Alzheimer's Disease Biomarker Disclosure Toolkit

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Information Sheet: Amyloid imaging for older adults who are not experiencing cognitive changes

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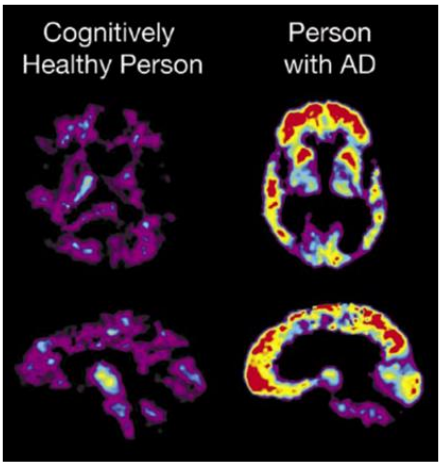
Learning your PiB Scan Amyloid Imaging Results:

- The PiB PET scan is being done as part of a research study using an experimental radiotracer. These results will not automatically appear in your medical record.
- Your results will be available approximately 2 months after having the PET Scan
- You may bring whomever you would like to the meeting where results will be discussed
- The following information provides a general overview of amyloid imaging.
- Information specific to you will be discussed during the Results Disclosure session.

About Amyloid PET imaging

- We use something called positron emission tomography, or PET, for short. PET scans allow doctors to see activity in a person's brain. The PET scan that you had uses a substance called Pittsburgh Compound-B (PiB) which is given through a shot in the arm at the time of the scan.
- PiB sticks to a protein in the brain called amyloid-beta (Aβ), or amyloid for short. Amyloid is often found in the brains of patients who have Alzheimer's disease (AD), but is sometimes present in the brains of older adults who do not have Alzheimer's.
- Many scientists believe that amyloid builds up over many years before any symptoms of memory loss begin. Up until recently, amyloid could only be seen by doing an autopsy after the patient died. By using a PiB scan, we can tell now whether or not you have amyloid build up in your brain during life.

Example of amyloid brain scan



Colored shading shows how much amyloid build up there is in the brain.

high
medium
low

There are two possible results from amyloid imaging for older adults who are not experiencing cognitive changes:

1. **A significant level of amyloid build-up**
   - Approximately 30% of older adults who are not experiencing cognitive changes are found to have amyloid build up in their brain.
   - The clinical meaning of this finding is not yet clear. Having amyloid build up in the brain may mean that these individuals are at a higher risk for eventually developing Alzheimer's than someone who does not have amyloid build up in their brain.
   - From a research view, you would be encouraged to continue to have yearly cognitive testing at the ADRC to check for any changes in your memory or thinking over time.

   Limitations of this information:

   We are still learning about other factors, both genetic and environmental, that determine risk for Alzheimer's. It's important to note that there aren't very many long-term follow-up studies of people with normal cognition who have amyloid build-up in their brains.

2. **No significant amyloid build-up**
   - This means that these individuals would likely have a lower chance of developing symptoms of Alzheimer's within the next few years as compared to someone who does have amyloid build-up in their brain.

   Limitations of this information:

   It is not possible for researchers to predict with certainty whether you will ever develop Alzheimer's in your lifetime. We are still learning about other factors, both genetic and environmental, that determine risk for Alzheimer's.

Things to consider when deciding whether to get your amyloid imaging results:

- Think about how you might feel if you were to learn that you had significant amyloid build up.
- Think about how you might feel if you were to learn that you did not have significant amyloid build up.
- Think about how you might use the information to plan ahead or plan for the future.
- Because the PET scan that you had was part of a research study, these results would be shared with you for your information only. These results would not appear in your medical record and should not be the basis for medical decision-making.

NOTES/QUESTIONS:

Information Sheet: Amyloid imaging for older adults with Mild Cognitive Impairment (MCI)

Contact: Betty Biomarker, PhD
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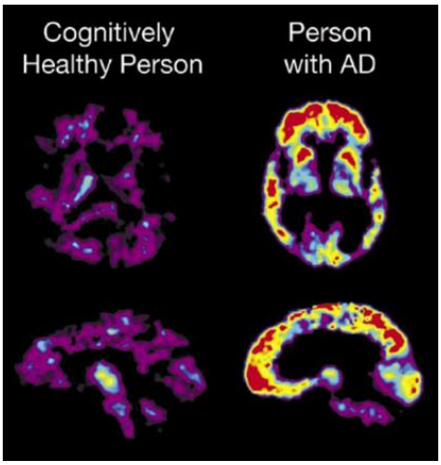
Learning your PiB Scan Amyloid Imaging Results:

- The PiB PET scan is being done as part of a research study using an experimental radiotracer. These results will not automatically appear in your medical record.
- Your results will be available approximately 2 months after having the PET scan.
- You may bring whomever you would like to the meeting where results will be discussed.
- The following information provides a general overview of amyloid imaging.
- Information specific to you will be discussed during the Results Disclosure session.

