Personal Independence Payments (PIP)

(PIP) The initial Contact

Contact by Telephone 0800 917 2222 (Mon to Fri 8am to 6pm)

If making the telephone call on behalf of someone, the person who the claim is about has to be present to clarify permission to speak on behalf of the claimant.

Details needed for the call

Full Name of claimant National Insurance number

Address and postcode Date of birth

Bank details (for payments) Daytime contact number

GP and other health professionals Details of any recent hospital stay

Nationality

Series of questions collecting basic information

* Previous surname
* If your condition affects you as below;
	+ Mental health condition
	+ Behavioural condition
	+ Learning difficulty
	+ Developmental disorder
	+ Memory problem
* Your contact details if acting on behalf of someone
* Details of time spent abroad for prolonged periods of time
* Details of time spent in hospital

Following this you will receive a **How your disability affects you** form (it has to be returned within 4 weeks).

This will need sending back to the given address.

In the majority of cases one to one assessment will be arranged where your support person can attend with you.

Confirmation of whether you have qualified will be sent via post.

**Also you have the opportunity to confirm at this stage that the claimant is vulnerable and may also need support either attending appointments or may need a visit to support them completing the form.**

When sending the form back try and photocopy or scan the form for your records and get the form recorded delivery if possible or UK signed.

The ‘How your disability affects you’ form follows the following headings, with the following points allocated per heading. We have made notes at the bottom of each box to try and help you think about these areas and given suggestions of some issues that are common for people with Huntington’s.

Daily Living activities

Question 3 – Preparing food

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| This activity considers a claimant’s ability to prepare a simple meal. This is not a reflection of a claimant’s cooking skills but instead a consideration of the impact of impairment on ability to perform the tasks required. It assesses ability to open packaging, serve food, peel and chop food and use a microwave oven or cooker hob to cook or heat food. **Notes:** * Preparing food means the activities required to make food ready for cooking and eating, such as peeling and chopping.
* Cooking food means heating food at above waist height – for example, using a microwave oven or on a cooker hob. It does not consider the ability to bend down – for example, to access an oven.
* A simple meal is a cooked one-course meal for one from fresh ingredients.
* Packaging includes tins, which may require the use of a tin opener.
* In this activity aids and appliances could include, for example, prostheses, perching stool, lightweight pots and pans, easy grip handles on utensils and single lever arm taps.

Pre-chopped vegetables are not considered an aid or appliance. However, a claimant who is reliant on them because they would be unable to peel or chop fresh vegetables may be considered as requiring an aid or appliance or support from another person to complete the activity. |
| A | Can prepare and cook a simple meal unaided. | 0 |
| B | Needs to use an aid or appliance to be able to either prepare or cook a simple meal. | 2 |
| C | Cannot cook a simple meal using a conventional cooker but is able to do so using a microwave. For example: may apply to claimants who cannot safely use a cooker hob and hot pans. | 2 |
| D | Needs prompting to be able to either prepare or cook a simple meal. For example: may apply to claimants who lack motivation, who need to be reminded how to prepare and cook food or who are unable to ascertain if food is within date. | 2 |
| E | Needs supervision or assistance to be able to either prepare or cook a simple meal. For example: may apply to claimants who need supervision to prepare and cannot safely use a microwave oven or to claimants who cannot prepare or safely heat food. | 4 |
| F | Cannot prepare and cook food. | 8 |
| Have you hurt yourself when preparing food? What happened and when did this last occur? Do you need prompting to start the activity? Do you need prompting or guidance throughout preparing? Do you check food is in date? Are you aware if food is cooked or not as a result of your health condition and not cooking ability? Do you struggle to turn appliances on / off (what appliances)? Do you have involuntary movements that make preparing food harder?Do you have decreased spatial awareness, and does this affect the way you prepare food? Are you able to peel and chop vegetables? Do you have difficulty with movements that makes things harder like opening a jar or a tin? Do you drop items (grip)? Do you fall or lose balance while cooking? Do you feel hot / cold like you used to – would you know if you had burned yourself?Have you stared to use easier options, such as microwave meals rather than preparing a meal yourself? Do you use any special equipment such as electronic tin openers? If so why do you use them and are they self-purchased or self-prescribed? |

