing key transitions in end of life care. *BMJ* 2010;341:c4863

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Palliative Performance Scale

Features


Community No disease-specific indicators


Hospital/Hospice

Method


Manual individual assessment

The palliative performance scale (PPS) is based on the Karnofsky performance scale, and is used to measure physical status in palliative care. The scale covers ambulation, activity and extent of disease, ability to take care of yourself, food intake, and level of consciousness. It can provide a brief description of a patient's current status, inform workload assessment, and it can also be used to estimate survival times.

The PPS is one of the most-studied prognostic tools. It has been externally validated, and consistently predicts survival in patients with advanced cancer.

Further reading

Simmons, CPL et al. Prognostic Tools in Patients with Advanced Cancer: A Systematic Review. *Journal of Pain and Symptom Management* 2017;53:5 962–970

Downing, M. et al. Meta-analysis of survival prediction with Palliative Performance Scale. *Journal of Palliative Care* 2007;23:4 245-254

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Necesidades Paliativas

Features

Method

Manual individual assessment

The Necesidades Paliativas (NECPAL) tool has been developed to identify patients with chronic advanced diseases who would benefit from a palliative approach to their care. It has the following sections, comprising yes or no questions:

- The Surprise Question: would you be surprised if this person dies within the next twelve months?
- Choice/request or need: has the patient or caregiver requested palliative care, or do you consider that the patient requires palliative care at this moment?
- General clinical indicators of severity and progression, covering nutritional markers, functional markers, other markers of severity and extreme frailty, use of resources and co-morbidity.
- Specific indicators of severity and progression for the following diseases: cancer, COPD, chronic heart disease, chronic neurological diseases, serious chronic liver disease, serious chronic renal disease, dementia

A person is identified as requiring palliative care if the answer to the first question is no, and the answer to at least one other question is yes.

It is based on SPICT and the Gold Standards Framework Prognostic Indicator Guidance.

Further reading

Gómez-Batiste, X. et al. Identifying patients with chronic conditions in need of palliative care in the general population: development of the NECPAL tool and preliminary prevalence rates in Catalonia. *BMJ Supportive & Palliative Care* 2013;3:300-308.

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e-Frailty Index

Features


Community


Frailty

Method


Electronic case finding

The electronic frailty index uses existing electronic health record data to detect and assess the severity of frailty. It uses a cumulative deficit model of frailty, in which frailty is defined through the accumulation of deficits, which can be clinical signs, symptoms, diseases and disability.

The eFI comprises 36 deficits, which have been developed using GP read codes. A person's frailty score is calculated by dividing the total number of deficits that they have by the total number of possible deficits. The score is a reliable predictor of those who are at risk of adverse outcomes, such as care home admission, hospitalisation and mortality.

The eFI enables services and treatments to be targeted on the basis of people's frailty status, rather than their chronological age and has the potential to transform care for older people living in the community.

Further reading

NIHR CLAHRC Yorkshire and Humber. *Development of an Electronic Frailty Index (eFI)*. Available from: http://clahrc-yh.nihr.ac.uk/our-themes/primary-care-based-management-of-frailty-in-older-people/projects/development-of-an-electronic-frailty-index-efi [Accessed 18th January 2018]

Clegg, A. et al. Development and validation of an electronic frailty index using routine primary care electronic health record data. *Age and Ageing*. 2016;45:3 353-360

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RADbound Indicators for Palliative Care Needs (RADPAC)

Features


Community


Cancer


Congestive heart failure, COPD

Method


Manual individual assessment

The RADboud indicators for PAlliative Care Needs (RADPAC) are three comprehensive sets of indicators to support GPs in the early identification of patients with congestive heart failure, COPD, and cancer, who could benefit from palliative care. The indicators were developed in the Netherlands through a three-step process comprising a literature search, focus group interviews and a modified Rand Delphi study. They aim to enable proactive palliative care and improve the quality of palliative care in general practice. The indicators were included in a training programme for GPs and consultants.

An evaluation found that while they helped GPs to identify patients who could benefit from palliative care and were considered clear, most GPs no longer used the physical tool in their daily practice. However, several GPs said that they had incorporated the indicators in their daily practice. Some GPs still reported difficulties in recognising people with organ failure who could benefit from palliative care.

Further reading

Thoonsen, B. et al. Timely identification of palliative patients and anticipatory care planning by GPs: practical application of tools and a training programme. *BMC Palliative Care* (2016)

Thoonsen, B. et al. Early identification of palliative care patients in general practice: development of RADboud indicators for PAlliative Care Needs (RADPAC). *British Journal of General Practice* 2012; 62(602):e625-31

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Functional Assessment Staging of Alzheimer's Disease (FAST)

Features


Community


Dementia


Hospital/Hospice

Method


Manual individual assessment

The FAST scale is a functional scale designed to assess people at the more moderate to severe stages of dementia when the Mini Mental State Examination (MMSE) can no longer indicate changes in a meaningful clinical way. A person in the earlier stages of dementia may be able to participate in the assessment, but usually the information should be collected from someone who knows the individual very well, or, if the person is a care home resident, from the care home staff.

The scale has seven stages:

1. normal adult with no cognitive decline
2. normal older adult with very mild memory loss
3. early dementia
4. mild dementia
5. moderate dementia
6. moderately severe dementia
7. severe dementia

A study of the reliability, validity, and progressive ordinality of FAST found that is a reliable and valid assessment technique for evaluating functional deterioration in people with Alzheimer's disease throughout the entire course of the illness.

Further reading

Sclan, S. G. and Reisberg, B. Functional Assessment Staging (FAST) in Alzheimer's Disease: Reliability, Validity, and Ordinality. *International Psychogeriatrics* 1992;4:3 55-69

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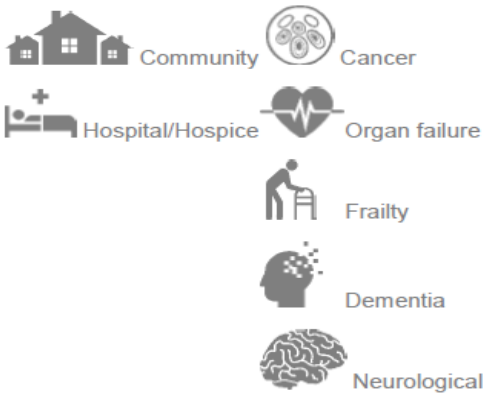
Gold Standards Framework Prognostic Indicator Guidance

Features



Method

Manual individual assessment

The Gold Standards Framework Prognostic Indicator Guidance comprises three triggers that indicate that a person is nearing the end of his or her life:

- The Surprise Question: 'Would you be surprised if this patient were to die in the next few months, weeks, days'?
- General indicators of decline - deterioration, increasing need or choice for no further active care. Or a deterioration as highlighted through specific functional assessments such as Barthel Index, Karnofsky Performance Status Score or WHO/ECOG Performance Status
- Specific clinical indicators related to cancer, organ failure, neurological disease and frailty/dementia.

Further reading

Thomas, K. et al. *The GSF Prognostic Indicator Guidance: The National GSF Centre's guidance for clinicians to support earlier recognition of patients nearing the end of life*. The Gold Standards Framework Centre In End of Life Care CIC. Available from: http://www.goldstandardsframework.org.uk/cd-content/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%202011.pdf [Accessed 18th January 2018]

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Karnofsky Performance Status Scale

Features

 Hospital  Cancer

Method

 Manual individual assessment

This scale is used to assess the functional status of people with cancer and has 11 points, ranging from normal functioning (100) to dead (0). The initial purpose of its development was to allow physicians to evaluate someone's ability to survive chemotherapy for cancer. It is also helpful in communicating between teams when referring for support, such as planning a care package.

100 — Normal, no complaints, no evidence of disease.

90 — Able to carry on normal activity, minor signs or symptoms of disease.

80 —Normal activity with effort, some signs or symptoms of disease.

70 — Cares for self, unable to carry on normal activity or to do active work.

60 — Requires occasional assistance, but is able to care for most of his personal needs.

50 — Requires considerable assistance and frequent medical care.

40 — Disabled, requires special care and assistance.

30 — Severely disabled; hospital admission is indicated although death not imminent.

20 — Very sick, hospital admission necessary, active supportive treatment necessary.

10 — Moribund, fatal processes progressing rapidly.

0 — Dead.

It can be used to compare the effectiveness of different therapies and to assess an individual's prognosis.

