



Social Protection

Innovative Investment in Long-Term Care

GLOSSARY

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Acronyms and Abbreviations

ADL	Activities of daily living
ASCOT	Adult social care outcomes toolkit
CBA	Cost-benefit analysis
CEA	Cost-effectiveness analysis
CUA	Cost-utility analysis
DALYs	Disability-adjusted life years
IADL	Instrumental activities of daily living
ICT	Information and communication technology
LTC	Long-term care
OECD	Organisation for Economic Co-operation and Development
QALYs	Quality-adjusted life years
SCRQoL	Social care-related quality of life
SIP	Social Investment Package
SPRINT	Social protection investment in long-term care
SROI	Social return on investment
WP	Workpackage

1 Introduction

The SPRINT project aims to give meaning to the concept of social investment as applied to long-term care provision. To support the SPRINT project, this deliverable explores key concepts that will be used in the project and their application within the project. It aims to set out a common vocabulary to support greater understanding of the notion of social investment in long-term care and related issues.

These concepts cover key aspects of the SPRINT project, from social investment (WP2; Lopez 2017), economic costs (WP4), social impacts (WP4) and return on investment (WP5). The core concept of the SPRINT project is that of “social investment in long-term care”. This concept is explored in detail in the accompanying *Conceptual Report on Long-term Care* (D2.1; Lopez 2017).

2 Methods

Following identification of the key concepts through dialogue among members of the SPRINT consortium, a range of individual experts and sources of commentary on and use of these concepts was consulted.

3 Key Concepts

There is some variation in the terms used when describing long-term care, social investment, economic evaluations and other relevant concepts. For example, the term ‘social care’ might be equivalent to ‘social work’ in some countries. Concepts are set out here in the form they are most widely recognised in long-term care across SPRINT partners’ countries.

SPRINT partners will draw upon this deliverable as a resource for authoritatively defined terms and concepts. This will provide a consistent approach within and across work packages as SPRINT progresses. While, in one sense, the availability of this Glossary means that some of the conceptual work necessary at future stages of the SPRINT research programme has already been done, it remains the case that a number of the concepts outlined below will need to be further operationalised in terms of variables or indicators for specific applications. In the view of SPRINT partners this is best done within the relevant work package as research plans become fully crystallised. The descriptions and definitions of key concepts set out below will serve as a frame of reference and provide a common vocabulary for the SPRINT research programme going forward.

Concepts are listed in alphabetical order. There is considerable interconnection between many concepts, as noted in the descriptions.

3.1 Assistive Technology

Assistive technologies have been available for many years. They generally use information and communication technology (ICT) to support people with health and/or social care needs remotely, often in the individual's own home, although there is now growing experimentation and utilisation in other settings such as nursing home facilities, and on a mobile basis. (Parts of this entry are adapted from Barlow and Knapp (2014).)

Development of assistive technologies has been driven, on the supply side, by technological advances in sensing equipment and data processing, and on the demand side by growing policy concerns about the affordability of conventional health and social care arrangements for supporting older people as populations age. Another demand-side factor has been growth in expectations about what individuals with care needs should receive, both in terms of the amount and quality of care, but also in terms of more personalised support arrangements.

There are many types of assistive technology, of varying degrees of complexity. They are delivered in many different ways, including mobile phones, smart sensors, consumer devices (e.g. 'Fitbit'), personal computers and television. They are designed for a variety of different populations, with a variety of different health and care needs. Terminology is also wide and includes telecare, telehealth, telemonitoring, home monitoring, telemedicine, assistive technology, assisted living technology, welfare technology, remote care and smart homes. These and other terms are often used interchangeably to describe remote delivery of health and/or social care to people outside conventional care settings. For example, a recent scoping review by Lorenz *et al.* (2017) mapped existing and evaluated technologies that support the life and care of people with dementia, their unpaid carers and paid carers, and other professionals: there was an impressive plethora of new technologies but only a trickle of robust studies of their effectiveness or cost-effectiveness.

A defining feature of these assistive technologies is connectivity between the long-term care user and (paid) care staff delivering care and treatment. The purpose of the connectivity is to provide better flows of information about individuals and data to help with their care. Assistive technologies could deliver: information and advice; safety and security monitoring; vital signs monitoring; or lifestyle monitoring (e.g. tracking movement). These technologies involve more than just the deployment of physical devices; they usually need to be accompanied by organisational and service delivery changes underpinned by interactive and non-interactive transmission of digital data.

Two salient considerations about assistive technologies should be emphasised. First, the speed of technological development is rapid, so that evaluations might sometimes be out of date by the time they are completed. Second, technology developers and suppliers, as well as public and private purchasers, are increasingly looking to customise or personalise technologies to fit better with the needs, circumstances and preferences of individuals with long-term care needs, and also with the care or support setting (where appropriate). Both of these considerations can cause complications when thinking about social investment.

3.2 Benchmarking

Benchmarking refers to the process of comparing the performance of an individual worker, service, organisation or system against an agreed standard. The criteria for making the comparison could therefore include any of the criteria discussed later in relation to performance assessment (effectiveness, efficiency etc.). The standard could be set externally, or could be defined by reference to the performance of other similar workers, services, organisations or systems (such as the mean level of performance, or third quartile level, etc.). The aim of benchmarking is to help a service, organisation or system to improve its performance.

3.3 Care Providers

There are a number of care providers involved in long-term care. The report – *The Role of Public and Private Actors in Delivering and Resourcing Long-term Care* (D2.3) – discusses this in detail.

