Dear [Name],

This letter is about [Yourself].

Thank you for agreeing to take part in our test. Your participation is voluntary and you can withdraw at any time.

**Explanation of the test**

The new system is called Activities for Managing Life, or AML's for short. It is being developed with the help of a group of people who represent disabled people and their organisations. It is based on a person's ability to perform a series of activities necessary for self-care. The purpose of the testing is to see how the new system may work in practice.

Participation in the test will not affect your claim to Disability Living Allowance (DLA) or Attendance Allowance (AA) in any way. Information from the test will be kept completely separate from your claim. Any information you provide for the test will only be used for research purposes and will not be seen by the decision maker assessing your current claim.

Please turn over >
If you think there is any information that is relevant to your current claim for benefit, you will need to inform the office dealing with your claim. All personal information obtained for the test will be destroyed once the test is completed.

**What we want you to do**

You have agreed over the telephone to a visit from one of our Visiting Officers, in order to complete an AML Questionnaire with you. Before we can proceed we need your agreement in writing. Please read the declaration at the end of this letter. If after reading it you agree to continue please:

- sign it
- tear it off at the dotted line
- place the signed portion in the pre-paid envelope provided
- return it to us as soon as possible.

Please let us know if you have any special needs or requirements for the visit (e.g., an interpreter, signer). If you have any special needs please record these on page 3 of this letter.

**What happens next**

Once we have received your signed agreement to take part in the test we will send you an AML Questionnaire. You will be asked to read the Questionnaire before the visit, as this may help you understand the type of questions that the Visiting Officer will be going to ask. Please do not fill the Questionnaire in before the Visiting Officer arrives.

Yours sincerely

[Signature]

John Sumner
Disability and Carer Benefits Director
Disability research questionnaire

Part 1 About you

If you are filling in this form for somebody else, please tell us about them, not yourself.

Surname or family name

Mr/Mrs/Miss/Ms

All other names in full

Sex

Tick the box that applies.

Male □ Female □

Address where you live

Postcode

Daytime phone number

Code Number

Where we can contact you or leave a message

Date of Birth

Letters Numbers

National Insurance (NI) number

You can find this on your NI numbercard, on letters from social security or on payslips.

For people completing this form for somebody else

Your surname

Mr/Mrs/Miss/Ms

Your other names

Relationship to person involved in the test

Date form completed

AML 1 July 2001

For research purposes only
Part 2 About your illness or disabilities

What are your illnesses or disabilities? 
Do not worry if you are unsure about the spelling.

What medicines, tablets or other treatments have been prescribed for your illness or disabilities?

Your family doctor or GP

Please tell us their name

Their address

Postcode

Their phone number, if you know it.

Code Number

When did you last see your doctor about your illness or disabilities?

If you are waiting for an operation or other major treatment please answer the questions below, if not go to page 3.

What is the operation or treatment?

Where will this take place?

When is this due to happen?
Part 2 About your illness or disabilities - continued

Your hospital doctor or specialist

Please tell us their name

Their address

Postcode

Their phone number, if you know it.

Code

Number

When did you last see this person about your illness or disabilities?

Please give us details, including address and telephone numbers (if known) of any other doctors, specialists or professionals you see for your disability.

For example:
- Head teacher of your school (for children with disabilities)
- District Nurse
- Community Psychiatric Nurse
- Counsellor
- Physiotherapist

Please tell us their name

Their address

Postcode

Their phone number, if you know it.

Code

Number

When did you last see this person about your illness or disabilities?

Please continue on a separate sheet with additional details, if necessary.
We may need to ask your doctor or other persons who care for you for further information. This information will only be used for our research and will not be considered for your actual benefit claim. In order to do this we need your permission. If you are agreeable, please sign the declaration below.

I agree that the Department of Social Security may ask the people or places listed in this form for any information, which is needed for this research, and that the information may be given to the Department.

I understand that this information will only be used for the purposes of this research and will not form part of the information used to decide my benefit claim. I also understand that when the research is completed the information will be destroyed.

