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Social Protection Innovative Investment in Long-Term Care

Social Protection

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FORMAL vs INFORMAL LONG-TERM CARE: ECONOMIC & SOCIAL IMPACTS

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Executive Summary

Social investment strategies look more widely than the direct outcomes of delivering care, taking a much broader perspective on impact. At the heart of any system of long-term care (LTC) provision is the need to balance the delivery of formal and informal care and to provide supportive strategies which deliver positive outcomes for individuals, the people who care for them, and society more broadly. The analysis in this report suggest that there is considerable potential for a social investment approach to address issues arising from the impacts of informal caregiving on caregivers and on the wider society and economy.

There is evidence of increasing reliance on family or informal care as European Union countries tackle the challenge of ensuring the sustainability of good quality LTC provision for older people over the coming years within constrained public spending budgets. This report examines the social and financial implications of substituting formal care with alternative forms of informal care. It considers whether informal care does or can substitute for formal care or whether it supplements or complements it.

This report provides a focused analysis form a social investment perspective of existing literature, supplemented with country examples provided by the partners in the SPRINT project. The analysis considers the impact of policy decisions on the public fiscal balance and labour force demography and the effects on the wellbeing and quality of life of carers and care recipients. A social investment perspective highlights a wider range of implications of substituting informal care for formal provision. These include effects in terms of fiscal flows, labour market participation (including gender equality in the context of Social Rights), and health and wellbeing as well as income and pension consequences for carers and the associated public costs. Thus costs arising from reorientation towards informal care may in some respects be hidden rather than apparent.

It also discusses the instruments and policies which have been put in place to support the provision of informal care and to improve the life conditions of carers, as well as considering the institutional and cultural settings in which these policies take place. Consideration is also given to measures to improve the position of informal carers or better align the functioning of the informal care sector with wider policy goals.

Assessment of the net effect of an increase of informal care provision is a complex task. Savings from limiting expenditure on formal provision may be offset by a reduction in tax revenue and productive capacity as informal carers leave or reduce employment to take up caregiving responsibilities, with extensive evidence that intensive informal caring correlates negatively with being active in the labour market. There is a wide range of public policies in place in European countries around informal care. Cash and in-kind benefits have been developed to support the

activities of the informal caregivers, but the effects on quality of care, the labour market and public finances are unclear. While strengthening formal care services (for example by providing community-based services) may be a priority in some LTC policies, the provision of informal LTC services is steadily increasing, with potential consequences for the employment rate of informal carers and for their life conditions.

Key messages

- While informal care by family members remains integral to the provision of LTC in all welfare systems, at the same time demographic changes mean that the need for LTC is expected to increase at the same time as the availability of informal care is expected to decline. These changes will have important effects on public finances.
- Alongside the positive contribution of informal care, there is evidence of non-beneficial effects for caregivers themselves and for the wider society and economy – for example, consequences for labour supply, with a lower likelihood of labour market participation among informal family caregivers and in particular, women. This is a key consideration when developing public policies to change the balance of formal and informal care provision.
- The informal care sector offers major opportunities for a social investment approach in LTC. Developing a stronger infrastructure for informal care provision, such as direct support for cares, stimulating the role of third sector or non-government organisations and promoting carer-friendly workplace arrangements can produce significant social returns.
- The nature of the relationship between formal and informal care is not straightforward. The extent that they are substitutes or complements is likely to be context dependent and decisive evidence on this question is not available.
- The evidence base for making policy decisions regarding measures to support informal care is limited. A comprehensive system of routine data collection would be an important starting point and robust evaluations are needed of specific interventions in order to identify best practice.

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Acronyms and Abbreviations

EU	European Union
LTC	Long-term care
LTCI	Long-term care insurance
OECD	Organisation for Economic Co-operation and Development
SPRINT	Social Protection Innovative Investment in Long-Term Care

1 Introduction

In all EU member states, LTC provision involves a mix of formal (state, local authority and non-government) and informal (primarily unpaid family) provision – though there are wide differences in the balance between these sectors in the context of national cultures and welfare traditions. While pressure on public budgets to fund LTC is growing as a result of demographic ageing and increasing demand, at the same time provision through the informal sector faces the challenge of declining number of carers as a result of trends towards reduced family size, an increasing proportion of single households, increasing geographic separation between parents and children and greater opportunities for women in the labour market. There is some evidence that in recent years the balance of provision is shifting towards greater reliance on the informal sector as countries respond to constraints on public expenditure by implementing policies which are reorienting provision towards greater responsibility for the families of individuals with LTC needs (Grootgoed and Van Dijk 2012). As Bouget and colleagues state in a report commissioned by the EU to support implementation of the Social Investment Strategy, synthesising findings from across member countries of the European Social Policy Network: 'The national experts' reports (with some rare exceptions) note that a consequence of economic austerity policies has been the halting in long-term development of the formal care services sector' (Bouget *et al.* 2015).

In this context, this report is concerned with exploring the implications of the substitution of formal long-term care (LTC) by compensated family or informal care. Shifting the burden of costs in this direction may seem an attractive policy option. Analysis of public expenditure on long-term care reported in the European Commission (2013) Staff Working Document (SWD) on long-term care, which accompanied the publication of the Commission's Social Investment Package, explicitly states that 'informal care is generally viewed as being of no direct cost to the public budget'. However, from a social investment perspective it is also important to analyse the indirect costs or wider impact that may be incurred – affecting health, wellbeing and social participation, employment and household income, social security and pension payments, and gender inequalities – and which may influence the overall balance sheet of costs and benefits associated with this policy. The report also considers policy measures aiming to support family provision or to improve the position of informal carers as this reorientation of care provision is implemented.