About Amyloid PET imaging

- We use something called positron emission tomography, or PET, for short. PET scans allow doctors to see activity in a person's brain. The PET scan that you had uses a substance called Pittsburgh Compound-B (PiB) which is given through a shot in the arm at the time of the scan.
- PiB sticks to a protein in the brain called amyloid-beta (Aβ), or amyloid for short. Amyloid is often found in the brains of patients who have Alzheimer's disease (AD), but is sometimes present in the brains of older adults who do not have Alzheimer's.
- Many scientists believe that amyloid builds up over many years before any symptoms of memory loss begin. Up until recently, amyloid could only be seen by doing an autopsy after the patient died. By using a PiB scan, we can tell now whether or not you have amyloid build up in your brain during life.

Example of amyloid brain scan



There are two possible results from amyloid imaging for older adults with Mild Cognitive Impairment (MCI):

1. **A significant level of amyloid build-up**

   - Having amyloid build up on a PiB scan would mean that these individuals are at a higher risk for eventually developing Alzheimer's as compared to someone who is noticing changes in their memory but does not have amyloid build up in their brain. Put another way, this finding suggests that Alzheimer's may be part of the underlying cause of the changes in memory or thinking that you have been noticing.

   - From a research point of view, this means that it may be a good idea for you to have cognitive testing once a year to check for possible changes over time.

   - Individuals who have a diagnosis of MCI may be appropriate for treatment with a recently approved medication if testing has confirmed that they have amyloid build up in the brain. Because PiB-PET is a research scan, it is possible that a person with such build up may be asked to undergo other testing in a traditional (non-research) medical setting to confirm eligibility for treatment.

   Limitations of this information:

   We are still learning about other factors, both genetic and environmental, that determine risk for Alzheimer's. It's important to note that there is no one, single definitive test for Alzheimer's. Alzheimer's is diagnosed based on results from a combination of tests including, for example, a physical exam, a review of a person's medical history and medication list, cognitive testing, as well as laboratory tests and brain scans.

2. **No significant amyloid build-up**

   - This finding would suggest that Alzheimer's may not be the underlying cause of the changes in memory or thinking that you are experiencing.

   Limitations of this information:

   Keep in mind that there are other causes of memory decline and changes in thinking besides Alzheimer's (for example, stroke and Parkinson's disease). PiB scans do not give us information about these non-Alzheimer's types of dementia.

Things to consider when deciding whether to get your amyloid imaging results:

- Think about how you might feel if you were to learn that you had significant amyloid build up. For example, some people find satisfaction in gaining more information about what is happening in their brain while others may experience worry or upset.
- Think about how you might feel if you were to learn that you did not have significant amyloid build up. For example, some people are relieved to hear this news, while others may find it frustrating that the test did not explain their symptoms.
- Think about how you might use the information to plan ahead or plan for the future.
- Because the PET scan that you had was part of a research study, the results would not automatically appear in your medical record.

NOTES/QUESTIONS:

Information Sheet: Amyloid imaging for older adults with dementia

Contact: Betty Biomarker, PhD
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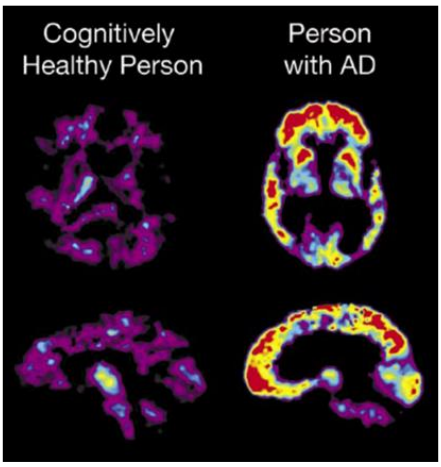
Learning your PiB Scan Amyloid Imaging Results:

- The PiB PET scan is being done as part of a research study using an experimental radiotracer. These results will not automatically appear in your medical record.
- Your results will be available approximately 2 months after having the PET Scan
- You may bring whomever you would like to the meeting where results will be discussed
- The following information provides a general overview of amyloid imaging.
- Information specific to you will be discussed during the Results Disclosure session.

