Improving terminally ill people's access to Special Rules

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Marie Curie

Contents

Executive summary

When someone becomes terminally ill, they often face a significant income shock. Several factors drive this, including having to leave work, and the significant costs that can come with a terminal illness such as needing to run medical equipment at home. Many terminally ill people will therefore need to turn to our social security system for support with their finances.

There is an important mechanism within our social security system – the Special Rules for End of Life – which allows terminally ill people to quickly access social security support through a streamlined process. This is critical when someone's time is limited. However, this mechanism is failing to support as many terminally ill people as it should.

New research shows that 1 in 3 people who die from a chronic illness (approximately 120,000 each year) in England and Wales do not claim the benefits they are entitled to under the Special Rules. This take up rate of benefits varies between people with different chronic conditions, with the lowest being among those with liver disease (44%), HIV (46%) and heart failure (52%), and the highest among those with dementia (75%) and neurodegenerative diseases (90%).

The Special Rules for End of Life mechanism isn't reaching as many people as intended, reducing its overall effectiveness. And there are some key practice and policy changes that are needed to ensure it fulfils its potential.

Steps must be taken to improve healthcare professional's awareness and use of this mechanism. Key to this is the Department for Work and Pensions (DWP) raising greater awareness of the Special Rules among clinicians likely to interact with terminally ill people. DWP must also work with relevant statutory regulatory bodies responsible for delivering healthcare professionals' training to ensure Special Rules is included in relevant educational standards, curriculum requirements, and competencies for healthcare professionals. And health leaders and clinical directors across NHS trusts, health boards, health and social care trusts, hospices and in primary care must embed financial probes – including about eligibility for Special Rules – into clinical processes.

The DWP should also expand the types of approved clinicians who can confirm that a patient is eligible for an SR1 form. This would help ensure more healthcare professionals who routinely engage with people who are terminally ill, are able to approve their access to benefits via Special Rules.

Policy change is also needed so more terminally ill people can access this mechanism. In England, Wales and Northern Ireland, the definition of terminal illness used for Special Rules requires a healthcare professional to not be surprised if a patient died within 12 months. However, it can be very difficult for healthcare professionals to prognose whether someone is likely to die within 12 months, and some terminally ill people are expected to live for longer than this – for example, 18 months or two years. That is why we are calling on the DWP to consider introducing a more flexible definition of terminal illness that removes the 12-month prognosis requirement. In particular we would encourage the Government to review the impact of the approach taken by

Social Security Scotland, where a person is considered to be terminally ill if they have a progressive disease from which death may reasonably be expected, with no time requirement.

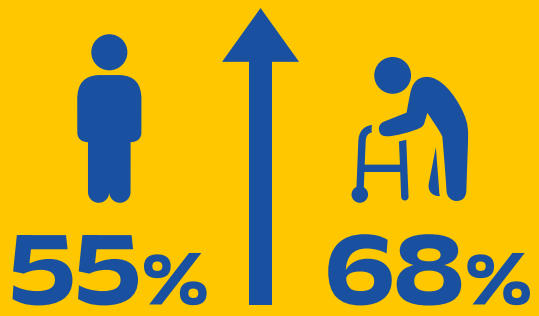
No-one should be worrying about their finances or fighting to get the social security support they vitally need at the end of their life. Taking these steps to improve terminally ill people's access to Special Rules is a key part of ensuring those with life-limiting conditions can quickly access financial support and focus on what really matters: making memories with their families and loved ones and living as well as they can for as long as they are able.

Key facts

1 in 3

In England and Wales, **1 in 3** people who die from a chronic illness (approximately **120,000** each year) do not receive the benefits they are eligible for under the Special Rules for End of Life

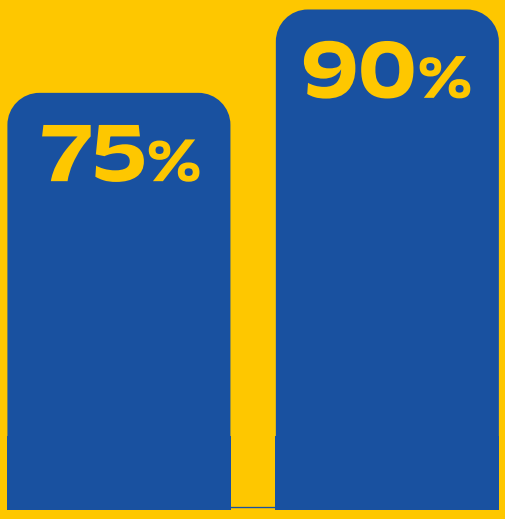
55% of working-age adults receive the benefits for which they are eligible under the Special Rules for End of Life, compared to **68%** of pension age adults



The take up rate of benefits varies between people with different chronic conditions

Lowest take up rates

Highest take up rates



While take-up rates are higher in more deprived areas in Wales and the North of England, substantial proportions of people in the most deprived neighbourhoods still do not receive these benefits.

