



End of Life Data Dictionary

Introduction

What is End of Life?

In November 2008, Professor Sir Michael Marmot was asked by the then Secretary of State for Health to chair an independent review to propose the most effective evidence-based strategies for reducing health inequalities in England from 2010.

The review produced the report 'Fair Society, Healthy Lives' which proposed a cradle-to-grave approach to reduce inequalities, commonly referred to as the Life Course Framework. This broke down people's lives into a number of different life phases.

It concluded that, to have a significant impact on health inequalities, action needs to be taken on six policy objectives. These policy objectives are listed below against their applicable life phase and focus area:

Policy Objective:	Life Phase:	Focus Area:
Give every child the best start in life.	Starting Well	Pre-Natal - Pre-School
Enable all children, young people and adults to maximise their capabilities and have control over their lives.	Developing Well	School
Create fair employment and good work for all.	Working Well	Training and Employment
Ensure a healthy standard of living for all.	Living Well	Family
Create and develop healthy and sustainable places and communities.	Living Well	Community
Strengthen the role and impact of ill health prevention.	Ageing Well	Retirement

As an extension of this process we have developed additional, stand alone, dictionaries that relate to specific service areas. The End of Live dictionary takes collates risks that relevant to palliative care.

What is this data dictionary?

The measures defined in this dictionary work with a preventative model of support. One of the most effective methods of measurement, when delivering preventative services, is that of risk and protective factors. The removal of risks and the addition of protective factors provides a statistical basis for evidence of impact.

The definitions in this dictionary result from the analysis of the relevant national outcome frameworks, programmes and clinical guidelines. These have then been combined to form a single document listing all of the measures relevant to the Living Well life stage.

For each measure there is a definition (taken from one or more of the source documents), an explanation of why the measure is recorded, a description of the data that is collected and the survey point(s) at which the data is recorded. There is also a separate table showing which framework or policy records the measure.

The dictionary is separated into three areas of risk: Personal Circumstances, Lifestyle and Behaviour, and finally, Status.

Personal Circumstances - related to the factor(s) that are relevant to the support people need. Personal circumstances are non-clinical factors that are likely to have an adverse effect on health. Many of these types of risk are unchangeable or may take a long time to resolve.

For example: Social isolation is a personal circumstance. Being socially isolated can cause stress and anxiety, increased risk of misusing alcohol or substances, and increased visits to the GP or Accident and Emergency.

Lifestyle and Behavioural factors - something that increases the likelihood of a poor long-term health outcome. These will form the basis of the support provided and are able to be reduced with the right support and services. The removal of this type of risk can be achieved in a shorter period.

For example: smoking is a lifestyle and behavioural factor that increases the risk of heart, lung and respiratory disease.

Status - the result of a lifestyle and behavioural factor. The removal or reduction of these risks is likely to be a long-term outcome.

For example: A person who has been diagnosed as pre-diabetic as a result of poor lifestyle and behavioural factor(s) now has 'pre-diabetic' as a status, however the focus of support will be on the removal and reduction of the lifestyle and behaviour issues.

The data dictionary is a shared reference document that describes what should be recorded. This is because it is important that everybody who collects the data has the same understanding of what is being collected.

The measures to be recorded are taken from the following frameworks:

Organisation:

Framework Title:

National Institute for Health
and Clinical Excellence

CG51: Drug Misuse
CG161: Falls in Older People
PH24: Alcohol use disorders
PH50: Domestic violence and abuse
QS13: Quality standard for end of life care for adults