Formal care

Formal care is the term given to the LTC services delivered by paid staff, employed through some kind of formal entity (one with a constitution, formal set of rules, legal incorporation or other nationally determined requirement). Formal carers have employment contracts that specify their duties and care responsibilities, their hours, pay and entitlements. Some formal care staff will have professional qualifications, or may need to be trained and/or licensed (see D2.3).

Formal care providers may be in the public (state or governmental) sector, the private non-profit sector (i.e. constitutionally independent of government, non-profit distributing and with a meaningful degree of voluntarism), the private for-profit sector (again constitutionally independent of government, but now with the ability to distribute profits among owners) or in a growing variety of hybrid organisations (Anheier 2005).

There are quite marked differences between countries, but a common core of formal long-term care services can be recognised, including: needs assessment processes; information and advice services; self-help support groups; respite care; crisis management services; day centres and programmes; support for people in their own homes ('home care', including home help, meals, community nursing); nursing home and residential care provision; and a variety of housing-with-support services (such as 'sheltered housing' and 'extra-care housing').

Informal care

The term 'informal care' has a number of different definitions; it generally refers to care delivered by individuals who have not received formal training in care delivery. Informal carers (sometimes called simply 'carers' or 'caregivers') are frequently partners, family members, friends or neighbours of recipients, providing care and support on a regular basis, typically at home. They can be unpaid or paid, either in cash or kind (adapted from Freeman *et al.* 2017.) The OECD definition of informal carers is 'individuals providing LTC services on a regular basis, often on an unpaid basis and without contract, for example spouses/partners, family members, as well as neighbours or friends' (Colombo *et al.* 2011). (It should be noted that terminology is not universally agreed, and the term 'informal' carer is not liked by some carer groups in the UK and now not often used.)

Across Europe and the rest of the world, the provision of informal long-term care far outweighs the provision of formal care. Friends and family, particularly women, are the mainstay of every long-term care system. A number of countries now have policy frameworks to support and encourage informal carers. Deliverable D2.4 describes variations in informal care provision across European countries.

3.4 Costs of Care

When considering new investment in long-term care, and in particular when evaluating a specific intervention, cost will always be a key component. Costs can be measured either broadly or narrowly, depending on the purpose of the discussion, decision or study. The purpose may be to inform resource allocation decisions within a particular agency (such as a municipality or a private sector provider agency), or in a wider care system in a city, covering all provider sectors and funding sources, both public and private. Another purpose might be to consider the value of an investment to the whole society. The costs to be measured would probably need to be different in each of these cases.

A distinction is sometimes made between direct and indirect costs. *Direct costs* are incurred by the 'main' organisation or sector, while *indirect costs* are incurred by other sectors (such as healthcare

or housing, or perhaps by individual service users or families). The distinction between the two is not always easy to maintain, and is anyway context-specific. A more useful way to distinguish different cost elements would be to separate the following:

- costs for the long-term care sector narrowly defined: these would be the resources needed to organise and operate the intervention (service or programme), and would include variable elements such as costs of staff salaries, equipment and transport, as well as fixed or overhead elements, such as costs associated with buildings and other capital inputs;
- costs for other service sectors, such as healthcare, housing or criminal justice;
- costs for people who use services and their families, such as out-of-pocket payments for services, travel costs, or lost income because of unpaid care commitments;
- costs of productivity losses because of disruptions to employment patterns for service users or carers, e.g. from short- or long-term absenteeism, reduced performance while at work (so-called 'presenteeism'), early retirement or reduced opportunities for career development; these productivity costs might be incurred by employers and the national economy, but might also affect an individual's earnings and household income.

In measuring those costs in practice, the theoretically correct approach is to measure the long-run marginal opportunity costs of resources (Knapp 1984). A *long-term* measure ensures that a long-term (i.e. multi-year) perspective is taken when considering investment, while short-term perspectives and decisions could be misleading because they might overlook the need for proper investment in durable physical or human capital. A *marginal* measure is needed: this is the additional cost of producing one more unit of service (e.g. one more home care visit or one additional day's residence in a nursing home). The word *opportunity* refers to the fact that using a resource in one way means that it cannot be used in another: in economics, an opportunity cost is the value of the opportunity forgone by not using the resource in its best alternative use, whatever that may be. The opportunity cost value will often not be the same as the amount of money actually spent (the 'accounting cost').

3.5 Economic Evaluation

Economic evaluation offers one way to help decision-makers with difficult decisions about how to use public and private resources – which are becoming increasingly scarce in some countries – so as to improve strategic decision-making, care practice and ultimately the lives of individuals affected by long-term care needs. It offers a structured, conceptually sound way to identify, measure and compare the costs and outcomes of two or more interventions or courses of action, and also (in some cases) a way to trade-off improvements in outcomes against increases in costs. (This section is adapted from Knapp and Kettunen (2017) and Knapp (1984).)

Two of the key questions that will frequently be asked when considering whether to recommend, commission or deliver a particular intervention are: does the intervention work, and is it worth it? (Here we use the term ‘intervention’ to refer to services, preventive strategies, specific therapies or configurations of support that are relevant to long-term care.) The ‘Does it work?’ question asks whether the intervention is effective in achieving outcomes (which are defined and discussed below), such as improving independence or wellbeing. If the answer to this first question is likely to be yes (i.e. the intervention appears to be effective, ideally because robust research has demonstrated that better outcomes are likely to be achieved), then the second question needs to be asked. The ‘Is it worth it?’ question asks whether the outcomes are worth the resources needed to achieve them. The second question is what an economic evaluation seeks to address. Both questions need to be answered by reference to a comparator: does the intervention ‘work *better than the alternative* (where the alternative could be ‘doing nothing’), and are the outcomes ‘worth it’ by reference to how the resources (money) *could otherwise* have been spent.