A social investment perspective guides our analysis of the consequences of this development. This takes into account the direct impact on carers themselves – in terms of employment, income, pensions, and health – together with implications for those with care needs and the wider impact on society and the economy in terms of government tax revenue, rates of employment and economic output and gender equality. In addition, the report identifies policy instruments

designed to strengthen the capacities of informal carers and help to integrate their contribution within a more managed overall framework of LTC provision.

European LTC systems rely heavily on the provision of services by informal carers (Pickard 2011). A number of developments, including changes in family structure, increased female participation in the labour market, and extended life expectancy will affect the availability of informal care (Pickard 2015). Providing informal care, especially at higher intensity or for long duration, has an impact on carers' employment, social participation and mental and physical health, and more broadly, on the quality of care, the state of the labour market and the wider economic conditions in each country. As care is disproportionately undertaken by particular groups, there are also equity considerations. However, wide differences in the nature and volume of informal care are reported across European countries.

It is useful to note the key elements of a somewhat formal definition of informal care used in a recent economic evaluation of informal care: 'A nonmarket composite commodity consisting of heterogeneous parts produced (paid or unpaid) by one or more members of the social environment of the care recipient as a result of the care demands of the care recipient' (van den Berg *et al.* 2004) This definition leaves open the potential for informal carers to be paid (or compensated). In more general terms we mean by informal care both 'help by family and friends which is either provided unpaid or for a monetary reward that falls clearly below the compensation for an equivalent service purchased at the market' (Schneider *et al*. 2015) and care provided in the 'grey market', where carers are informally employed by families outside the formal LTC system. Informal care includes a broad range of support activities, extending over a period of time rather than episodic, including help with housekeeping, personal care and support with mobility. As Schneider and colleagues point out, cultural patterns and national traits will influence what counts as 'informal' in different countries.

Informal carers are usually individuals already in contact with the care recipients because of direct personal ties, for example, as family members, friends or neighbours. They are usually non-professionals who are not formally trained to provide care, even though they may benefit from training. Informal carers often take multiple responsibilities which are rarely formalised (in, for example, contracts) and therefore have no formal limits to the time they spend on caregiving. These caregiving responsibilities can substitute, supplement or complement the tasks performed by formal, paid caregivers. Informal carers may obtain financial assistance through the state, but entitlements to receive other types of support (e.g. respite care) are generally not widely available. A mixed offer of LTC services supported by cash-benefits provisions is in place in some countries, positioning the services somewhere between formal and informal care. This is explored further below.

Heterogeneous models of LTC provision are in place across Europe, together with a range of existing policies with varying implications for the quality of informal care provision, for the quality

of life of those with care needs, for carers' health, wellbeing, income and employment, and for the labour market and the wider economy. There are innovative policies to expand or diversify the supply of informal carers, aiming for example to bring people in from the grey labour market. In this 'shadow economy', operating outside the system of taxation, social security contributions and government regulation, the employer-employee relationship is likely to involve a cash transaction and limited security or stability of provision – with implications for the quality of care. Various schemes, such as the provision of vouchers in Belgian Flanders (Willemé 2010), can make links between informal and formal care provision models and bring informal providers within the scope of social insurance and tax systems, with fiscal benefits for the state and potential improvements in care quality.

Valuable lessons can also be learned from policies outside Europe, for example in Japan, where the use of public LTC insurance benefits to compensate family members for providing care services has been deliberately excluded in response to calls by the women's movement and as part of a policy of promoting external, more professional provision (Campbell *et al.* 2010). This will be further considered below.

This report examines policies which influence the balance between formal and informal care and the extent of substitution, complementarity or supplementation. Public policies set the legislative and financial framework in which these sectors operate. A range of factors, for example unemployment rates or the unit cost of the services provided, will affect policies concerning the balance of informal and formal provision. Informal care may be used instead of formal care because of particular circumstances (such as co-residence), attitudes (such as the nature and quality of the relationship between the individuals) and the opportunity costs of caring (in terms for example, of employment opportunities or leisure time). Reorienting care towards the informal sector involves considerations directly concerning the carers – their physical and mental status, attitudes and values regarding unpaid caring, and their income. These factors raise questions about the potential complementarity of formal and informal care, the substitution effect between providing care and delegating the provision to formal carers, and safeguarding the welfare and working conditions of the potential informal carers. The substitution of formal care by informal care affects the overall economy. Providing financial incentives (and setting appropriate legislative instruments) for the provision of care and favouring one form of care provision over another can impact on the budget for provision and, indirectly, other health and social care expenditures, as well as on revenue raised through taxation.

The analysis in this report is intended to contribute to the debate around the development of social investment in LTC. The paper builds on previous research in the SPRINT Project, specifically about the role of public and private actors in the LTC sector (Ghibelli *et al*. 2017) and the identification and benchmarking analysis of existing schemes for the resourcing of LTC in different

institutional settings (Greve 2017). This report contributes to the analysis of LTC outcomes which are related to the balance of formal and informal care later in the SPRINT project.

2 Aims and Objectives

This report aims to provide an evaluation of the substitution of formal care by compensated family or informal care. It addresses a number of research questions:

- What are the consequences for informal carers of undertaking care provision?
- What are the wider effects for society and the economy of substitution of informal for formal care?
- What measures are available for improving the position of informal carers and reducing negative effects?
- To what extent are formal and informal care substitutes or complementary?

From a social investment perspective, concerned with strengthening capacities and improving opportunities for participating in the economy and society, it is important to consider implications of informal care arrangements for:

- Health and wellbeing
- Social impact
- Labour market opportunities
- Incomes
- Pensions
- Quality of care
- Fiscal consequences
- Gender inequalities.

