

Disability and Carers Benefits Expert Advisory Group: Assessments Workstream

To: Shirley-Anne Somerville, Cabinet Secretary for Social Security and Older People
By e-mail

17th December

Dear Ms Somerville,

Sources of evidence

Background

At the meeting of the Disability and Carers Benefit Expert Advisory Group (DACBEAG) on 30th August, you asked for advice on sources of evidence by the end of this calendar year. The Group's Assessments Workstream was established to carry out in depth investigation into disability assessments and includes non-members with relevant expertise to ensure advice is thorough and well-informed. One early consideration was to re-frame terminology in a way that is reflective of the core values, principles and commitments. For that reason we advise that 'sources of evidence' be referred to as 'supporting information'.

We welcome the commitment by the Scottish Government to ensure safe and secure delivery of the newly-devolved benefits, and to improve the claiming process for all recipients, including reducing face-to-face assessments. Ensuring appropriate gathering of supporting information is likely to be a key factor in bringing that about. We understand that our advice may incur risks, implications and challenges for the Scottish Government. These will be made explicit in the current advice note and we aim, where possible, to signpost a proposed solution.

Our advice is based on the best information currently available to us, but makes some assumption about how the process of determining an entitlement to disability assistance will work. Should our assumptions prove incorrect, or new information become available, our advice may change.

We have focused on disability assistance for individuals of working age. We understand the assessment process for disability assistance for children and those over pension age will, in most cases, be paper-based.

We are grateful for the information that has been provided by officials that has helped shape our advice. This includes:

- Information on the PIP 'Discovery' process and how this work feeds into the proposed new system which promotes a client-led service.

In order to consider the best sources of supporting information that are available we felt it was important to look at the whole assessment process. We found the above document very useful in informing our discussions.

We have also considered the findings of the two independent reviews of PIP conducted by Paul Gray.

As you know, the current PIP system is designed in such a way that most claimants undertake face-to-face assessments. However there has been a policy commitment by the Scottish Government to reduce the number of face-to-face assessments. The Act is drafted in such a way to ensure that individuals are required to undergo a face-to-face assessment if it is the only practicable way to obtain the information needed. You have asked us to advise on how to implement the new system, and through numerous discussions, we acknowledge the challenge to design a system that provides robust decisions about entitlement to the PIP criteria that meets these requirements.

This advice note builds on our previous recommendation to use the individual's account as the starting point for deciding eligibility.

“There is a need for an empathetic and consistent approach which builds upwards from the individual's account, proactively seeking out further evidence where that is appropriate.

Key recommendation: Taking into consideration all the above, we are confident that in most cases an individual's account of the impact of their condition or impairment on their functionality should be sufficient to obtain an accurate and robust decision.”

Before outlining our additional recommendations, we feel it is essential to raise the following:

We have noted your concern that results of consultation activity suggest that there is not support for an approach based solely on the individual's account of the impact of their condition or impairment. To that we would say that trust in the social security system, both by those who use it and the general public, is low. There is disparity in the perception of the benefits system; individuals with experience of the system may believe they have been treated unfairly, whilst there is public perception that the system is open to widespread fraud despite official figures showing fraud is rare.

We also note your concerns regarding the difficulties decision-makers may have in determining whether an individual's account requires supporting evidence. We nonetheless believe there is scope to create a system that is fair whilst minimising the risk of incorrect awards

Recommendations

We hope our recommendations will be useful in aiding the design of our proposed system. There should be ongoing testing and learning to ensure it evolves in line with the core principles, values and commitments.

Our recommendations are also based on the following expectations of the new system:

- The application form will be designed well, to better elicit functional impact of an individual
- There will be support and advocacy for individuals to report their impact well
- Suitably qualified assessors will be trained in functional impact, be aligned with the core values, principles and commitments, and have robust Agency training and guidance.
- The operational ethos of the assessments process will presume credibility of the individual's account as a starting principle and build upwards in a way that supports, not questions their information.

Recommendation 1: Information on diagnosis should be collected when the individual completes the self-assessment questionnaire.

Recommendation 2: A full account of a person's situation should be collected early during the process through:

- the design of the self-assessment form;
- provision of support and advocacy services;
- prompting the individual to include relevant evidence they already have; and
- gathering information from carers and family members.