Further reading

Nikoletti et al. Performance Status Assessment in Home Hospice Patients Using a Modified Form of the Karnofsky Performance Status Scale. *Journal of Palliative Medicine* 2000;3(3):301-311

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ECOG Performance Status

Features


Community


Cancer


Hospital/Hospice

Method


Manual individual assessment

This scale was developed by the Eastern Cooperative Oncology Group (ECOG), and published in 1982. It is used to measure the functional status of people with cancer, and describes a person's level of functioning in terms of their capacity to care for themselves, daily activity, and physical ability (walking, working, etc.). It often informs the decision making process regarding commencement of treatments

ECOG Performance Status:

0 - Fully active, able to carry on all pre-disease performance without restriction

1 - Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work

2 - Ambulatory and capable of all self-care but unable to carry out any work activities; up and about more than 50% of waking hours

3 - Capable of only limited self-care; confined to bed or chair more than 50% of waking hours

4 - Completely disabled; cannot carry on any self-care; totally confined to bed or chair

5 – Dead

Further reading

ECOG-ACRIN Cancer Research Group. (2017) *ECOG Performance Status*. Available from: http://ecog-acrin.org/resources/ecog-performance-status [Accessed 18th January 2018]

Sørensen, J.B. et al. Performance status assessment in cancer patients. An inter-observer variability study. *British Journal of Cancer* 1993;67(4):773-775

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Supportive and Active Palliative Care Register (SPAR)

Features


Community No disease-specific indicators


Hospital/Hospice

Method


Manual case finding

This register is being used in Glasgow, where it was developed by the Primary Care Palliative Care Team and Lead for Non-Malignant Palliative Care, and stratifies people into the following categories:

- **Rate of deterioration nil/minimal – 'Green'** – Those who do not appear to be failing or who are failing very slowly, whose needs do not appear to be changing and who hardly seem any different over a number of months. In this situation it is likely that the individual's expectancy can probably be estimated in a large number of months if not years. This group's requirement for supportive and palliative care is fairly small.
- **Rate of deterioration moderate – 'Amber'** – Those who are noticeably failing and whose care needs are increasing but in a fairly slow manner, perhaps over a few weeks to a month. It may be that you might expect an individual in this category to survive for a few months (e.g. 3 -6 months). This group's supportive and palliative care needs should be assessed.
- **Rate of deterioration rapid/major – 'Red'** – Those who are failing quickly, whose care needs are increasing equally quickly and who are thus deteriorating rapidly. In this situation death might be anticipated in just a few weeks (or even a few days). This group has a high level of need for supportive and palliative care.

The most important point is that there is evidence of **changing need** as a result of **irreversible deterioration**.

In Glasgow this tool is being used in conjunction with the Palliative Performance Scale.

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Prospective Prognostic Planning tool

Features


Community No disease-specific indicators


Hospital/Hospice

Method


Manual case finding

This tool has been adapted from Macmillan Foundations in Palliative Care for Care Homes, and has been used with the 'surprise question' in care homes to identify residents whose condition may be deteriorating in order to plan care accordingly. The tool comprises a chart that allows care home staff to plot a resident's deterioration pattern over time, on a weekly or monthly basis.

If a resident is considered to have months or less to live, this is a trigger to contact the GP about DNACPR status and to ensure that an anticipatory care plan is completed or updated. If a resident is identified as in the final weeks of life, the GP is asked to provide anticipatory medication, and a referral is sent to the district nurse.

A paper on the 'Steps to Success' end of life care programme found that this tool was valued by all of the care homes participating in the programme, and that it helped staff to identify where a resident's trajectory was in decline.

Further reading

Kinley, J. et al. Developing, implementing and sustaining an end-of-life care programme in residential care homes. International Journal of Palliative Nursing 2017;24(4):186-193

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Scottish Patients at Risk of Readmission and Admission (SPARRA)

Features


Community No disease-specific indicators


Hospital/Hospice

Method


Electronic case finding

Information Services Division have developed Scottish Patients at Risk of Readmission and Admission (SPARRA), a risk prediction tool which predicts an individual's risk of an emergency hospital admission or readmission within the next year.

SPARRA is informed by a number of service-based criteria and statistical models to predict an individual's risk of admission based on recent healthcare resource use.

SPARRA data can be used to inform a preventative and anticipatory approach to service planning and help to prioritise patients with complex care needs who are most likely to benefit from this approach.

Further reading

Information Services Division. *SPARRA*. Available from: http://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/SPARRA/ [Accessed 15th February 2018]

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Prognosis in Palliative Care Study

Features

 Community  Cancer

 Hospital/Hospice

Method

 Manual individual assessment

The PiPS scoring algorithms are used to estimate prognosis in advanced cancer. Both PiPS-A and PiPS B use information on cancer diagnosis, symptoms and a clinician's estimate of survival, while PiPS includes recent blood test results. Both tests are at least as accurate as a multi-professional survival estimate, while the PIPS-B is significantly more accurate than either a doctor's or a nurse's estimate of survival. The scales have been internally validated, although their use in clinical practice is yet to be properly evaluated.

The prognostic scales should only be used in patients who fulfil the following criteria:

- Patients must have been referred to palliative care services
- Patients must have advanced (i.e. locally advanced or metastatic), incurable cancer
- Patients must not have received any new anti-cancer therapy within the previous four weeks and no further disease-modifying treatments must be planned (with the exception of purely palliative treatments such as radiotherapy for painful bone metastases)
- PiPS scores can be used in patients with hormone-sensitive cancers (e.g. prostate cancer) who have now developed hormone-resistant disease even if they remain on hormone therapy and provided that they also fulfil the above criteria

Further reading

St George's, University of London. (2011) *The PiPS Prognosticator*. Available from: http://www.pips.sgul.ac.uk/ [Accessed 15th February 2018]

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Other relevant and emerging research

Improving access to palliative care through computer searching

GP computer systems contain a database of Read codes and notes from patient consultations. Software that can interrogate these databases can potentially find indicators of palliative care needs. This project developed an algorithm that can search accessible data in GP databases, tested the concept with a search template and tested a data extract module over an extended period in eight GP surgeries. It demonstrated that a search using available GP data can help to identify people with palliative care needs at an earlier stage.

Between 0.75% to 1.6% of patients on each practice list were identified by the search. Between 30% to 60% of patients identified by each search were assessed by at least one GP as "at risk of dying in the next 6-12 months." In all cases, multidisciplinary team members were able to identify at least one patient each who they considered to be in need of additional supportive or palliative care.

Actions following the results included starting a Key Information Summary, adding people to the palliative care register and considering power of attorney.

Further reading

Mason, B. et al. *Improving Access to palliative care through computer searching*. Available from: http://www.gov.scot/Resource/0050/00505191.pptx [Accessed 8th June 2017]

Mason, B. et al. Developing a computerised search to help UK General Practices identify more patients for palliative care planning: a feasibility study. *BMC Family Practice* 2015;1:1

Computer screening for palliative care needs in primary care: a mixed-methods study

This paper refines and evaluates the utility of a computer application (AnticiPal) to help primary care teams screen their registered patients for people who could benefit from palliative care. It concluded that screening through computer searching can increase the number of people identified for consideration of a palliative care approach.

Through computer searching GPs can produce a list of around 1% of their practice population who are candidates for an anticipatory or palliative care approach, and this can supplement case-finding during routine clinical practice.

However, there are still challenges with initiating conversations about palliative care.

Further reading

Mason, B. et al. Computer screening for palliative care needs in primary care: a mixed-methods study. *British Journal of General Practice* 26 March 2018

Adapted American National Hospice Organisation guideline for the identification of nursing home residents with non-malignant diseases

This Australian study found that:

- An adapted version of the American National Hospice Organisation (NHO) guidelines provided an initial indicative framework for measuring the eligibility of patients with end-stage non-cancer diseases for palliative care services in Australian residential care facilities for older people.
- The WARP Karnofsky Performance Scale, the 10-item modified Barthel index, two pain scales— one verbal and nonverbal—plus an assessment of nutritional status and identification of other problematic symptoms could provide confirmatory data.

It concluded that the use of the adapted NHO guidelines, combined with pain scales and close monitoring, can help to ensure the provision of appropriate end-of-life care for older people with non-cancer diagnoses and their families.

Further reading

Maas, E. et al. What tools are available to identify patients with palliative care needs in primary care: a systematic literature review and survey of European practice. BMJ Supportive & Palliative Care 2013;3(4):444-451.

Grbich, c. et al. Identification of patients with noncancer diseases for palliative care services. Palliative and Supportive Care 2005;3(1):5-14

The Early Identification of Palliative Care Patients: Preliminary Processes and Estimates from Urban, Family Medicine Practices

Rainone et al developed a methodology for identifying people with palliative care needs at an earlier stage in primary care settings. The criteria consisted of the surprise question, general indicators for decline and parameters for advanced stages of illnesses. The authors concluded that electronic databases may be used to create a preliminary screen to assist clinicians in the early identification of patients in need of palliative care, and that 1% to 3% of patients in primary care practices could benefit from palliative care services.

Further reading

Maas, E. et al. What tools are available to identify patients with palliative care needs in primary care: a systematic literature review and survey of European practice. BMJ Supportive & Palliative Care 2013;3(4):444-451.

Rainone, F. et al. The early identification of palliative care patients: preliminary processes and estimates from urban, family medicine practices. American Journal of Hospice and Palliative Medicine 2007;24(2):137–40.