The report will also examine factors influencing the provision of informal care and measures for improving the position of informal carers (such as care allowances, flexible working arrangements and respite care).

As Schneider *et al*. (2015) observe, in the context of recent austerity policies 'there is an increased interest in informal care as a low-cost mode of providing help to dependent older people'. The

considerations identified above – impacts on care recipients, informal carers and wider society – are important in assessing policy options, focusing attention on longer-term or wider factors to set against potential short-term budgetary savings that may be anticipated from retrenchment of formal long-term care provision and substitution of informal care.

3 Methods

This report builds on earlier reports from the SPRINT project and incorporates information from three different sources: analysis of relevant academic literature and policy documents; the responses from a brief questionnaire completed by six of the SPRINT partners; and additional input from a number of SPRINT partners.

3.1 Literature Review

We carried out an extensive review of economic, health and social care literature, in order to explain what is meant by informal care and to provide useful theoretical insights about the discussion on public policy choice on formal versus informal LTC. We reviewed both conceptual and applied policy literature, to identify valuable sources not only in terms of theory but also to identify empirical studies and lessons from country case studies.

The following terms were used to identify relevant publications: long-term care (LTC), informal and formal care, substitution and income effects, respite care, care allowances, LTC labour market, third sector in LTC, gender and cultural issues in informal caring. The selected articles were screened by their abstracts for relevance, and those selected were then reviewed. Additional web searches were conducted, employing the same key terms, to identify grey literature from international organisations such as the Organisation for Economic Cooperation and Development, the World Health Organisation and the European Commission.

3.2 Assessment of National Cases

This report was informed by six SPRINT partners who completed a short questionnaire to provide country-specific information. The questionnaire sought information on the approach of the

different countries on a number of policy mechanisms: the financial support measures for informal carers, and whether these are provided through remuneration or means-tested allowances; the in-kind services available for informal carers, for example, flexible working and leave; respite services and counselling, coordination and information services. The questionnaire also asked for information where the costs of these policy mechanisms are known (see Annex 1).

3.3 Contributions from SPRINT Partners

To supplement the literature review and country information, we consulted the other researchers in the SPRINT network and other external experts from academia and the third sector. We asked these partners and experts to highlight the existence of additional peer-reviewed articles and literature, as well as any statistical data about informal care in their country. We also used previous SPRINT research outputs, consisting of analysis of the current literature on social investment and LTC.

4 Informal Long-term Care Provision: Features and Trends

The balance and nature of informal care is linked to differences in the design of formal LTC systems (Riedel 2012). The level of provision of informal care differs, both between countries and also within the same countries, but consistently across Europe women are more likely to be informal carers (Pickard 2011).

4.1 Use of Formal and Informal Care Provision

Greve (2017) and Ghibelli *et al*. (2017) have also covered this ground. The range in the balance of formal and informal care across Europe is indicated in country case studies of long-term care systems in EU member states recently published by SPRINT partners (Greve 2017). Formal care is more prevalent in northern Europe. In particular, in respect of the most intensive type of informal care, previous research has shown that the Nordic countries (and the Netherlands) have relatively low provision of informal help (Pickard 2011). On the other hand, countries with what has been referred to as the Mediterranean 'all in the family' model – such as Italy, Spain and Greece – have relatively limited formal or public provision (Schneider *et al*. 2015). Around 40 per cent of informal

carers are in full-time employment (Hoffmann and Rodrigues 2010). There is estimated to be at least twice as many informal carers as professional carers (EU, 2014). The financial value of unpaid informal care as a percentage of the overall cost of LTC in EU member states is estimated to range from 50 per cent to 90 per cent (Lamura 2015). As an example of the value of informal care even where there is strong public provision, it has been estimated that in Finland 'without informal care, public expenditure would be two times higher than at present' (Kehusmaa *et al*. 2013).

The availability of informal carers is likely to decline in coming years due to falling family sizes, policies promoting female participation in the labour force and decreasing fertility rates, but patterns and trends are likely to differ between countries. The ability or propensity to provide unpaid care is also likely to be a factor (Pickard, 2015). The rate of decline in intergenerational care provision will be subject to factors such as the reduction of residence of older people with their children and the increasing participation of women in the labour market. It is unclear whether increases in care provided by spouses and partners will compensate for the reduced levels of care from children (Pickard, 2015).

Changes are occurring in nature of informal provision – for example, over the last decade Italy as well as Spain have shifted from an emphasis on family-based care towards a model that still relies heavily on informal care, but less so on family caregivers (Hoffmann and Rodrigues 2010). It can be noted here that a significant development in response to the pressures on access to both formal and informal long-term care is the growing private market in provision by individual migrant care workers (Da Roit and Weicht 2013). This pattern of 'outsourcing' of care – already prevalent in Italy – may become an increasingly important feature of the long-term care landscape in particular European countries (Pavolini *et al*. 2017).

4.2 Who Provides Informal Care and Why?

Data on and identification of informal carers is weak in most countries, even though this is important for informing LTC policy. In some cases, informal carers are identified via the cared-for person. In England, the first national strategy for carers was launched in 1999. The other countries in Europe do not have national policies in place specifically targeting informal carers, although as Courtin *et al.* (2014) point out, the lack of central policy might not reflect the actual support available at either the local or national level.

European data show that most informal carers are women, as shown in Table 1.

Table 1: **Female carers as percentage of total informal carers**

Country	Percentage of female carers
Hungary	> 70%
Italy	64%-66%
Poland	
Portugal	
France	60%-62%
Austria	
Germany	
Belgium	
Netherlands	57-58%
UK	
Denmark	< 55%

Source: Adapted from Colombo et al. 2011.