There are therefore three principal components to a cost-effectiveness evaluation: (a) two or more interventions that are being compared; (b) the outcomes of each of them; and (c) the costs associated with each of them.

Economic evaluations come in different forms: in health and social care contexts the most common are cost-effectiveness analysis, cost-utility analysis and cost-benefit analysis.

Cost-effectiveness analysis

If the policy, practice or research question to be addressed to social investment is solely concerned with improving the wellbeing of a particular group of people – say older people with dementia – then, for an economic evaluation, information is needed on the comparative costs of the various interventions being considered, and also on the comparative outcomes, which could be measured in terms of (say) wellbeing, behaviour, cognition, independence in the activities of daily living. This type of evaluation is usually referred to as a **cost-effectiveness analysis** (CEA) in health economics, and the same label can be (and has been) used in social care contexts for more than 30 years (Knapp 1984). A CEA tells decision-makers what course of action most efficiently meets a specific set of clinical needs.

We should also note that the term ‘cost-effectiveness’ is used in health economics to describe both a specific type of economic evaluation (as here) as well as to refer generically to the group of all economic evaluations.

Cost-utility analysis

Many decisions that need to be taken with regard to the deployment of resources raise broader questions. For example, how should resources be allocated between supporting adults with

learning disabilities and older people with dementia? A cost-effectiveness analysis may not be able to help in this instance because different outcome measures would be needed for the two groups of service users. The decision-maker therefore needs a *common measure of outcome* that is relevant across both groups. In healthcare research, two commonly used generic measures are utility – operationalised in terms of quality-adjusted life years (QALYs) – and disability – often measured by disability-adjusted life years (DALYs). Using this kind of generic outcome measure allows the evaluation to address more strategic issues. This type of evaluation is often called a **cost-utility analysis** by health economists. In social care, there has not been an equivalent to the QALY until relatively recently, but there are now two such generic outcome constructs being used in some countries: social care-related quality of life (SCRQoL) as measured by the Adult Social Care Outcomes Toolkit (ASCOT; Netten *et al.* 2012) and wellbeing as measured by ICECAP (Grewal *et al.* 2006). [See Outcome measures below.]

Cost-benefit analysis

Some decision-makers need to decide how to allocate expenditure between social care, education, housing or other interventions, in the hope that available resources can be used to achieve their maximum impact. Until recently, the only outcome measure considered to be appropriate for such broad comparisons (alongside the costs) was monetary: the consequences of the different programmes would need to be converted to monetary values. This type of evaluation is called a **cost-benefit analysis** (CBA) in health economics contexts. In more general evaluative parlance, the term cost-benefit has also been used in more generic ways (to refer to all types of economic evaluation) as well as in narrower ways (such as when comparing the amount of money expended with the amount that is subsequently saved). Cost-benefit analyses of the conventional variety (with monetary benefits) are generally very difficult to undertake in long-term care contexts, because the most relevant outcomes (such as personal functioning and independence in daily living) are hard to convert into monetary values. Recently, growing attention has been given to the possibility of expressing these common outcomes in terms of a common measure of wellbeing (e.g. the current work of Richard Layard and others at LSE). See also the section on social return on investment below.

Discounting

If costs are incurred over more than one year, or if outcomes flow from an intervention over more than one year, there will usually be a need to adjust future figures (costs or outcomes) so that they are comparable to present values. The reason for this is because most people attach lower value to future costs than they do to present costs; i.e. €1,000 next year is worth less to me than €1,000 today, even after adjusting for price inflation. This is often called time preference.

An economic or other evaluation should therefore generally discount (as in the sense of ‘downplay’) the value of future euros so as to be able to compare them to today's euros. The rate of discount rate used in an evaluation might follow what is recommended at national level for public investment appraisals.

3.6 Equity

Equity relates to the extent to which outcomes, access to outputs and payments for them are distributed fairly across individuals, regions or parts of a society. Most long-term care and healthcare systems are inequitable in that their benefits are not distributed in ways that might widely be seen as fair, due to the influence of social, economic, political or underlying demographic factors. Access to services (and, hence, access to the potential impacts of those services in terms of better outcomes) may be unfairly distributed by gender, ethnicity, age, language, religion, income, socioeconomic group or place of residence.

An examination of equity requires that a definition must be specified for ‘fairness’. Equity is generally not the same as *equality* in the provision of services, as people do not have identical needs, so that an equitable allocation of resources would be likely to require giving more resources to people with greater needs. Similarly, it might be seen to be more equitable to ensure that individuals with the lowest ability to pay for care are asked to pay lower amounts than those with greater ability to pay (i.e. with greater wealth or higher incomes). The most commonly discussed aspects of equity are (a) whether incidence and prevalence of need are linked to socioeconomic status, ethnicity or other personal characteristics; (b) whether access to (evidence-based) interventions is linked to type and level of need, as well as to these personal characteristics; and (c) whether individual financial contributions are linked to ability to pay.

