ACTIVE & INDEPENDENT LIVING IMPROVEMENT PROGRAMME

AHP LIFECURVE SURVEY
PARTICIPANT INFORMATION & CONSENT FORM
We are doing a Survey to improve our services
The Survey asks you 2 types of questions: the first are about some everyday activities and the second are about your general living circumstances.
The survey should take about 5 minutes to do. If you need help the member of staff who you are seeing today will help you. Or you can ask a family member or friend to help. It might take longer to complete the survey if you need help.

What do I need to do?
1. Look at the list of activities and tell us which you can do on your own without any help. Then tell us which of the activities you do need help with. For all activities without help means from either a person or by using equipment.

2. Now tell us how long you have needed help for those activities.

3. Next answer the general questions about your life circumstances.

4. If you agree for us to use the information please sign the consent form. Your guardian can sign on your behalf.

Is it confidential? Yes

What will we do with the information?
1. We will use the information to improve the services we provide across Scotland.

2. To do this we want to collect your personal health number (CHI number) so we can link today’s Survey information with other health and social care information about you.

3. We need your permission to do this and you will be asked to sign the consent form. Your Guardian can do this for you.

4. We will share the information in the Survey with other organisations who can help us make improvements now and in the future. This has nothing to do with and will not affect other services you receive eg benefits or pension payments. None of your personal information will be shared.

There is more detailed information later in this booklet.
If you need the information in another format please let the AHP member of staff know and they will arrange this for you.
1. Please look at the list of activities below and tick every one you **CAN** manage unaided i.e. without help.
2. Next tick every activity which you **CANNOT** manage unaided i.e. without help.
   **NB:** without help means from a person or using equipment.
3. Next tell us how many months and/or years you have needed help with the activity or activities.

<table>
<thead>
<tr>
<th>CAN do this unaided</th>
<th>Activity of Daily Living</th>
<th>CANNOT do this unaided</th>
<th>How long since you were able to do this?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Number of months?</td>
</tr>
<tr>
<td><img src="image" alt="Heavy Housework" /></td>
<td>Heavy Housework (eg moving furniture to hoovering)</td>
<td><img src="image" alt="Using steps / stairs" /></td>
<td>Using steps / stairs</td>
</tr>
<tr>
<td><img src="image" alt="Eat your food independently" /></td>
<td>Eat your food independently</td>
<td><img src="image" alt="Get dressed" /></td>
<td>Get dressed</td>
</tr>
<tr>
<td><img src="image" alt="Wash your face and hands" /></td>
<td>Wash your face and hands</td>
<td><img src="image" alt="Get on / off a toilet" /></td>
<td>Get on / off a toilet</td>
</tr>
<tr>
<td><img src="image" alt="Have a full wash" /></td>
<td>Have a full wash</td>
<td><img src="image" alt="Walk 400 yards" /></td>
<td>Walk 400 yards</td>
</tr>
<tr>
<td><img src="image" alt="Cook a hot meal" /></td>
<td>Cook a hot meal</td>
<td><img src="image" alt="Get on / off a bed" /></td>
<td>Get on / off a bed</td>
</tr>
<tr>
<td><img src="image" alt="Shopping" /></td>
<td>Shopping</td>
<td><img src="image" alt="Cut your toenails" /></td>
<td>Cut your toenails</td>
</tr>
<tr>
<td><img src="image" alt="Get up / down from a chair" /></td>
<td>Get up / down from a chair</td>
<td><img src="image" alt="Light housework (eg ironing, dusting)" /></td>
<td>Light housework (eg ironing, dusting)</td>
</tr>
<tr>
<td><img src="image" alt="Moving around" /></td>
<td>Moving around</td>
<td></td>
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</tr>
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</table>

Now please turn over to answer a few more questions.
Who are Allied Health Professionals?

Allied Health Professionals (AHPs) are a group of 12 different professions which include: Arts Therapists, Dieticians, Occupational Therapists, Physiotherapists, Podiatrists, Paramedics, Speech and Language Therapists, Orthoptists, Orthotists, Prosthetists and Diagnostic and Therapeutic Radiographers.

Most AHPs work in health where they make up around a third of the health workforce as well as around 500 AHPs (mainly Occupational Therapists) working in social work services.
Permission to use health and social care information

Allied Health Professionals work in health and social care and are undertaking a National Lifecurve Survey.

Most of the information gathered in the Survey will be anonymous. However, we want to collect your unique NHS number – called your CHI number – to allow us to link to your health and social care records without accessing your personal information. We need your permission to use this. This means we will be able to see your health and social care information but we won’t know your name or address. (Please see the National Lifecurve Survey Participation Information Sheet for more information)

We want to use your health and social care information as part of the Survey to help us improve our services. We need your permission to do this.

Please read this form carefully. You don’t have to sign it.

What does “health and social care information” include?

- Information in your health and medical record and/or social care record relevant to this Survey
- Information about your health condition or health conditions

How will your information be used?

Your information will be used as part of the Survey report and research. We may also share this information only with health and social care organisations that provide health and social care services now and in the future.

Important: we won’t share any personal information about you – you will not be able to be identified. No-one will know your name and/or address.