Usually – in more than 90 per cent of cases – informal carers have family relationships with the cared-for people and are typically spouses or daughters (Pinquart and Sörensen 2011). Belgium has the highest percentage of informal carers aged 50+ (20.6 per cent) followed by Italy (which has the lowest rate of paid LTC carers) and the UK (European Union 2014). The lowest percentage of informal carers is in Denmark and Sweden (which is the country with the highest percentage of paid carers) (European Commission 2013).

Widespread differences between countries in the intensity of caregiving is reported. For instance, in Portugal, Italy, and Poland, where the tradition of family caring is stronger, more than 75 per cent of informal carers report that they provide daily care. In Sweden and Denmark, where caring is largely provided by paid LTC workers, the percentage of informal carers providing daily care is considered to be negligible (European Union 2014). Informal carers tend to be aged over 45 (European Union 2014) and rarely receive any formal training for providing care.

Relationship factors often provide the main motivation for individuals to provide care to their relatives. Economic incentives may play a part but are unlikely to determine that informal care is provided, especially (as discussed below) where allowances for informal carers are much lower than ordinary wages. A significant literature around caregivers' reasons for caring exists. Factors

influencing the likelihood of someone becoming an informal carer include familial expectation, cultural norms, altruistic reasons or reciprocity for past help. For instance, Walker *et al*. (1990) observe a 'connection between obligatory and discretionary motives for caregiving and relationship quality for caregiving daughters and their dependent older mothers', emphasising the importance of discretionary reasons. Quinn *et al*. (2010) underline the importance of the quality of the relationship of the caregivers with the care-recipient on the quality of the care provided. Kuscu *et al*. (2009) show the main reasons for providing informal care are connected to personal feelings and family relationships. Other authors (Cicirelli 1993, Ng *et al*. 2016) acknowledge the role of personal feelings but also the role of societal values associated to giving care (for example, because of filial relationships or gender norms) and practical issues. Cultural differences can influence the filial responsibility (Lee and Sung 1997). To assess the reasons behind the decision to become an informal caregiver it is therefore important to consider the experiences of the carers but also the social and cultural framework in which they operate (Kabitsi and Powers 2002).

Key issues for countries which rely predominantly on informal cares are equity of access to care and quality of care, which are important elements in assessment of the impact of social investment in LTC. These issues arises because, firstly, not all individuals in need have family members able, or willing, to be carers and, secondly, the provision of satisfactory quality informal care can be guaranteed only if informal carers receive similar support services (i.e. training, supervision, guidance) to those received by formal carers (Triantafillou *et al*. 2010). This issue will be addressed further below.

5 Health and Wellbeing of Informal Carers

Providing informal care can be challenging to the health and wellbeing of carers. The extent of the challenge and its effects will be influenced by the intensity and duration of caring responsibilities. It is also important to take into account the nature of the local policy environment in terms of levels of public provision of home care and support for informal carers (Verbakel 2014). In assessing the overall cost-effectiveness of informal care within the long-term care system, it is important to take into account indirect costs such as detriment to carers' physical and mental health, which may then produce further costs through extra treatment episodes and medication.

Analysis of data from the Survey of Health, Ageing and Retirement in Europe (SHARE) showed a strong correlation between providing care to a person residing in the same household and poor mental health and the results also indicate that there is a strong relationship between providing informal care inside the household and physical health – the likelihood of reporting worse health

are 68% higher for carers compared to non-providers (Rodrigues 2013). Analysis of data from the European Social Survey also shows that informal carers report significantly lower levels of mental wellbeing than non-caregivers, with a stronger effect when caregiving was intensive (i.e. over 11 hours per week), and with a significant gender effect (i.e. women are more negatively affected) (Verbakel *et al.* 2017b). A recent extensive analysis of SHARE data (waves 1, 2, 3 and 5) together with the English Longitudinal Study of Ageing (ELSA) found that in most countries people who started caring within a household experienced a deterioration in their mental health, suggesting that 'caregiving inside the household results in psychological stress irrespective of the type of welfare state' (Kaschowitz and Brandt 2017). However, some caution regarding these results is necessary since the caring roles were not specifically or only concerned with long-term care for older people.

Informal carers often have limited time to devote to their own needs and commonly experience social isolation (Triantafillou *et al*. 2010). Their risk of social exclusion is increased because they often experience higher levels of poverty than non-carers due to lower or non-participation in the labour market and the extra expenses of care provision (Aldridge and Hughes 2016). The high rate of women providing informal care relative to men, also raises issues about the resulting gender effects and inequalities.

Balancing work and family tasks can be a source of stress for informal carers. Informal care provision is often time-consuming and may affect the physical and emotional health of caregivers. Caregivers are reported to have high rates of depression and health care utilisation (Ansah *et al*. 2016). Providing care combined with a regular workday can affect the opportunity for leisure activities (Bauer and Sousa-Poza 2015) and this in turn can have dramatic health and wellbeing effects on both the carer and the person they care for. As reported by Schulz and Sherwood (2008), caregiving can be physically demanding and this effort, when lasting many hours, can cause physical injuries and aggravate chronic health conditions. As shown by Coe and Van Houtven (2009), caregiving involves stressful situations and may also prompt individuals to abandon a healthy lifestyle, increasing the rate of depression and risk of heart attacks (especially for single men).