How then is the concept of ‘fairness’ chosen? Equity could be defined or operationalized by reference to various political philosophies. For example, conventional welfare economics is often associated with utilitarian philosophy, seeking that distribution of resources that will maximize total welfare (wellbeing) (Barr 2014). Rawls (1972) is one of a number of philosophers to have criticised utilitarianism; he suggested the *maximin principle* that policies should be designed (and hence social investments planned) so as maximize the wellbeing of the least well-off members of society. Collectivist philosophies emphasise equality, and libertarians emphasise autonomy and freedom of choice when make judgements about equity. These are just some examples of equity theories.

3.7 Long-term Care

Long-term care refers to the organisation and delivery of a broad range of services and assistance to people with a reduced degree of functional capacity, physical or cognitive, and who are consequently dependent for an extended period of time on help with basic activities of daily living (ADL). This *personal care* component may be provided in combination with help with basic medical services such as *nursing care*, as well as prevention or rehabilitation or palliative care. Long-term care services can also be combined with lower-level *domestic help* or help with instrumental activities of daily living (IADL) such as bathing, dressing, eating, getting in and out of bed or chair, moving around and using the bathroom. Although people of all ages may become dependent on long-term care, the risk of dependency for those in older age is far more significant. Long-term care services are crucial to many people in older age groups, whose needs may result from long-standing chronic conditions, causing physical or mental disability (OECD 2013).

3.8 Mixed Economy and Marketisation

Some services used by people with long-term care needs are provided by or located within the state (public) sector, some by private (for-profit or third sector) entities, and some by families or through informal community arrangements. This multiplicity of sectors and services – sometimes called the *mixed economy of provision* - is characteristic of all long-term care systems in Europe, although the balances between the sectors varies a great deal from country to country. Prevention strategies might be dominated by the state (locally, regionally or nationally), but will still need inputs from employers and local communities (the ‘social capital’ effect). The for-profit and third (non-profit) sectors are major providers of day and residential care in some countries.

Underpinning most formally based provision are the many and various contributions of family carers and volunteers. These are not ‘free’ resources, of course, because they can impose quite high opportunity costs on families.

Distinctions between the sectors are pertinent because providers with different legal forms may behave differently in responding to various incentives. Different governance structures and motivations may affect their *modus operandi*, their patterns of resource dependency, their chosen styles of management, their ability and willingness to respond to changes in market opportunities, pricing regimes and competition. They might therefore also have divergent costs, ‘casemix’, quality of care and perhaps even user outcomes. Different provider types may also vary with respect to the ways they initiate, cultivate and reinforce trust and reputation, with implications for commissioning.

Each provider of long-term care services could have a number of funding sources, including government (tax revenues), social insurance funds, voluntary (private) insurance companies, users and families (out-of-pocket payments). Those providers might also benefit from the inputs of (unpaid) volunteers. Informal care by family members or others is 'resourced' by the unpaid inputs of those individuals. This has been called the *mixed economy of funding*. Different sources of funding come with a host of potentially different conditions, constraints, incentives and opportunities.

Cross-classifying the main funding and provider types generates a matrix of transaction types (not illustrated here). These multifarious transaction types remind us of the inherent economic, social and political complexity of most pluralist long-term care systems. Each transaction type has accompanying needs for appropriate legislative frameworks to control, audit and monitor the links between funding and provision. A version of the *mixed economy of welfare matrix* was first proposed by Judge (1982) and further developed in Judge and Knapp (1985) and used to describe a rapidly changing long-term care system in England by Wistow *et al* (1994, 1996).

Against this background, there has been more recent focus on what has been called '*marketisation*'. The term has a number of different meanings, each of them reflecting some part of a mixed economy of welfare. For example, Antonnen and Meagher (2013) use the term to refer to a policy change that has 'two dimensions: whether or not market practices and logics (most notably competition) are used in organising services and whether or not private actors, particularly for-profit companies, are involved in providing service' (p.16). Marketisation by this definition, therefore, refers to a particular sub-set of the various transaction types contained within a broader mixed economy of welfare matrix. Many European countries have seen a move towards greater marketisation of long-term care services for older people and other population groups.

3.9 Outcome Measures

The outcomes achieved by a long-term care intervention (whether it is a care service, specific therapy, prevention programmes or other type of intervention) should be defined by reference to the individuals who are potentially affected by those interventions, and specifically by the extent to which their needs have been met. These outcomes therefore relate both to the individual who is the primary recipient of care and also to their unpaid family and other carers. Synonyms for outcomes include 'final outcomes' and (especially in economic evaluation) 'effectiveness' (Knapp 1984, Knapp and Kettunen 2017).

When assessing the outcomes of a long-term care intervention, there are potentially many dimensions to take into consideration. The Adult Social Care Outcomes Toolkit (ASCOT; Netten *et al.* 2012) offers a very helpful framework for identifying those dimensions, as well as a means by

which to measure achievement along each of them. There are eight domains to the ASCOT approach: (a) to feel clean and comfortable; (b) to get enough nutritious and appropriate food and drink; (c) to feel safe and secure; (d) to have accommodation that is clean and comfortable; (e) to have control over one's daily life and activities; (f) to be sufficiently occupied in meaningful activities; (g) to feel involved and to have meaningful relationships; and (h) dignity - not to experience any negative psychological impact of support and care on one's personal sense of significance.

There are many other tools for measuring long-term care outcomes, spanning some or all of these same eight domains.

3.10 Performance Assessment

Performance assessment is a review of how well an individual, service, organisation or system undertakes a defined task. Many criteria could be used to specify more precisely what is meant by 'how well'. These criteria might include: effectiveness in terms of delivering a particular set of services or better quality care (see below); improving outcomes for people who use services (see above); efficiency (for example, as measured in an economic evaluation – see above); equity (see above); empowering individuals to take more control over their lives; protecting vulnerable individuals from abuse or discrimination; improving social inclusion; promoting social solidarity; and ensuring longer-term system sustainability.