About Amyloid PET imaging

- We use something called positron emission tomography, or PET, for short. PET scans allow doctors to see activity in a person's brain. The PET scan that you had uses a substance called Pittsburgh Compound-B (PiB) which is given through a shot in the arm at the time of the scan.
- PiB sticks to a protein in the brain called amyloid-beta (Aβ), or amyloid for short. Amyloid is often found in the brains of patients who have Alzheimer's disease (AD), but is sometimes present in the brains of older adults who do not have Alzheimer's.
- Many scientists believe that amyloid builds up over many years before any symptoms of memory loss begin. Up until recently, amyloid could only be seen by doing an autopsy after the patient died. By using a PiB scan, we can tell now whether or not you have amyloid build up in your brain during life.

Example of amyloid brain scan



<u>There are two possible results from amyloid imaging for older adults with dementia</u>:

1. **A significant level of amyloid build-up.**
   - This finding would suggest that Alzheimer's may be part or all of the cause of the changes in memory or thinking that you are experiencing.
   - Individuals who have a diagnosis of early Alzheimer's dementia may be appropriate for treatment with a recently approved medication if testing has confirmed that they have amyloid build up in the brain. Because PiB-PET is a research scan, it is possible that a person with such build up may be asked to undergo other testing in a traditional (non-research) medical setting to confirm eligibility for treatment.

   Limitations of this information:

   It is important to note that there is no one, single definitive test for Alzheimer's dementia. Alzheimer's dementia is diagnosed based on results from a combination of tests including, for example, a physical exam, a review of a person's medical history and medication list, cognitive testing, as well as laboratory tests and brain scans.

2. **No significant amyloid build-up**
   - This finding would suggest that Alzheimer's is not likely to be the cause of the changes in memory or thinking that you are experiencing.

   Limitations of this information:

   Keep in mind that there are other causes of memory decline and changes in thinking besides Alzheimer's (for example, stroke and Parkinson's disease). PiB scans do not give us information about these non-Alzheimer's types of dementia.

Things to consider when deciding whether to get your amyloid imaging results:

- Think about how you might feel if you were to learn that you had significant amyloid build up. For example, some people find satisfaction in gaining more information about what is happening in their brain while others may experience worry or upset.
- Think about how you might feel if you were to learn that you did not have significant amyloid build up. For example, some people are relieved to hear this news, while others may find it frustrating that the test did not explain their symptoms.
- Think about how you might use the information to plan ahead or plan for the future.
- Because the PET scan that you had was part of a research study, the results would not automatically appear in your medical record.

NOTES/QUESTIONS:

Result Feedback Guide for PITT ADRC Participants: Cognitively Healthy, Aβ+

Background

We used something called positron emission tomography, or PET, for short. PET scans allow doctors to see activity in a person's brain. The PET scan that you had uses a substance called Pittsburgh Compound-B (PiB) which is given through a shot in the arm at the time of the scan.

PiB sticks to a protein in the brain called amyloid-beta (Aβ), or amyloid for short. Amyloid is often found in the brains of patients who have Alzheimer's disease (AD), but is sometimes present in the brains of older adults who do not have AD dementia.

Many scientists believe that amyloid builds up over many years before any symptoms of memory loss begin. Up until recently, amyloid could only be seen by doing an autopsy after the patient died. By using a PiB scan, we can tell now whether or not you have amyloid build up in your brain.

Result

Your scan showed a significant level of amyloid build up in your brain.

Approximately 30% of older adults who are not experiencing cognitive changes are found to have amyloid build up in their brain. The clinical meaning of this finding is not yet clear. Having amyloid build up in the brain may mean that you are at a higher risk for eventually developing Alzheimer's disease (AD) than someone who does not have amyloid build up in their brain. From a research view, you are encouraged to continue to have yearly cognitive testing at the ADRC to check for any changes over time.

Limitations of this information - We are still learning about other factors, both genetic and environmental, that determine risk for AD. It's important to note that there aren't very many long-term follow-up studies of people with normal cognition who have amyloid build-up in their brains.