Department of Health

Improving Outcomes and Supporting Transparency

Department of Health

CCG Improvement and Assessment Framework

Department of Health

NHS Outcome Framework

Department of Health

Adult Social Care Outcome Framework

Department of Health

End of Life Care Strategy

End of Life – Example Risk Map

Personal circumstances	Behaviour	Status
<p>Current Score : C Score on assessment : C Highest Score : C</p>	<p>Current Score : 1 Score on assessment : 1 Highest Score : 1</p>	<p>Current Score : 2 Score on assessment : 2 Highest Score : 2</p>
<p>Accommodation</p> <p>Housing - homeless UNASSIGNED Assign</p> <p>The client has nowhere to live: someone is not homeless if they are in temporary accommodation</p> <p>Housing - temporary accommodation UNASSIGNED Assign</p> <p>The client is living in temporary accommodation, this includes hostel accommodation, sofa surfing, or short-term arrangements outside the family</p> <p>Housing - unsuitable housing UNASSIGNED Assign</p> <p>The client feels they are living in unsuitable accommodation, this might be because it is unsafe, unsanitary, overcrowded, in disrepair or at risk of domestic abuse.</p>	<p>Alcohol</p> <p>Alcohol UNASSIGNED Assign</p> <p>The client is drinking more than the recommended units of alcohol per week on average: 14 units for both women and men, 4 units for pregnant women</p> <p>Exercise</p> <p>Physically inactive UNASSIGNED Assign</p> <p>The client is doing less than 30 minutes of moderately intense physical activity per week in bouts of 10 minutes or more</p> <p>Moderately physically active ASSIGNED Resolve Delete</p> <p>The client is doing more than 30 minutes but less than 150 minutes of moderate intensity physical activity per week</p>	<p>Employability</p> <p>Limited IT skills UNASSIGNED Assign</p> <p>Client who reports that they have not independently looked for a job and submitted a job application online</p> <p>Health</p> <p>Poor Management of Pain UNASSIGNED Assign</p> <p>People approaching the end of life who self declare that their pain is not being managed effectively</p> <p>Religious and spiritual needs not met UNASSIGNED Assign</p> <p>People who self-report that they have not been offered spiritual and religious support appropriate to their needs and preferences</p>
<p>Domestic abuse</p> <p>Disclosed domestic violence and abuse UNASSIGNED Assign</p> <p>Client who self-reports that they are or have been subject to domestic violence and abuse. Including physical, mental and emotional abuse.</p>	<p>Independence</p> <p>Poor management of long term conditions UNASSIGNED Assign</p> <p>The client feels unsupported or has had 2 or more unplanned admissions to hospital due to LTC</p> <p>Risk of falls UNASSIGNED Assign</p> <p>Two or more falls risk factors are present</p> <p>Requires help with control over daily life UNASSIGNED Assign</p> <p>The client reports that they have some control over their daily lives but not enough</p> <p>Not had sight test UNASSIGNED Assign</p> <p>Adults who have not had eye test in last 2 years or 1 year for over 70s</p>	<p>Health check</p> <p>High blood pressure UNASSIGNED Assign</p> <p>The client has a blood pressure reading over 140/90</p> <p>Raised blood pressure UNASSIGNED Assign</p> <p>The client has a blood pressure reading of between 120/80 and 140/90</p>
<p>Environment</p> <p>Outdoor spaces ASSIGNED Resolve Delete</p> <p>The client reports that they have not taken a visit to the natural environment for health or exercise over the previous seven days</p> <p>Noise UNASSIGNED Assign</p> <p>The client reports that excessive noise is having an adverse effect on their health. 'Noise' includes environmental, neighbour, and neighbourhood</p> <p>Environment - Community safety UNASSIGNED Assign</p> <p>The client reports that they do not feel safe in their own home or their community</p>	<p>Smoking</p> <p>Smoking UNASSIGNED Assign</p> <p>The client smoked cigarettes in the last week, regardless of number per day</p>	<p>Independence</p> <p>Care plan ASSIGNED Resolve Delete</p> <p>Clients with a completed and up-to-date personalised care plan</p> <p>Not treated in preferred place of care UNASSIGNED Assign</p> <p>Clients who are not being treated in their preferred place of care</p> <p>Death in usual place of residence UNASSIGNED Assign</p> <p>People who do not die in their usual place of residence</p> <p>Frail UNASSIGNED Assign</p> <p>The client is assessed with mild to severe frailty</p>
<p>Family</p> <p>Caring responsibility UNASSIGNED Assign</p> <p>Client is a carer who helps look after someone with a health condition</p>	<p>Substance misuse</p> <p>Substance misuse UNASSIGNED Assign</p> <p>The client regularly uses intoxicants (excluding alcohol) to an extent where physical dependence or harm is a risk</p>	<p>Mental health</p> <p>Dementia UNASSIGNED Assign</p> <p>Clients with dementia</p> <p>Low wellbeing UNASSIGNED Assign</p> <p>The client has a low sense of wellbeing, as indicated by their result on either SWEMWBS, WEMWBS or the ONS Measuring National Well-being Programme</p>
<p>Financial hardship</p> <p>Financial hardship UNASSIGNED Assign</p> <p>Client who self-discloses that they have unmanaged debt, rent arrears, or low income</p>		<p>Weight</p> <p>Obese UNASSIGNED Assign</p> <p>The client has a BMI over 30, with the exception of South Asian and Chinese clients where a BMI over 27.5 indicates obesity</p> <p>Underweight UNASSIGNED Assign</p> <p>Client has a BMI of 18 or less</p> <p>Overweight UNASSIGNED Assign</p> <p>The client has a BMI of 25-30, with the exception of South Asian and Chinese clients where a BMI of 23-27.5 indicates overweight</p>
<p>Health</p> <p>Late diagnosis UNASSIGNED Assign</p> <p>People at the end of life who were not diagnosed in a timely way</p>		
<p>Safeguarding</p> <p>Vulnerable adult UNASSIGNED Assign</p> <p>The client meets the criteria for a vulnerable adult</p>		
<p>Social isolation</p> <p>Social isolation UNASSIGNED Assign</p> <p>Client who is socially isolated or lonely</p>		