Signature

Date / /
Part 2 Important notes about carrying out activities

Please read the notes below before you fill in the following parts of this form that deal with carrying out certain activities

- Tick either No or Yes box at the beginning of each activity. If you tick Yes, then tick the following box that applies to you or is closest to your needs.

- The answers should be based on the amount of help you need to safely carry out the activity, not the amount that you actually get.

- If you can carry out any of the activities only with severe pain or breathlessness or if it causes severe fatigue, answer as though you are unable to carry out that activity.

- If you have problems because you cannot see and need somebody to check that you are doing the activity properly and appropriately, then indicate that you need another person’s help to complete the activity.

- Some of the activities mention the need for guidance, encouragement or supervision. "Guidance and encouragement" means the need for continual intervention by another person – not occasional guidance or prompting – to enable you to carry out an activity. "Supervision" means the need for another person to continually stand by or watch over you in readiness to intervene, should the need arise, while you are carrying out an activity." You are asked to put a tick in a box of you need continual guidance/encouragement or supervision. This is to help us identify the type of help needed.

- If your disability or illness changes throughout the day or from day to day, show what help is needed for most of the time. Where you get attacks of your illness, please show what help you need for most of the time, how often an attack happens and how long each attack lasts. You can use the box at the bottom of each page for this.

- If you use any aids to help you to manage, please give details at the bottom of each page.

Some examples may be
- a walking aid or hearing aid, or
- adaptations to your home (bath rails or a raised toilet seat).

For research purposes only
Part 2 The activities covered in this questionnaire

There are 16 activities listed in the pages that follow. Some will be relevant to your disability and some will not. Please look at each one, if any do not apply to you, you only need to put a tick in a box and go on to the next activity.

The activities are:

1. Feeding and drinking
2. Dressing and undressing
3. Washing and bathing
4. Using the toilet
5. Getting in or out of bed and turning in bed
6. Mobility
7. Rising and sitting
8. Fits or blackouts requiring the supervision of somebody else
9. Orientation
10. Taking medication and undergoing therapeutic procedures
11. Reliance on machines and equipment
12. Communication
13. Budgeting
14. Hygiene
15. Daily routine
16. Awareness of danger or unsafe behaviour
17. Childhood Development (for children 12 and under)
18. Help children need in connection with their treatment (for children 12 and under)
Part 3 Activity 1 - Feeding and drinking

This means being able to get food or drink that has already been prepared into your mouth. Please answer this section as if you are using your normal aids and appliances such as adapted cutlery. If you are only able to do this with somebody to guide or encourage you, please answer as though you are not able to manage. If this is the case, please tick this box as well as one of the Boxes below.

Do you need help with feeding and drinking?  

No  [ ] Go to page 8.

Yes  [ ] Tick one of the boxes below, which is closest to your needs.

1. You are not able to eat or drink without continual help from somebody else.

2. You are able to hold a cup and drink through a straw, but need help from somebody else with all other aspects of eating and drinking.

3. You are able to eat using your fingers, but need help from somebody else with cutlery.

4. You are able to feed yourself, but you spill things or make a mess that somebody else needs to clear up.

5. You only need help with cutting up meat and similar food items.

6. You are able to eat and drink without help.

Use the box below to add anything about the problems you have with feeding and drinking. Please give details of any aids and appliances you use.
Part 3 Activity 2 - Dressing and undressing

This is about the act of changing between nighttime and daytime clothes. Please answer this section as if you are using your normal aids and appliances such as long handled shoehorn.

If you are only able to do this with somebody to supervise, guide or encourage you or you need somebody to select clothes because you are unable to see, please answer as though you are not able to dress or undress, if this is the case, please tick this box.

Do you need help with dressing and undressing?  

No ☐ Go to page 9.

Yes ☐ Tick one of the boxes below, which is closest to your needs.