Assessment of performance could be undertaken for a host of reasons: to inform a contractual agreement or monitor contract compliance; for inspection purposes; to guide local purchasing or commissioning decisions; to inform broader strategic policy discussions; or so that people who use services or their families can make judgements. Some performance assessment will therefore be quite formal and structured, while some will be relatively informal. Some performance criteria might be objectively assessed while others will rely on more subjective views.

3.11 Prevention

Prevention is usually defined as an action aimed at eradicating, eliminating or minimising the impact of a disease or disability, or aimed at slowing down the decline in functioning, health or quality of life associated with disease or disability. The focus of prevention is therefore on tackling causes and risk factors.

Different types of prevention are commonly distinguished. *Primary prevention* is action taken prior to the onset of a disease or the emergence of a need, with the aim of reducing or removing the

possibility that the disease or need will ever occur. This could include action to inhibit the emergence of risk factors themselves, such as poor environmental, economic or social conditions. This is sometimes called *primordial prevention*, and is focused on the broad health or social care determinants rather than individual exposure to them.

Secondary prevention is action which halts the progress of a disease or other condition at its incipient stage in order to prevent complications arising. Successful secondary prevention would then restore health or wellbeing by treating a disease or responding to a need before irreversible changes take place.

Tertiary prevention aims to reduce or limit the consequences of a disease or need, and to promote adjustment by an individual to irremediable conditions. It is therefore concerned with supporting individuals to cope with or manage their long-term health or social care problems or permanent impairments, in that way helping them to improve their ability to function independently and their quality of life.

Another type of prevention is sometimes distinguished: *quaternary prevention* is defined as protection from unnecessary medical or other care activity that could harm individuals or populations. An example in the health field would be over-medicalisation of what might be considered a 'normal' human condition or supplier-induced demand. In the social care area it could include creating unnecessary dependency by not empowering an individual to make independent decisions in their lives.

3.7 Quality of Care

A commonly discussed indicator of achievement in long-term care is quality of care, but it needs to be seen as only an '*intermediate*' measure of benefit. This is because quality of care, while potentially an important determinant of user outcome, is not directly a measure of that outcome itself. It is concerned with staff-client ratios, the suitability of the built environment, staff-client relationships, social environment, safety and so on. Good quality of care by those criteria is potentially important as an achievement, and goes beyond simply measuring the resources expended on or devoted to long-term care, but the association between any quality of care indicator and user outcomes is likely to be heavily context-specific and individual-specific (Davies and Knapp 1981). In using any quality of care indicator (e.g. in an inspection process, or in writing contracts for public sector commissioning), it is therefore fundamentally important to be confident that the indicator is strongly associated with outcomes as experienced in the lives of the people who use that care.

A number of measures of quality of long-term care have been suggested. One of the best known formal measures is the RAI (Resident Assessment Instrument; Hawes *et al.* 1997). Other quality of

care measures have now been developed in many European and other countries (summarised and discussed well in OECD 2015, especially chapter 3; and see volume 16 of *Eurohealth* published in 2010 for some country examples). In England, the current approach to quality assurance in long-term care includes assessment of user experience: the User Experience Surveys ask about aspects of the care process, such as timeliness and flexibility of care, characteristics and behaviour of care workers, and include a question on satisfaction with care (Malley 2010). In this way, the approach tries to overcome a major limitation of quality of care measures of being poorly connected to how people with care needs live their lives and view the support they receive. These processes are linked to performance assessment (see above).

Given the inherent practical (and often conceptual) difficulties in measuring user outcomes from long-term care, quality of care measures might provide an intermediate indicator of achievement, but their limitations need to be recognised.

3.8 Quality of Life

The Institute of Medicine (2001) in the US defined quality of life as 'subjective or objective judgment concerning all aspects of an individual's existence, including health, economic, political, cultural, environmental, aesthetic, and spiritual aspects'. Narrower definitions have been offered in particular contexts, such as health care, where the term health-related quality of life is now widely employed to refer to those aspects of quality of life that might be influenced by poor health or by health care. Disease-specific quality-of-life measures have also been suggested, focusing on those aspects of an individual's life that might be affected by the illness or disease in question. In the dementia area, for example, it is recognised that quality of life extends beyond the cognitive or other symptoms of the condition (Banerjee *et al.* 2006), but that most generic health-related quality of life measures fail to pick up those aspects of life affected by the condition or its successful treatment, leading to the development of dementia-specific tools (e.g. Smith *et al.* 2007).

These health-focused measures will generally not be sufficient to capture changes in quality of life that result from long-term care, because such care is concerned primarily with how an individual functions and their wellbeing, rather than with the biomarkers or symptoms of a disease. There have consequently been a number of suggested ways to conceptualise quality of life that are relevant to the long-term care context. Sloane *et al.* (2005) and Rodrigues (2017) describe a number of such approaches, and discuss some of the most widely used measures. Most such conceptualisations identify three broad domains as relevant: physical, psychological and also social dimensions. There is also conceptual and operational discussion about who is best placed to judge quality of life along these dimensions, given that some people who use long-term care might have cognitive or other difficulties in reporting accurately their state of psychological or other

wellbeing. Consequently, LTC quality of life measures might be completed by the individual service users themselves, a family member who knows them well, another unpaid carer, a member of care staff in a residential or other setting, or by third party proxies. Another approach is to use direct behavioural observation. Each of these methods has its advantages and disadvantages.