34%
in the most depived quintile do not receive these benefits

37%
in the second most depived quintile do not receive these benefits

Introduction

Marie Curie's Dying in Poverty report reveals the 'double burden' of income loss and increased costs brought on by a terminal illness.[1] This can leave those who were previously comfortably-off struggling to make ends meet. It can also push those who were already on lower incomes or struggling to get by below the poverty line. For more than one in six people who died in the UK in 2024, the last period of life was marked by financial difficulty.[2] This means many people with a terminal illness need support from the social security system, often for the first time.

Benefits make up around half of the income of working-age households including someone in the last year of life, rising to almost three-quarters among households in poverty.[3] When someone is terminally ill, it's especially pressing that they get social security support as quickly as possible to meet the often rapid and significant income drop experienced after a terminal illness diagnosis.

The Special Rules for End of Life is a vital route to helping achieve that. It enables individuals with a progressive, life-limiting illness to access key welfare benefits more quickly without the need for medical assessments, and to get the highest rate of some benefits. However, the Special Rules route is currently failing to protect too many people with a terminal illness.

Progress has been made with this provision. As a result of Marie Curie and the MND Association's joint campaign, the qualifying period for Special Rules extended from someone having a life expectancy of 6 to 12 months in England, Wales and Northern Ireland. And in Scotland, the government has replaced the previous time-limited life expectancy rule with a clinical judgment model. However, further action is needed to ensure more terminally ill people can access this vital mechanism. Specifically, to ensure the definition of terminal illness used in England, Wales and Northern Ireland doesn't lock terminally ill people out of support, and to ensure more healthcare professionals are aware of and feel confident and able to use this vital provision.

Improving access to social security benefits for people with a terminal illness has the potential to alleviate some of the effects of financial hardship at the end of life. No-one should be worrying about their finances or fighting to get the social security support they vitally need when they have limited time left to live. Improving terminally ill people's access to Special Rules is a key part of addressing that.

Take-up of benefits via the Special Rules for End of Life route

In England, Wales and Northern Ireland, to access benefits via the Special Rules route, an individual needs to have a progressive disease. Because of that disease, a healthcare professional needs to not be surprised if that person was to live for less than 12 months. This is evidenced through an SR1 form, which is the basis of a Special Rules benefits application.

In Scotland, access to non-means tested benefits via the Special Rules route is a bit different. A healthcare professional needs to verify that an individual has an illness that will get worse over time and be expected to cause death. But healthcare professionals do not have to prognose how long you might live for. And instead of an SR1 form, a BASRiS form is used.

Applying for benefits via the Special Rules route means a claim can be looked at more quickly. If a Special Rules application is approved, access to benefits is expedited without the need for further medical assessment, and applicants are automatically entitled to a higher rate of support for some benefits. The purpose of fast-tracking access to benefits for terminally ill people is to ensure the rapid provision of essential financial support. However, new research shows that terminally ill people are routinely missing out on accessing social security support via the Special Rules route.[4]

In England and Wales, 1 in 3 people (34%) who died from a chronic illness did not receive the non-means tested disability benefits they are eligible for via the Special Rules route at any point during the last 12 months of life. This includes Personal Independence Payment (PIP), Disability Living Allowance (DLA), and Attendance Allowance (AA).[5] That equates to approximately 120,000 people dying each year from a chronic illness in England and Wales without receiving this vital financial support. Within this cohort of terminally ill people, there are also some noteworthy differences in levels of take-up. Specifically in relation to condition, where in England and Wales someone lives and age.