Contents

Personal Circumstances:

Indicator	Page
<u>Caring Responsibility</u>	7
<u>Domestic Abuse</u>	8
<u>Financial Hardship</u>	9
<u>Housing - Homeless</u>	10
<u>Housing - Temporary Accommodation</u>	11
<u>Housing - Unsuitable Accommodation</u>	11
<u>Late Diagnosis</u>	12
<u>Social Isolation - Loneliness</u>	13
<u>Vulnerable Adult</u>	14

Behavioural Factors:

Indicator	Page
<u>Alcohol Misuse</u>	15
<u>Not Had Sight Test</u>	16
<u>Physical Activity – Physically Inactive</u>	16
<u>Poor Management of Long-Term Conditions</u>	17
<u>Poor Mobility and Balance – Risk of Falls</u>	18
<u>Requires Help with Daily Life</u>	19
<u>Smoking</u>	20
<u>Substance Misuse</u>	21

Status:

Indicator	Page
<u>Care Plan</u>	22
<u>Death in Usual Place of Residence</u>	23
<u>Dementia</u>	23
<u>Frailty</u>	24
<u>Mental Health - Low Reported Well-being</u>	25
<u>Pain Management</u>	26
<u>Religious and Spiritual Needs</u>	27
<u>Treated in Preferred Place of Care</u>	28

Personal Circumstances

Personal circumstances are measures of socio-economic factors that are present in a person's life. These can be quite profound factors that have an impact on a person's ability to manage health lifestyle choices or even to make changes that can change clinical factors.

Measure: Caring Responsibility

Definition:	A carer is someone who helps look after a relative who has a condition such as a disability, illness, mental health condition, or a drug or alcohol problem.
Reason for Collecting:	<p>There is a clear relationship between poor health and providing care that increases with the duration and intensity of the caring role. Those providing high levels of care are twice as likely to have poor health compared with those without caring responsibilities.</p> <p>Lack of access to replacement or respite care poses a greater risk of ill health and low wellbeing for the carer.</p>
Data Collected:	Number of clients with a caring responsibility.

Outcome Framework:

Reference:

Adult Social Care Outcome Framework	1D
Public Health Outcome Framework	1.18
National Strategy For Carers	Reference
NHS Outcome Framework	2.4
CCG Improvement and Assessment Framework	Reference

Measure Disclosed domestic violence and abuse

<p>Definition</p>	<p>The cross-government definition of domestic violence and abuse is: any incident or pattern of incidents of controlling, coercive, threatening behaviour, violence or abuse between those aged 16 or over who are, or have been, intimate partners or family members regardless of gender or sexuality. The abuse can encompass, but is not limited to:</p> <ul style="list-style-type: none"> • psychological • physical • sexual • financial • emotional <p>Where this is historic then it will be recorded if that abuse still affects the client's life presently.</p>
<p>Reason for collecting</p>	<p>People experiencing domestic violence and abuse may experience additional physical and mental health needs as a result of abuse. In addition, people may have additional support needs during their training and early employment.</p> <p>Domestic violence and abuse are safeguarding issues where children are involved.</p>
<p>Data collected</p>	<p>Number of people who self-report that they are or have been subject to domestic violence and abuse.</p>

Outcome Framework

Reference

<p>NICE Guidance</p>	<p>PH50 CG110</p>
<p>Healthy Child Programme: Pregnancy and the First Five Years</p>	<p>HCP – P17 HCP – P45</p>
<p>Public Health Outcome Framework</p>	<p>1.11</p>
<p>Social Justice Outcome Framework</p>	<p>KI-1</p>

