Justification for Non-Substantive Changes for Form SSA-454-BK and i454 Continuing Disability Review Report 20 CFR 404.1589 & 416.989 OMB No. 0960-0072

<u>Justification for Non-Substantive Changes to the Collection</u>

On 1/17/23, OMB approved the Information Collection Request for 0960-0072 with the following Terms of Clearance:

No later than May 31, 2023, the agency will conduct a second non-substantive change to complete further revisions to this ICR as agreed-upon by the agency and OMB during this review. This revision will include removing the Activities of Daily Living Questions "A" ("Typical day") and "B" ("Hobbies and Interests") as well as minor changes to instructions and verbiage as already agreed-upon between the agency and OMB. The agency may also make additional changes to verbiage and instructions contingent on agreement related to outstanding items of discussion.

As per these Terms of Clearance, we are making the following revisions to collection instruments for the Continuing Disability Review (CDR) Report:

• <u>Change #1</u>: We moved the "Your Medical Record" section above the "What You Need to Complete this Report" section.

Justification #1: In moving the "Your Medical Record" section prior to the section regarding what the respondent needs to complete the CDR Report, we help to clarify that the respondent will not need to obtain their medical records to complete the report. We believe this will satisfy several public comments we received on this topic, including a suggestion that SSA add a list of "What You Need to Complete This Form" at the beginning of the instructions to provide a way to limit the physical and mental requirements of the respondent to track down those items or make it easier for the respondent to ask for help from others to complete the form. In addition, the Consortium for Citizens with Disabilities (CCD) mentioned in their public comments that CDRs are costly to beneficiaries, who often need to pay for medical records or appointments with doctors and other providers to fill out the forms (and any transportation required to get to and from these appointments). In moving this section, we ensure that prior to reviewing the "What You Need to Complete this Report" section, respondents will know that there is no need to request or pay for medical records and that SSA will obtain medical records for the medical CDR. This revision reduces the burden and stress that one may experience thinking that there is a need to gather medical records for the medical review. The individual does not need to obtain any medical records or contact their medical provider for assistance to complete the form. With the respondent's permission, SSA will request their medical records.

• <u>Change #2</u>: In the "WHAT YOU NEED TO COMPLETE THIS REPORT" section, we are revising bullet #4 to:

Name of organization who we can contact that would have medical information about your condition(s) **in the last 12 months**. (Such as social services agencies, welfare agencies, case workers, attorneys, prisons, workers' compensation and insurance companies who have paid you disability benefits.)

<u>Justification #2</u>: Multiple commenters, including the CCD, suggested the form needs to be reformatted for fluency of the questions being asked throughout the form. During the Usability paper Testing, at least one advocate suggested "case manager" be added to the drop-down list of contacts, which was suggested in the prior round of testing as well.

SSA policy requires that we make sufficient attempts to contact individuals, including medical sources. We also provide accommodations to individuals who require additional help (for example, individuals who are homeless, children, and individuals with mental disorders).

Based on public comment and Usability Testing, we reviewed the current form identifying areas to simplify and streamline the form. Adding "case worker" to this question provides an additional source that may have information to assist in the respondent's medical review. This revision will assist the respondent by reducing the burden and stress of remembering information and providing all known sources to complete this form.

• Change #3: In Section 3, Page 4, question 3.D. we are adding the word "Remember" in the "Medical Information" section to the providing address field.
The sentence will read as follows: You may find this information on medical bills or the internet. If you don't have the full street address, give as much as you can remember. Example: "On Main St. next to the Courthouse."

Justification #3: In their comments, the CCD requested SSA either remove the request for specific medical information or add the modifier "(if known)" after all questions soliciting the name and dates seen of the healthcare professional that provided care. The CCD also stated they found that many claimants do not know the name of the medical provider who treated them, sometimes because providers serve them as a team, or the claimant cannot recall their name(s). In addition, the CCD reiterated that many claimants experience stress when they realize they cannot provide this information and, in some cases, may stop completing the form, or may spend a significant amount of time collecting this information. As the CCD pointed out that this level of detail is not required for medical records requests; they believe the burden caused to claimants outweighs its utility to SSA.