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What tools are available to identify patients with palliative care needs in primary care: a systematic literature review and survey of European practice

This literature review explored tools in the published literature to identify patients with palliative care needs, and how GPs in Europe identify patients for palliative care. The following tools were identified through literature searching, and a survey of key informants:

- RADbound indicators for Palliative Care needs
- SPICT
- Residential home palliative care tool (adapted from an American National Hospice Organisation guideline)
- Criteria developed by Rainone et al (see opposite)
- Gold Standards Framework Prognostic Indicator Guidance
- Necesidades Paliativas
- A 'Quick Guide' developed and implemented around London

It concluded that many identification tools have been developed, but none of them has been validated or widely implemented in Europe.

Further reading

Maas, E. et al. What tools are available to identify patients with palliative care needs in primary care: a systematic literature review and survey of European practice. BMJ Supportive & Palliative Care 2013;3(4):444-451.

The "surprise question" for predicting death in seriously ill patients: a systematic review and meta-analysis

Several of the identification tools use the 'surprise question'. This question asks whether the assessor would be surprised if the person in question were to die within the next few months or year. This Canadian review looked at the performance of the surprise question in predicting death. It found that the surprise question performs poorly to modestly as a predictive tool for death, with worse performance in prognosis for non-cancer illness. The review concluded that further studies are required to develop accurate tools to identify patients with palliative care needs and to assess the use of the surprise question for this purpose.

Further reading

Downar, J. et al. The "surprise question" for predicting death in seriously ill patients: a systematic review and meta-analysis. Canadian Medical Journal. 2017 Apr 3;189(13):E484-E493.

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https://ihub.scot/media/2079/palliative-care-identification-tools-comparator.pdf[58]

[58] https://ihub.scot/media/2079/palliative-care-identification-tools-comparator.pdf

Outcome Assessment and Complexity Collaborative – Summary of Suite of Measures

Healthcare Improvement Scotland's Scottish Future Care Programme

https://ihub.scot/project-toolkits/future-care-planning-toolkit/future-care-planning-toolkit/

EXPERIENCE OF FINANCIAL HARDSHIP AND DEPRIVATION

Evidence has shown that 8,200 people die in poverty in Scotland at the end of life every year, equating to one in four working age people, and one in eight pensioners[59]. Your assessment of a person's terminal condition may also reveal other circumstances of existing financial hardship and/or deprivation, which can significantly exacerbate an individual's physical and mental health while terminally ill. They may benefit from additional support, including financial, housing, bereavement and mental health support.

Below are links to resources that you may wish to refer to:

Sage Journals - dying at home for people experiencing financial hardship and deprivation[60]

Sage Journals - The impact of poverty and deprivation at the end of life: a critical review -[61]

[59] Poverty at the end of life in the UK | Centre for Research in Social Policy | Loughborough University (lboro.ac.uk)
[60] Sage Journals - dying at home for people experiencing financial hardship and deprivation
[61] Sage Journals - The impact of poverty and deprivation at the end of life: a critical review -

ANNEX C

WORKED EXAMPLES (ADULTS, BABIES, CHILDREN AND YOUNG PEOPLE)

Adult Examples

Until Pension Age Disability Payment has been launched, individuals who are state pension age or over and who may have less than 12 months to live, should continue to use the SR1 and send this to the Department for Work and Pensions to support an application for Attendance Allowance.

Pancreatic cancer (patient in a hospice) – Daniel

Daniel, 58, has pancreatic cancer that can no longer be treated. He is now being cared for at his local hospice, receiving palliative care to help manage his symptoms and support him both practically and emotionally. It has been explained to Daniel that his condition is advanced and no longer responsive to treatment.

Daniel is not currently in receipt of any disability benefits. Since Daniel is terminally ill his specialist nurse explains that he is eligible to apply for Adult Disability Payment (ADP) under the special rules. With Daniel's consent, his wife Sandra submits a special rules ADP application to Social Security Scotland.

Having spoken with Daniel's consultant oncologist to gather comprehensive clinical information, Daniel's nurse promptly completes a BASRiS form, ensuring she records the date the clinical judgement of terminal illness was made. In the '*Condition Continued*' section of the BASRiS form, she indicates that Daniel is aware of his condition and prognosis. That same day, Daniel's nurse submits the BASRiS form by email to Social Security Scotland in support of his ADP application. Daniel's special rules application will be fast-tracked so that he receives the support he is entitled to as quickly as possible.

Daniel may also be eligible to apply for Universal Credit, delivered by DWP. If he applies under the special rules because his nurse believes Daniel to be in his last 12 months of life, she will complete form SR1 in support of the application. DWP require form SR1 (not a BASRiS) because of their terminal illness definition.

Multi-morbidity, and existing financial hardship - Donna

Donna is 56 and lives in Glasgow. She lives with multiple terminal and chronic conditions, including COPD which she has had for many years, as well as cirrhosis (which developed into liver cancer), emphysema, pancreatitis, arthritis and osteoporosis. Together, her conditions cause her a lot of pain and breathlessness.

Donna's care, provided by a wide range of health and social care professionals, is not joined up, and she struggles to get doctors to sort out her medications and stay on top of her symptoms. She spends a lot of time seeing different doctors for her

different illnesses and going in and out of hospital. She is also housebound because of her terminal conditions, and struggles with isolation and loneliness.

Donna has experienced financial insecurity for many years from being unable to work because of her illnesses and is a single parent with caring responsibilities. She has also experienced a series of bereavements over the last decade, including the sudden death of her son.

Donna would benefit from a trauma-informed approach to her support.

Donna has had some support from a Community Link Worker to try to join up her care, but there are things she feels she has not been told by medical professionals, mainly about her prognosis, and what to expect in the future.

Donna's conditions are such that she would be eligible for Adult Disability Payment under the special rules, and a BASRiS form could be completed by her GP or hospital doctor. A trauma-informed approach to Donna's physical, mental and financial health should be implemented from all professionals in contact with her.

Colon cancer (break-down in relationship with GP) – Simon

Simon is 45. He was diagnosed with colon cancer and liver metastasis, and is undergoing palliative chemotherapy. He was not issued a BASRiS form at his initial referral.

Simon had been seeing his GP for up to two years with symptoms consistent with his diagnosis. Simon's view is that the GP failed to send him for tests until recently, leading to a delay in the diagnosis. Simon does not want to approach his GP due to a breakdown in their relationship.

Simon has a number of options in this situation. He is still able to make an application to Social Security Scotland for Adult Disability Payment, indicating that he has a terminal illness and explaining his declining condition. Social Security Scotland could seek to obtain a BASRiS form on his behalf by contacting the healthcare practitioner Simon names on the application form and enquiring whether a BASRiS is appropriate.

Simon could approach another GP in the practice, who has access to his clinical records, as well as reports from other professionals involved in his care. He could also approach the specialist doctor involved in his care. Either doctor would be able to sign the BASRiS form.

Simon would also be able to make a complaint through the NHS complaints procedure if he wished to do so. This would not be a matter for Social Security Scotland.

COPD - Marilyn

Marilyn is 58. she has severe COPD and graded as Medical Research Council (MRC) grade 4 (Stops for breath after walking about 100 metres or after a few minutes on level ground.)

She can walk up to 500 metres with frequent pauses for breath, using a wheeled trolley, continues to smoke, experiences infective exacerbations perhaps 4 times per year, and has required one admission for this in the last year.

She would be graded as Group D in the Global Initiative for Chronic Obstructive Lung Disease (GOLD) criteria (Group D: high risk (≥2 exacerbations per year, or one or more requiring hospitalisation) and more symptoms Modified Medical Research Council dyspnoea scale (mMRC)≥ 2 or COPD Assessment Test (CAT)≥ 10).

Marilyn will almost certainly die within the next few years, but currently there are no signs of rapid decline and completion of a BASRiS form at this stage would be inappropriate.

COPD (choosing not to take clinical advice) – Archie

Archie is 52 and has COPD. He has refused to comply with medical advice about his lifestyle and does not take his prescribed medication. If this continues, Archie's GP expects that he will die within a year.

It is Archie's human right to choose his course of treatment (including refusing treatment), and if his GP's diagnosis is that Archie's condition presents an imminent threat to his life without management, then the GP should complete a BASRiS form to support a special rules application for Adult Disability Payment if Archie wishes to apply.

Dementia, frailty with one or more co-morbid diseases/conditions, and recurrent pneumonia – Moira

Moira is an 87 year old who lives with her husband. Over the last few years, she has been developing symptoms of dementia and has become increasingly frail. Owing to a desire to maintain independence, and a fear that contact with health and social care would result in Moira "being put into a home", they have not sought help until recently, when Moira developed recurrent pneumonia. It is felt that this was as a result of swallowing problems caused by her dementia.