Quality of life is closely linked to wellbeing (or psychological wellbeing). Terminology in the LTC field is rather loose, and these different terms have often been used interchangeably. There are huge swathes of academic theoretical discussion and empirical research dedicated to the conceptualisation, definition, measurement and interpretation of quality of life and wellbeing, and it is not possible even to summarise those debates here. What is important is to recognise that the consequences of LTC interventions or policies can impact upon both objective and subjective aspects of life, and that there will usually be a need to distinguish between (and ideally measure both) hedonic and eudaimonic well-being. The former is linked to happiness or life satisfaction ('pleasure attainment and pain avoidance' according to Ryan & Deci, 2001), while eudaimonic wellbeing, in the Aristotelian approach, emphasises processes of fulfilment and achievement of potential: it is 'living well'. Quality of life as operationally defined in many LTC studies comes closer to eudaimonic wellbeing.

3.9 Rehabilitation

Rehabilitation is a process or action (service, therapy or training) to restore someone to health or normal life following illness or disability or (in other contexts) after imprisonment or addiction. It helps the individual to regain lost skills and independence (fully or partly). The World Health Organization website (accessed 10 February 2017) defines rehabilitation of people with disabilities as 'a process aimed at enabling them to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels. Rehabilitation provides disabled people with the tools they need to attain independence and self-determination.' A Cochrane review of physical rehabilitation operationalised the concept as 'Physical rehabilitation was defined as those interventions that aim to maintain or improve physical function' (Crocker *et al.* 2013).

3.10 Social Investment

Investment is the allocation of current resources, which have alternative productive uses, to an activity whose benefits will accrue over the future. The benefits take the form of production of goods and services that are of individual or social (public) benefit. The cost of an investment is the benefit that could have been derived by using the resources in some other activity. An investment is justified if the benefits anticipated are greater than the costs. (Arrow 1965)

An approach to investment in the present period that is intended to produce social (or public) benefits rather than purely financial returns in the future may be described as social investment, socially responsible investing, social impact investment or impact investing (OECD 2015).

The term social investment is more commonly used in Europe. Indeed, in February 2013 the European Commission launched its ‘Social Investment Package’ (SIP) (European Commission 2013). This offered an innovative social policy instrument in the context of demographic change and economic pressures across Europe. The social investment approach promotes policy measures that frame welfare or public spending as investments aiming to enhance the stock of human capital stock, maintain social protection buffers and enable people to live an independent life, and facilitate flow in the labour market (Hemerjick 2015).

The fundamental pillars of social investment as a policy paradigm involve a significant change in the core elements of the policy-making process inherited from the post-war welfare models of many European states, moving from a focus on “repairing” the unforeseen damages caused by events to a focus on “preparing” individuals and families to address life chances and deal with disruptive events, preventing or lessening the damages they can cause. The philosophy underpinning social investment involves advocating for three main social policy functions: (i) the creation of capacities, which involves a shift in policy analysis from an exclusive focus on present costs to a focus on current and future impacts; (ii) addressing social risks within life-course dynamics, which involves a move from a clear cut divide between those that pay and those who are recipients of welfare provision to a more dynamic and better adjusted vision of contemporary social reality where individuals have different status in different phases of their lives; and (iii) the reconciliation of work and family life, not only responding to ideologies of gender that pressure towards gender equality but also as a pre-requisite to deal with the consequences of demographic ageing and the need to secure economic and fiscal sustainability.

Another SPRINT report – *Conceptual Report on Long-term Care* (D2.1; Lopez 2017) – discusses this in detail.

Social investment in long-term care

The social investment approach applies to the whole life-course, including older age and long-term care. Simultaneously with the launch of the ‘Social Investment Package’ by the EC, a Commission Staff Working Document was published on ‘Long-term care in ageing societies – Challenges and policy options’ (European Commission SWD 2013a), calling for a ‘social investment-oriented strategy’ to address the specific policy challenges of long-term care for older people. The focus of SI in this context is on: initiatives that promote ‘active ageing’, sustaining participation in society and the economy; preventive strategies to reduce needs for care; or measures to improve efficiency in the utilisation of care resources.

In the context of SPRINT, social investment is defined as:

Welfare expenditure and policies that generate equitable access to care to meet the needs of ageing populations, reduce current and future costs of care, improve quality of care and quality of life, increase capacities to participate in society and the economy, and promote sustainable and efficient resource allocation.

This definition contains many elements that in themselves would merit extensive further consideration – and thereby considerably extend the length of this report. However, a number of key terms are further defined below.

3.11 Social Return on Investment (SROI)

Social return on investment (SROI) has its origins in the third sector, originally developed by the Roberts Enterprise Development Foundation in 1996 as a response to the perceived shortcomings of CBA (Roberts Foundation 1996). From its inception, SROI has developed with influences also from sustainability reporting and financial accounting.

SROI is essentially a framework of seven principles (Social Value International 2015) that places the experiences of stakeholders at the centre of analysis to understand what has changed as a result of activities. Subsequently, the monetisation of direct and indirect changes, framed by concerns of materiality and a desire not to over-claim is designed to increase the accountability of decision-makers.

SROI studies seek to take account of various aspects of personal and social wellbeing – tangible and intangible – as experienced by a potentially wide variety of stakeholders. It has been suggested that there are differences between SROI and CBA (Social Value 2014), but these are differences in process, implementation and stakeholder involvement, rather than fundamental differences in underlying approach.