The take up rate of benefits varies between people with different chronic conditions, with the lowest being among those with liver disease (44%), HIV (46%) and heart failure (52%), and the highest among those with dementia (75%) and neurodegenerative diseases (90%). This may be because neurodegenerative diseases and dementia are associated with a long period of low function and disability which may mean that people have both a greater need, and more time, to claim benefits.[6,7] Comparatively, deaths from cancer (where take-up is 62%) often have a shorter period of low function before death, and deaths from heart failure are characterised by episodic decline in function and an unclear prognosis.[8] What's more, conditions like liver disease and HIV aren't inherently considered terminal, and trajectories can change significantly – for example, through a liver transplant or with effective HIV treatment – making it harder to apply standard approaches to end of life.[9,10]

While take-up rates are higher in more deprived areas in Wales and the North of England, substantial proportions of people in the most deprived neighbourhoods still do not receive non-means-tested benefits – 34% in the most deprived quintile group

and 37% in the second-most deprived. This indicates that lack of need for financial support is unlikely to be the only factor driving the take-up deficit.

The take up rate of these benefits is also notably higher for older people. Fifty five per cent of working-age adults receive the benefits they are eligible for under the Special Rules for End of Life, compared to 68% of pension age adults. This may partly reflect the fact that older people may have lived for longer with their disability and therefore had more opportunity to claim. The analysis also found that there were some differences to this pattern according to underlying cause of death.

For example, among people who died from heart failure, liver disease, HIV, and stroke, those of pension age had a higher take-up rate. Whereas among people who died from renal failure, those of pension age had a lower take-up rate. And for those who died from cancer, dementia, neurodegenerative disease and respiratory failure, there was little difference in the take-up rate between those of working and pension age.

It's clear that as it stands, too many people with a terminal illness are failing to access the benefits that they are entitled to. This is leaving terminally ill people without vital support when they need it most.

> "My wife was the main earner in our family at the time she was diagnosed with triple negative breast cancer . . . even as her condition deteriorated and she appealed for a reconsideration for PIP; she was still turned down. In her last two months before being admitted to hospital she no longer had the mental strength to go through that application process again, especially knowing that it would take months before she would receive any payment."
>
> – Marie Curie campaign supporter

> "My best friend died from leukaemia before 50. I only heard her cry twice, both times about the benefits system. They kept saying she wasn't ill enough for PIP. Even when dying, she still couldn't get fast tracked. She died still trying to claim."
>
> – Marie Curie campaign supporter

Challenges with prognosis for Special Rules

A terminal illness is an illness or condition which cannot be cured and is likely to lead to someone's death. It's sometimes called a life-limiting illness. There is no set list of illnesses which are terminal. People who are terminally ill may have a single illness or several different conditions. Someone with a terminal illness may live for days, weeks, months or years. It often depends on their diagnosis and any treatment they are having. It can be difficult for healthcare professionals to predict exactly how long someone with a terminal illness will live (their prognosis).

In England, Wales and Northern Ireland the Special Rules are not designed to identify everybody living with a terminal condition. These rules are intended to identify people who should be reasonably expected to die within the coming year. This presents particular challenges for two cohorts: those who are terminally ill but not expected to die within the coming year, and those who are expected to die within the coming year but are without such a prognosis.

Regarding the first cohort, these pen-portraits – which are not case studies, but realistic scenarios based on Marie Curie's clinical expertise – demonstrate the challenge for terminally ill people who are likely to die in, for instance, 18 months or two years and therefore do not qualify for Special Rules.

Pen portrait 1

Around 90% of people diagnosed with Stage 4 bowel cancer will die in the following five years. Laura has incurable Stage 4 bowel cancer. She has had previous surgery to remove the cancer, but it has now spread to one of her lungs. She has abdominal pain, and some mild shortness of breath, as well as difficulties with fatigue.

At the moment, Laura doesn't qualify for the Special Rules for End of Life, because her clinicians don't expect her to die in the next 12 months. She also doesn't yet meet the Severe Conditions Criteria, because her function is not so affected that she meets the criteria to be placed in the Limited Capability for Work and Work-Related Activity group in Universal Credit.

This means that until either her function gets worse, or until she is expected to die in the next 12 months, Laura will only receive basic Universal Credit. She might also be required to regularly meet with a Work Coach at the JobCentre or do things like improve her CV, or else face a benefit sanction.