It should certainly be acknowledged that there is potential for positive impacts on the wellbeing of informal carers, stemming from a sense of fulfilment from providing care to a loved one (Verbakel 2014). Overall, however, the negative effects on health of caregiving are well-established and policies promoting greater use of family provision and the role of informal carers should in particular take into account that 'the double burden of care and employment preys on the health and wellbeing of carers and reduces life chances' (Heitmueller 2007). Such policies need to incorporate measures to reduce the physical and psychological burden of care. There are grounds for considering investment in support for informal carers not only to reduce direct negative health and wellbeing effects but also to enhance wider social value through facilitating greater

opportunities for social participation and reducing the potential indirect costs arising from extra service or treatment utilisation.

6 Informal Care and Employment

Earlier research by Carmichael and Charles (1998) suggested that the effect of caring on labour supply could be analysed in terms of a substitution and an income effect. Given that time is a scarce resource, undertaking caring responsibilities will reduce the supply of labour (a substitution effect) and working less will reduce earnings (an income effect). It has frequently been reported that informal caregiving restricts employment opportunities, though the impact is not necessarily a large one (Lilly *et al.* 2007, Bauer and Sousa-Poza 2015). In the context of the previous section, remaining in formal employment while also caring can be a positive influence on the quality of life of the carer since it allows individuals to maintain an adequate income level and pension plan, facilitates social life and alleviates the burden of constant caring. Single women in particular with care responsibilities and not in employment face a greater risk of poverty in older age (Hoffmann *et al*. 2013).

There is a large literature and many variable factors – type of care, national care regime, endogeneity of care-employment relationship and so on – to consider in assessing the employment effects of informal care. Some illustrative findings will be presented here. Using longitudinal data from the British Household Panel survey (1991-2002), Heitmueller finds that for co-residential carers (primarily looking after spouses), providing care reduces employment probability by up to 15%. There is no effect for extra-residential care (covering a wider range of cared-for persons). Furthermore, intensive care activity – more than 20 hours per week – reduces labour market participation by up to 26% (Heitmueller 2007). In this context the substitution effect of caring dominates the income effect.

Female carers will be particularly affected since they tend to provide more hours of care (higher intensity care). In a study specifically focused on women, Kotsadam (using ECHP data) finds that there is a negative association between informal caregiving and women's employment in terms of probability of being employed and number of hours worked, which is particularly strong in southern European countries and least strong in Nordic countries. This geographical pattern is attributed to the variation in availability of formal care and 'gendered care norms' across European countries (Kotsadam 2011).

Research findings on the effect of informal are on employment tend to show negative but not necessarily large effects. Using SHARE data, Bolin and colleagues estimate that a 10% increase in

weekly hours of care is associated with a 3.7% reduction in employment probability and a 2.6% reduction in hours worked. This effect for women was greater and strongest in central European countries (Bolin *et al.* 2008a).

The causal relationship between informal care and employment is a complex one for researchers to tackle. It is likely that many informal carers would remain – for various reasons – outside the workforce even without caring responsibilities. The effect of endogeneity - those who are under-employed or unemployable may be more likely to adopt a caring role - is commonly addressed but often not resolved.

Intensive carers usually have lower incomes than non-intensive carers, often because they have left employment completely (European Union 2014). With the exception of the Scandinavian countries, where appropriate formal care support and adequate measures to balance work and family are in place, in almost all the other European countries, providing informal care can lead to significantly lower income because informal carers have to leave employment or reduce their hours. Informal carers may also find it hard to accumulate sufficient pension funds, risking poverty at pension age. An exception to this is Germany, which has put in place mechanisms for carers to build up pension rights (Eurocarers 2016).

Many working carers leave employment, possibly due to limited support (Colombo *et al*. 2011). Although some studies (for example, Bauer and Sousa-Poza, 2015) do not find sufficient evidence to support any significant impact of informal caregiving on labour supply decisions, the majority have found a lower likelihood of labour market participation among informal family caregivers. For example, studies have shown that employment is affected when care is provided for as little as ten hours a week (King and Pickard 2013). Greater public investment in social care, supporting carers and reducing the need for them to retire early, could lead to a reduction in public spending on direct allowances and from higher income from taxation (Pickard *et al*. 2018).

Van Houtven *et al*. (2013) show that informal caregivers tend to have less attachment to the labour force, and that female caregivers are more likely to be retired. Female care providers who continue to work tend to reduce their weekly hours and are paid less than non-caregivers. The same authors reported a negligible effect of caregiving on working men's hours or wages. Individuals may choose, or indeed need, to work to ensure a stable income source. The balance between the need to work to generate income and the need to care determines the direction of the impact of informal caregiving on labour market participation, if any. At the policy level therefore, decreases in LTC funding may lead working women to leave the labour force to provide more informal care (Yoo *et al*. 2004). The effects on paid employment are greater for women. Employment rates in formal care for women in Southern and Eastern European countries show much lower levels of employment, if compared to Northern and Central European countries. No differences are reported for men (European Union 2014).

Reconciling work and care is a crucial issue: older people in Europe generally prefer to receive informal care at home, heavily involving the family in care (Tomini *et al*. 2016). This preference should be considered in the context of broader social changes. Smaller families, increasing rates of divorce, migration trends and increasing rates of female employment undermine traditional patterns of family care provision (Triantafillou *et al*. 2010).

It could be expected that higher earners would prefer to continue their careers, and would therefore pay to purchase care services. Those on lower wages would possibly be more likely to give up their job in order to take on caring. Informal and formal care cannot always be considered close substitutes, with the provision of more of the latter diminishing the provision of the former. Indeed, several factors may influence utilisation/substitution between formal and informal care: for instance, the perceived or actual lack of alternative sources of care and inadequate quality or quantity of alternative sources of care (Brimblecombe *et al.* 2017). If we only look at the opportunity costs for potential carers in terms of complete or partial withdrawal from the labour market and career advancement we will miss the crucial role of social and economic context. As discussed above, relational and motivational factors should be considered, and the cultural and social characteristics of a society could also affect ability or willingness to care. Unsurprisingly, where the provision of formal care is better organised and support services for informal carers are satisfactory, there is little evidence for the 'crowding out' thesis (which suggests more formal services will necessarily lead to less informal care provision) (Verbakel 2017a). On the contrary, there is some evidence that the availability of formal care services may encourage the supply of informal care (see, for example, Schaffer 2015).