Recommendation 3: An additional step should be included in the 'To-be decisions user journey' flowchart (our suggested addition is provided in Annex A). After the individual completes the self-assessment form then, unless a decision can be reached immediately on the basis of the information provided, the case is reviewed by a decision maker who determines:

- what, if any, further information is needed to get a complete account of the individual's situation; and
- what, if any, supporting information is needed to corroborate the information provided by the individual.

Recommendation 4: Corroboration of the individual's account, beyond confirmation of an individual's diagnosis, should not be required in every case in order to reach a decision about entitlement to disability assistance.

Recommendation 5: If any additional information or supporting information is required the Agency should have an obligation to collect such information (the individual may also choose to do so).

Recommendation 6: Clear guidance should be issued as to when face-to-face assessments should be undertaken and the purpose of these.

Recommendation 1

We recommend that information on diagnosis should be collected when the individual completes the self-assessment questionnaire.

We have reviewed the 'To-be application user journey' (with our suggested addition in Annex A) that has been developed during the disability benefits discovery phase. There is no specific step that gathers details of a claimant's diagnosis.

Although we understand that disability assistance will be based on function, in those cases where there is a clear diagnosis this can be useful information that can contribute towards making a robust decision.

In most cases the decision maker will expect that supporting information is provided that confirms an individual's diagnosis. Examples of such supporting information may include, but are not limited to:

- Prescription history
- Certificate of visual impairment
- Summary Care Record – automated short summary of the individual's GP medical record¹ that can be requested in writing.
- Existing information from DWP

In some cases a medical report or an individual's full medical records may be used to confirm a diagnosis.

Recommendation 2

A full account of a person's situation should be collected early during the process through:

- **the design of the self-assessment form;**
- **provision of support and advocacy services; and**
- **prompting the individual to include supporting information they already have; and**
- **gathering information from carers and family members.**

A survey of HMCTS First-tier Tribunal judges found that an individual's own account of their situation was the determining factor when making their decision in a majority of cases.

A system that collects a full account of the individual's circumstances and difficulties early in the process is best placed to make an accurate decision about entitlement.

The assessment form should be designed to ensure it collects a full account of the person's circumstances in a way that is accessible and not unnecessarily long and onerous. It should include clear definitions of key words that the individual needs to understand in order to provide the correct information. This may include defining terms such as "regularly" or "reliably".

¹ We recognise that the summary may not be sufficiently detailed, accurate or relevant to the reported functional impact. In such cases where additional medical information needs to be sought, the Agency has an obligation to acquire such information. This is to mitigate the heavy administrative burden that would befall healthcare services if a letter from the individual's GP/medical professional were automatically required and/or sought by the individual via appointment in the first instance.

The form should include a prompt to include relevant supporting information along with the self-assessment form. This could include care plans or doctors' letters, if held by the individual.

Assessors must take into account reasons behind why there may be little supporting information. In many cases a claim for disability benefit is made before an individual has been assessed for any other support. There will also be cases where individuals are not aware of support available to them or are in localities with pressures on local support services.

Our workshop on sources of supporting information confirmed the findings of Paul Gray's second review into PIP, that carers and family members are often well-placed to provide information on someone's care and mobility needs. The process of collecting information from carers and family members should be made as easy as possible. This information should be collected early in the assessment process. The Agency should consider how best to collect this supporting information, which could be accepted in writing, or audio or visual recordings, or by completing care diaries.

The information gathering process should support the individual. We advise robust signposting to advocacy and support services to help applicants provide a thorough account of their condition and impact, including people with additional accessibility needs or people who need help articulating their account.

Recommendation 3

We have reviewed the 'To-be decisions user journey' flowchart that has been developed during the disability benefits discovery phase.

We recommend that another step should be included in the 'To-be decisions user journey' flowchart (with our suggested addition in Annex A). After the individual completes the self-assessment form, unless a decision can be made immediately, the case should be reviewed by a decision maker who determines:

- **what, if any, further information is needed to get a complete account of the individual's situation; and**
- **what, if any, additional information is needed to corroborate the information provided by the individual.**

This is intended to avoid an unnecessarily onerous process. We foresee a risk in the individual identifying potential sources of supporting information for the Agency without knowing what, if any, supporting information is required. This may result in a delayed process while the person gathers unnecessary supporting information. We would hope that this new stage would act as a filter to expedite non-complex cases.