Pen portrait 2

Corticobasal degeneration (CBD) is a rare condition caused by brain cells becoming damaged or dying. It causes gradually worsening problems with lots of daily activities, and the average life expectancy after symptoms start to appear is 6 to 8 years.

Sathnam is in the early stages of CBD. He has some difficulties with swallowing and speech, as well as fine motor tasks such as writing, and sometimes struggles with his balance and falls. He doesn't yet need any assistance with activities of daily living, but things often take him longer to do than they used to. These symptoms are not enough to score him enough points on the Work Capability Assessment to be placed in the Limited Capability for Work and Work-Related Activity group – meaning he does not meet the Severe Conditions Criteria. He's also not expected to die in the next 12 months, so does not qualify under the Special Rules for End of Life.

Sathnam's condition is sadly only going to worsen. Yet until it does, he has to live on basic Universal Credit, and has to undertake activity that is supposed to move him closer to returning to work – something he is not realistically ever going to do. This is not only entirely unnecessary, but it puts him at risk of having his benefits reduced by a sanction.

Pen portrait 3

Huntington's Disease is a progressive, neurodegenerative disorder. There is currently no cure, and no treatments that can stop the symptoms getting worse.

Jasper has Huntington's Disease, which causes him difficulty concentrating and memory problems. He has noticed some changes in his mood, including mood swings, and he also has some slight jerking movements which he is unable to control. However, he does not qualify for either the Special Rules for End of Life, nor the Severe Conditions Criteria. This means he's not able to receive the additional health-related Universal Credit and has to get by on the basic rate. Jasper's symptoms are also going to worsen over time, not improve. Yet because he is in the Limited Capability for Work group in Universal Credit, he has to undertake 'work-related activity' – work that his condition is only going to gradually move him further away from. If he doesn't do these activities, he could have his benefits cut by a sanction.

Regarding the second challenge for accessing Special Rules – where someone is expected to die within the coming year but doesn't have such a prognosis – it can be very difficult for healthcare professionals to determine whether someone has less than 12 months to live. New research demonstrates the complexity and nuance involved in conversations about prognostic uncertainty in serious illness and palliative care. Prognostic discussions are sometimes avoided or delayed until uncertainty is reduced, which could result in delays completing SR1 forms, and in access to benefits under special rules.[11] What's more, clinicians' prognostic accuracy for people at the end of their life is routinely poor and inconsistent.[12]

The SR1 form does not require a specific estimation of prognosis beyond the expectation that someone is in the last year of their life, and the DWP are clear in their guidance to clinicians that there are no repercussions for healthcare professionals if their patient lives for longer than 12 months.[13] However, new qualitative research shows that prognostic uncertainty can make discussions about access to benefits under the Special Rules route harder, particularly for some diagnostic groups when prognosis is less clear, including with non-cancer conditions and some cancers such as haematological cancers. And some healthcare professionals still fear that they will face repercussions if their patient lives for longer than 12 months.[14]

Furthermore, if a patient is not aware of their prognosis, or have indicated that they do not want to discuss this, it can be especially challenging for healthcare professionals to discuss access to benefits under the Special Rules.[15]

Research suggests that widening the statutory prognostic threshold for Special Rules from 6 to 12 months has increased the number of terminally ill people who are receiving benefits via this route, especially for people with non-cancer diagnoses and older adults.[16] However, given the high levels of people in the last year of their life who continue to miss out on this mechanism, prognosis may not be the best mechanism for determining eligibility for Special Rules.

The DWP should therefore consider introducing a more flexible definition of terminal illness that removes the 12-month prognosis requirement. This could be modelled on the approach taken by Social Security Scotland, where a person is considered to be terminally ill if they have a progressive disease from which death may reasonably be expected.

In the meantime, changes need to be made to the way DWP engages with applicants about the 12-month prognosis. While DWP guidance to clinicians does state that they need to not be "surprised" if a patient were to live for less than 12 months, and there are "no negative consequences for the clinician or patient if a patient who claims under the Special Rules lives longer than expected",[17] the same nuance is not provided to applicants.

The DWP guidance for applicants explains you could be eligible for Special Rules if "your doctor or medical professional has said you might have 12 months or less to live" and doesn't mention the lack of repercussion if you live longer.[18] What's more, when you call the PIP new claims phone line, it states that you might be eligible for a different application route if your doctor or healthcare professional has said you "may have less than 12 months to live".