Question 4 – Eating and Drinking

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| This activity considers a claimant’s ability to be nourished, either by cutting food into pieces, conveying to the mouth, chewing and swallowing; or through the use of therapeutic sources. **Notes:** * A therapeutic source means parenteral or enteral tube feeding using a rate limiting device such as a delivery system or feed pump.
* A key consideration when considering whether supervision is required should be whether the claimant has a real risk of choking when taking nutrition.
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| A | Can take nutrition unaided.  | 0 |
| B | Needs – to use an aid or appliance to be able to take nutrition; or supervision to be able to take nutrition; or assistance to be able to cut up food. | 2 |
| C | Needs a therapeutic source to be able to take nutrition. For example: may apply to claimants who require enteral or parenteral feeding but can carry it out unaided. | 2 |
| D | Needs prompting to be able to take nutrition. For example: may apply to claimants who need to be reminded to eat or who need prompting about portion size. | 4 |
| E | Needs assistance to be able to manage a therapeutic source to take nutrition. For example: may apply to claimants who require enteral or parenteral feeding and require support to manage the equipment. | 6 |
| F | Cannot convey food and drink to their mouth and needs another person to do so. | 10 |
| Do you need reminding to eat, if so why? Does someone need to prompt you when you are eating? Is this required throughout the activity or will you eat if the food is placed in front of you? If not, why is this? Does someone help you to eat? Have you got any equipment that helps you eat or drink (for example a modified cup or cutlery), if so who provided this? Do you choke or do you need modified food to prevent you choking (e.g. do you choose softer foods? If you choked previously, when did this last happen? Do you cough on liquids or food? Have you had any input from a Speech and Language Therapist? If so, when and how often?Is your swallow worse when you are distracted or tired? Do you need any physical assistance with either cutting up food or getting this to your mouth and, if so, why is this? Do you spill drinks or drop food? Does it take you a long time to eat?Does your food get cold because you take a long time eating?(If you have seen a Speech and Language Therapist, it is likely to be helpful to use a copy of their report / guidance in assessment)  |

Question 5 – Managing treatments

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| This activity considers a claimant’s ability to: 1. appropriately take medication in a domestic setting and which are prescribed or recommended by a registered doctor, nurse or pharmacist;
2. monitor and detect changes in a health condition; and
3. manage therapeutic activities that are carried out in a domestic setting and prescribed or recommended by a registered doctor, nurse, pharmacist or healthcare professional regulated by the Health Professions Council;

**and** without any of which their health is likely to deteriorate. **Notes:** * Managing medication means the ability to take prescribed medication in the correct way and at the right time. Monitoring a health condition or recognise significant changes means the ability to detect changes in the condition and take corrective action as advised by a healthcare professional.
* This activity does not take into account medication and monitoring requiring administration by a healthcare professional.
* Examples of prescribed or recommended medication include tablets, inhalers and creams and therapies could include home oxygen, domiciliary dialysis, nebulisers and exercise regimes to prevent complications such as contractures. Whilst medications and therapies do not necessarily have to be prescribed, there must be a consensus of medical opinion that supports their use in treatment of the condition.
* Supervision due to the risk of accidental or deliberate overdose or deliberate self-harm is captured in these descriptors as the person would require continuous support from another person in order to prevent this.
* For the purpose of this activity, the majority of days test does not require the individual to actually be receiving therapy on the majority of days in a year. However, the descriptor would still need to accurately describe the claimant’s circumstances on a majority of days –on a majority of days the statement about how much support an individual needs a week must be true. For example, if a claimant needs assistance to undergo home dialysis for three hours on Monday and Friday, they would not actually be receiving therapy on a majority of days in a year. However, on a majority of days in the year, the statement that they need “assistance to be able to manage therapy that takes more than 3.5 but no more than 7 hours a week” would still apply as it accurately describes the level of support needed in a week.
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| A | Either –does not receive medication or therapy or need to monitor a health condition; or can manage medication or therapy or monitor a health condition unaided. | 0 |
| B | Needs either – to use an aid or appliance to be able to manage medication; or supervision, prompting or assistance to be able to manage medication or monitor a health condition. | 1 |
| C | Needs supervision, prompting or assistance to be able to manage therapy that takes no more than 3.5 hours a week. | 2 |
| D | Needs supervision, prompting or assistance to be able to manage therapy that takes more than 3.5 hours a week but no more than 7 hours. | 4 |
| E | Needs supervision, prompting or assistance to be able to manage therapy that takes more than 7 hours a week but no more than 14 hours. | 6 |
| F | Needs supervision, prompting or assistance to be able to manage therapy that takes more than 14 hours a week. | 8 |
| Do you take medication? And if so, how often? Do you take it on time with or without prompting? Do you remember to order your medication before it runs out? Are you compliant with medication? Is your medication in date? Do you know how to manage changes in dosage? Do you struggle to open the medication packaging? Is your medication in regular form or blister pack? Are regular reviews held? How often? Any medication used for as and when needed (PRN) e.g. pain killers sensitivity to pain etc. |