1. You need help from somebody else with all aspects of dressing and undressing

2. You need help from somebody else with most aspects of dressing and undressing, but you are able to physically help

3. You are able to dress and undress, but need help from another person with certain awkward garments.

4. You are able to dress but need help from somebody else to check your appearance.

5. You are able to dress and undress, but need help from another person with small buttons and laces

6. You are able to dress and undress without help

Use the box below to add anything about the problems you have with dressing and undressing. Please give details of any aids and appliances you use.
Part 3 Activity 3 - Washing and bathing

This is about being able to get into and out of the bath or shower, turn a shower on and off and washing and drying yourself. Please answer this section as if you are using your normal aids and appliances such as special taps. If you can only do things with somebody else to supervise, guide or encourage you, please answer as though you are not able to manage. If this is the case, please tick this box as well as one of the boxes below.

Do you need help with washing and bathing?  

No  []  Go to page 10.  

Yes  []  Tick one of the boxes below, which is closest to your needs.

1. You are unable to wash or bathe and you need help to be bed bathed by somebody else.

2. You are able to wash your hands and face on your own, but you need help from somebody else to wash more extensively, or to wash your hair or give you a shave.

3. You are able to wash and shower yourself, but need help from somebody else to get in and out of the bath.

4. You are able to wash and shower yourself, but need somebody else to check that you have done it properly.

5. You are able to wash and shower yourself, but can only use the bath with a special seat and/or aids to get in or out of it.

6. You can wash and take a bath without help.

Use the box below to add anything about the problems you have with washing and bathing. Please give details of any aids and appliances you use.
Part 3 Activity 4 - Using the toilet

This is about getting on and off the toilet or commode, using a urine bottle, wiping and cleaning yourself, dealing with menstruation and dealing with incontinence pads. It is not about getting to and from the toilet.

If you can only do these things if somebody is supervising you or if somebody has to tell you to do them then you should tick as if you are unable to do them. If this is the case, please tick this box as well as one of the boxes below.

Incontinence includes having accidents because of the need to go to the toilet frequently or not being able to control yourself until you reach the toilet.

Do you need help with your toilet needs?

No ☐ Go to page 11.

Yes ☐ Tick one of the boxes below, which is closest to your needs.

1. You are incontinent of both urine and faeces, and dependent on incontinence pads and the help of somebody else.

2. You are incontinent of either urine or faeces, and dependent on incontinence pads and the help of somebody else.

3. You are dependant on a colostomy bag, or similar item that leaks frequently, and you need the help of somebody else dealing with the leaks.

4. You are continent of urine and faeces, but need help from another person with all aspects of using the toilet or commode.

5. You need somebody to get you on and off the toilet, but can deal with your clothes and wipe yourself unaided.

6. You are able to get on and off the toilet on your own but you need help with your clothes or with wiping, or you are dependent on a colostomy bag, or similar item, and need help to change the bag.

7. You are able to use the toilet without help from anyone else, but only with special adaptations to the bathroom or toilet, like rails or a special seat.

8. You are able to use the toilet without any help.

Use the box below to add anything about the problems you have with your toilet needs. Please give details of any aids and appliances you use.
Part 3 Activity 5 - Getting in or out and turning in bed

Do you need help with getting into, out of or turning in bed?

No ☐ Go to page 12.

Yes ☐ Tick one of the boxes below, which is closest to your needs.

1. You are completely bed bound and need help from somebody else to turn in bed.

2. You are not completely bed bound but you need help from somebody else to turn in bed.

3. You are able to turn in bed, but you need help from somebody else to get in and out.

4. You are able to get into and turn in bed, but you need help from somebody else to get out of bed.

5. You are able to get into and turn in bed, but you need help from special aids, or some other form of assistance. For example, leaning on furniture to get out of bed.

6. You are able to get into and out of bed and turn in bed without help.

Use the box below to add anything about the problems you have with getting into, out of bed or turning in bed. Please give details of any aids and appliances you use.
This is about being able to get about both inside and outside your home with any aids and appliances you normally use. Please take account of difficulties you have because of your physical problems with walking.

When you estimate how far you can walk you should take account of the time it takes you, if you walk normally, if you suffer pain, fatigue or breathlessness, how consistently you can walk that distance and how much help you need from somebody else.

Use box at the bottom of this page to explain if necessary.

Do you need help with walking?

No [ ] Go to page 13.

Yes [ ] Tick one of the boxes below.