The same level of nuance provided to healthcare professionals – that states there are no repercussions if someone lives longer than 12 months – must be communicated to applicants.

Low levels of awareness of Special Rules

All too often, Marie Curie hears from people who weren't made aware of the Special Rules route by their respective healthcare professionals and miss out on this support as a result.

Qualitative research suggests the revised definition of terminal illness in Scotland has made it easier for some practitioners to assess eligibility across a broader range of conditions. But it's clear that the definition for this mechanism is only half of the picture. This research also suggests that clinicians in Scotland are still failing to let patients know about Special Rules, continuing to misunderstand which conditions and illnesses may be in scope, misconceiving that assistance under Special Rules is means tested, and failing to regularly use accompanying guidance prepared by the Chief Medical Officer.[19]

That's why, as well as adopting a more flexible definition of terminal illness, the **DWP should undertake an awareness campaign about the Special Rules for End of Life targeted at clinicians likely to interact with terminally ill people**. And so long as the 12-month prognosis route exists for Special Rules in England, Wales and Northern Ireland, DWP should more clearly communicate that there are no repercussions if someone is awarded Special Rules and lives for longer than 12 months, empowering more clinicians to feel able to use the SR1 form.

This awareness campaign needs to be directed at a range of clinicians beyond just those working in palliative and end of life care settings. That includes those in primary care settings such as GPs, and disease-specific Clinical Nurse Specialists working in oncology, for example. This is necessary for two reasons. First, not everyone with a terminal illness receives care from specialist palliative care services. Second, if clinicians outside of palliative and end of life care settings are better aware of Special Rules, they will be encouraged to refer into palliative and end of life care services where clinicians have more experience discussing people's finances, including their eligibility for certain benefits. This, in turn, would support more terminally ill people to get earlier access to services that can support them to apply for social security support.

There has been some positive work undertaken by Kings College London, where bite-sized training has been produced for clinicians on helping patients

> "My mam was never given any financial guidance when she was diagnosed with Cancer, there were a number of benefits which she could have received which would have made her final years less of a struggle."
>
> – Marie Curie campaign supporter

to access benefits via the Special Rules for End of Life.[20] The DWP should build on this work as part of this awareness campaign.

Even where healthcare professions do know about Special Rules, they can sometimes have less knowledge about the value of the benefits that patients can access, and as a result, underestimate their worth.[21] This, in turn, can limit prioritisation of completing SR1 forms.

A key part of this awareness campaign should also involve telling clinicians how much money an individual could receive from certain benefits. If clinicians knew how transformative this could be, that could help incentivise them to have the conversation.

Key to enabling more targeted outreach of this campaign is better data on which healthcare professionals are completing SR1 forms, to help identify if and where there appear to be gaps in awareness and use of these forms. That is why the **DWP should improve its process for capturing data on who exactly is completing SR1 forms, to enable identification of where more targeted outreach is needed.**

Finally, as well as DWP delivering an awareness campaign about the Special Rules, it's also vital that all clinicians likely to interact with terminally ill people receive routine and up to date training on SR1 forms and Special Rules. **The DWP should work with the relevant statutory regulatory bodies responsible for delivering healthcare professionals' training to ensure SR1 forms and Special Rules are embedded in relevant educational standards, curriculum requirements, and competencies required to enter and practice in the field.**

Better embedding Special Rules within clinical processes

As we outlined in our Money Matters at the End of Life guide, a discussion about finances should begin at the onset of a chronic or terminal diagnosis, with health professionals continuing to ask all patients about financial matters periodically as a matter of routine.[22]

However, qualitative research shows how healthcare professionals can find it difficult to discuss finances with patients, given the sensitive nature of the topic. And while some doctors, nurses and social workers see discussing finances as a key part of their role, others can be more reluctant to do so due to their competing clinical priorities and lack of knowledge about benefits.[23]

To help ensure these conversations are had as a matter of routine, **health leaders and clinical directors across NHS trusts, health boards, health and social care trusts, hospices and in primary care must embed financial probes – including about eligibility for Special Rules – into clinical processes**. This includes consultant appointments, advance care planning, Electronic Palliative Care Coordination Systems, hospital discharge planning and GP palliative care registers.