SROI aims to value outcomes from the perspective of the stakeholder, and this could be done for various non-marketed consequences by using different techniques, such as revealed preference, stated preference, or (more recently) wellbeing valuation techniques. (This last approach is mirrored in developments in relation to CBA; see above.) SROI also requires verification, audit process, using an appropriate range of possible methods. The aim is to provide information that is ‘good enough’, which means different levels of rigour according to use and audience. Putting monetary values on non-market goods is challenging in SROI (as it is in any evaluation), especially in the long-term care field, where social valuation studies are still scarce. Consequently, results of different SROIs are not always comparable. SROI has been promoted by the UK Department of Health as a measurement tool especially for social enterprises in health and social care (Millar and Hall 2013, Social Value UK 2014, The SROI Network 2012).

SROI principles – applied in SPRINT

To effectively appreciate the social value of activities, it is required that all principles of SROI are applied. However, given the nature of SPRINT it is necessary that these are adapted, since direct stakeholder involvement is not feasible. However, all data that will be incorporated will stem from stakeholder engagement at the national level and collated by credible sources. Similarly, rather than being able to enquire directly as to the costs and benefits (outcomes) of LTC interventions, extensive literature and evidence reviews have identified the material issues for consideration. The ability to understand what has changed is therefore satisfied, and the subsequent SROI principle to value the things that matter is also addressed using means of valuation such as life-satisfaction (well-being valuation) (see below).

Concerns of materiality – that which addresses not only the inclusion/exclusion of outcomes, but also consideration of which stakeholders are to be incorporated – is again addressed through the extensive review of existing literature and evidence conducted in SPRINT, as are matters that ensure that the principle to not over-claim is included.

All work abides by the need to ensure transparency, an SROI principle that ensures all sources of evidence are presented for scrutiny, as are all metrics, and any assumptions or estimations. Finally, the need to verify the result (another SROI principle) will be addressed through the internal processes of SPRINT that involve all partners and the Advisory Group, and is that which ensures that all other principles are applied accordingly.

3.12 Stakeholders

Within SPRINT, a stakeholder is any individual, organisation or other entity with an interest in long-term care. This will include decision-makers such as government ministers; elected politicians (national, regional or local); public/civil servants (in national, regional or local public bodies); quasi-governmental organisations; chief executives and boards of large and small provider organisations and funding bodies; third sector (non-profit) organisations, small enterprises and small community groups that deliver, finance or broker long-term care; front-line workers in provider bodies; organisations or individuals that lobby for individual rights or better long-term care. The long-term care sector spans not only the health and social care systems, conventionally defined, but also housing, social security (welfare benefits), employment and other systems.

Individuals with long-term care needs and their families are the most important stakeholders.

3.13 (Non-market) Valuation methods

Stated preference

Stated preference approaches ask people to ‘state their preference’ directly for a good or service using questionnaire surveys. For example, contingent valuation surveys ask respondents the equivalent value through their willingness to pay for a good or service, or their willingness to accept as a compensating value for its loss (Fujiwara and Campbell 2011). As the name suggests, contingent valuations are contingent on specific characteristics. For example, this could include the willingness to pay for a specific increase in personal health or an improved local ecosystem, or conversely the willingness to accept a reduction in health or the damaged local ecosystem.

Revealed preference

Revealed preference techniques examine the way in which people reveal their preferences for goods or services through market production and consumption, and the prices that are therefore given to these goods (explicitly or implicitly). Where direct markets for goods or services exist, the value that people place on it is revealed directly using market prices, either for that or a similar good (substitute prices). Where an impact causes a change in production, then effect on production (or change in productivity) can be used (Natural Capital Coalition 2016).

Within these techniques, values can also be revealed by analysing data on the time and cost incurred to visit (say) the facility in question (the *travel cost method*). Alternatively, they can be based on analysing how the price of an asset changes with different attributes, such as housing prices for access to favoured schools, ecosystems view, or the number of bedrooms (called *hedonic pricing*). This approach can also use wage differentials between similar jobs to value (say) environmental quality differences between regions.

Life satisfaction (Wellbeing valuation)

Wellbeing valuation uses statistical analyses of large questionnaire datasets to value changes in life circumstances, by calculating the increase in income which would be necessary for an equivalent increase in wellbeing (Trotter *et al.* 2014). For example, if the increase in wellbeing associated with improved mental health is equivalent to the increase in wellbeing associated with a €2,000 increase in income, then it can be inferred that the value of improved mental health is €2,000 per year. A combination of the wellbeing valuation and stated preference approaches can be used (called *hybrid stated preference / wellbeing valuation*), whereby respondents are asked to state the amount of compensation they would be willing to accept for a particular loss, in order to maintain their current level of wellbeing.

