

National Lifecurve Survey

Frequently Asked Questions

NEW FAQ's!	
Q.	I work in NHS Forth Valley but in the Falkirk Council area. How do I complete the box for LA/Partnership, NHS Board – do I tick both?
A.	All local data will be shared via your local AHP Director/Associate Director and some practitioners/Team Leads have indicated that it would be very helpful to have their data by partnership area. If you are employed by NHS, in order to do this you would need to provide both the NHS Board where you work and the LA/Partnership area you are provide your service in.
Q.	How do I record the length of time a person hasn't been able to do an activity when they have never been able to do it?
A.	You can record the length of time they have been unable to do the activity unaided as their actual age.
Q.	I work in a palliative care setting where all of the people I work with are very poorly and in the end stages of life. I don't do a Lifecurve Survey with them do I?
A.	No. This is why we have asked practitioners to use their professional judgement in choosing which people to ask to take part in the Survey. Clearly it wouldn't be appropriate to ask someone in these circumstances.
Q.	In radiology a patient may have attended on numerous occasions previously for other examinations but it may be their first attendance for another examination. Do I log this as a First or return visit?
A.	Record the appointment according to the referral - so if the person has had previous appointments that don't relate directly to the current referral/reason for appointment then mark that as a first visit. If the person is coming for a subsequent appointment relating to the same referral/reason for referral then mark it as a return visit.
Q.	The Survey document talks about sharing of information – what does this mean? What information will be shared? Will it be the persons own health and/or personal records?
A.	The Survey asks people to give consent to share their personal Health Number i.e. their CHI number (or their date of birth and postcode where this is not available, as these will be used to identify their CHI number). We will not be accessing peoples' own individual health or social care

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	<p>records held by either NHS, social care or health and social care partnerships.</p> <p>The CHI number will allow ISD to retrieve the health and social care services the person has received via the Source data (already provided by health and social care bodies). ISD will provide this data anonymised to the Lifecurve Survey Team. Only ISD will hold the CHI number for the Survey participants. This anonymised information will be shared as described in the Consent Form.</p>
Q.	Is it possible to have a ‘letter of comfort’ for local Caldecott Guardian or managers who are concerned about the governance for the Survey?
A.	The Governance for the Survey has been completed nationally so there is no need for any further approval to be agreed locally. A letter has been sent to the local AHP Director or Associate Director describing the process (also please see other FAQs about governance). The letter will be posted on the Community of Practice for all staff reference.
Q.	What if someone answers the Lifecurve Survey questions but decides not to sign the Consent Form – do I still return the form?
A.	Yes. We would like to get as high a return as possible with the CHI numbers as this will enable us to cost the services received at different points on the Lifecurve – but do return all completed Survey forms.
Q.	When completing the staff section of the Survey – how do I complete the Partnership area question - do I complete the Partnership area that I, as the member of staff, work in or the Partnership are the Survey participant is from?
A.	Please record the Partnership area where the person is attending for the AHP service.
Q.	The Lifecurve is about ageing – what about people with neurological conditions – their functional loss will look different. Won’t this ‘skew’ the data? Should I include people with neurological conditions in the Survey?
A.	YES! Whilst the Lifecurve does describe a model of ageing, we want to capture all adults that are seen by AHP staff during the Survey period.
Q.	What do I do if someone cannot do one of the activities and is asking for help/advice for them? Or about any of the other additional questions?