Measure Financial Hardship

Definition	The client reports that their household are on a low income (60% of average wages before housing costs) Indicators are: <ol style="list-style-type: none"> 1. The family cannot afford a number of food and clothing items 2. They claim Job Seekers Allowance, Employment Support Allowance or Income Support 3. They have required fuel costs that are above average or, were they to spend that amount, it would leave them with a residual income below the fuel poverty line. 4. They have unmanaged debt; this includes rent arrears
Reason for collecting	Clients may be perceived to be in a 'benefits trap' where they are unable to earn enough to equal or exceed their current rate of benefit. Recent legislation has capped benefits resulting in increased need to obtain employment. Many clients may find the cost of training and work-focused activity difficult to manage.
Data collected	Number of clients who self-disclose that they have unmanaged debt, rent arrears or low income.

Outcome Framework

Reference

Public Health Outcomes Framework	<u>1.1, 1.17</u>
Social Justice Outcomes Framework	<u>KI-4</u>
Healthy Child Programme	<u>HCP – P17</u>

Measure: Housing - Homeless

Definition:	<p>You may be legally homeless if:</p> <ol style="list-style-type: none">1. You've no legal right to live in accommodation anywhere in the world.2. You can't get into your home - eg. your landlord has locked you out. It's not reasonable to stay in your home - eg. risk of violence or abuse.3. You're forced to live apart from your family or people you normally live with because there's no suitable accommodation for you.4. You're living in very poor conditions - eg. overcrowding. <p>If you're legally homeless, your council must provide you with help – this could range from giving advice to arranging accommodation. The amount of help they give you will depend on things like:</p> <ul style="list-style-type: none">• If you became homeless through no fault of your own• If you're eligible for assistance• If you're in priority need
Reason for Collecting:	Being homeless is an indication of social risk. This has implications for financial status.
Data Collected:	Number of people who are homeless and not living in temporary accommodation provided by their local authority.

Outcome Framework:

Reference:

Public Health Outcome Framework

[1.15i](#)

Social Justice Outcome Framework

[KI-1](#)

Measure: Housing - Temporary Accommodation

Definition:	Temporary accommodation includes sofa-surfing, hostel accommodation and short-term arrangements as a non-dependent.
Reason for Collecting:	Living in temporary accommodation is an indication of social risk. It often leads to a period of financial crisis for someone as benefits will usually be delayed.
Data Collected:	Number of clients who are living in temporary accommodation as defined above.

Outcome Framework:**Reference:**

Public Health Outcome Framework	1.15ii
Healthy Child Programme: Pregnancy and the First Five Years	HCP - P17
Social Justice Outcome Framework	KI -1

Measure: Housing - Unsuitable Accommodation

Definition:	Accommodation is self-declared unsuitable by the client.
Reason for Collecting:	Unsuitable accommodation might include housing repairs or overcrowding. Typically, this will have an adverse effect on the client and the wider family's physical and mental health.
Data Collected:	Does the client feel that they are living in unsuitable accommodation? This might be because it is unsafe, unsanitary, overcrowded or in disrepair.

Outcome Framework:**Reference:**

Public Health Outcome Framework	1.15i
Healthy Child Programme: Pregnancy and the First Five Year	HCP – P17
Social Justice Outcome Framework	KI-1

Measure: Late Diagnosis

Definition:	Person at the end of life was not diagnosed in a timely way. Service providers should ensure that systems are in place to identify people approaching the end of life in a timely way. It is accepted that a proportion of deaths will be unexpected and therefore unlikely to be identified in time to be included on a register or equivalent system. Also, some people may not wish to be identified and/or may not consent to being included on a register or equivalent system.
Reason for Collecting:	People approaching the end of their life should be identified at the right time so they can receive care and support to meet their needs and preferences.
Data Collected:	Number of clients at the end of life who were not diagnosed in a timely way

Outcome Framework:

NICE Guidance

Reference:

[QS13](#)

Measure: Social Isolation - Loneliness

Definition:	An adult is considered to be socially isolated if they have no support from either a partner, family or a friend. The client reports that they do not have as much social contact as they would like.
Reason for Collecting:	Social isolation may be a trigger for mental ill-health problems, reduction in physical activity and the inability to access services. Social isolation is all considered an indicator for higher risk of suicide.
Data Collected:	Number of adults who define themselves as socially isolated or lonely.