A decision about what, if any, further supporting information is required following an initial application should be made in line with the principles outlined in our advice note of 11 July 2018 (included in Annex B).

Recommendation 4

Corroboration of the individual's account, beyond an individual's diagnosis, should not be required in every case in order to reach a decision about entitlement to disability assistance.

In many cases where the assessor can determine that the diagnosis is consistent with the individual's self-assessment of their functionality, no further supporting information should be required in order to make a robust decision. Testing and learning within the Agency will determine how effective this approach is, and when supporting information is required in order to make a robust decision.

The additional costs, to both the Agency, third parties and the individual, of gathering supporting information should be weighed up against the benefits such information provides when determining whether supporting information is required.

Guidance will be crucial in ensuring the assessment process works for claimants and staff. Guidance should aim to improve consistency across the assessment process. We have included our expectations in the Suitably Qualified Assessors² note though stress once again the importance of the Agency implementing an iterative process of testing and learning from actuality.

Recommendation 5

If any additional information or supporting information is required, the Agency should have an obligation to collect such information (the individual may also choose to do so).

Paul Gray's report states that it is important that there is clarity around who is responsible for gathering supporting information. We appreciate the intention that individuals are given a choice as to how supporting information is gathered. However we would recommend that the Agency collect any information that needs to be sought from other agencies/healthcare services. This is to mitigate the cost faced by individuals requesting certain types of information and to reduce the administrative burden on health services should individuals arrange appointments solely to request information. Should the individual nonetheless prefer to collect this information, they should be advised to do so in writing.

If the individual does not want the Agency to collect information and does not themselves proceed to collect it within a reasonable timescale, the Agency will make a decision on the basis of the information it has.

Recommendation 6

Clear guidance should be issued as to when face-to-face assessments should be undertaken and the purpose of these.

² Submitted 17th December with the current advice note.

We considered when a face-to-face assessment may be required and concluded that it would be appropriate in the following circumstances.

1. Where there are inconsistencies in the information provided. This could be where the functionality described in the account is not consistent with the diagnosis or condition, or if information provided is improbable or contradictory.
2. To fill a significant gap in the individual's account of their condition and impact, e.g. in cases where there is a diagnosis but little information about the impact and there is no other way to get information about functional impact.
3. If the individual or representative requests one. We agree that this form of engagement could be beneficial for the individual who is more confident detailing their account in person. We believe this should be an option in claims to AA and DLA as well as PIP.
4. The Agency may identify other circumstances where a face-to-face assessment is required for the purposes of robust decision-making and auditing. These could include claims that fall into a category that means there is a high risk that an incorrect award is made without a face-to-face assessment or for the purposes of auditing the assessment process.

Overview of supporting information

We have developed a matrix showing our assessment of the benefits and risks of different types of supporting information. We caveat the below matrix with a caution that it is not comprehensive and in particular has been informed by organisations who attended the workshop on sources of supporting information. We acknowledge that other stakeholders may have different perspectives and useful additions to make.

We also wish to reiterate the expectation that this will be a functional assessment, requiring supporting information of functional impact. This will not come from medical input or medicalisation of the workforce involved in these assessments. The purpose and limit of medical input is to confirm diagnosis where needed. Our advice makes this distinction clear.

Type of Supporting Information	Benefits	Risk	Comments
Person's own account.	Consistently shown to be the most accurate source of information.	Perception that it may not be sufficient.	

Accounts from family members and carers	An account of impact by people closest to the individual.	May not be considered sufficiently independent.	A written report, phone call, video or audio recording may be suitable ways of collecting such information.
Social care packages	Evidence of needs and functional impact.	Strict eligibility criteria mean people with high need may still not qualify for social care. Absence of a social care package should not be taken as evidence of lack of need.	
Blue Badge applications	Evidence individual has undergone rigorous process of assessment		
Access to Work packages	Evidence individual has undergone rigorous process of assessment	This is an under-used fund. Absence of an Access to Work package should not be taken as evidence of lack of need	The Agency could usefully promote the existence of Access to Work
Third sector and voluntary organisations	Often work closely with a person and have a good understanding of the impact of a condition	May lack time to provide information. Some may have concerns that doing so will jeopardise relationship. Organisations may perceive providing such information as a risk. They would also need to be funded accordingly.	Written report or phone call
Specialist nurses, OTs, physiotherapists	Good understanding of impact of particular conditions.	May not have detailed knowledge of individual case.	Written report or phone call
Current repeat prescription lists	Current data	May not be able to make assumptions about the existence of a condition from the prescription of a particular medication.	
Social workers, key workers or	Social workers and key workers may have good	May lack time to provide information. Care co-ordinators	Written report or phone call