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	What action should I take?
A.	We appreciate that the Survey has questions that some AHP staff do not routinely cover. Do make use of your multi-disciplinary/cross sector colleagues for advice as required and where appropriate make onward referrals. Where you identify or a concern is raised or noted that requires immediate/urgent actions (e.g. Adult Support and Protection, Child Protection, serious mental health concern), as in standard practice- discuss the matter with your line manager.
Which people should I do the Lifecurve Survey with?	
Q.	Who is included in the Lifecurve Survey?
A.	All adults across all services, all settings and all care groups eg people in acute and inpatient hospital settings, in community settings, primary care settings, intermediate care, specialist services, social work, housing services, Independent and Third Sector services – including those commissioned by the public sector.
Q.	What age are you counting as adult’s services - 16 or 18?
A.	Whatever age your own service accepts as adults.
Q.	Is anyone excluded from the Survey?
A.	Yes. We are excluding children and young people as the Lifecurve Survey is about adults and ageing. And we are excluding people who do not have Capacity to give consent to share their CHI number and who do not have a Power of Attorney or welfare guardian in place.
Cognition/Capacity/Mental Health/Learning Disability/Insight/Communication Questions	
Q.	I work in an older people’s mental health service and lack of insight is a common occurrence. How can I make sure that service user views are an accurate reflection of their abilities?
A.	Where you know the person you have asked to complete a Lifecurve Survey is likely to over-estimate or under-estimate their abilities then you need to use your professional judgement and skills to help the person complete the Survey questions (this is likely to be the level of support you offer anyway when working with the person -either during the assessment, appointment or intervention. You could also complete the

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	Survey with the person in a collaborative/discursive manner to agree what activities the person can and can't do. You could also ask the person to complete the Survey with a family member present – eg at ward visiting times or in the waiting room or at the persons' home.
Q.	What do I do if someone I am doing the Survey with needs it produced in alternative format/language?
A.	Please contact the AILIP team via the ailip.info@nhs.net email.
Q.	Will we produce the Survey for people who have profound communication difficulties?
A.	We have made the Survey Form as easy to read as possible, using pictures and symbols. We also have an easy read section of the Participant Information Sheet. Please remember that people need to have capacity to give consent in order to take part in the Survey or have a welfare guardian or Power of Attorney in place. We also would anticipate that members of staff may need to support people to complete the Survey Form for a variety of reasons, as they would with any other aspect of their intervention.
Q.	Can people with learning disability take part in the Survey?
A.	Yes. Where there are issues of consent as long as the person has a welfare guardian or power of attorney in place they CAN take part in the survey
Q.	Is the Lifecurve Survey accessible for people with Learning Disability to complete?
A.	We have made the Survey as easy to read as possible, using pictures and symbols. We also have an easy read section of the Participant Information Sheet. We liaised with Scottish Government Health Literacy and Speech and Language Therapy colleagues and amended the Participant Information Sheet according to their comments. However some people are likely to need help to complete the Survey form – as they would with other information provided as part of an AHP intervention.
Q.	Can people who are unable to give consent take part in the Survey?

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A.	Where someone is unable to give consent to share their CHI number and has a welfare guardian or power of attorney in place they CAN take part in the survey
Q.	What about people I am completing an Adults with Incapacity form for? Can they take part in the Survey?
A.	No. Without a welfare guardian or Power of Attorney in place the person cannot take part as they have no-one to act on their behalf.
Q.	If someone has a welfare guardian or a relative has power of attorney are they allowed to participate in the survey and answer the questions on the persons' behalf? (eg where people attend for AHP intervention and their welfare guardian has consented on their behalf for them to receive this).
A.	Yes. There is a space for a welfare guardian or power of attorney to sign the consent form in these circumstances.
General Survey questions	
Q.	How is information about the Lifecurve Survey being circulated?
A.	All designated Communication Leads will receive regular updated via direct email to them and all information will also be placed on the Knowledge Network Community Of Practice (COP). Follow this link to the COP. You do not need an Athens logon or password to access AILIP information as it is all in the public domain. http://www.knowledge.scot.nhs.uk/ahpcommunity.aspx Also find out who your local Communication Leads are. Questions can also be asked via the AILIP email address (ailip.info@nhs.net) or posted on the COP.
Q.	Do I need approval from the local Caldecott Guardian or ethics approval to participate in the Survey?
A.	NO. Local ethics approval is NOT required – approval was given in March 2017 by the Scottish Government Public Privacy Benefit Panel for all Scotland.
Q.	Does my NHS Board/Partnership have to get local approval from the Caldecott Guardian to use the CHI number?
A.	No. We have submitted the Lifecurve Survey and all relevant papers