Question 6 – Washing and bathing

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| This activity considers a claimant’s ability to wash and bathe, including washing their whole body and getting in and out of an un-adapted bath or shower.  |
| A | Can wash and bathe unaided. | 0 |
| B | Needs to use an aid or appliance to be able to wash or bathe.For example: suitable aids could include a long-handled sponge, shower seat or bath rail. | 2 |
| C | Needs supervision or prompting to be able to wash or bathe.For example: may apply to claimants who lack motivation or need to be reminded to wash or require supervision for safety. | 2 |
| D | Needs assistance to be able to wash either their hair or body below the waist.For example: may apply to claimants who are unable to make use of aids and who cannot reach their lower limbs or hair. | 2 |
| E | Needs assistance to be able to get in or out of a bath or shower. | 3 |
| F | Needs assistance to be able to wash their body between the shoulders and waist.  | 4 |
| G | Cannot wash and bathe at all and needs another person to wash their entire body. | 8 |
| Do you need prompting and reminding to wash or bathe? Are you able to get into and out of a standard bath and shower? If not, why is this? Do you need someone to break the task down, for example helping you to prepare to wash? Do you have anxiety because you are unclear of how to start the task?Do you have any obsessions around hygiene potentially around your hair, teeth, makeup, or cleanliness?Do you wash / bathe in short intervals to reduce distress? Have you fallen when washing or bathing? If so, when did this last occur? Are you able to bathe alone?Do you require physical assistance with washing and bathing and if so, what aspects? Can you manage some aspects of the activity? For example the lower but not the upper limbs? If so, why? Do you have any equipment to help you wash / bathe? If so, who provided this, was it self-bought or prescribed? |

Question 7 – Managing toilet needs

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| This activity considers a claimant’s ability to get on and off the toilet, to clean afterwards and to manage evacuation of the bladder and / or bowel, including the use of collecting devices. This activity does not include the ability to manage clothing, for example fastening and unfastening zips or buttons, as this is covered in activity 6. **Notes:** Toilet needs means the ability to get on and off the toilet and clean oneself afterwards. Managing incontinence means the ability to manage evacuation of the bladder and / or bowel including using collecting devices and clean oneself afterwards. Claimants with catheters and collecting devices are considered incontinent for the purposes of this activity. |
| A | Can manage toilet needs or incontinence unaided. | 0 |
| B | Needs to use an aid or appliance to be able to manage toilet needs or incontinence. For example: suitable aids could include commodes, raised toilet seats, bottom wipers, bidets, incontinence pads or a stoma bag.  | 2 |
| C | Needs supervision or prompting to be able to manage toilet needs. For example: may apply to claimants who need to be reminded to go to the toilet or need supervision to get on and off the toilet safely.  | 2 |
| D | Needs assistance to be able to manage toilet needs. | 4 |
| E | Needs assistance to be able to manage incontinence of either bladder or bowel. | 6 |
| F | Needs assistance to be able to manage incontinence of both bladder and bowel.  | 8 |
| Do you have any difficulties with your toilet needs? Do you need physical assistance to get on or off the toilet or attend to your hygiene needs? If so, why is this? Do you need prompting to go to the toilet? Do you use any aids / pads for toileting? If so, are they prescribed or self-purchased? Are you incontinent of urine or faeces? Do you become obsessed with going to the toilet frequently? |