On its own, Moira's dementia would be unlikely to lead a clinician to diagnose her as terminally ill for the purposes of access to disability assistance. However, the multimorbid combination of dementia with recurrent pneumonia may lead a clinician to judge Moira's condition as terminal, and to complete a BASRiS form in relation to an application for Pension Age Disability Payment (which only has a care component), once that benefit is being delivered by Social Security Scotland.

Duchenne Muscular Dystrophy – John

John is a 24 year old man with Duchenne Muscular Dystrophy. In general, he has done better than his elder brother who died 5 years ago from complications of the same condition. This discrepancy between John and his brother is likely to be due to a number of medical interventions, which John has undergone, including: the orthopaedic insertion of rods in his back, the introduction of feeding by gastrostomy, robust management of his underlying cardiac condition, and the use of overnight non-invasive ventilation. In recent months, John has required the use of his non-invasive ventilator for longer periods throughout the day and night. So far, he and his parents have not wanted to discuss detailed planning for the future, and have preferred not to engage with statutory services about Adult Disability Payment.

John develops a significant chest infection, and after a 2 week period in hospital is discharged home, where it is clear that both parents will now both need to stay at home to help look after him. After much discussion with their Respiratory Physician and their District Nurse, they approach their GP to assist them with an application for Adult Disability Payment.

In this case, the GP must use their clinical judgement, consulting the Clinical Assessment of Terminal Illness section – as well as evidence gathered from John's specialist, nurse, and family – to establish whether John's condition is likely to lead to his death. If John's condition is judged to be terminal, then the GP should complete a BASRiS form in relation to Adult Disability Payment. This would fast-track John to the highest rates of both care and mobility for the benefit. However, if John's condition has worsened, *but* has since stabilised and he does not require expedited access to benefits, the family should apply for Adult Disability Payment through the standard route.

In either case, the GP should also sign-post John's parents to Carer's Allowance (a devolved benefit currently being delivered by DWP and being replaced in Scotland by Carer Support Payment in pilot areas in November 2023 and nationally in 2024), and the Carer's Allowance Supplement (a Scottish benefit administered by Social Security Scotland), since one of them may be eligible.

Elderly with several conditions – Chen

Chen is 84. She has a longstanding diagnosis of Alzheimer's disease and has previously been thought to be mildly affected, managing to live alone with a minimal package of care. She was unfortunately hospitalised 3 months ago with an intracerebral haemorrhage, which has left her with significant left-sided weakness. Shortly after hospital discharge, she developed worsening confusion and agitation. She was again admitted to hospital and treated for urinary tract infection. Since subsequent discharge 2 months ago, she remains significantly confused, her mobility has deteriorated substantially, and she is requiring maximal package of care at home.

Chen's condition is such that she would be eligible for Pension Age Disability Payment under the special rules, once that benefit is being delivered by Social

Security Scotland, and a BASRiS form can be completed by her GP or hospital doctor.

Glioblastoma (appointee) – Abdul

Abdul is a 56 year old man who was diagnosed with Glioblastoma in September 2016. Because of diminished mental capacity as a result of his condition, Abdul had an appointee until recently. However, following a breakdown in their relationship, he has appointed MacMillan's Welfare Rights Service as responsible for his benefits until his death.

Abdul has an existing SR1 form (replacement for DS1500) in relation to Universal Credit (UC) and for his Personal Independence Payment (PIP) award with the Department for Work and Pensions (DWP). Abdul's GP need not take any action. The SR1 will remain in place for his UC and PIP awards. The SR1 will be automatically accepted in place of a BASRiS form when Abdul transfers from PIP to Adult Disability Payment via the expedited case transfer process. If approached by the MacMillan Welfare Rights Service, in their capacity as Abdul's appointee, this should be explained to them.

Heart Failure - Harry

Harry is 56, and was diagnosed with Heart Failure recently. He gave up work quite suddenly as his fatigue and breathlessness were triggered by even minor physical activity and he found it difficult to keep up with the physical demands of his job.

Harry recently had an admission to hospital because of his heart failure. Even though his prognosis is unpredictable, Harry has significant supportive care needs. Harry's GP was reluctant to sign a SR1 form (replacement for DS1500) to support an application for Universal Credit (delivered by the Department for Work and Pensions) because she could not predict that he was in his last 12 months of life. People with Heart Failure often experience periods of decline and recovery, which can make this prediction particularly difficult.

Under BASRiS rules, Harry's GP has the discretion to use her clinical judgement about his deterioration in being able to cope with activities of daily living, his recent hospital admission and the persistence of worrying symptoms despite optimal treatment. If Harry is deemed to be terminally ill according to the Scottish definition, his GP should fill in a BASRiS form to support an Adult Disability Payment application under special rules. This would entitle Harry to the highest rates for both the mobility and daily living components.

Harry may also be eligible for Employment and Support Allowance (ESA). However, if he wished to apply for this benefit under the Special Rules for End of Life (SREL), he would need to meet the DWP's terminal illness 12-month life expectancy definition, since the benefit is currently reserved to the UK Government. However, he is still able to apply through the standard route. Since the benefit is currently

reserved to the UK Government he would need to contact DWP to apply for this benefit.

Cancer of the intestine (migration from SR1) – Gary

Gary is 67. He is currently not in receipt of any disability benefits. He has a diagnosis of cancer of the intestine. Following unsuccessful surgery, the cancer spread throughout his abdomen and lungs. Gary is the main carer for his wife (66), who has a rare heart condition that leaves her very breathless, dizzy and fatigued. His wife currently receives Attendance Allowance (a reserved benefit delivered by DWP).

Gary's consultant established that he was "terminally ill" as per the DWP definition, and completed form SR1 (replacement for DS1500) on his behalf. Following this Gary was fast-tracked onto Attendance Allowance (which only has a care component), at the higher rate.

When BASRiS was introduced, Gary presented at his GP requesting that he be transferred to the Scottish system, to take advantage of the special rules under BASRiS. Since he already has form SR1, Gary will be transferred to the Scottish system in time, and the GP will not need to do anything further. If he is not already claiming Carer's Allowance (a devolved benefit currently being delivered by DWP and being replaced by Carer Support Payment in Scotland in pilot areas in November 2023 and nationally in 2024) and Carer's Allowance Supplement (a Scottish benefit being administered by Social Security Scotland), the GP may also flag his potential eligibility for this benefit in relation to the care he provides to his wife.

Terminal lung cancer (but patient currently feels well) – Frank

Frank is 55. He was diagnosed with lung cancer 9 months ago. Frank's very direct-talking oncologist has told him that his illness is advanced and progressive. However, at the moment, Frank feels surprisingly well. Aside from a bit of a cough (which is not really any worse than the one he usually has), he is free of symptoms. He can do pretty much everything he wants to do – get out and about, look after himself and still take care of his grandchildren.

Frank's oncologist has been clear that his condition is deteriorating, and is likely to result in his death in the near future. Furthermore, his condition may deteriorate suddenly, and without warning. Frank would be eligible for Adult Disability Payment under BASRiS based on Frank's oncologist's assessment.

Although Frank currently feels well, it is very likely that his care needs will increase quickly. It is advisable that Frank applies for Adult Disability Payment under special rules, supported by a BASRiS form completed by his oncologist, at his earliest convenience so that he can receive the support he is entitled to as quickly as possible.

Motor Neurone Disease (rapid decline in condition) – Derek

Derek is 54 years old and, 3 months ago, was diagnosed with Motor Neurone Disease (MND), a rapidly progressing terminal illness. Already, Derek has lost much of the use of his hands and is walking with a limp. It is anticipated that he will soon need to use a wheelchair. Derek tells his registered medical practitioner (RMP) that he needs additional financial support. His RMP agrees to look into completing a BASRiS for him.

Consulting the Clinical Assessment of Terminal Illness section of the Guidance (currently Section 7), and speaking to Derek's MND clinical specialist, his GP sees that, with a diagnosis of MND, Derek meets or surpasses the indicators listed.

His GP decides that, clearly, Derek qualifies for a BASRiS and needs to be fast-tracked for his benefits. Derek's GP promptly completes the BASRiS form and sends it to Social Security Scotland. With Derek's consent, his partner (also his carer) applies on his behalf for Adult Disability Payment (ADP) under the special rules. This means Derek's application will be fast-tracked, and he will be awarded ADP at the enhanced rates. Derek will receive his payments much quicker than if he had applied under the normal application route for ADP. Additionally, he will receive his payments weekly in advance. Derek's partner may be eligible to access Carer's Allowance, (a devolved benefit currently being delivered by DWP and being replaced in Scotland by Carer Support Payment in pilot areas in November 2023 and nationally in 2024) and Carer's Allowance Supplement (a Scottish benefit administered by Social Security Scotland).