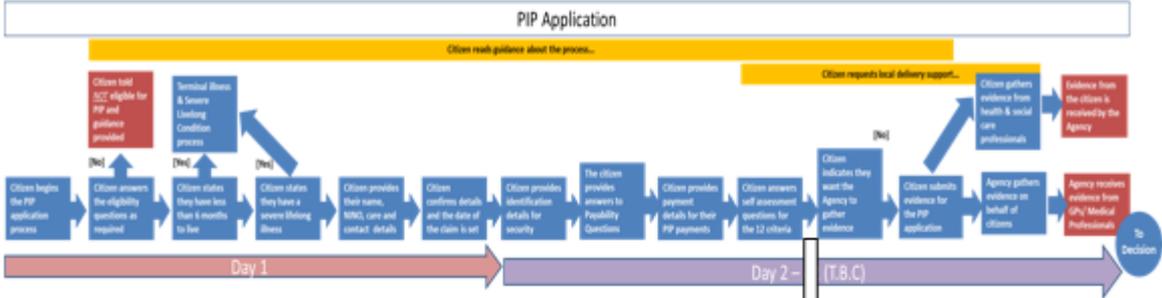
care co-ordinators	understanding of whole context of person's situation.	may have little contact with individuals.	
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We would be pleased to discuss this note with you and your officials and look forward to hearing your response.

With best wishes,

Tressa Burke
Workstream Co-chair

PIP 'to be' flowchart (with our suggestion addition below)



Recommendation 3:
 After the individual completes the self-assessment form the case is reviewed by an SQA (paper-based assessment) who determines:

- What further information is needed to get a complete account of the individual's situation;
- What, if any, additional supporting information is needed to corroborate the information provided by the individual.

Case is reviewed by an SQA (paper-based)

Tressa Burke: Co-Chair Assessment Workstream Disability and Carers Benefits Expert Advisory Group

To: Shirley-Anne Somerville, Cabinet Secretary for Social Security and Older People
By e-mail
11 July 2018

Dear Shirley-Anne,

I am writing to update you on the Assessment Workstream's most recent discussions, reflections and considerations in relation to four areas: automatic entitlement, best sources of evidence, award durations and the delivery body for assessments.

1 Automatic Entitlement

Workstream members recognise and welcome the fact that the values of fairness, justice and dignity are driving the consideration of auto-entitlement. Workstream members considered a number of challenges with the concept of auto-entitlement and make the following recommendation. The key points underpinning this recommendation are summarised on the next page.

At this stage we would like to offer interim guidance pending further information regarding the payments to be introduced. We would like to review this guidance when further information about the regulations and guidance is available.

We note, however, that Part 1 of the Act is clear on the principles that need to underpin assessment decisions and outcomes including a commitment to respect the dignity of individuals.

Recommendation on automatic entitlement

Key recommendation: Under a new system of disability assistance, with the exception of terminal conditions, we recommend a presumption against extending automatic entitlement.

At present there is no auto-entitlement for Personal Independence Payment and auto-entitlement only in a very few limited circumstance for Disability Living Allowance and Attendance Allowance (please refer to Annex B). The workstream believes that the system should continue as it is at present with a view to reviewing it after the safe and secure transition.

The following points were raised by the workstream in reaching the recommendation above:

- A number of difficulties with the overall concept of auto-entitlement were identified, including:
 - The narrow range of conditions currently being considered, with no mental health conditions being included;
 - The current list being considered only includes medical conditions – there is no consideration of other non-condition specific circumstances that could lead to automatic entitlement to benefits, e.g. being under a Compulsory Treatment Order or other Mental Health Act related order.
 - However, no attempts to re-define a list of conditions are likely to produce a fairer system, for the reasons outlined below;
 - There are difficulties associated with making decisions purely on a diagnostic label;
 - A system of auto-entitlement allows no recognition of the effects of co-morbidity on functionality – it is based on presence or absence of single conditions. This is an over simplification and does not reflect the demographics of claimants.
 - A system of auto-entitlement allows no recognition that conditions may affect individuals' functionality in different ways;
 - Most medical conditions vary in their impact on the individual's life and also vary in that impact over time;
 - Given the system will be based on functionality, making *some* awards condition specific is unfair and inconsistent;
 - This creates a two-tier system and inequality of outcomes;
 - The principle that *any* person with 'x' condition has auto-entitlement leads to assumptions about the capability and potential of people with listed conditions, which can spread into other areas such as employment and education. We would want to avoid a deficit based system rooted in ill health conditions or disabilities per se rather than their functional impacts on individuals.

- We recognise that auto-entitlement eliminates the need for face-to-face assessments for some individuals. However even if the number of conditions covered by auto-entitlement is increased this will not have a significant impact on the number of face-to-face assessments that will need to be undertaken. A significant reduction in face-to-face assessment can be achieved with an improved system of assessment and evidence gathering. Reducing face-to-face assessments will be a major consideration when we undertake further work looking at award duration and the best sources of evidence (see below). However, we should be mindful that some people may wish to have a face-to-face assessment for access reasons. This should be respected and accommodated, even if the overall goal is to reduce them.

- We do not yet know what the assessment process in the new system will look like. However, early indications, through helpful conversations we have had with officials, show there is every intention it will be based on a light touch and that the most appropriate sources of evidence will be sought. Whilst we appreciate this endeavour, it is wise to anticipate problems in the new system and to recognise that scrutiny, feedback and user experience must be present from the outset if robust and fair decisions are to be made with least inconvenience to claimants.
- Under such a system, entitlement to benefits should be quickly recognised during the assessment process, and no separate parallel auto-entitlement system would therefore be necessary. It is important that decision makers consider the range of functional impacts faced as a result of a condition rather than the condition itself. We welcome the potential opportunity to bring enlightened perspectives to evidence, assessments and decision making.
- We are aware that there is pressure to extend auto-entitlement to protect the interests of some claimants. This is in the context of the current system that is perceived as broken and hostile. However, we concluded that auto-entitlement is only needed in a system that is not functioning properly. There is now an opportunity to get the system right and your officials have demonstrated how they are looking at appropriate evidence gathering. This will be the key to a future system with no condition specific auto-entitlement.
- Our recommendation is that auto-entitlement is not extended in Disability Living Allowance, Attendance Allowance or Personal Independence Payment when these are transferred. Further, any new form of disability assistance developed in future should not be based on auto-entitlement, subject to the new system delivering on principles of dignity and respect, and values of fairness.

2 Best sources of evidence

Workstream members welcome a new system which will be based on a light touch form of assessment with the most appropriate source of evidence being the applicant. We are encouraged that officials are working to promote the principle of reducing the number of face-to-face assessments.

We have sought evidence from a range of stakeholders and we are mindful that while there is broad support for this principle, some people may prefer, in the first instance, to have a face-to-face assessment to explain their claim in person. This includes people who may not be confident about expressing themselves in writing or who would prefer a home visit. We think leaving the

door open to face to face meetings for people who would prefer them would enhance the claiming process.

To consider what sources of evidence should be used in order to determine someone's entitlement to disability assistance we decided to establish a set of principles to guide our discussion. The following principles have been considered by a wide range of stakeholders (please refer to Annex A) and there was a broad consensus that these should be applied.

The principles we established are:

- 1 The agency should take a proactive approach to establish, determine and assess an individual's impairment and its impact on functional ability. This should include deciding:
 - a. What facts need to be established;
 - b. What information is required to establish those facts;
 - c. What gaps there are in the individual's evidence and how best to plug those gaps including, where appropriate and with the individual's consent, relevant information from a third party; and
 - d. Identifying whether there are any inconsistencies in the evidence.
- 2 The starting point should be a clear and full account of the individual's situation.
- 3 The agency should use the least, most relevant and specific evidence required to get an accurate and robust decision.
- 4 The individual's own account should be the most important source of evidence.
- 5 Any further evidence needed should be identified on a case by case basis.
- 6 Where it is needed, the agency should gather easily available relevant and specific evidence.