Question 8 – Dressing and undressing

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| This activity assesses a claimant’s ability to put on and take off culturally appropriate, un-adapted clothing that is suitable for the situation. This may include the need for fastenings such as zips or buttons and considers the ability to put on / take off socks and shoes.  |
| A | Can dress and undress unaided. | 0 |
| B | Needs to use an aid or appliance to be able to dress or undress.For example: suitable aids could include modified buttons, zips, front fastening bras, trousers, Velcro fastenings and shoe aids.  | 2 |
| C | Needs either – 1. prompting to be able to dress, undress or determine appropriate circumstances for remaining clothed; or
2. prompting or assistance to be able to select appropriate clothing.

For example: may apply to claimants who need to be encouraged to dress. Includes a consideration of whether the claimant can determine what is appropriate for the environment, such as time of day and the weather.  | 2 |
| D | Needs assistance to be able to dress or undress their lower body. | 2 |
| E | Needs assistance to be able to dress or undress their upper body. | 4 |
| F | Cannot dress or undress at all. | 8 |
| Do you need help or prompting to dress or undress? Does this occur for the majority of days? Do you need direction from others for dressing / undressing, and if so, what aspects is this with? Is it to change your clothes, instructions on how to dress or undress or to ensure you wear weather appropriate clothing? Do you feel anxious about getting dressed / undressed, if so why is this? Do you need prompting to start activity?Do you use any adapted clothing due to difficulties with buttons, zips, shoes etc. Do you need physical assistance to dress and undress? If so, what aspects can you manage independently and what do you need help with? |

Question 9 – Communicating

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| This activity considers a claimant’s ability to communicate verbally with regard to expressive (conveying) communication and receptive (receiving and understanding) communication. **Notes:** This activity considers the ability to convey and understand verbal information with other people in one’s native language. Communication support means support from another person trained or experienced in communicating with people with specific communication needs (for example, a sign language interpreter) or someone directly experienced in communicating with the claimant themselves (for example, a family member). Basic verbal information is information conveyed in a simple sentence. Complex verbal information is information conveyed in either more than one sentence or one complicated sentence. Verbal information can include information that is interpreted from verbal into non-verbal form or vice-versa – for example, speech interpreted through sign language. |
| A | Can express and understand verbal information unaided. | 0 |
| B | Needs to use an aid or appliance to be able to speak or hear.For example: may apply to claimants who require a hearing aid or an electrolarynx.  | 2 |
| C |  Needs communication support to be able to express or understand complex verbal information.For example: may apply to claimants who require a sign language interpreter.  | 4 |
| D | Needs communication support to be able to express or understand basic verbal information.For example: may apply to claimants who require a sign language interpreter.  | 8 |
| E | Cannot express or understand verbal information at all even with communication support. | 12 |
| Do you struggle with communication when speaking to people? Is this with people who are known, not known or both, what is it that causes you this difficulty? Do you struggle with slurred speech, word retrieval, processing getting words out, volume, clarity? Do you struggle to understand a conversation if the sentences are too long and require information breaking down into simple sentences?Do you find yourself confused by what people are saying?Do you avoid conversations because of worry that you might not understand someone, or they may not understand you?Do you struggle to concentrate for any prolonged period of time? Do you struggle with short memory and forgetting what was being said in a sentence? Do you find complex conversations difficult?Have you stopped answering the phone?Do you rely on another person for direction and sometimes to communicate on your behalf? |