Multi-morbidity and frailty – Brenda

Brenda is 103 and lives at home, supported by her daughter and great neighbours. She has diagnoses of dementia (early stage), arthritis, macular degeneration, diabetes and is generally very frail, and getting less mobile and able to look after herself. She has periodic chest infections, which can get quite bad – sometimes these are managed at home, but a couple of times in the last 5 years she has been admitted to hospital.
BASRiS may be appropriate in this case, if the clinical judgement after consulting the Clinical Assessment of Terminal Illness section is that Brenda has severe frailty. Were Brenda to apply for the Pension Age Disability Payment when it is implemented in Scotland, (which only has a care component), and qualify under BASRiS, her claim would be fast-tracked. Her award would be at the higher rate, with no review period. Brenda's daughter or one of her neighbours may be eligible for Carer's Allowance (a devolved benefit currently being delivered by DWP and being replaced by Carer Support Payment in Scotland in pilot areas in November 2023 and nationally in 2024) and the Carer's Allowance Supplement (a Scottish benefit being administered by Social Security Scotland).

Unknown neurological disorder – Kate

Kate is 47. She is an ex healthcare worker who lives alone, with a supportive son and daughter nearby. There is a background of COPD with longstanding heavy smoking. She has been under neurology review for a year with steadily progressive imbalance and speech problems, which have been deteriorating over the year. She is now using a wheelchair and able to walk only a few steps. Despite detailed investigation, no specific cause has been found. Attempted treatments have not helped. Her consultant believes she may have a cancer-related (paraneoplastic) disorder related to an unidentified tumour, or perhaps a degenerative disorder. She cannot suggest any further treatments. Her son and daughter are increasingly struggling to support her because of her poor mobility and shortness of breath. She was recently hospitalised with pneumonia.

If it is Kate's consultant's clinical judgement that Kate is likely to die from her condition, then she should fill out a BASRiS form, to allow Kate to access Adult Disability Payment under special rules. Kate's son or daughter may be eligible for Carer's Allowance (a devolved benefit currently being delivered by DWP, and being replaced by Carer Support Payment in Scotland in pilot areas in November 2023 and nationally in 2024) and Carer's Allowance Supplement (a Scottish benefit being administered by Social Security Scotland). It is not necessary for the consultant to be certain, nor is it necessary for the condition to have a confirmed named diagnosis if Kate displays indicators set out in the CMO guidance.

Old age - Ina

Ina is a 92 year old lady who lives alone in a retirement flat. She has been active and independent since an aortic valve replacement ten years ago. She receives blood thinning for her metallic heart valve and treatment for high blood pressure, previous angina, and an underactive thyroid. She was managing 9 holes of golf a week until the end of last summer, but has given this up for fear of slowing her friends down. Since then, visitors have commented to her that she seems to be losing weight. After a discussion with her GP, she has decided against any investigations regarding this, but her weight loss continues and she has recently started to rely on her neighbours more and more.

Ina's clinician would need to establish whether she was likely to die from one, or a combination, of these diagnosed or undiagnosed conditions. If it is the clinical judgement of the GP, after consulting the Clinical Assessment of Terminal Illness section, that Ina's condition/s are terminal, and she is likely to die soon, they should complete a BASRiS form in relation to a claim for Pension Age Disability Payment, (which only has a care component), when it is implemented in Scotland. However, if it is the clinician's judgement that Ina's condition is consistent with, and typical of old age alone, this would not be grounds alone for completion of the BASRiS, and Ina should be encouraged to make an application for Pension Age Disability Payment (which only has a care component), by the standard route.

Reduced mental and physical capability following a stroke – Jennifer

Jennifer is 52. Jennifer has reduced mental and physical capability following a stroke, and currently receives the highest rates of Adult Disability Payment, for both care and mobility. Jennifer presents at her GP with symptoms including headaches and vomiting. After a specialist appointment, Jennifer's GP informs her that she has advanced Glioblastoma. Exercising clinical judgement, Jennifer's GP deems her condition terminal under the Clinical Assessment of Terminal Illness section.

Although Jennifer is already on the highest rates of Adult Disability Payment the special rules under BASRiS e.g. the lack of review period, make it worthwhile reporting a change of circumstances under the terminal illness rules. This should be done through the BASRiS form, as with any other person who is terminally ill.

Children and Young People's examples

Rare brain tumour - Fiona

Fiona is a 6 year old girl with a rare brain tumour, which is very unresponsive to chemotherapy, radiotherapy or surgery. She is being considered for phase one and 2 trials, but none fits with her condition. She is being maintained on low doses of dexamethasone with boost of doses, and with oral etoposide, which is a form of palliative chemotherapy. Fiona has spent a number of months as an inpatient in the local children's ward.

She has twin sisters who are 2 years old, and her Mum has not returned to work since their birth, which was just after Fiona's initial diagnosis. Both of Fiona's parents are still hopeful that she can improve and are in touch with multiple specialist groups across the world, but at present her father is about to be made redundant because of a re-organisation at his work.

Using clinical judgement consulting the Clinical Assessment of Terminal Illness section – and having gathered evidence from specialist nurses who have worked with Fiona on the children's ward – the medical practitioner should establish whether Fiona is likely to die from her condition. Following this diagnostic process, the medical practitioner has a number of options.

1. If Fiona's condition is judged to be terminal:

    a) Fiona's parents are hopeful, but this may not reflect the seriousness of Fiona's condition, then the medical practitioner may fill out a BASRiS form (in relation to a claim for Child Disability Payment without informing the parents of the terminal nature of Fiona's condition (if this information is deemed to be harmful); or

    b) The medical practitioner may wish to have the difficult conversation with the parents, to inform them of the nature of Fiona's condition, and complete a BASRiS form with their full knowledge and consent.

Both options – 1a and 1b – would fast-track Fiona's claim, and automatically entitle her to the highest rates for both care and mobility.

2. If it is established that Fiona is likely to recover, the medical practitioner should still signpost the family toward Child Disability Payment. They would simply apply through the standard route, without recourse to the special rules.

In all cases above, the medical practitioner should also signpost Fiona's parents to Carer's Allowance (a devolved benefit currently being delivered by DWP and being replaced by Carer Support Payment in Scotland in pilot areas in November 2023 and nationally in 2024) and the Carer's Allowance Supplement (a Scottish benefit administered by Social Security Scotland), since one of them may be eligible.

Inherited condition which is terminal – Rizwan

Rizwan is a 3 month old baby who was born by Caesarean Section at 32 weeks gestation, following the antenatal diagnosis of an inherited condition. It was not clear if he would survive beyond the first few days, and at this point is being considered for transfer to a high dependency unit. Rizwan may require a tracheostomy to maintain his airway in the long term, but he remains at considerable risk of a deterioration, which could lead to death in the next few years. Six years ago, Rizwan's parents had a little girl who sadly died from a variant of the same condition.

Rizwan's parents are unable to work, and they have two other children aged 4 and 7. Rizwan's clinician may use their clinical judgement to establish whether Rizwan is likely to die of this condition. If Rizwan's clinician, consulting the Clinical Assessment of Terminal Illness section, judges that he is terminally ill, she should fill out the BASRiS form in relation to a special rules application for Child Disability Payment. This would fast-track Rizwan's application, and automatically entitle him to the highest rate of care. The clinician should also signpost Rizwan's parents to Carer's Allowance (a devolved benefit currently being delivered by DWP and being replaced by Carer Support Payment in Scotland in pilot areas in November 2023 and nationally in 2024) and the Carer's Allowance Supplement (a Scottish benefit administered by Social Security Scotland), since one of them may be eligible.

ANNEX D

Social Security Scotland
Tèarainteachd Shòisealta Alba

Benefits Assessment under Special Rules in Scotland (BASRiS) Form for Terminal Illness

(Applies to Child Disability Payment, Adult Disability Payment and Pension Age Disability Payment) **Please complete promptly**

Patient

1 Surname

2 Other names

3 Date of birth D D M M Y Y Y Y

4 CHI number

5 Address

6 Postcode

The Condition:

Part 1

1 What is the diagnosis?

2 Other relevant diagnosis

The Condition Continued:

3 Is the patient aware of their condition? Yes ☐ No ☐

4 Is the patient aware of their prognosis? Yes ☐ No ☐

If the patient is an adult and the answer is no to either 3 or 4, please provide the name, conta details of their legal representative (address, email, telephone) and relationship to the patient (guardian/appointee);

OR

If the patient is a child, please provide below, the name, contact details of their parent or lega representative and their relationship to the child (parent/guardian/kinship carer/appointee)

Name	
Relationship	
Address	
Postcode	
Phone number	
Email if available	

Part 2 - Clinical Indicators which support your clinical judgement

Please give details of the three Indicators which support your clinical judgement. In filling in this section, you should provide details related to the indicators set out in section 7, also with particular reference to bullet points five to eight in section 8 (highlighted in bold), of the accompanying guidance. The indicators can be used for conditions which go beyond cancer to include other areas, whether they are single or multiple conditions, such as organ failure (respiratory disease, heart/ vascular disease, kidney disease, liver disease); neurological diseases (Parkinson's disease, Motor Neurone Disease, Multiple Sclerosis); Stroke; Frailty with one or more co-morbid diseases/conditions; Dementia; and rare conditions or diseases. This list is not exhaustive. In addition, individuals' eligibility for BASRiS also could be established based on a combination of diseases with conditions, and your clinical judgement about the requirement for expedited access to disability assistance.