4 References

- Anheier, H. (2005) *Nonprofit Organizations: Theory, Management, Policy*. London: Routledge.
- Anttonen, A. & Meagher, G. (2013) Mapping marketisation: concepts and goals. In Meagher, G. & Szebehely, M. (editors) *Marketisation in Nordic Eldercare: A research report on legislation, oversight, extent and consequences*. Stockholm: Department of Social Work, Stockholm University.
- Arrow, K. (1965) Criteria for social investment. *Water Resources Research*, 1 (1), 1-8.
- Banerjee, S., Smith, S., Lamping, D. *et al.* (2006) Quality of life in dementia - more than cognition. An analysis of associations with quality of life in dementia, *Journal of Neurology, Neurosurgery and Psychiatry*, 77, 146-148.
- Barlow, J. & Knapp, M. (2014) Evaluating telehealth and telecare: note for the Medical Research Council. London: Imperial College & London School of Economics and Political Science.
- Barr, N. (2004) *Economics of the Welfare State*. Oxford: Oxford university press.
- Crocker, T., Forster, A., Young, J. *et al* (2013) *Physical rehabilitation for older people in long-term care*. Oxford: Cochrane Database of Systematic Reviews.
- Davies, B. & Knapp, M. (1981) *Old People's Homes and the Production of Welfare*. London: Routledge.
- European Commission (2013) *Towards Social Investment for Growth and Cohesion – including implementing the European Social Fund 2014-2020*. COM(2013). Brussels: EC.
- European Commission (2013) *Long-term care in ageing societies - Challenges and policy options*. Commission Staff Working Document. Brussels: EC.
- Freeman, E., Knapp, M., Somani, A. (2017) Long-term care organization and financing. In Qhah, S. (editor in chief) *International Encyclopedia of Public Health*. New York: Elsevier.
- Fujiwara, D. & Campbell, R. (2011) Stated Preference, Revealed Preference and Subjective Well-Being Approaches: A Discussion of Current Issues. London: HM Treasury.
- Grewal, I., Lewis, J., Flynn, T., Brown, J., Bond, J., Coast, J. (2006) Developing attributes for a generic quality of life measure for older people: preferences or capabilities? *Social Science and Medicine* 62(8), 1891-1901.
- Hawes, C., Morris, J., Phillips, C., Fries, B., Murphy, K., More, V. (1997) Development of the nursing home Resident Assessment Instrument in the USA. *Age and Ageing*, 26, 19-25.
- Hemerijck A. (2015) The quiet paradigm revolution of social investment, *Social Politics*, 22(2), 133-46.
- Judge, K. (1982) Is there a crisis in the weffare state? *International Journal of Sociology and Social Policy*, 2, 1-21.

Judge, K. & Knapp, M. (1985) Efficiency in the production of welfare: the public and private sectors compared. In Klein, R. & O'Higgins, M. (editors) *The Future of Welfare*. Oxford: Basil Blackwell.

Knapp, M. (1984) *The Economics of Social Care*. London: Macmillan.

Knapp, M. & Kettunen, A. (2017) *SSCR Methods Review: Cost-Effectiveness Analysis*, NIHR School for Social Care Research, London, forthcoming.

Lopez A (2017) *Conceptual Report on Long-term Care*, SPRINT Working Paper D2.1, SPRINT, Brussels.

Lorenz, K., Freddolino, P., Comas-Herrera, A., Knapp, M. & Damant, J (2017) Technology-based tools and services for people with dementia and carers: mapping technology onto the dementia care pathway. *International Journal of Geriatric Psychiatry*, in press.

Malley, J. (2010) Measuring the quality of long-term care in England. *Eurohealth* 16, 21-24.

Netten, A., Burge, P., Malley, J., Potoglou, D., Towers, A.-M., Frazier, J., Flynn, T., Forder, J. & Wall, B. (2012) Outcomes of social care for adults: developing a preference-weighted measure, *Health Technology Assessment* 16 (16).

Millar, R. & Hall, K. (2013) Social Return on Investment (SROI) and performance measurement: the opportunities and barriers for social enterprises in health and social care. *Public Management Review* 15(6), 923-941.

Natural Capital Coalition (2016) Natural Capital Protocol. London: Natural Capital Coalition.

OECD (2013) *A Good Life in Old Age? Monitoring and Improving Quality in Long-Term Care*. Paris: OECD.

OECD (2015) *Social Impact Investment: Building the Evidence Base*. Paris: OECD.

Rawls, J. (1972) *A Theory of Justice*. Oxford: Oxford University Press.

Roberts Foundation (1996) *New Social Entrepreneurs: The Success, Challenge and Lessons of Non-Profit Enterprise Creation*. San Francisco: The Roberts Foundation.

Rodrigues, R. (2017) Evaluating long-term care policies: challenges and advancements. In Greve, B. (editor) *Handbook of Social Policy Evaluation*. London: Edward Elgar.

Ryan, R.M. & Deci, E.L. (2001) To be happy or to be self-fulfilled: a review of research on hedonic and eudaimonic wellbeing. In Fiske, S. (editor) *Annual Review of Psychology* 52. Palo Alto, CA: Annual Reviews/ Inc.

Sloane, P.D., Zimmerman, S., Williams, C.S *et al.* (2005) Evaluating the quality of life of long-term care residents with dementia. *The Gerontologist* 45, 37-49.

Smith, S., Lamping, D., Banerjee, S. *et al.* (2007) Development of a new measure of health-related quality of life for people with dementia: DEMQOL, *Psychological Medicine*, 37, 737-746.

Social Value (2014) *SROI and Cost Benefit Analysis*. London: Social Value.

Social Value International (2015) *Principles of social value*. Liverpool: Social Value International.

Trotter, L., Vine, J., Leach, M. & Fujiwara, D. (2014). *Measuring the Social Impact of Community Investment: A Guide to using the Wellbeing Valuation Approach*. London: HACT.

Wistow, G., Knapp, M., Hardy, B. & Allen, C. (1994) *Social Care in a Mixed Economy*. Buckingham: Open University Press.

Wistow, G., Knapp, M., Hardy, B., Forder, J., Kendall, J. & Manning, R. (1996) *Social Care Markets: Progress and Prospects*. Buckingham: Open University Press.

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