1. You are not able to walk at all.

2. You can only walk a few steps.

3. You are able to walk but no more than about 50 metres on level ground.

4. You are able to walk but no more than about 200 metres on level ground.

5. You are able to walk more than 200 metres on level ground.

Use the box below to add anything about the problems you have with walking, such as the time taken. Please give details of any aids and appliances you use.
Part 3 Activity 7 - Rising and sitting

This is about being able to stand up after you have been sitting for about 15 minutes. It is not about being able to remain standing or remain in a sitting position for any length of time.

By a normal chair we mean an upright chair with arms and with a hard back.

Do you need help with rising and sitting?  
No ☐ Go to page 14.
Yes ☐ Tick one of the boxes below, which is closest to your needs.

1. You are not able to rise and sit using any sort of chair unless you have help from somebody else. ☐

2. You are not able to rise and sit using a normal chair without help. You can sit in a raised chair without help, but you need help from somebody else to rise. ☐

3. You are not able to rise and sit using a normal chair without help from somebody else, but you are able to rise and sit using a raised chair. ☐

4. You are able to sit in a normal chair, but you need help from somebody else to rise. ☐

5. You do not need any help with rising and sitting. ☐

Use the box below to add anything about the problems you have with rising and sitting. Please give details of any aids and appliances you use.

For research purposes only
Part 3 Activity 8 - Fits or blackouts requiring supervision by somebody else

This is about sudden losses or changes to your consciousness for any reason.

Do you need help with fits or blackouts?  

No  [ ] Go to page 15.

Yes  [ ] Tick one of the boxes below, which is closest to your needs.

1. You have fits or blackouts that occur without warning **every day**. 
   You also have a history of injury and/or your behaviour is unpredictable and dangerous either before or after the fit or blackout.

2. You have fits or blackouts that occur without warning at least once a week, but not on a daily basis. You also have a history of injury and/or your behaviour is unpredictable and dangerous either before or after the fit or blackout.

3. You have fits or blackouts that occur without warning at least once a month, but not weekly. You also have a history of injury and/or your behaviour is unpredictable and dangerous either before or after the fit or blackout.

4. You have fits or blackouts that occur with a warning at least daily. 
   You also have a history of injury and/or your behaviour is unpredictable and dangerous either before or after the fit or blackout.

5. You have fits or blackouts that occur without warning **less than monthly**, or with warning **less than daily**. Or you have fits at any time but you have no history of injury and/or your behaviour is not unpredictable and dangerous either before or after the fit or blackout.

If you have ticked boxes 1, 2, 3 or 4 please use the box below to tell us what injury you have received because of a fit or blackout. Also tell us about any examples of unpredictable or aggressive behaviour, or anything else about the problems you have with fits or blackouts.

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For research purposes only
This is about your ability to find your way around safely.

Do you need help finding your way around?  

No [ ] Go to page 16.

Yes [ ] Tick one of the boxes below, which is closest to your needs.

1. You are completely unaware of your surroundings and you need constant guidance both indoors and outdoors to find your way around safely.

2. You have little perception of your surroundings and you need constant guidance to find your way around safely outdoors, even in a place which is familiar to you.

3. You need guidance from somebody else most of the time to find the way to an unfamiliar place, or a place you do not know very well.

4. You can get about outdoors but need help to find facilities such as the toilet or reception area in a building.

Use the box below to add anything about the problems you have with getting about.
This is about taking medicine that you have been prescribed and any therapy that you have to undertake. It includes being able to handle medicine and being able to understand which medicines, and what amounts, you have to take.

By therapeutic procedures we mean things like physiotherapy and speech therapy.

If you need somebody to tell you to take medicine you should answer as though you need help. If this is the case, please tick this box as well as one of the boxes below.

**Do you need help with medication or therapy?**

- No [ ] Go to page 17.
- Yes [ ] Tick one of the boxes below, which is closest to your needs.

1. **Every day** you need help from somebody else with taking your medicine and with therapeutic procedure.

2. **Every day** you need help from somebody else with therapeutic procedures, but you are able to take your medicine without help from somebody else or you do not have any medicine prescribed.