Your health and social care information may also be shared with the following:

- Newcastle and Strathclyde Universities who are involved in analysing the Survey results. Both are experienced health research institutions familiar with holding health research data securely and are fully compliant with the Data Protection Act.
- The sponsor of the Survey and its representatives. Sponsor Name: Chief Health Professions Officer, Scottish Government
- Government agencies, ethics review boards, data and safety monitoring boards, and others responsible for watching over the safety, effectiveness, and conduct of the Survey.
To take part in the National Lifecurve Survey you must sign this consent form. By giving consent we will be able to have access to your health and social care information, but we will not have access to any personal information eg your name or address. If you do not want to sign the form this will not affect the care or treatment you receive today or in the future. Your Guardian or Power of Attorney can sign on your behalf.

I agree to the use of my health /social care information for purposes of the National Lifecurve Survey.

<table>
<thead>
<tr>
<th>Printed Name of Participant</th>
<th>Signature of Participant</th>
<th>Date</th>
</tr>
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Consent provided by welfare or legal guardian

<table>
<thead>
<tr>
<th>Printed Name of Participant</th>
<th>Printed Name of Guardian</th>
<th>Signature of Guardian</th>
<th>Date</th>
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More Information about why we are doing the Lifecurve Survey

People in Scotland are living much longer than they used to – this is due to a number of factors including better nutrition, improvements in modern medicine and better public health. We all want to be able to age well, and to continue living in as good health as we can for as long as possible.

We are asking you to take part in this National Survey to help us plan how we, as Allied Health Professionals, can best support the people of Scotland to remain as healthy, active and independent for as long as possible.

Why should I take part?

Everyone wants to stay well, healthy and enjoying life as they get older but some age related decline is inevitable. As Allied Health Professionals (AHPs) we know we need to make some changes to how we are currently working to support people to be as active, healthy and independent as possible. This Survey is designed to help find out what some of those changes should be.

Service User/Patient Participation

We have involved a number of people who use our services in the design of the Survey and have made changes according to their feedback. This has been a vital part of the development of the Survey form and Survey information.

What do I need to do?

You can choose whether you want to take part in this Survey or not – you do not need to take part if you choose not to. Whatever you decide will not affect your treatment today or in the future. Your Guardian/Power of Attorney can make this decision on your behalf.

The survey asks 2 types of questions. It takes a few minutes to complete. If you need help to complete the Survey you can ask a member of your family or friend or the member of staff you are seeing today. The first section asks you to look at each activity and tell us whether you can manage to do them without any help, or whether you are not able to do this.

For all activities without help means from either a person or by using equipment.

Please see the example on next page:
Example: If you CAN manage to go up and down stairs/steps without any help – this means you don’t need to hold onto a banister or rail to go up and down steps or have help from another person, then you tick:

1. Please look at the list of activities below and tick every one you CAN manage unaided i.e. without help.
2. Next tick every activity which you CANNOT manage unaided i.e. without help.
3. Next tell us how many months and/or years you have needed help with the activity or activities.

### Activity of Daily Living

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<td>Using steps / stairs</td>
<td></td>
<td>Number of months? Number of years?</td>
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However, if you CANNOT manage to go up and down stairs/steps without getting help (e.g. holding onto a rail or banister or without help from someone else) then you tick the second box, and then tell us how long you have needed this help for – so if it is 1 year and 4 months:

1. Please look at the list of activities below and tick every one you CAN manage unaided i.e. without help.
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|                     |                        | X                      | 4 1                                    |

You need to repeat this for each of the different activities. Remember for all activities without help means from either from a person or by using equipment.

We know that you may be asked similar questions for other purposes – e.g. benefit applications or a parking concession (e.g. Blue Badge), however, we are asking these questions purely for the purposes of the Survey, and the information you provide here will not be passed on or shared with another organisation for any other purpose than that stated for the Survey.

The general questions are to help us get a better idea of your overall life circumstances. This will help us plan better services in the future.

The final section in the Survey is for the AHP member of staff to complete – this will tell us about which AHP profession the member of staff is from and what service they work in.

What will we do with the information?

Every AHP member of staff across Scotland who works with adults will ask at least 2 people they see to take part in this Survey. We will record all the Survey information and use this to help us decide what kind of changes we need to make to our services to help people keep active and independent for longer. We will share this information with other service providers who support people with their health and wellbeing and with independent living. Any information we share will be anonymous. We will NOT share any personally identifiable information.

Confidentiality

We are asking for your personal health number – called your CHI number. This means that the information health and social care have about you can be linked to your responses on the Lifecurve Survey.

We need your consent to be able to do this. You will be asked to sign a consent form to allow us to do this. Where you have a welfare guardian or Power of Attorney in place they can sign this on your behalf. We will not use your CHI number in any information we publish or share about the Survey. Your personal information will not be shared.

Lifecurve Survey Team

Date: May 2017
LIFECURVE SURVEY

There is growing evidence of the key role of AHPs in improving health and wellbeing across all ages. For AHPs to support people in living healthy, active and independent lives, we need to have a better understanding of where our workforce is intervening as per the bespoke needs of the individual.

*Based on continuing research carried out at the Newcastle University institute for Ageing*