Outcome Framework:

Reference:

Public Health Outcome Framework	<u>1.18</u>
Adult Social Care Outcome Framework	<u>1L</u>
Preventing Suicide in England	<u>Reference</u>
WHO - Preventing Suicide - A Global Imperative	<u>Reference</u>

Measure: Vulnerable Adult

Definition:	<p>A “vulnerable adult” is aged 18 or over; receives or may need community care services because of a disability, age or illness; and who is/or may be unable to take care of themselves or protect themselves against significant harm or exploitation.</p> <p>“A person lacks capacity in relation to a matter if, at the material time, he is unable to make a decision for himself (in relation to the matter) because of an impairment of, or disturbance in the functioning of, the mind or brain.” [Definition of a ‘vulnerable adult’ from the Mental Capacity Act, 2005]</p>
Reason for Collecting:	<p>Vulnerable people are at particular risk of being able to access important services that can improve their mental and physical wellbeing.</p> <p>In addition, vulnerable people are at greater risk of being victims of abuse and violence.</p>
Data Collected:	<p>Number of clients who meet the criteria for being a vulnerable adult.</p>

Outcome Framework:

Reference

Adult Social Care Outcome Framework

4B

Behavioural Factors

These are issues that increase the likelihood of a poor long-term health outcome. These will form the basis of the support provided and are able to be reduced with the right support and services. The removal of this type of risk can be achieved in a shorter period.

Measure: Alcohol Misuse

Definition:	Clients who regularly exceed the advised maximum amount of alcohol. For both men and women: 2 - 3 units per day (guideline: <14 units per week)
Reason for Collecting:	Alcohol consumption is a contributing factor to hospital admissions and deaths from a diverse range of conditions. Alcohol can be a contributory factor to falls in older people. As the metabolic rate slows down with ageing the effect of alcohol is greater.
Data Collected:	The number of clients who regularly exceed the advised maximum amount of alcohol units per day.

Outcome Framework:

Reference:

NICE Guidance	CG110 , CG45 , CG100 , PH24 , CG127
Public Health Outcome Framework	2.1 , 2.15
Social Justice Outcome Framework	KI5
Healthy Child Programme: Pregnancy and the First Five Years	HCP – P17 HCP – P45

Measure: Not Had Sight Test

Definition:	Adults who have not had an eye test in the last two years and adults over 70 who have not had an eye test in the last year.
Reason for Collecting:	An eye test can pick up eye diseases, such as glaucoma and cataracts, as well as general health problems including diabetes and high blood pressure. It can also reduce the risk of falls.
Data Collected:	Number of adults between 65 - 70 who have not had an eye test in the last two years and adults over 70 who have not had an eye test in the last year.

Outcome Framework:

Public Health Outcome Framework

Reference:[4.12](#)**Measure: Physical Activity - Inactive**

Definition:	<p>Adults (16+) who do less than 30 “equivalent” minutes of moderate intensity physical activity per week in bouts of 10 minutes or more.</p> <p>All adults should aim to be active daily. Over a week, activity should add up to at least 150 minutes (2½ hours) of moderate intensity activity in bouts of 10 minutes or more – one way to approach this is to do 30 minutes on at least 5 days a week.</p>
Reason for Collecting:	Increasing physical activity has the potential to improve physical and mental health, reduce the risk of developing a life limiting illness and improve life expectancy
Data Collected:	Number of adults (16+) who do less than 30 “equivalent” minutes of moderate intensity physical activity per week in bouts of 10 minutes or more.

Outcome Framework:

NICE Guidance

Public Health Outcome Framework

No Health Without Mental Health

Reference:[PH17 CG43](#)[2.13](#)[Reference](#)

Measure: Poor Management of Long-Term Condition(s)

Definition:	Client with a Long-Term Condition (LTC) who reports that they: <ol style="list-style-type: none">1. Have had two or more unplanned admissions to hospital, relating to that LTC, in the past 12 months.2. Feel unsupported with managing their LTC.
Reason for Collecting:	LTCs have a significant impact on a person's ability to work and live a full life. People from lower socio-economic groups have increased risk of developing a LTC – better management can help to reduce health inequalities
Data Collected:	Number of clients with a long-term condition who report that they have had two or more unplanned admissions to hospital in the past 12 months or feel unsupported to manage their condition

Outcome Framework:

Reference:

NICE Guidance

[NG22](#)