During the public comment period, some users also stated that they had a difficult time remembering the date of their last medical review. Based on public comments and Usability Testing in reference to the burden of gathering and remembering information, we revised this question by adding the clarifier "**remember**" to the question. This revision will assist the respondent by reducing the burden and stress of remembering information to complete this form.

• **Change #4:** In Section 3, Page 6, question 3.E. we are adding Facility/Organization or the Doctor's name to the Medical Test section.

The sentence will read as follows: Within the last 12 months, did any of the providers listed in 3.D. order any medical tests for you? (Include tests already performed and those scheduled in the future, and the healthcare provider, or facility, that scheduled them.)

In addition, we are also making the following revisions:

- We are revising the Table Header, second column as follows: NAME OF HEALTHCARE PROVIDER OR FACILITY
- We are also adding "if known" next to (list body part) for MRI/CT scan, and X-ray.
 - O Example from the Table, First column:
 - MRI/CT scan (list body part, if known)
 - X-ray (list body part, if known)

<u>Justification #4</u>: As mentioned above, in their comments, the CCD requested SSA either remove this requested information or add the modifier "(if known)" after all questions soliciting the name and dates seen of the healthcare professional that provided care. The CCD requested this change as they found that many claimants do not know the name of the medical provider who treated them, sometimes because providers serve them as a team, or the claimant cannot recall their name(s), and that requiring this information may cause stress on the claimants, cause them to stop completing the form, or to spend a significant amount of time collecting this information causing undue burden on the claimant. The CCD finds that this level of detail is not required for medical records requests; thus, they believe the burden caused to claimants outweighs its utility to SSA.

During the public comment period, some users stated that they had a difficult time remembering the date of their last medical review. Based on public comment and Usability Testing in reference to the burden of gathering and remembering information, we revised this question by adding the clarifiers "if known" and "Facility" to the question. This revision will assist the respondent by reducing the burden and stress of remembering information and providing all known medical sources to complete this form.

• **Change #5:** In Section 3, page 6, question 3.F., we are adding a note to the introductory sentence in the Medication section.

We will add the following sentence after the question mark in the first sentence in 3.F.: "Please put any side-effects you may have in Section 9 - Remarks"

O In addition, we will add "If known" in the Medication section table for the prescriber.

The heading of second column in table will read as follows: "IF PRESCRIBED, GIVE DOCTOR NAME (IF KNOWN)

Justification #5: As mentioned above, in their public comments, the CCD requested SSA either remove this requested information or add the modifier "(if known)" after all questions regarding names and dates of healthcare professionals who provide care to the claimant. The CCD requested this change as they found that many claimants do not know the name of the medical provider who treated them, sometimes because providers serve them as a team, or the claimant cannot recall their name(s), and that requiring this information may cause stress on the claimants, cause them to stop completing the form, or to spend a significant amount of time collecting this information causing undue burden on the claimant. The CCD finds that this level of detail is not required for medical records requests; thus, they believe the burden caused to claimants outweighs its utility to SSA. During the public comment period, we also found some claimants who stated that they had a difficult time remembering the date of their last medical review, which corroborated the CCD finding. Therefore, we are adding "if known" to the heading of the second column in the table.

In addition, based on the Usability Testing, the advocates who tested the updated form felt that documenting side effects is important since it is not normally found in medical records. Therefore, we are adding a request at the beginning of the section to include side effects of these medications in Section 9 (the Remarks section). We believe these revisions will assist the respondent by reducing the burden and stress of remembering information and also allowing them to include side effects of medication that affects their medical condition(s) which may help them better present more thorough information to SSA.