Healthcare professionals can also face some very practical challenges to discussing Special Rules with patients and signing SR1 forms. It can be difficult to have these conversations when patients are very unwell, confused or unconscious. It can also be hard for healthcare professionals to know whether a claim is worthwhile if a patient is close to death, or likely to remain in hospital or a local authority funded care home until the point of death, which could lead to any disability benefits being suspended or stopped.[24]

Doctors, nurses, physiotherapists and occupational therapists frequently describe how support from a dedicated social worker or benefits advisor meant that they felt able to speak to patients about access to benefits under the Special Rules and then refer the patient on to someone who had expertise in applying for these benefits. They also outline how such professionals can help educate and upskill clinical colleagues on Special Rules. However, healthcare professionals also noted the 'postcode lottery' in the availability of social workers and benefits advisors, citing a lack of access to these members of the team with specialist knowledge of benefits as a major barrier to supporting patients.[25]

Considering the challenges healthcare professionals can face completing SR1 forms, **the DWP should consider expanding the types of approved clinicians who can confirm that a patient is eligible for an SR1 form**. For example – paramedics employed by hospices. This would help ensure more healthcare professionals who routinely engage with people who are terminally ill, are able to approve their access to benefits via Special Rules. It's also important DWP considers the practical effects of the fee system for completing SR1 forms as part of this. As it stands, only General practitioners and GMC-registered consultants can receive a fee for completing an SR1 form, with no financial incentive for other clinicians to do so.

We also recommend that when an approved clinician has confirmed that a patient is eligible for an SR1 form – they should be able to delegate completion of this form to a colleague – before submitting it themselves via the portal or for submission via post.

A final practical barrier to healthcare professionals completing SR1 forms can be the lack of access to shared records.[26] As it stands, there's no consistent way for a healthcare professional to check whether an SR1 has already been completed for a patient. **As part of the DWP's online Special Rules portal, clinicians should be able to search for whether an SR1 form has already been completed for an individual**. This would save both clinician time and avoid risk of duplication.

Conclusion and recommendations

When the Special Rules route works well, it can be one of the most effective parts of the benefits system. It can enable terminally ill people to get support as quickly as possible, something that's key to providing financial dignity in the final period of someone's life. However, as it stands, the potential of this mechanism is not being fully realised.

That's because too many terminally ill people struggle to access it. Despite recent changes, the 12-month prognosis definition for Special Rules in England, Wales and Northern Ireland remains restrictive, healthcare professionals face barriers to using this mechanism, and all too often terminally ill people aren't routinely having their finances or this potential offer of support discussed with them as part of the care they receive.

This briefing outlines clear policy and practice changes that could help change that. Better approaches to the Special Rules definition are in practice in Scotland that the DWP would do well to consider for adoption. And the DWP also has a role to play in better communicating about and promoting the Special Rules route among healthcare professionals, while health and care systems could better embed prompts about financial difficulty and Special Rules when engaging with terminally ill patients.

Action on this is vital to ensure terminally ill people get the financial security they deserve. No-one should be worrying about their finances or fighting to get the social security support they vitally need at the end of their life.

Recommendations in this briefing

- DWP should consider introducing a more flexible definition of terminal illness that removes the 12-month prognosis requirement.
- DWP should provide the same level of nuance provided to healthcare professionals – that states there are no repercussions if someone lives longer than 12 months – to applicants.
- DWP should undertake an awareness campaign about the Special Rules for End of Life targeted at clinicians likely to interact with terminally ill people.
- DWP should improve its process for capturing data on who exactly is completing SR1 forms, to enable identification of where more targeted outreach is needed.
- DWP should work with the relevant statutory regulatory bodies responsible for delivering healthcare professionals' training to ensure SR1 forms and Special Rules are embedded in relevant educational standards, curriculum requirements, and competencies required to enter and practice in the field.
- Health leaders and clinical directors across NHS trusts, health boards, health and social care trusts, hospices and in primary care must embed financial probes – including about eligibility for Special Rules – into clinical processes.
- DWP should consider expanding the types of approved clinicians who can confirm that a patient is eligible for an SR1 form.
- DWP should permit the completion of an SR1 form to be delegated to a colleague, when an approved clinician has confirmed that a patient is eligible for one.
- As part of the DWP's online Special Rules portal, clinicians should be able to search for whether an SR1 form has already been completed for an individual.

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Becca Stacey

Senior Policy Manager - Financial Security

becca.stacey@mariecurie.org.uk

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