Recommendation on evidence sources

There is a need for an empathetic and consistent approach which builds upwards from the individual's account, proactively seeking out further evidence where that is appropriate.

Key recommendation: Taking into consideration all the above, we are confident that in most cases an individual's account of the impact of their condition or impairment on their functionality should be sufficient to obtain an accurate and robust decision.

In order to test these principles further we propose to explore their potential application with officials and to produce an additional advice note in due course. In particular we would like to explore the use of a wide range of

sources that could provide relevant information, including information from, or provided by:

- family members and carers
- social care packages
- Blue Badge applications
- Access to Work packages
- ILF packages or award
- third sector and voluntary organisations
- specialist nurses, OTs, physiotherapists
- health and social care IT systems.

We recognise that gathering relevant information from these and other sources presents challenges and opportunities including data sharing between agencies. Some work has already been carried out and we would like to further explore this with your officials.

The workstream also recognises the merits of the 'test and learn' principle: given the significance of getting the assessment system as good as it can be, we believe there is a strong case for trying out different approaches to information gathering to gauge effects on reaching the right decision first time around.

3 Award Duration

The workstream has held early discussions on award duration which we intend to revisit at our next meeting. Following this we will provide you with full advice.

Workstream members reflected that appropriate consideration of duration of awards flows naturally from a system, as described above, that is working well and seeking the most appropriate sources of evidence.

4 Delivery Body for Assessments (Options Appraisal)

The workstream were grateful to receive a copy of the options appraisal on the delivery body for assessments in February. We discussed this at our February meeting and communicated our views to officials. We now take the opportunity to convey that view directly to you.

The workstream strongly agreed that agency delivery seemed the correct option. The principle of separation from Scottish Government is important, but appropriate distance can be achieved through robust reporting arrangements. There are compelling practical and cost advantages to agency delivery, plus there is a reasonable public expectation that all functions happen under one roof. We agreed that the agency should be responsible for both paper-based and face-to-face assessments.

We also considered the issue of data protection. Information about individuals will be coming in to the agency anyway; if another body was involved to which this information was then being passed, this would complicate and build in

risks. There are also advantages in having one system and body for audit, complaints and standards.

If you or officials have any questions about these points, please get in touch. We look forward to your response.

With best wishes,

Tressa Burke
Assessment Workstream Co-Chair

Annex A - Contributors

Organisations represented at the workshop

Child Poverty Action Group; Glasgow Disability Alliance; Joseph Rowntree Foundation; Scottish Commission for Learning Disability; Scottish Government; Scottish Independent Advocacy Alliance; Social Security Advisory Committee; Disability Agenda Scotland; Citizens Advice Scotland; Carers Scotland; Castle Rock Edinvar Housing Association; NHS Lanarkshire; Independent Living Fund; Scottish Association for Mental Health; BMA Scotland; Glasgow City Health and Social Care Partnership.

Membership of the Disability and Carers Benefits Expert Advisory Group Workstream on Assessments

Chairs: Tressa Burke and Alan McDevitt - Disability and Carers Benefits Expert Advisory Group

Jim McCormick – Disability and Carers Benefits Expert Advisory Group

Chris Creegan - Disability and Carers Benefits Expert Advisory Group

Shaben Begum - Disability and Carers Benefits Expert Advisory Group

Ewan MacDonald - Disability and Carers Benefits Expert Advisory Group

Ed Pybus – Child Poverty Action Group

Nicolas Watson – University of Glasgow

Carolyn Lochhead – Scottish Association for Mental Health

Annex B – Current automatic entitlement

Automatic Entitlement (AE)

There is currently a limited degree of AE in legacy DLA and AA benefits. It extends the range of people who are entitled to these benefits, including for example, blind children, children with no feet, and children and pensioners undergoing some forms of dialysis who may otherwise not be entitled. We are not saying that this form of AE should be removed after the transition to the Scottish system.

We are not including entitlement based on benefit ‘passporting’ or other forms of eligibility to benefits. For example, a paper-based assessment could be made for a claimant who has an ILF award. The information from the ILF assessment may be used to decide, for example, their PIP entitlement. The information supplied for the ILF application may be well sufficient evidence to make an accurate decision but getting an ILF award would not automatically give entitlement to DLA, PIP or AA. This issue was discussed at the assessment workstream’s recent workshop on sources of evidence and we aim to cover this in our next assessment note.