Because the PET scan that you had was part of a research study, these results are being shared with you and your loved one for your information only. These results will not appear in your medical record and should not be the basis for medical decision-making.

Follow-up: (ADRC staff member's name here) will be phoning you in a few weeks to check-in with you. If you have questions about these results or wish to speak with someone sooner, please call (# here), at any time.

Result Feedback Guide for PITT ADRC Participants: Cognitively Healthy, Aβ-

Background

We used something called positron emission tomography, or PET, for short. PET scans allow doctors to see activity in a person's brain. The PET scan that you had uses a substance called Pittsburgh Compound-B (PiB) which is given through a shot in the arm at the time of the scan.

PiB sticks to a protein in the brain called amyloid-beta (Aβ), or amyloid for short. Amyloid is often found in the brains of patients who have Alzheimer's disease (AD), but is sometimes present in the brains of older adults who do not have AD dementia.

Many scientists believe that amyloid builds up over many years before any symptoms of memory loss begin. Up until recently, amyloid could only be seen by doing an autopsy after the patient died. By using a PiB scan, we can tell now whether or not you have amyloid build up in your brain.

Result

Your scan did not show significant levels of amyloid build up in your brain at this time.

This means that you likely have a lower chance of developing symptoms of Alzheimer's disease (AD) within the next few years as compared to someone who has amyloid build up in their brain.

Limitations of this information – It is not possible for researchers to predict with certainty whether you will ever develop Alzheimer's disease in your lifetime.

We are still learning about other factors, both genetic and environmental, that determine risk for AD.

Follow-up: (ADRC staff member's name here) will be phoning you in a few weeks to check-in with you. If you have questions about these results or wish to speak with someone sooner, please call (# here), at any time.

Result Feedback Guide for PITT ADRC Participants: Mild Cognitive Impairment, Aβ+

Background

We used something called positron emission tomography, or PET, for short. PET scans allow doctors to see activity in a person's brain. The PET scan that you had uses a substance called Pittsburgh Compound-B (PiB) which is given through a shot in the arm at the time of the scan.

PiB sticks to a protein in the brain called amyloid-beta (Aβ), or amyloid for short. Amyloid is often found in the brains of patients who have Alzheimer's disease (AD), but is sometimes present in the brains of older adults who do not have AD dementia.

Many scientists believe that amyloid builds up over many years before any symptoms of memory loss begin. Up until recently, amyloid could only be seen by doing an autopsy after the patient died. By using a PiB scan, we can tell now whether or not you have amyloid build up in your brain.

Result

Your scan showed a significant level of amyloid build up in your brain.

Having amyloid build up on a PiB scan means that you are at a higher risk for eventually developing Alzheimer's dementia as compared to someone who is noticing changes in their memory but does not have amyloid build up in their brain. Put another way, this finding suggests that Alzheimer's disease may be part of the underlying cause of the changes in memory or thinking that you have been noticing.

From a research view, this means that it may be a good idea for you to have cognitive testing once a year to check for possible changes over time.

Limitations of this information - We are still learning about other factors, both genetic and environmental, that determine risk for Alzheimer's dementia. It's important to note that there is no one, single definitive test for Alzheimer's dementia. Alzheimer's dementia is diagnosed based on results from a combination of tests including, for example, a physical exam, a review of a person's medical history and medication list, cognitive testing, as well as laboratory tests and brain scans.

Because the PET scan that you had was part of a research study, these results will not automatically appear in your medical record. A summary of your results may be shared with your medical provider upon request and completion of a HIPAA release form.

Individuals who have a diagnosis of MCI may be appropriate for treatment with a recently approved medication if testing has confirmed that they have amyloid build up in the brain. It is possible that you may be asked to undergo another, confirmatory test in a traditional medical setting outside of this research study.

Follow-up: (ADRC staff member's name here) will be phoning you in a few weeks to check-in with you. If you have questions about these results or wish to speak with someone sooner, please call (# here), at any time.

Result Feedback Guide for PITT ADRC Participants: Mild Cognitive Impairment, Aβ-

Background

We used something called positron emission tomography, or PET, for short. PET scans allow doctors to see activity in a person's brain. The PET scan that you had uses a substance called Pittsburgh Compound-B (PiB) which is given through a shot in the arm at the time of the scan.