If it is not possible to a give a definitive diagnosis, please apply the indicators as described in the previous paragraph, and give details of condition (e.g. a neurological condition, multisystem disorder), relevant current treatment, its purpose and response e.g. palliative care, decreasing reversibility, deteriorating symptoms, increasing input of health and social care providers.

Is there any other intervention or treatment planned which may significantly alter the progression of the condition?

Declaration

I have been professionally involved in the diagnosis and/or care of the patient and had access to the relevant clinical records to provide this report to the best of my knowledge and belief.

I believe that this patient is terminally ill according to the indicators laid out in the "Clinical Assessment of Terminal Illness" (Section 7) of the CMO GUIDANCE FOR DOCTORS AND NURSES COMPLETING BENEFITS ASSESSMENT UNDER SPECIAL RULES IN SCOTLAND (BASRiS) FORM FOR TERMINAL ILLNESS.

I have sought and obtained valid consent from the patient and or their legal representative to share the information included in this form with Social Security Scotland. This has been noted in the patient's clinical records. Yes ☐ No ☐

OR

I have not obtained consent because disclosure of information included in this form would be likely to cause serious mental and / or physical harm to the patient or a child's parent/individual with legal parental responsibilities, if they were to become aware of it. This has been noted in the patient's clinical records. Yes ☐ No ☐

I have not disclosed the information included in this form to the patient's legal representative. Yes ☐ No ☐

This is because:

It would be likely to cause serious mental and / or physical harm to the patient's legal representative. Yes ☐ No ☐

OR

For any other reason (for example I have not spoken to them). Yes ☐ No ☐

This has been noted in the patient's clinical records. Yes ☐ No ☐

I am a Registered Medical Practitioner or I am a Registered Nurse.

1 Name

2 GMC No

3 NMC No

4 Work Phone number

5 Work Email Address

6 Work Address

7 Postcode

8 Signature

9 Date of Clinical Judgement of Terminal Illness D D M M Y Y Y Y

Please post the completed form to: BASRIS PO Box 27165 GLASGOW G4 7BR

ANNEX E
CURRENT BENEFITS DEVOLVED TO SCOTLAND - Social Security in Scotland by Recipient Group

Key *Benefits covered by this guidance are marked with **

Devolved benefits are in bold type

Benefits for people out of work	Benefits for elderly people	Benefits for people who are ill or disabled	Benefits for families with children	Benefits for people on low incomes	Other
• Income Support • In Work Credit & Return to Work Credit • Job Start Payment • Jobseeker's Allowance	• **Winter Fuel Payments** • Financial Assistance Scheme • Pension Credit • State Pension • State Pension Transfers • TV Licences	• **Attendance Allowance *** • **Carer's Allowance** • **Carer's Allowance Supplement** • **Disability Living Allowance *** • **Personal Independence Payment *** • **Severe Disablement Allowance** • Employment & Support Allowance • Incapacity Benefit • **Industrial Injuries** • Specialised Vehicles fund • Statutory Sick Pay	• Child Benefit • Child Tax Credit • Guardians Allowance • Maternity Allowance • Statutory Maternity Pay	• **Discretionary Housing Payments** • **Scottish Welfare Fund** • **Regulated Social Fund (Sure Start Maternity Grant, Healthy Start Scheme, Cold Weather Payments and Funeral Expenses Payments)** • New Deal & Employment Programme Allowances • New Enterprise Allowance • Working Tax Credit • Housing Benefit	• Universal Credit, inc. **UC Scottish Choices** • Bereavement benefits • Christmas bonus • Other small benefits such as child trust fund etc.

	Devolved Benefits that are Affected or Not Affected by BASRiS	
	Benefit	**Primary benefit purpose**
Disability Benefits Requiring BASRiS when their Scottish replacements are in place in Scotland	Attendance allowance [62]	To help with personal care for individuals of State Pension Age with a physical or mental disability. Attendance Allowance will be replaced by Pension Age Disability Payment (PADP).
	Disability Living Allowance[63]	Help if your disability or health condition means one or both of the following are true: You need help looking after yourself, or you have walking difficulties. DLA is closed to new working age claimants and being replaced by Personal Independence Payment (PIP).
	Personal Independence Payment[64]	Helps with some of the extra costs caused by long term ill health or disability for individuals aged 16 to 64. Replacement for DLA for working age individuals. Adult Disability Payment (ADP) is the Scottish replacement for PIP.
Devolved Benefits a patient or carer may be entitled to.	Carer's Allowance[65]	To help an individual look after someone with substantial caring needs. To be eligible the individual must be 16 or over and spend at least 35 hours a week caring for them. Carer's Allowance will be replaced by Carer Support Payment.
	Carer's Allowance Supplement[66]	An extra payment to help carers in Scotland who get Carer's Allowance
	UC Scottish Choices[67]	UC Scottish choices[68] give recipients of Universal Credit (UC) in Scotland a choice to have their UC award paid either monthly or twice monthly, and have the housing costs in their award of UC paid direct to their landlord.

Details of *all* devolved benefits can be found here

[62] https://www.gov.uk/attendance-allowance
[63] https://www.gov.uk/browse/disabilities/benefits
[64] https://www.gov.uk/pip
[65] https://www.gov.uk/carers-allowance
[66] https://www.gov.scot/policies/social-security/benefits-for-carers/
[67] Social security: Universal Credit (Scottish choices) - gov.scot (www.gov.scot)
[68] Social security: Universal Credit (Scottish choices) - gov.scot (www.gov.scot)

ANNEX F
SR1 FORM (replacement for DS1500, required by DWP)

Department for Work & Pensions

SR1 form for providing medical evidence to support a benefit claim made under the Special Rules for End of Life

Read the instructions on the pages overleaf.

They tell you:
- about the SR1 form
- how to complete the form
- how to claim a fee if you are eligible.

Do not print this form. Please fill it in electronically and email to **form.e-SR1@dwp.gov.uk**

If you need a paper version of this form, you can order from HH Global Limited on **0300 373 0125**.

For more information about completing and returning SR1 forms, go to **www.gov.uk/dwp/special-rules**

Department for Work & Pensions

SR1 form

This SR1 form is not a claim form. It is used to support your patient's claim that has been made under the Special Rules. To complete this form type in the boxes and fill in both pages.

Patient's details

01 Surname

02 Other names

03 Date of birth
DD/MM/YYYY

04 National Insurance (NI) number
If known.

05 Address

Postcode

Part 1 - Condition

06 What is the diagnosis?

07 Date of diagnosis
DD/MM/YYYY

08 Date from which patient is thought to meet the Special Rules
Please see **page 5** of the notes for guidance about completing this question.
DD/MM/YYYY

09 Other relevant diagnoses

10 Is the patient aware of their diagnosis?
☐ Yes
☐ No

11 Is the patient aware of their prognosis?
☐ Yes
☐ No

Go to question 12

Part 2 - Clinical features

12 **Clinical features which indicate a severe progressive condition**
For example: rate of progression, recurrence, staging, tumour markers, bulbar involvement, end-stage disease etc.

Part 3 - Treatment

13 **Give details of relevant past or current treatment, its purpose and any response seen**
For example: treatment may be ongoing, palliative or symptom control/ psychosocial only.

Declaration

14 **The person named above is my patient. This is a full report of their condition and treatment. I have read and understood the notes attached to this form and I am satisfied that the form is appropriate. I am the patient's:**