3. **Every day** you need help from somebody else with taking your medicine and you have to take it **more than twice a day**, but not with therapeutic procedures.

4. **Every day** you need help from somebody else with taking your medicine and you have to take it **twice a day or less**, but not with therapeutic procedures.

5. You are able to take medicine by yourself and you do not need any help with therapeutic procedures.

Use the box below to add anything about the problems you have with medication or therapeutic procedures.

---

*For research purposes only*
Part 3 Activity 11 - Reliance on machines and equipment

This is about relying on machines and equipment when you are not able to manage them on your own.

Do you need help with a machine or using equipment listed below?

No ☐ Go to page 18.

Yes ☐ Tick one of the boxes below.

1. You need help using a machine all the time in order to breathe (mechanical ventilation) ☐

2. You need help because you rely on a tube to allow you to breathe (tracheal suction). ☐

3. You need help because you are totally reliant on intravenous feeding (Total Parenteral Nutrition). ☐

4. You need help because you are reliant on continuous drug infusion. ☐

5. You need help because you are reliant on a kidney dialysis machine (haemodialysis). ☐

6. You need help because you are reliant on continuous ambulatory peritoneal dialysis (or similar procedure). ☐

7. You are not reliant on any machine or special equipment ☐

Use the box below to add anything about the problems you have with the use of a machine or equipment.

For research purposes only
Part 3 Activity 12 - Communication

This is about difficulty communicating with other people because of a physical, sensory and intellectual or mental health problem. Please answer this section as if you are using your normal aids and appliances such as a hearing aid. Conversation means the content of the communication and not necessarily that it has to be through speaking and hearing.

Do you need help communicating?  

No ☐ Go to page 19.

Yes ☐ Tick one of the boxes below, which is closest to your needs.

1. You are not able to communicate with friends and family in any meaningful way and not at all with strangers.

2. You are able to communicate basic needs only to friends and family.

3. You are able to communicate basic needs to strangers as well as friends and family.

4. You are able to hold a conversation, but in order to do so you need help from somebody else.

5. You are able to communicate using hearing and speech but you need help or special assistance with written communication.

6. You do not have any problems with communication.

Use the box below to add anything about the problems you have with communicating. Please give details of any aids and appliances you use.
Part 3 Activity 13 - Budgeting

This is about problems you may have with handling money because you have a mental health problem. It is not about having enough money.

Do you need help budgeting because of a mental health problem?

No □ Go to page 20.

Yes □ Tick one of the boxes below, which is closest to your needs.

1. You do not have any idea of the value of money.
   □

2. You are not able to budget for your daily needs.
   □

3. You are not able to budget for your weekly bills
   □

4. You are not able to budget for your irregular bills.
   □

5. You do not have any problems handling money and budgeting.
   □

Use the box below to add anything about the problems you have with budgeting.

For research purposes only
Part 3 Activity 14 - Hygiene

This is about how you attend to your hygiene because of a mental health problem. It includes the ability to wash, shave, comb and get your haircut and attend to menstrual hygiene on a regular basis.

Do you need help with hygiene because of mental problems?  

No  [ ] Go to page 21.

Yes  [ ] Tick one of the boxes below, which is closest to your needs.

1. You do not attend to personal hygiene in any way and you need daily supervision to cope with this.  

2. Your personal hygiene is poor. You need supervision more than once a week.

3. Your personal hygiene is poor. You need supervision on a weekly basis.

4. You do not have any problems with your hygiene.

Use the box below to add anything about the problems you have with hygiene.

...
Part 3 Activity 15 - Daily routine

This is about any difficulties you may have in managing your daily routine because of a mental health problem, learning disability or related disorder.

Do you need help with your daily routine because of a mental health problem?  

No ☐ Go to page 22.

Yes ☐ Tick one of the boxes below, which is closest to your needs.

1. You will not get out of bed unless somebody urges you to and your 24 hour cycle is constantly out of phase.

☐

2. You need somebody to urge you get out of bed and to go to bed every day.

☐

3. You need somebody to urge you get out of bed every day.

☐

4. You sometimes need somebody to urge you get out of bed.

☐

5. You do not have any problems with your daily routine.

☐

Use the box below to add anything about the problems you have with your daily routine.