PiB sticks to a protein in the brain called amyloid-beta (Aβ), or amyloid for short. Amyloid is often found in the brains of patients who have Alzheimer's disease (AD), but is sometimes present in the brains of older adults who do not have AD dementia.

Many scientists believe that amyloid builds up over many years before any symptoms of memory loss begin. Up until recently, amyloid could only be seen by doing an autopsy after the patient died. By using a PiB scan, we can tell now whether or not you have amyloid build up in your brain.

Result

Your scan did not show significant levels of amyloid build up in your brain at this time.

This finding suggests that Alzheimer's disease (AD) may not be the underlying cause of the changes in memory or thinking that you are experiencing.

Keep in mind that there are other causes of memory decline and changes in thinking besides AD (for example, stroke and Parkinson's disease). PiB scans do not give us information about these non-Alzheimer's types of dementia.

Because the PET scan that you had was part of a research study, these results will not automatically appear in your medical record. A summary of your results may be shared with your medical provider upon request and completion of a HIPAA release form.

Follow-up: (ADRC staff member's name here) will be phoning you in a few weeks to check-in with you. If you have questions about these results or wish to speak with someone sooner, please call (# here), at any time.

Result Feedback Guide for PITT ADRC Participants: Dementia Syndrome, Aβ+

Background

We used something called positron emission tomography, or PET, for short. PET scans allow doctors to see activity in a person's brain. The PET scan that you had uses a substance called Pittsburgh Compound-B (PiB) which is given through a shot in the arm at the time of the scan.

PiB sticks to a protein in the brain called amyloid-beta (Aβ), or amyloid for short. Amyloid is often found in the brains of patients who have Alzheimer's disease (AD), but is sometimes present in the brains of older adults who do not have AD dementia.

Many scientists believe that amyloid builds up over many years before any symptoms of memory loss begin. Up until recently, amyloid could only be seen by doing an autopsy after the patient died. By using a PiB scan, we can tell now whether or not you have amyloid build up in your brain.

Result

Your scan showed a significant level of amyloid build up in your brain.

This finding suggests that Alzheimer's disease may be part of the cause of the changes in memory or thinking that you are experiencing.

However, it is important to note that there is no one, single definitive test for Alzheimer's dementia. Alzheimer's dementia is diagnosed based on results from a combination of tests including, for example, a physical exam, a review of a person's medical history and medication list, cognitive testing, as well as laboratory tests and brain scans.

Because the PET scan that you had was part of a research study, these results will not automatically appear in your medical record. A summary of your results may be shared with your medical provider upon request and completion of a HIPAA release form.

Individuals who have a diagnosis of early Alzheimer's dementia may be appropriate for treatment with a recently approved medication if testing has confirmed that they have amyloid build up in the brain. It is possible that you may be asked to undergo another, confirmatory test in a traditional medical setting outside of this research study.

Follow-up: (ADRC staff member's name here) will be phoning you in a few weeks to check-in with you. If you have questions about these results or wish to speak with someone sooner, please call (# here), at any time.

Result Feedback Guide for PITT ADRC Participants: Dementia Syndrome, Aβ-

Background

We used something called positron emission tomography, or PET, for short. PET scans allow doctors to see activity in a person's brain. The PET scan that you had uses a substance called Pittsburgh Compound-B (PiB) which is given through a shot in the arm at the time of the scan.

PiB sticks to a protein in the brain called amyloid-beta (Aβ), or amyloid for short. Amyloid is often found in the brains of patients who have Alzheimer's disease (AD), but is sometimes present in the brains of older adults who do not have AD dementia.

Many scientists believe that amyloid builds up over many years before any symptoms of memory loss begin. Up until recently, amyloid could only be seen by doing an autopsy after the patient died. By using a PiB scan, we can tell now whether or not you have amyloid build up in your brain.

Result

Your scan did not show significant levels of amyloid build up in your brain at this time.

This finding suggests that Alzheimer's disease (AD) may not be the cause of the changes in memory or thinking that you are experiencing.

Keep in mind that there are other causes of memory decline and changes in thinking besides AD (for example, stroke and Parkinson's disease). PiB scans do not give us information about these non-Alzheimer's types of dementia.

Because the PET scan that you had was part of a research study, these results will not automatically appear in your medical record. A summary of your results may be shared with your medical provider upon request and completion of a HIPAA release form.

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