Question 10 – Reading

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| This activity considers a claimant’s ability to read and understand signs, symbols and words. **Notes:** This activity considers the capability to read and understand written or printed information in the person’s native language. Basic information is signs, symbols or dates. Complex information is more than one sentence of written or printed standard size text. To be considered able to read, claimants must be able to see the information. For the purpose of this activity, accessing information via Braille is not considered as reading. |
| A  | Can read and understand basic and complex written information either unaided or using spectacles or contact lenses.  | 0 |
| B | Needs to use an aid or appliance, other than spectacles or contact lenses, to be able to read or understand either basic or complex written information. For example: may apply to claimants who require low vision aids.  | 2 |
| C | Needs prompting to be able to read or understand complex written information. For example: may apply to claimants who require another person to explain information to them.  | 2 |
| D | Needs prompting to be able to read or understand basic written information. For example: may apply to claimants who require another person to explain information to them. | 4 |
| E | Cannot read or understand signs, symbols or words at all. For example: may apply to claimants who require another person to read everything for them.  | 8 |
| Do you have difficulty understanding information what needs reading or any concentration?Do you have to ask others to complete complex arrangements? If so, can you provide specific examples of what you can manage and what you cannot? \*PIP definition of a complex sentence is anything more than one sentence and not complex language / text. Simple is understanding signs, symbol and words so it would be good to know what they can and cannot manage.Have you stopped opening letters, if so why is this? Are you able to complete forms? |

Question 11 – Mixing with other people

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| This activity considers a claimant’s ability to engage with other people which means to interact face to face in a contextually and socially appropriate manner, understand body language and establish relationships. **Notes:** An inability to engage socially must be due to the impact of impairment and not simply a matter of preference by the claimant. Social support means support from a person trained or experienced in assisting people to engage in social situations, or someone directly experienced in supporting the claimant themselves (for example a family member), who can compensate for limited ability to understand and respond to body language, other social cues and assist social integration. ‘Psychological distress’ means distress related to an enduring mental health condition or an intellectual or cognitive impairment. |
| A | Can engage with other people unaided. | 0 |
| B | Needs prompting to be able to engage with other people.For example: may apply to people who need encouragement to interact with others by the presence of a third party.  | 2 |
| C | Needs social support to be able to engage with other people.For example: may apply to people who are only able to interact with others by the presence of a third party.  | 4 |
| D | Cannot engage with other people due to such engagement causing either –1. overwhelming psychological distress to the claimant; or
2. the claimant to exhibit behaviour which would result in a substantial risk of harm to the claimant or another person.
 | 8 |
| Do you feel anxious when communicating with other people (people you know, don’t know or both)?How does that anxiety manifest? What symptoms do you experience and can you overcome these?Are there occasions when you are withdrawing due to not knowing what to say or how to start a conversation?Are you considered vulnerable? Would you understand body language of others? Do you need somebody with you when engaging face to face with other people for support or do you need a third party presence with you at all times? If so, why? |

Question 12 – Making decisions about money

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| This activity considers the ability of a claimant to make every day budgeting decisions. **Notes:** Complex budgeting decisions are those that are involved in calculating household and personal budgets, managing and paying bills and planning future purchases. Simple budgeting decisions are those that are involved in activities such as calculating the cost of goods and change required following purchases. Assistance in this activity can include carrying out elements, although not all, of the decision making process for the individual. |
| A | Can manage complex budgeting decisions unaided. | 0 |
| B | Needs prompting or assistance to be able to make complex budgeting decisions.For example: may apply to claimants who need to be encouraged or reminded to make complex budgeting decisions.  | 2 |
| C | Needs prompting or assistance to be able to make simple budgeting decisions.For example: may apply to claimants who need to be encouraged or reminded to make simple financial decisions.  | 4 |
| D | Cannot make any budgeting decisions at all. | 6 |
| Do you monitor your own finances? Do you pay your bills? Do you know what money is left for certain items? Do you understand payments and budgets? Do you think about the priority of payments? Do you check finances in place before making budgeting decisions? If you have any problems with any of this, why is this? If you were in a shop and required to hand over money for goods, would you understand what to hand over and what to expect back? If not, why is this? |