When there are no family members willing or able to provide informal care or formal care is not available, a solution can be to hire migrant workers. The employment of (often illegal) migrant workers has increased and is often undeclared, especially in countries like Italy, potentially with an impact on quality of the care provided, as well as on tax revenues. In these situations, families need to retain formal employment in order to pay for the support of migrant workers (European Union 2014). Another problem results from a lack of incentives for many family carers to enter into formal employment. This issue is even more pressing if we consider that many carers are aged over 45 and may be tempted by early retirement, especially when high replacement rates (the percentage of a worker's pre-retirement income that is paid out by a pension program on retirement) are available (Duval 2003). A cash-benefit system is also risky, if the supply of formal care is scarce, because over-reliance on informal provision may affect the creation of a formal provider market.

Accepting more foreign migrant workers is one option to support family carers to return to employment. However, this approach can have the unintended consequence of lowering the available family income and increasing the need for public subsidies (Ansah *et al.* 2016). Increasing

the reliance on migrant workers can also result in exploitation of immigrants and consequences for the supply of labour in the home country of the migrant (Williams 2010).

Overall, the relationship between informal care and participation in the labour market highlights the potential wider economic opportunity costs of reliance on informal carers to deliver long-term care for older people. The overall labour supply is diminished together with the productive potential in the economy. As already noted, there is a significant gender dimension, with a number of EU member states reporting that underdevelopment of formal long-term care 'remains a major barrier to female employment' (European Union 2014). This is an issue that will need to be addressed in the context of the recent proclamation of the European Pillar of Social Rights, which includes the right to equal opportunities between men and women for participation in the labour market (Council of the European Union 2017).

7 The Fiscal Implications of Informal Care Provision

Informal care is often considered by policymakers as less costly than providing formal care or vouchers or other allowances to pay for formal care services. Informal care may indeed reduce some elements of public expenditure where it reduces the need for publicly-financed care (Van Houtven and Norton 2004, Yoo *et al*. 2004). However, in assessing the respective impacts of formal and informal care on the wider economy, it is necessary to be careful about which costs and benefits are being accounted for. Assessments of the cost of informal care need to include the costs of supporting carers financially through care allowances, and in other ways such as respite care or psychological support. Cost considerations must also be reconciled with the potentially negative impacts of informal care on tax revenues and social security contributions (Geyer at al. 2015, Määttänen and Salminen 2017). The fiscal implications of the use of informal care vary greatly across countries. For example, public expenditure on informal care varies because many allowances are means-tested (Määttänen and Salminen 2014). Cash incentives are often designed to favour formal care over informal care, but also need to be considered as part of the fiscal cost of informal care.

A high reliance on provision of informal care may reduce both private wage income and government tax revenue when compared to a reliance on formal LTC (Määttänen and Salminen 2014). Providing informal care may result in an individual switching from full-time to part-time employment or leaving the workplace completely. There are therefore high individual costs, such as reduced household income and higher poverty levels for both working age and retirement age informal carers (Age UK 2012, Aldridge and Hughes 2016). Määttänen and Salminen (2014) show

that the reductions in income tax revenues mean that some of the opportunity costs of informal care provision are borne by the state rather than the individual, but that on balance informal care usually reduces the fiscal burden of LTC.

The overall impact of losing workers from the labour force may be less of an issue where there is full employment although the overall productivity of economies could be diminished by the resulting reductions in labour supply (Casey 2011). The costs of replacing a worker to employers – estimated as between 50% to 150% of an annual salary – also results in lost productivity (Rayton *et al*. 2012).

The fiscal consequences of informal care provision change depending on the characteristics of the person providing informal care. If the provider of informal care is a non-taxpaying retired person, then there may be minimal effects on tax revenue. The income tax revenue loss in general only applies to informal carers of working age. However, there may be other costs to the individual or the state, such as those that arise from the worse health of informal carers. Actual wage earnings and the forecasted value of pensions may vary depending on the person, and it is therefore important to consider the levels of wages and income when evaluating the fiscal effects of relying on informal care provision. According to Määttänen and Salminen (2014) 'the fiscal implications depend both on opportunities of carers in the labour market, as well as on the income level of those receiving informal care in place of formal care' (5). Fiscal cost of informal care can be greater than that of formal care

Further variations in the fiscal consequences of informal care provision may arise from differences in employment hours both between countries and in subgroups within countries. For example, while the literature tends to find that higher female labour force participation increases the use of formal LTC (Yoo *et al*. 2004), there is less research on the effects of whether this employment is full-time or part-time. Schmitz and Westphal (2016) have suggested that, if increases in female labour force participation are primarily in part-time work, formal LTC expenditure is likely to decrease, while for increases in full-time work, formal LTC sector expenditure is likely to increase. To be reliable, projections of future formal LTC demand should therefore consider the distinction between part-time and full-time female employment. Study of the fiscal impact of public LTC funding decisions should also consider this distinction and the impact on female employment (Yoo *et al*. 2004). It is possible that reductions in public funding could encourage women to transfer from full-time to part-time work (Yoo *et al*. 2004). It would follow that increasing the number of part-time working women might result in a reduction in the provision of formal LTC, although reduced employment hours also have costs for individuals and the state. Alternatively, increases in females entering full-time employment are likely to create higher levels of need for formal care, due to women no longer being able to take on caring tasks.