- **Change #6:** In Section 3, page 7, question 3.G., we are adding clarifying instructions to the Assistive Devices section on when to use "always/sometimes":
 - O We will add the following after the question mark in the opening sentence in 3.G.: Note: Even if you do not always use an assistive device at home, if you always use it when outside your home, please select "always."
 - **o** We will change the third column heading in Assistive Device table to: NAME OF HEALTHCARE PROVIDER, IF PRESCRIBED (IF KNOWN)

<u>Justification #6</u>: Multiple commenters, including the CCD, suggested SSA needs to include Plain Language on the form. They also stated that SSA should ensure the form is written in as clear and concise language as possible, and that SSA should analyze the form for literacy level. In response to this request, we are providing additional clarity of adding an example of frequency when using an assistive device.

Adding this information also assists the respondents in understanding why SSA is requesting the information in this section and how to respond to this question.

In addition, as mentioned above, the CCD requested SSA either remove this requested information or add the modifier "(if known)" after all questions regarding names and dates of healthcare professionals who provide care to the claimant. The CCD requested this change as they found that many claimants do not know the name of the medical provider who treated them, sometimes because providers serve them as a team, or the claimant cannot recall their name(s), and that requiring this information may cause stress on the claimants, cause them to stop completing the form, or to spend a significant amount of time collecting this information causing undue burden on the claimant. The CCD finds that this level of detail is not required for medical records requests; thus, they believe the burden caused to claimants outweighs its utility to SSA.

During the public comment period, some users stated that they had a difficult time remembering the date of their last medical review. Therefore, based on public comments and Usability Testing in reference to the burden of gathering and remembering information, we revised this question by adding the clarifier "if known" to the question.

- **Change #7:** In Section 5, page 8, question 5.B., we are adding "If date not known, use best estimate" in the Participating in a Program section.
 - O The wording will read as follows: (Select answer below. If date not known, use best estimate.)

<u>Justification #7</u>: Since the CCD requested in their public comments (mentioned above) that SSA either remove or add the modifier "(if known)" after all questions soliciting the name and dates seen of the healthcare professional that provided care, we are adding that here.

In addition, during the public comment period, some users stated that they had a difficult time remembering the date of their last medical review. Based on the public comments and Usability Testing results in reference to the burden of gathering and remembering information, we revised this question by adding the clarifier "if date not known, use best estimate." to the question. This revision will assist the respondent by reducing the burden and stress of remembering specific dates when completing this form.

- **Change #8:** In Section 6, page 8, question 6, we are adding "Case Worker" to the list of examples in the Other Medical Information section
 - O The second sentence will read as follows: Examples include places like social services agencies, welfare agencies, case workers, attorneys, prisons, workers' compensation, insurance companies who have paid you disability benefits.

- O We are removing the Date of First Contact (in last 12 months).
- O We are revising the Date of Last Contact (in last 12 months) to: Date of Last Contact (in last 12 months, if known)

Justification #8: We are making these changes because multiple commenters, including the CCD, suggested the form needs to be reformatted for fluency of the questions being asked throughout the form. In addition, during the Usability paper Testing, at least one advocate suggested we add "case manager" to the drop-down list of contacts, which was suggested in the prior round of testing as well. Also, as we mentioned previously, the CCD requested in their public comments that SSA either remove the requested information or add the modifier "(if known)" after all questions soliciting the name and dates seen of the healthcare professional that provided care, therefore, we are adding "if known" here. We are not removing this requested information, as SSA policy requires that we make sufficient attempts to contact individuals, including medical sources. We also provide accommodations to individuals who require additional help (for example, individuals who are homeless, children, and individuals with mental disorders). Even so, we believe these revisions will assist the respondent by reducing the burden and stress of remembering specific information and providing all known medical sources to complete this form.

- Change #9: In Section 7, page 9, question 7.A., we are adding the following sentence language after the first sentence under section heading: Please provide any information about your education, training, and literacy since your last disability decision. Information about Individualized Education Plans (IEPs) or other support services should be recorded in "SECTION 5 SUPPORT SERVICES.
 - O We are adding "If date not known, use best estimate" on the dates in the Education, Training and Literacy section.
 - O The date field will read: DATE(S) OF ATTENDANCE If date not known, use best estimate.
 - O The date field will also read: Date Completed (or scheduled to be completed) If date not known, use best estimate.