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	to the Public Benefit and Privacy Panel (PBPP) and have undertaken a Privacy Impact Assessment for this Panel. They have approved the use of the CHI number for this Survey. Linking the health and social care costs via the CHI number will be undertaken by ISD.
Q.	Why are we asking additional questions to the Lifecurve Survey?
A.	We want to get as broad an understanding of people who use our services as possible. These are key areas which impact on health and wellbeing and are priority areas for health and social care services.
Q.	Will there be a one page publication for staff groups?
A.	The first communication bulletin was circulated in December 2016 and regular updates have been published on the AILIP Community of Practice on the Knowledge Network. To access this -follow this link. You do not need an Athens logon or password to access this material – it is all in the public domain. http://www.knowledge.scot.nhs.uk/ahpcommunity.aspx
Q.	Is the Lifecurve a research project?
A.	No. The Lifecurve Survey is that – a Survey where we are collecting information about people who use AHP services.
Q.	Do I have to do both Surveys on the Survey date?
A.	No. You can complete the Surveys as soon as you have the Survey documentation. All staff have 2 weeks to complete the Surveys ensuring all completed Surveys are at their local collection point by Friday 26 th May.
Q.	Can I do more than 2 Surveys?
A.	Yes! We are asking all staff to do the Survey with a MINIMUM of 2 people. If you are able to do more than this we are happy to receive as many Surveys as you are able to complete.
Q.	I don't have access to the persons' CHI number what do I do?
A.	If you do not have access to the persons' CHI number please record their date of birth and postcode. This will allow us to capture the CHI number from ISD.
AHP questions – what AHP professions/staff should take part in the Lifecurve Survey?	

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Q.	Does every member of staff in all AHP professions have to take part?
A.	Yes. Whether you are part time or full time, whatever your Grade/Band or designation is - all AHP staff in all professions working in adults services are expected to participate - the survey is part of the National AHP Programme and is therefore for all AHP staff to engage in their National Programme.
Q.	Does it involve all AHP professions?
A.	YES. We want to include all AHP professions so we can get a Scotland wide and AHP wide picture of where AHPs intervene on people's Lifecurve. So even if your professional intervention doesn't usually involve discussing activities of daily living eg diagnostic radiography, we still need every AHP professional group to participate. We are working with Paramedics separately given the emergency nature of some of their work.
Q.	Are students able to take part in the Lifecurve Survey?
A.	Yes –students who are on practice placement are included.
Q.	Where different Allied Health Professionals work in a multidisciplinary team – can they ask the same person to do a Lifecurve Survey?
A.	In theory there is nothing to stop this. However, from a person experience perspective it will be better not to ask the same person twice. Staff should discuss in their team and agree who they will ask and/or where they ask a person to complete a Survey. Not all staff work in a MD Team and work across different parts of the organisation as well as across organisations – so where the person reports they have already completed a Survey, we recommend that the member of staff choose another person to ask.
Q.	The information circulated about the Survey has very little or no information about speech, language and communication that speech and language therapists will be able to contribute to. Is this work relevant to speech and language therapists?
A.	The Lifecurve describes how all of us age regardless of our abilities/difficulties. It allows us to understand where a person is in their ageing journey. And help predict what activity of daily living they are

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	likely to have difficulty with next. This it true for everyone unless we have a particular neurological difficulty – in which case the loss of functional ability will be specifically related to the particular condition. Clearly many people AHPs work with will be “left of the Curve” i.e. they are able to manage all of the everyday activities in the Survey.
Q.	What is the relevance of the Lifecurve Survey to therapeutic radiographers? Interventions are only provided following referral by an oncologist and people receive radiotherapy at the appropriate stage in their cancer pathway. In many cases the people radiographers see are fit apart form their cancer and are still continuing to work and lead fairly normal lives.
A.	The Lifecurve describes how all of us age regardless of our abilities/difficulties. It allows us to understand where a person is in their ageing journey. And help predict what activity of daily living they are likely to have difficulty with next. This it true for everyone unless we have a particular neurological difficulty – in which case the loss of functional ability will be specifically related to the particular condition. Clearly many people AHPs work with will be “left of the Curve” i.e. they are able to manage all of the everyday activities in the Survey.
Guidance on Completing the activities of daily living questions	
Q.	Is there any guidance on how to answer the activities of daily living questions? For example – does walking 400 yards mean with a walking stick or not?
A.	Yes. Please see Appendix 1 in the Lifecurve Staff Checklist which gives more detail about how to answer each activity of daily living question. For example if the person doesn’t cut their own toenails but could still manage to do this they should answer that they can do the activity unaided. So where a person uses a walking aid to walk 400 yards they are deemed unable to do this activity unaided (this includes where a person has purchased their own equipment and uses it).
Q.	Does it make a difference in walking 400 yards whether the person can do this on a level environment or on a hill/slope?
A.	No. The Lifecurve research identifies whether the person is able to do this at all whether on the flat, with stops or up a gradient. Just - can they do it.
Q.	What about using a rail or bannister for steps and stairs – what if