Mobility activities

Question 13 – Going out

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| This activity considers a claimant’s ability to work out and follow a route. **Notes:** A person should only be considered able to follow an unfamiliar journey if they are capable of using public transport (bus or train). Orientation aids are specialist aids designed to assist disabled people in following a route. Safety and reliability are particularly important considerations here if there would be a substantial risk to the claimant or others if they went out alone. ‘Psychological distress’ means distress related to an enduring mental health condition or an intellectual or cognitive impairment. |
| A | Can plan and follow the route of a journey unaided. | 0 |
| B | Needs prompting to be able to undertake any journey to avoid overwhelming psychological distress to the claimant.For example: may apply to claimants who are only able to leave the home when accompanied by another person.  | 4 |
| C | Cannot plan the route of a journey. | 8 |
| D | Cannot follow the route of an unfamiliar journey without another person, assistance dog, or orientation aid. | 10 |
| E | Cannot undertake any journey because it would cause overwhelming psychological distress to the claimant.For example: may apply to claimants who are unable to leave the home at all. | 10 |
| F | Cannot follow the route of a familiar journey without another person, an assistance dog or an orientation aid. | 12 |
| Can you plan a route to a familiar and unfamiliar journey? If so, why is this? Can you follow a route if someone else has planned if for you and what stops you from being able to plan this for yourself?If deviations occur on a familiar journey can you cope with this and use an alternative route? Do changes to a journey result in increased anxiety or / and disorientation How does that anxiety manifest? What symptoms do you experience and how does that make you feel?Do you carry an ID card explaining Huntington’s whilst out should any situations occur? Are you safe to be out alone? If no, why is this? Are you aware of dangers or risks from other people and vehicles? Are you able to identify safety measures?Are you considered vulnerable when outdoors? |

Question 14 – Moving around

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| This activity considers a claimant’s physical ability to move around without severe discomfort such as breathlessness, pain or fatigue. This includes the ability to stand and then move up to 20 metres, up to 50 metres, up to 200 metres and over 200 metres. **Notes:** This activity should be judged in relation to a type of surface normally expected out of doors such as pavements and roads on the flat and includes the consideration of kerbs. 20 metres is considered to be the distance that a claimant is required to be able to walk in order to achieve a basic level of independence in the home such as the ability to move between rooms. 50 metres is considered to be the distance that a claimant is required to be able to walk in order to achieve a basic level of independence such as the ability to get from a car park to the supermarket. 50 to 200 metres is considered to be the distance that a claimant is required to be able to walk in order to achieve a higher level of independence such as the ability to get around a small supermarket. Standing means to stand upright with at least one biological foot on the ground with or without suitable aids and appliances (note – a prosthesis is considered an appliance so a claimant with a unilateral prosthetic leg may be able to stand whereas a bilateral lower limb amputee would be unable to stand under this definition) Aids or appliances that a person uses to support their physical mobility may include walking sticks, crutches and prostheses. As with all activities, the person must be able to perform the activity safely and in a timely fashion - however, for this activity this only refers to the actual act of moving. For example, danger awareness is considered as part of activity 11.  |
| A | Can stand and then move more than 200 metres, either aided or unaided. | 0 |
| B | Can stand and then move more than 50 metres but no more than 200 metres, either aided or unaided. | 4 |
| C | Can stand and then move unaided more than 20 metres but no more than 50 metres. | 8 |
| D | Can stand and then move using an aid or appliance more than 20 metres but no more than 50 metres, | 10 |
| E | Can stand and then move more than 1 metre but no more than 20 metres, either aided or unaided | 12 |
| F | Cannot, either aided or unaided, - 1. Stand: or
2. Move more than 1 metre
 | 12 |
| Do you use a wheelchair or walking aid? If so, are they prescribed or did you self-purchase these?Do you fall over? If so, how often does this happen?On a typical day, how far are you able to walk in metres before you need to stop for a rest? How long do you take a break for and why do you need to have a break? Once you have had a break, how far are you then able to walk?What pace do you walk and do you have any difficulties with balance and gait? Once you have completed the above distance, are you able to repeat this again later in the day? If not, why is this and how far could you manage to walk? |

Personal Independence Payment (PIP) daily living component points scores

To get an award of the daily living component, you need to score:

8 points for the standard rate

12 points for the enhanced rate