Public policies to support formal care are usually justified with the rationale that there are high costs associated with a reduced labour supply and tax returns and possible negative health effects

of informal care. LTC systems benefit from informal care but the net fiscal benefit for society may not be positive. The picture is complex and other factors, including non-economic factors, need to be considered when looking at the fiscal implications of policies for informal care, especially for policies that aim to change the level of provision of informal care.

8 Instruments and Policies

This section will briefly analyse the main measures adopted by public actors in supporting informal care. Instruments and policies for carers and care recipients can consist of financial support (Carers Allowance or more extensive benefits or allowances), services and policies for the care recipients (formal care, assistive technologies), services and policies for carers (respite services and breaks, psychological support, information provision, training) and policies on carers' employment rights (including care leave and rights to request flexible working).

Providing these policy options also involves making decisions about how to fund support for informal carers – by the state or privately, through LTC insurance or a combination. Some countries have implemented relatively universal and comprehensive LTC support schemes for carers (for example, Denmark and Finland). In Finland, informal carers can be divided into compensated informal carers and (other) informal carers. Compensated informal carers contract with their municipality of residence and are eligible for carers' allowance. Support for informal care consists of the carer's allowance and services provided for both informal carers and cared-for persons. Municipalities assess the eligibility of both the carer and the person requiring care for support.

In other countries, social provisions are mainly to the person with care needs and specific support to the carer (for example, Belgium, Hungary, Italy, Portugal and England – see Boxes 1, 2 and 3). In Portugal, there is no care allowance for informal carers. Cash benefits are assigned to the person requiring care but without any obligation to use it to pay for care provided by informal carers. A different form of financial benefit is in place in Belgium, where time spent for caring for family members counts towards pension contributions. Informal carers in Belgium also receive allowances and, in addition, service users can access support for the financial costs of non-medical care-related expenses. A 'familistic model', in which specific provisions are (nearly) non-existent, is in place in Lithuania and Poland. In Lithuania, there are no specific support schemes for informal carer, although officially recognised carers may be eligible for sick or parental leave where the person they care for is sick (Štreimikiene and Štreimikis 2013).

Box 1: Extensive provisions for supporting informal carers in England

In England, financial support, but also in-kind and other services for informal carers, are in place. The main source of financial support for informal or unpaid carers in the UK is Carer's Allowance. Unpaid carers are eligible to receive Carer's Allowance if they care for someone for at least 35 hours a week.

The Care Act 2014 introduced a legal duty on local authorities to provide a carer's assessment to any carer who requests one or who needs support. The carer's assessment considers the impact the care and support provided has on the carer's wellbeing, as well as impacts on other aspects of their life such as employment and education. After the assessment, a carer may receive services such as help with housework. Counselling, coordination and information services from health professionals to informal carers are also available.

Carers are consulted during the assessment of needs where appropriate. Counselling, coordination and information services are generally provided because of an assessment by local authorities (non-health professionals).

Box 2: Supporting informal carers in Italy

In Italy, public services only provide a small part of the services for older people in need of care and their families. Estimates suggest that two-thirds of families provide care themselves, even for complex care needs. The majority of the supporting measures for informal carers are subject to the policies of each administrative region. In general, the regions promote training and support groups for relatives, economic contributions to the fees for residential care, social and healthcare vouchers and other initiatives.

Pilot services have recently been initiated, consisting mainly of respite care to enable informal carers to take breaks, but also including day care and temporary residential services, as well as counselling and psychological support. Tutoring services for informal caregivers are also provided.

Box 3: Support for informal care in Hungary

In Hungary, there are no cash-for-care schemes for the care recipient to pay for services, apart from government payments towards the 'nursing fee'. This allowance is not specifically targeted at the long-term care of older people. Relatives can apply for 'settlement support', which replaced the nursing fee of local governments together with many other types of provisions. Older people in need can receive state-subsidised home assistance. Local governments and churches can employ public workers as carers. There are no specific in-kind benefits or flexibility/parental leave/respite measures for informal carers, or counselling, coordination or information services provided by health professionals to informal carers.

The application of assistive technologies for reduction of carer burden has been investigated but, while some benefits have been observed, studies have failed to demonstrate cost effectiveness (Khosravi and Ghapanchi 2015, Steventon *et al*. 2013).

5.1 Long-term Care Insurance

Insurance-type instruments to guarantee some autonomy to the care recipient in choosing the type of care provision represent an interesting tool to improve quality of care while attempting to minimise the effects on the public budget (see also Ghibelli *et al*., 2017 for details). For example, in Germany, Geyer and Korfhage (2015) show that insurance type instruments produce significant and positive spill-over effects on caregivers' labour force participation (see also Campbell *et al*., 2010).