NHS Outcome Framework

[1.08](#)

Measure: Poor Mobility and Balance - Risk of Falls

Definition:	<p>There is a risk of falls when two or more of the following risk factors are present:</p> <ul style="list-style-type: none">• Living Alone• Presence of an LTC• Impaired Mobility and Gait• Use of Sleeping Medication• Sedentary Lifestyle• Low BMI• Impaired Cognition• Visual Impairment• Food Problems• Poor Footwear• Inappropriate Assisted-Living Aids
Reason for Collecting:	<p>Falls and fall-related injuries are a common and serious problem for older people. People aged 65 and older have the highest risk of falling, with 30% of people older than 65 and 50% of people older than 80 falling at least once a year.</p> <p>The human cost of falling includes distress, pain, injury, loss of confidence, loss of independence and mortality. Falling also affects the family members and carers of people who fall. Falls are estimated to cost the NHS more than £2.3 billion per year - therefore falling has an impact on quality of life, health and healthcare costs.</p>
Data Collected:	Number of clients who have two or more risk factors.

Outcome Framework:

Reference:

NICE Guidance

[CG161](#)

NHS Outcome Framework

[2.24](#)

Measure: Requires Help with Control Over their Daily Life

Definition:	Adults who report that they have some control over their daily lives, but not enough, or those who report that have no control over their daily lives. Control includes: <ul style="list-style-type: none">● Meal Preparation● Shopping● Transportation● Telephone Usage● Housekeeping● Laundry● Managing Money● Taking Medications
Reason for Collecting:	Not being able to complete these tasks alone presents challenges to maintaining 'functional independence'. People at the end of life will often lose the ability to complete some or all of these tasks alone.
Data Collected:	Number of clients who report that they have some control over their daily life but not enough, or those who report they have no control over their daily life.

Outcome Framework:

Reference:

Adult Social Care Framework

1B

Measure: Smoking

Definition:	Client who smokes, regardless of number of cigarettes. Also, clients that co-habit with smokers are at increased risk of smoking related disease.
Reason for Collecting:	Smoking is a major cause of preventable morbidity and premature death, accounting for 79,100 deaths in England in 2011 and some 18 per cent of all deaths of adults aged 35 and over.
Data Collected:	Number of clients who smoke, regardless of number per day.

Outcome Framework:**Reference:**

NICE Guidance	<u>CG62</u> , <u>PH14</u> , <u>CG127</u>
Public Health Outcome Framework	<u>2.3</u> , <u>2.9</u> , <u>2.14</u>
Healthy Child Programme: Pregnancy and the First Five Years	<u>HCP – P18</u> <u>HCP – P22</u>

Measure: Substance Misuse

Definition:	Adults who regularly use recreational drugs, misuse over-the-counter medications, misuse prescription medications or misuse volatile substances (such as solvents or inhalants) to an extent whereby physical dependence or harm is a risk.
Reason for Collecting:	Individuals misusing substances pose significant risks in terms of overall health and well-being, reduced life expectancy, increased blood-borne virus transmission and reduced physical and psychological health. Substance misuse can also be risk factor in increased suicide risk.
Data Collected:	Number of adults who report that they misuse substances.

Outcome Framework:**Reference:**

NICE Guidance	CG110 , NG64
Public Health Outcome Framework	2.15
Social Justice Outcome Framework	KI-5
Healthy Child Programme: Pregnancy and the First Five Years	HCP – P17 HCP – P45
No Health Without Mental Health	Reference
Preventing Suicide in England	Reference

Status

Status measures are generally more intractable issues such as clinical diagnosis or issues relating to skills and employment. These issues are likely to be heavily dependent on the resolution of things relating to healthy behaviours and socio-economic factors.

Measure: Care Plan

Definition:	A personalised care plan is a tool that records the outcome of the care planning discussion between an individual and their healthcare professional. Plans are owned by individuals and contain all the information they need to manage their own care.
Reason for Collecting:	Personalised care plans are essential tools for managing care between providers in relation to community-based care, mental health services, substance misuse services and others. Plans minimise duplication of processes and promote integration.
Data Collected:	Number of clients who have been identified as requiring a personalised care plan and have plan that is up-to-date.