- ☐ General Practitioner
- ☐ Consultant
- ☐ Other, specify below

15 **Your signature**

16 **Your name**

17 **Your GMC/NMC number**

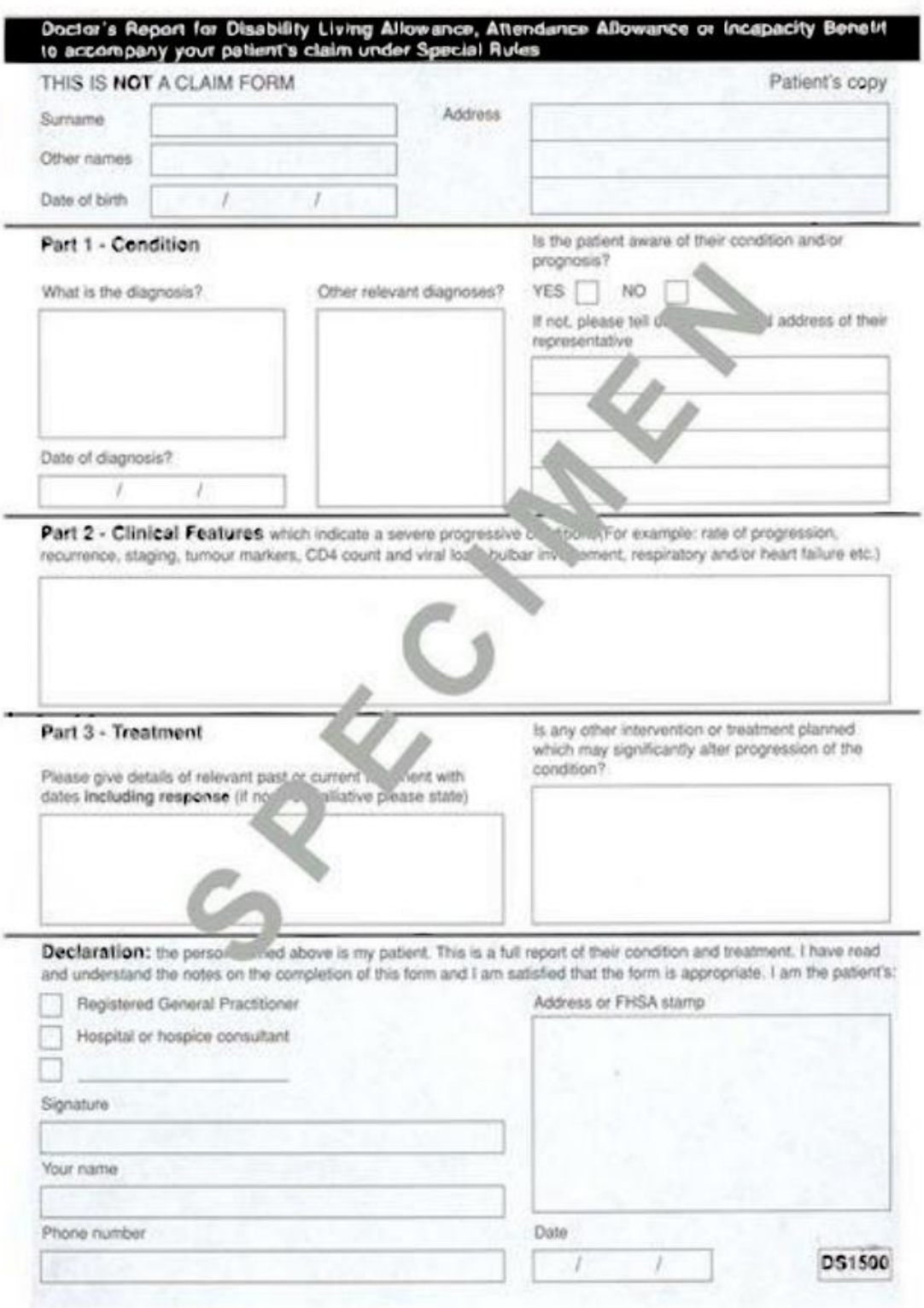
18 **Phone number**

19 **Address**

Postcode

20 **Date**
DD/MM/YYYY

DS 1500 (replaced by SR1)



Doctor's Report for Disability Living Allowance, Attendance Allowance or Incapacity Benefit to accompany your patient's claim under Special Rules

THIS IS **NOT** A CLAIM FORM

Patient's copy

Surname

Other names

Date of birth / /

Address

Part 1 - Condition

What is the diagnosis?

Other relevant diagnoses?

Date of diagnosis? / /

Is the patient aware of their condition and/or prognosis?

YES ☐ NO ☐

If not, please tell us the name and address of their representative

Part 2 - Clinical Features which indicate a severe progressive condition (For example: rate of progression, recurrence, staging, tumour markers, CD4 count and viral load, bulbar involvement, respiratory and/or heart failure etc.)

Part 3 - Treatment

Please give details of relevant past or current treatment with dates **including response** (if none palliative please state)

Is any other intervention or treatment planned which may significantly alter progression of the condition?

Declaration: the person named above is my patient. This is a full report of their condition and treatment. I have read and understand the notes on the completion of this form and I am satisfied that the form is appropriate. I am the patient's:

☐ Registered General Practitioner

☐ Hospital or hospice consultant

☐ _____

Signature

Your name

Phone number

Address or FHSA stamp

Date / /

DS1500

SPECIMEN

ANNEX G

THE SCOTTISH SOCIAL SECURITY PRINCIPLES

The Scottish social security principles are:

- social security is an investment in the people of Scotland
- social security is itself a human right and essential to the realisation of other human rights
- the delivery of social security is a public service
- respect for the dignity of individuals is to be at the heart of the Scottish social security system
- the Scottish social security system is intended to contribute to reducing poverty in Scotland
- the Scottish social security system is should be designed with the people of Scotland on the basis of evidence
- opportunities should be sought to continuously improve the Scottish social security system in ways which -
    - put the needs of those who require assistance first, and
    - advance equality and non-discrimination
- the Scottish social security system should be efficient and deliver value for money.

Effect of the principles

The Scottish social security principles are to be reflected in the Scottish social security charter

The Scottish Commission on Social Security is to have regard to the principles in preparing reports on proposals for legislation

A court or tribunal in civil or criminal proceedings may take the Scottish social security principles into account when determining any question arising in the proceedings to which the principles are relevant.

Breach of the principles does not itself give rise to grounds for any legal action.

Link to the Social Security (Scotland) Act 2018:
http://www.legislation.gov.uk/asp/2018/9/pdfs/asp_20180009_en.pdf[69]

Link to Schedule 5 – Disability Assistance Regulations (introduced by Section 31 of the Act):
http://www.legislation.gov.uk/asp/2018/9/schedule/5/enacted[70]

Implications for Disability Benefits under Special Rules – Terminal illness

If eligible for special rules, the patient's application for benefits assistance will be processed differently to standard benefit applications. 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.

[69] http://www.legislation.gov.uk/asp/2018/9/pdfs/asp_20180009_en.pdf
[70] Social Security (Scotland) Act 2018 (legislation.gov.uk)

- 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 are calculated, at the latest, from the date of application by the patient.
- Patients who qualify under special rules are automatically entitled to the highest rate of the component part(s) of whichever benefit they are entitled to e.g. the current Attendance Allowance and Pension Age Disability Payment, once implemented, do not have a “mobility” component.

It may also enable the patient’s carer(s) to access Carer’s Allowance (a devolved benefit currently being delivered by DWP and being replaced by Carer Support Payment in pilot areas in November 2023 and nationally in Scotland in 2024) quicker, as this is a ‘passported’ benefit, dependent on the patient receiving one of the disability benefits.

The information in this guidance will also be relevant to other practitioners who advise patients regarding benefits assistance e.g. Citizens Advice Scotland.

FURTHER SUPPORTING INFORMATION

Resources

Resources have been developed. These are intended to highlight the recent changes and new processes in Scotland for accessing disability assistance for people who are terminally ill.

Please use this link to access the guidance for clinicians completing a BASRiS form[71].

Please use this link to access the leaflet for terminally ill children[72] and Adult Disability Payment for people who are terminally ill[73].

Frequently Asked Questions

To further support clinicians in using this guidance and supporting patients who are terminally ill a list of frequently asked questions has been developed. Please use this link to access the FAQs[74].

Information Hub

All related information to support clinicians using the new terminal illness definition is being published in one place on Social Security Scotland's website. This includes:

- CMO guidance
- FAQs
- CMO / CNO letter to all RMPs and RNs
- Information leaflets (for clinicians and for people who are terminally ill and those who support them)
- Clear information regarding launch dates of each new disability benefit and clear guidance regarding when the new terminal illness definition is live for each age group
- Clear guidance on whether a SR1 form (replacement for DS1500) or a BASRiS form is required
- Information on where BASRiS forms can be obtained and where they need to be sent
- Information on Social Security Scotland's 'Clinical Helpline' which has been established to support clinicians

Please use this link to access the Information Hub[75].

[71] https://www.socialsecurity.gov.scot/guidance-resources/guidance/special-rules-for-terminal-illness-factsheet-for-clinicians
[72] Child-Disability-Payment-terminal-illness-client-flyer-March-2023.pdf (socialsecurity.gov.scot)
[73] https://www.socialsecurity.gov.scot/guidance-resources/guidance/special-rules-for-terminal-illness-leaflet-for-patients
[74] https://www.socialsecurity.gov.scot/guidance-resources/guidance/special-rules-for-terminal-illness-frequently-asked-questions
[75] https://www.socialsecurity.gov.scot/terminal-illness

BASRiS FEE PAYMENT FORM

For General Practitioners and RMPs and RNs in GP Practices and in third sector organisations not employed by Health Boards

This is an example of the Fee Payment Form which can be used to claim a fee for a submitted BASRiS form. Please complete all the boxes on this form to assist payment. Payment can only be made if the completed Fee Payment Form (and the related BASRiS form) is received by Social Security Scotland.