☐

For research purposes only
Part 3 Activity 16 - Awareness of danger or unsafe behaviour

This is about your ability to recognise dangers and live safely with acceptable behaviour.

Do you need help with awareness of danger or unsafe behaviour?

No ☐ Go to page 23.

Yes ☐ Tick one of the boxes below, which is closest to your needs.

1. You are totally unaware of common dangers or your behaviour is constantly antisocial. ☐

2. You are unaware of some common dangers and you need to be frequently warned about the effects of your actions. ☐

3. You are generally aware of common dangers and your behaviour is acceptable, but only if your surroundings are well ordered and familiar. ☐

4. You are aware of common dangers and your behaviour is acceptable. ☐

Use the box below to add anything about the problems you have with awareness of danger or unsafe behaviour.
If you are completing this questionnaire for a child of 12 years or under, please also complete the following 2 activities. Otherwise, please go to Page 26 and complete the section called “your views”.
This is about the development of a child and achievement of milestones, such as how a child sees and uses objects, their hearing and speech, movement and social behaviour. Consider adult stimulation that is required to ensure the best possible development, including playing. Do not include attention with activities such as feeding, dressing and bathing.

This is about adult stimulation that is significantly greater than that needed for a child without disabilities.

Is greater adult stimulation needed to ensure childhood development?

No [ ] Go to page 25.

Yes [ ] Tick one of the boxes below.

1. Significantly greater adult stimulation is required continuously throughout the child's waking hours.

2. Significantly greater adult stimulation is required at frequent intervals, but not continuously throughout the day.

3. Significantly greater adult stimulation is required at irregular or infrequent intervals.

4. Adult input is not significantly greater than it would be for a child without disabilities.

Use the box below to add anything about the adult stimulation needed.
Part 3 Activity 18 – Help children need in connection with their treatment
(for children aged 12 or under)

This is about the help adults may have to give to a child in connection with the treatment of their
disability. The treatment must be prescribed/recommended by a doctor or other health care
professional.

By treatment we mean

• giving medication
• monitoring conditions eg blood sugar
• therapeutic procedures eg
  physiotherapy
  speech therapy
  “play therapy”
  to treat their condition, help their development, achieve
milestones or develop social behaviour.

Does your child need to be
given medication or
therapy from an adult to
ensure childhood
development?

No [ ] Go to page 26.

Yes [ ] Tick one of the boxes below.

1. Needs help with medication and/or monitoring and help with therapeutic
   procedures at least three times a day everyday [ ]

2. Needs help with medication and monitoring or help with therapeutic
   procedures at least three times a day everyday [ ]

3. Needs help everyday with therapeutic procedures. [ ]

4. Needs help with therapeutic procedures at least twice a week. [ ]

5. Needs help with medication at least twice a day everyday. [ ]

Use the box below to give details of the type(s) of prescribed therapy/monitoring
that the child needs from an adult.

[Box for details]

25  For research purposes only
YOUR VIEWS

We are very interested in your views on this form, and would be grateful if you could answer a few questions.

What we want you to do

Please tick the relevant box for questions 1 to 4

1. The instructions were easy to understand
   Strongly agree ☐  Agree ☐  Disagree ☐  Strongly disagree ☐

2. The questions were easy to understand
   Strongly agree ☐  Agree ☐  Disagree ☐  Strongly disagree ☐

3. I found all parts of this form easy to fill in
   Strongly agree ☐  Agree ☐  Disagree ☐  Strongly disagree ☐

4. I felt I could explain my needs fully on this form
   Strongly agree ☐  Agree ☐  Disagree ☐  Strongly disagree ☐

5. We are interested in any further comments you might have about this form. We are particularly interested in any parts you found difficult to fill in, or any questions or words which were not clear. Please write your comments in the box below.

   [Blank Space for Comments]

Did you need help to complete this form? ☐ Yes ☐ No

If yes, who provided the help? [Blank Space for Input]

THANK YOU FOR YOUR TIME

For research purposes only