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	someone doesn't always use a rail/bannister?
A.	Where a person cannot go up and down steps or stairs without using a bannister or rail (or using equipment or help from another person)– they are deemed to not to be able to do this activity unaided. However, where someone only sometimes or occasionally uses a bannister or rail going up/down stairs/steps, then they are deemed able to do this activity unaided. This because everyone will use bannisters/rails on stairs at times.
Q.	If someone can 'prepare a meal' by using a microwave for a ready made meal are does this mean they can do the activity 'cook a hot meal' unaided?
A.	No. The Lifecurve research identifies 'cook a hot meal' as part of the impairment group 'Upper limb control and standing balance'. Therefore, from the evidence this includes being able to stand for a period of time, cut/peel and prepare food is an important part of the task.
Q.	For the 'moving around' activity does this include where someone can get around using a mobile device eg wheelchair or scooter?
A.	No. Lifecurve research identifies 'moving around' by walking. Remember for all the activities of daily living – we are not looking at independence, we are looking at their ageing journey and the underlying impairments they are experiencing. So a person may be independent by using equipment and adaptations or by using a microwave – which is great for the person, but for the purposes of the Survey we need to record whether they can do the activity unaided ie without the help of equipment or another person.
Q.	If I am seeing a person who I know will have an improved ability to carry out activities of daily living in a short time after intervention (eg hip replacement), how should they complete the Survey questions?
A.	The Lifecurve Survey is about a person's ability on the actual day you are seeing them and asking them the Survey questions. They should answer the questions based on their ability on the actual day they are completing the Survey questions.
Q.	Where someone is able to manage peg feeding independently, or have

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	other forms of nutrition (and they don't eat or cook a hot meal) – how does this get recorded on the Survey?
A.	Remember, the activities of daily living are a 'proxy' for a series of underlying impairments – thus cooking a hot meal involves being able to stand, manipulate food and implements etc – so if the person cannot do this unaided, then this is how the activity is recorded
Q.	Is there a way to record waiting times for intervention and the impact that may have on a person's ability to carry out every day activities?
A.	No. Not on the Survey form. However, each area will receive their own data back and this is one of the reasons we are undertaking the Survey – to provide data which enables discussion about supporting people earlier with prevention/early intervention/supported self management etc
Q.	Will the sample size of people who take part in the Survey be representative of the range and complexity of clients that are seen in AHP services?
A.	Yes – but you need to ensure that when you choose who to ask to participate in the Lifecurve Survey that they are 'typical' of people you generally see within your service.
Q.	What about ensuring there is no 'bias' in how people are identified to take part?
A.	We considered establishing parameters for this – eg choose the first and last person you see. However, this wouldn't necessarily fit with all professions and all settings. Please use your professional judgement to ensure that the 2 people you identify to take part are "typical" of people who use your service.
Q.	Given the variety and complexity of our clinical activity across pathways, is there any research data about correlation with diagnosis and rapidity of decline? Does diagnosis matter?
A.	The Lifecurve is about the ageing process and therefore describes how people without a neurological condition age, so is true for everyone. Clearly there are a number of other factors which impact on our ageing - and therefore will impact on our ability to undertake activities of daily living such as our overall health status, our cognitive function, socio-demographic factors, how socially connected we are, our risk factors such

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	as adverse childhood events etc.
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