Social Security Scotland
Tèarainteachd Shòisealta Alba

Payment Form
Benefits Assessment Under Special Rules in Scotland (BASRiS)

BASRiS Payment Section:

Eligibility to claim a fee for completing the BASRiS and the fee amount is contained within the 'Guidance for Doctors and Nurses Completing Benefits Assessment Under Special Rules for Scotland Advice from the Chief Medical Officer'. If you are eligible to claim the fee, please complete the information below and send this form for payment to: **BASRiS Payment, PO Box 27165, Glasgow G4 7BR**

Confirm that you have checked and are eligible to claim the fee ☐

1 GP Practice or Organisation or Name

Address

Town/City

Postcode

Country

Email address

2 Are you registered for VAT Yes ☐ No ☐

VAT reference Number

Fee Amount

3 Please enter details below

Name of Bank or Building Society

Account Name

Sort code ☐ ☐ ☐

Account number

Roll Number (building society only)

Social Security Scotland
Tèarainteachd Shòisealta Alba

4 To help us process the payment, please complete the following:

A Patient CHI Number

b Patients Surname

c Patients First Name

d Patients Date of birth D D M M Y Y Y Y

e Date BASRiS Submitted D D M M Y Y Y Y

(Please Note – The legal situations described in the framework reflect the position when the framework was developed in March 2021)

Framework for Audit of Effectiveness of Implementation of CMO guidance

Implementation of CMO Guidance for fast-tracked access to disability assistance for those with terminal illness: analysis of effectiveness of implementation

1. Situation

This scoping document aims to outline the analysis of the effectiveness of implementation of the CMO guidance supporting fast-tracked access to disability assistance for patients with terminal illness.

This document will be used to agree analysis between key stakeholders.

2. Background

Provision of disability assistance has been devolved to Scotland and when the new forms of assistance launch, Scotland will administer new applications for disability assistance in a phased approach. Those already in receipt of disability assistance will transfer from The Department for Work & Pensions to Social Security Scotland in a similarly phased approach.

A proportion of those who apply for disability assistance are those who have terminal illness. For this group of clients 'Special Rules' may apply which fast-track applications and automatically provide the highest levels of assistance. As Scotland takes over administering this aspect of disability assistance and following extensive consultation, Scottish Government has widened the definition of 'terminal illness'. This was set in law in the Social Security (Scotland) Act 2018. See Table 1.

In order to support clinical judgements around terminal illness and supporting applications for fast-tracked disability assistance through completion of a BASRiS form, the Chief Medical Officer has produced guidance for clinical professionals. This guidance was developed by clinicians in a Short Life Working Group and a Stakeholder Reference Group and has undergone a managed consultation.

Table 1 Definitions of terminal illness for the purposes of claiming disability benefits

	Department of Work and Pensions (UK Government)	**Social Security Scotland**
Definition of terminal illness	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 six months.	A person is deemed terminally ill if it is the clinical judgement of an appropriate healthcare professional that the individual has a progressive disease that can reasonably be expected to cause the individual's death. An appropriate healthcare professional for this purpose is defined in legislation as a

		registered medical practitioner or a registered nurse.
Form used by a clinician to confirm an individual meets terminal illness definition	DS1500	BASRiS form

In order to demonstrate the effect of the change in definition of terminal illness and the effectiveness of the CMO guidance, an analysis of applications for disability assistance under Special Rules is planned. This document describes the initial scoping steps of that analysis. Scottish Government will undertake routine audit of applications and awards of disability assistance which should be viewed in conjunction with any analytical output described below.

This scoping document has been developed while the policies associated with disability assistance are at an early stage in development. While the broad assumptions underpinning it can be expected to remain largely the same, the scope and methods of analyses outlined may change in time as these policies are implemented and as the analytical requirements and associated feasibility become clearer post-implementation.

3. Key questions to answer

Is fast-tracked access to disability assistance for those with terminal illness fair, equitable and consistent?

- Is access equitable for all disease areas?
- Is access equitable for all ages (in proportion to Scottish demographic)?
- Is access equitable by sex?
- Is access equitable by ethnicity?
- Is access equitable by deprivation score?
- Is access equitable geographically?
- How do trends in access change over time for each of these?

How does fast-tracked access compare to standard route access to disability assistance for those with terminal illness?

- Are there differences in the disease areas of clients?
- Are there differences in the ages of clients?
- Are there differences between the sex of patients?
- Are there differences between the ethnicities of clients?
- Are there differences in the deprivation score of clients?
- Are there differences in the geographical distribution of clients?

Is the process of obtaining fast-tracked access to disability assistance for those with terminal illness of good quality?

- Is the guidance sufficient to support completion of BASRiS?
  - Have any complaints/suggestions/omissions been identified by users?

- Are BASRiS forms being completed appropriately? Do any forms need to be queried for further completion or clarification?
- Are any clients being refused fast-tracked access to terminal illness benefits? If so, why?
- Has additional support been sought by direct access to Social Security Scotland or CMO Directorate (telephone or emailed queries)?
- Feedback from users of the guidance obtained by survey could identify particular sections of guidance which is being interpreted in different ways in different situations.

- Who is using the guidance?
  - Is the guidance being used in primary and/or secondary care and/or the third sector?
  - What types of clinician are completing the form?
  - Is there unexplainable variation in use by clinicians geographically?
  - Are all disease areas represented by these clinicians?
- Is the award turnaround time from application to payment being met?
- Is the definition of 'terminal illness' being applied appropriately?
  - How long do clients receive the benefit after the award is made?
  - Is the processing time the same for all disease areas, age groups, sex, ethnic groups, deprivation scores, and geographically?
- Do clients have any feedback about the process of application, completion of paperwork, timeliness of decision-making and receipt of payments? As identified in any user surveys that Social Security Scotland may undertake or direct feedback they receive.

Questions to include in any qualitative work undertaken with those completing BASRiS forms

- Are you familiar with the CMO guidance supporting the completion of BASRiS forms?
- If yes, which sections were helpful?
- What additional information should be included in this guidance?
- If no, did you seek advice for completion of BASRiS? If so, from where?

4. Data sources

BASRiS form – Data items in relation to applicant details, primary healthcare provider, details of parents, details of payment mechanism and diagnosis will be collected in section 1; clinical information where data fields are all free-text/essay-type responses will be collected in section 2; work to develop an electronic version of this form for completion on the web is underway as at March 2021.

User feedback –Analysts from Social Security Scotland plan to gather feedback from applicants/receivers of disability assistance following their application; this survey will principally be to understand respondents' experience with Social Security Scotland but there may be scope to put in specific questions to inform assessment of use of the fast-tracked access pathway.

Routine official statistics – Social Security Scotland will publish regular official statistics publications including information on applications received, awarded and paid for disability assistance.

Policy Evaluation - Analysts at the Scottish Government intend to share their approach to evaluating disability benefits shortly. Part of this approach will include analysis of those cases where the application for disability assistance has been made through the Special Rules route and where BASRiS information would be required. This activity may involve qualitative analysis to gather feedback from clients, those completing application forms and healthcare professionals completing/contributing to the BASRiS form.

5. In-scope

Analysis of the implementation and utilisation of the CMO guidance for rapid access to disability assistance for those with terminal illness in Scotland.

6. Out-of-scope

Analysis of the implementation and utilisation of disability assistance through the standard application route in Scotland.

7. Stakeholders

CMO Directorate
Social Security Policy Team
Social Security Common Processes and Delivery Team
Scottish Government Communities Analysis Division
Social Security Scotland
National Implementation Group for Terminal Illness
Scottish Ministers

8. Timelines

Due to the COVID-19 pandemic and redeployment of staff into emergency response, the initial goal of launch of phase one of disability assistance (Child Disability Payment) in summer 2020 has not been possible. At March 2021, launch of Child Disability Payment is planned for summer 2021 as part of a pilot, with full rollout by autumn 2021. Adult Disability Payment is planned for spring 2022 again beginning with a pilot, with full rollout in summer 2022.

The BASRiS paper form was finalised by the end of 2020. However, work on a digital form and potential links into existing medical information systems is still in progress as at March 2021. Work is progressing to clarify what information will be collected from the BASRiS forms and available digitally for analysis.

At March 2021, the SG Communities Analysis Division have undertaken a Delphi exercise which will be used to estimate the numbers of clients for whom a BASRiS form would be completed. This work was delayed due to the COVID-19 pandemic but is due to report in the first half of 2021 and will be used to inform planning before the launch of disability assistance.

Analysts at the Scottish Government intend to share their approach to evaluating disability benefits shortly and work is underway to define the scope and methods for relevant analysis.

At March 2021, it is anticipated that Social Security Scotland will publish routine official statistics about disability assistance, however, this is not yet described.

9. Next steps

This document will be shared with the Scottish Government Communities Analysis Division and the Scottish Government Social Security Delivery Team. Overlaps with analyses in these teams have been identified and these team leads will feed this audit into any designs for routine Social Security Scotland audits of processes.

Next steps should be:

- To maintain contact with the Analysis and Social Security Delivery Teams.
- Ensure that relevant aspects of this audit continue to be included in the outputs of any analyses and audits these teams design.
- Work with these teams to implement this audit following the launch of Scotland's new forms of disability assistance.

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