Outcome Framework:

Reference:

NICE Guidance	QS13 , NG21 , NG58 , NG53 , NG67
Public Health Outcome Framework	1.06 , 4.16
Adult Social Care Outcome Framework	1H

Measure: Death in the Usual Place of Residence

Definition:	People who die in their usual place of residence.
Reason for Collecting:	“Most people would prefer to be cared for at home, as long as high quality care can be assured and as long as they do not place too great a burden on their families and carers” End of Life Care Strategy (2008)
Data Collected:	Number of people who die in their usual place of residence.

Outcome Framework:

End of Life Care Strategy

Reference:

[Reference](#)

Measure: Dementia

Definition:	Dementia is a progressive and largely irreversible clinical syndrome that is characterised by a widespread impairment of mental function
Reason for Collecting:	Dementia changes the way that people think and feel. This could mean that wider health and wellbeing issues go unmet and that people find it difficult to access a range of services.
Data Collected:	Number of clients with dementia.

Outcome Framework:

NICE Guidance

Reference:

[NG97](#)

Measure: Frailty

Definition:	A client who is assessed as having mild to severe frailty on the Edmonton Frail Scale.
Reason for Collecting:	<p>People with frailty have a substantially increased risk of falls, disability, long-term care and death. Frailty develops as a consequence of age-related decline in multiple body systems, which results in vulnerability to sudden health status changes triggered by minor stress or events such as an infection or a fall at home.</p> <p>Between a quarter and half of people older than 85 are estimated to be frail, with overall prevalence in people aged 75 and over approximately 9%.</p>
Data Collected:	Number of clients who have been assessed as having mild to severe frailty on the Edmonton Frail Scale.

Outcome Framework

Reference

CCG Improvement and Assessment Framework 2017/18

[Reference](#)

Edmonton Frailty Scale

[Reference](#)

Measure: Low Reported Wellbeing

Definition:	<ol style="list-style-type: none">1. Scoring 40 or less on the Warwick-Edinburgh Mental Well-being Scale.2. Scoring 16 or less on the Short Warwick-Edinburgh Mental Well-being Scale3. Low sense of Wellbeing.4. ONS Measuring National Well-being Programme.
Reason for Collecting:	Low sense of wellbeing is an indicator of social risk.
Data Collected:	<ol style="list-style-type: none">1. Number of adults scoring 40 or less on the Warwick-Edinburgh Mental Well-being Scale.2. Number of people scoring 16 or less on the Short Warwick-Edinburgh Mental Well-being Scale3. Number of adults scoring 4 measures on ONS programme.4. Self-reported stress.

Outcome Framework:**Reference:**

Public Health Outcome Framework

[2.23](#) [2.24](#)

Healthy Child Programme: Pregnancy and the First Five Years

[HCP – P17](#)

No Health Without Mental Health

[Reference](#)

Measure: Poor Management of Pain

Definition:	A person approaching the end of life who self declares that their pain is not being managed effectively.
Reason for Collecting:	Much can now be done medically to make their last few weeks or months relatively pain-free. Patients frequently express the desire to have open and honest dialogue with medical carers about pain. The patient should be the prime assessor of their pain and be encouraged to take an active role in their pain management. Pain Control in Palliative Care - End of Life Care Department of Health
Data Collected:	Number of people approaching the end of life who self-declare that their pain is not being managed effectively.

Outcome Framework:

Reference:

NICE Guidance

[QS13](#)

End of Life Care Strategy

[Reference](#)

Measure: Religious and Spiritual Needs Not Met

Definition:	A person approaching the end of life who self-reports that they have not been offered spiritual and religious support appropriate to their needs and preferences.
Reason for Collecting:	Having a person's religious and spiritual needs met helps them to die at peace and with dignity.
Data Collected:	Number of people who self-report that they have not been offered spiritual and religious support appropriate to their needs and preferences.

Outcome Framework:

Reference:

NICE Guidance

[QS13](#)

End of Life Care Strategy

[Reference](#)

Measure: Treated in Preferred Place of Care

Definition:	Person who is not being treated in their preferred place of care
Reason for Collecting:	Peoples' wishes as to their preferred place of care should be respected as part of their personalised care plan. It also delays the need for additional care and support.
Data Collected:	Number of clients who are not being treated in their preferred place of care.

Outcome Framework:

NICE Guidance

Reference:

QS13, QS15

The data dictionaries are licensed under a [Creative Commons Attribution-ShareAlike 4.0 International License](https://creativecommons.org/licenses/by-sa/4.0/).

If you would like further information on the dictionaries, and how they can support your work please email info@insideoutcomes.co.uk.