<u>Justification#9</u>: We are including the additional sentence because one advocate noted that the "'Type of services' choices list is not very comprehensive list, if we add Individualized Education Plan (IEP), it might include more tests. In an IEP, the type of support varies. They do testing for learning disability and other impairments." The advocate also noted that, "IEP program might not have individual coach or instructor." Further, the advocate stated that "IEP or accommodations at school might not be thought of as they are educational programs." The same advocate asked if this was duplicative of the prior screen – specifically of the training (because of the IEP).

In addition, during Usability Testing, several users found the main question confusing. We are including the "if known" statement here as well, as per the CCD request that we mentioned above, asking SSA to either remove this type of information or add the modifier "(if known)" to requests for this type of information. Therefore, we revised this question by adding the clarifier "**if date not known, use best estimate.**" to the question. We also provided a statement that any information involving an IEP should be recorded in Section 5 – Support Services. These revisions will assist the respondent by reducing the burden and stress of remembering specific dates and assure that the information in this section is not the same as the information already asked in Section 5. Adding this information also assists the respondents in understanding why SSA is requesting the information in this section and how to respond to this question.

• **Change #10:** In Section 7, page 9, question 7.B., we revised the date field to read: Date Completed (or scheduled to be completed) **If date not known, use best estimate.**

<u>Justification #10</u>: As mentioned above, we are making this revision based on both the CCD's public comments requesting this change, and Usability Testing in reference to the burden of gathering and remembering information. Therefore, we revised this question by adding the clarifier "if date not known, use best estimate." to the question. This revision will assist the respondent by reducing the burden and stress of remembering specific dates when completing this form.

• Change #11: In Section 8, page 10, we removed questions 8.A and 8.B, and we added the following sentence after the question mark at the end of the sentence in 8.C.: You should think about the difficulty you experience in performing these tasks *alone* and without assistance from other people or assistive devices. If other people or assistive devices help you perform a task or perform a task for you because it would be difficult for you to perform the task without the assistance, choose "Yes."

Justification #11: We made this revision per the request of the CCD in their public comments. In the CCD's public comments, they mention that they understand that the information about daily activities, solicited in Section 8, is essential to understanding ongoing disability; however, they recommend revising this section to remove questions 8.A and 8.B as these essay questions are very burdensome for claimants, and they duplicate the information gathered in 8.C. In addition, they expressed concern that the claimants do not complete these sections with information the DDSs or SSA needs to review the CDR. Finally, the CCD and some of the other public commenters (as well as some Usability testers) noted that the request in 8.C was a bit confusing, as some claimants may perform these tasks with assistance. Therefore, we removed the two essay questions and revised the instructions for 8.C to provide more clarity. We believe these revisions will assist respondents by reducing the burden and stress of completing these questions.

• **Change #12:** In Section 9, page 11, we updated the first sentence the instructions in section 9 to read:

Please provide any additional information you did not give in earlier parts of this report, that you think would help us understand your disability and how it affects you. If you did not have enough space in prior sections of this report to provide the requested information, please use this space here to provide the additional information requested in those sections. For example, if you experience any side effects from the medication listed in 3.D., please provide that information in this section. Be sure to note the name of the section (and question number) you are referring to.

Justification #12: We made this change as multiple commenters, including the CCD, suggested the form needs to be written in Plain Language. They also stated that SSA should ensure the form is written in as clear and concise language as possible, and that SSA should analyze the form for literacy level. In addition, during the Usability paper Testing, all advocates felt that documenting side effects is important since it is not going to be found in medical records. Based on both the public comments and Usability Testing, we added clarity to the narrative by providing an example of what information can be added in this section. This revision assists respondents in providing additional information that supports us understanding their disability and how it affects them.

As per our agreement with OMB, we have made these revisions and implemented changes to the i454 screens and paper form. We ask that OMB approve these revisions quickly, as we hope to implement them by **May 20, 2023**.

Resubmission of the Collection within One Year of OMB Approval

Per the Terms of Clearance OMB placed on the approval for 0960-0072, we are submitting this Change Request showing the revised documents prior to May 31, 2023.