The experience of Japan is of interest, where the population has aged faster than any other country (Fu *et al*. 2017) and at the same time, the traditional caring attitude toward older people is declining (Tamiya *et al*. 2011). To counteract this trend, mandatory public long-term care insurance (LTCI) was implemented in 2000, to support older people to be more independent, and to lessen the burden on family carers (Geyer *et al*. 2015). The benefits of this insurance are coherent with the principles of social insurance, provided regardless of the level of income or other family circumstances. With the aim of mitigating the caregivers' burden and increasing labour force participation, cash allowances are not delivered but generous formal services were made available and beneficiaries can choose which service and provider they prefer. As in Germany, the system has had significant and positive spill-over effects on caregivers' labour force participation (Campbell *et al*. 2010). However, dissatisfaction with home-based care is reported: support for family carers is also needed, and fiscal sustainability was considered a problem (Tamiya *et al*. 2011). In 2006, a major cost-containment reform took place, reducing benefits in particular for those with milder care needs. A carer-blind principle has been maintained, but the effects showed that many recipients do away with home help services or rely on family members. This suggests that cost-efficiency should be matched by increased support to carers (Tamiya *et al*. 2011). The extensive longitudinal data analysis undertaken by Fu and colleagues, covering before and after the reform, found that the gains in labour force participation observed prior to the reform have been reversed and a significant reduction in labour force participation has occurred in particular among the group most affected by the reform (Fu *et al.* 2017). Indeed, further restrictions on benefits have been introduced and Fu and colleagues refer to these as 'myopic policies' commenting, at the same time, that the Japanese approach of providing benefits in kind 'would provide a good example too other countries where encouraging care givers' labour force participation is a priority' (Fu *et al.* 2017).

5.2 Cash Benefits

Support for informal care is mainly financial. Indirect financial support has been recently introduced, but with more emphasis on the personalisation of LTC services.

Care allowances for informal carers, mostly in Eastern European countries and the UK (King and Pickard 2013), consist of allocating funds directly to informal carers to compensate for loss of employment or reductions in earnings. It is important to highlight that LTC funds are very limited in several countries: this explains why the carers receive payments only in limited cases, for instance, when the carer has an extremely low income (Ferrant *et al*. 2014). Indeed, if the payment to the carer was at the 'market level', this might act as a disincentive for individuals to stay in work, even though many carers are retired or unlikely to enter or re-enter the labour market (Triantafillou *et al*. 2010). The opportunity costs of reducing working hours or dropping out of the labour market completely are lower if benefits are only available to carers on low salaries, and these carers may also be deterred from entering the labour market in the first place (Bauer and Sousa-Poza 2015). However, too low a level will fail to increase informal care provision, except perhaps for very low income earners, or to alleviate the poverty that many informal carers (and their households) experience. The social benefit of carer's allowance may be due to the increases in the supply of informal care which then reduces the use of formal care (that is, informal care substitutes for formal care), and the cost of formal care system might be lower as a result. However, this effect, or apparent effect, is mainly observed at higher cash benefit levels, which as outlined above can have a negative effect on labour force participation.

Care allowances in the Scandinavian countries are comparable to contracts of employment and are managed by the municipalities. The value of these care allowances is almost at the market level and they are part of a benefit scheme which includes direct support services in kind (with some exceptions). This care allowance has a value of 40% to 100% of the caregiver's original wage (Bauer and Sousa-Poza 2015). However, market levels of entitlements are only available to a small number of informal carers, who are usually the carers of older people in remote areas, where the organisation of formal services is not feasible or too costly. In Finland the minimum allowance is only the 12% to 15% of the salary of professional nurses, but extra payment from the municipalities is possible. In Finland, the carers' allowance is also lower than salaries paid to professional carers (Colombo *et al.* 2011).

These schemes are restricted partly to reduce the incentives for low-wage earners to leave the workforce to provide care. These incentives are greater where eligibility and benefits are means-tested, as in the UK (European Union 2014). In some countries (as in the Netherlands) a solution has been found in employing relatives on contracts, depending on the level of hours per week of

care provided. Both in the Netherlands and in Germany, holiday leave and other respite measures are available.

Attendance allowances are benefits that are transferred directly to cared-for individuals, depending on a variety of criteria. These allowances can also include the payment of an informal carer. Attendance allowances are of two kinds: cash payments given to the cared-for persons, letting them to decide how to use the funds (for example, as in Germany and Italy), or 'vouchers' for beneficiaries following an assessment of their individual needs. Beneficiaries can then use the vouchers to purchase services, using providers selected by public actors (as the regions do in Italy) or directly on the market (as happens in France).

Tax relief is another type of indirect financial support to caregivers. Specific tax incentives for carers are rarely provided, although tax exemptions for carer's allowances are available in many countries. An interesting point of view is that providing direct cash benefits may reduce the administrative burden, delegating the decision on how to use the money directly to the care receiver. This could increase the flexibility in the use of money and possibly lead to improved satisfaction with care (Bauer and Sousa-Poza 2015). Another possible effect of cash benefits is to encourage the development of private care providers. A distortion in the use of cash benefits is reported in some countries such as Italy, where the family in many cases use this money to hire informal carers (such as migrant workers) instead of buying formal care (see Box 4). Financial incentives could, however, affect the intrinsic motivation to care (Deci 1971), in effect 'monetising' family relations.

A related issue is whether promoting a substitution of formal for informal care has an impact on the quality of care. In very few cases, for example in France, informal carers can attend training similar to that provided for professional care workers.

Box 4: The 'grey' market in Italy

Italy is characterised by a high reliance on migrant care workers for the provision of practical care for older people at home. A lack of regulation around attendance allowance has resulted in the development of a large unregulated care sector, employing more than 800,000 immigrant care workers (Courtin *et al*. 2014).

The government is working on the implementation of radical reforms of the LTC system. This will include the regularisation of planning and implementing structural reforms in the LTC system, including regulating the situation of migrants working as informal carers, the definition of user satisfaction standards, the improvement of the quality of care provision and efficiency improvements.

Even where cash benefits are in place and are an important support to care recipients, they are only one element of national LTC systems and do not in themselves reflect the overall extent of the LTC system (Riedel 2012). This applies for Scandinavian countries, where formal care is usually provided in kind, even if cash benefits have recently become increasingly important (Da Roit and Le Bihan 2010). This does not mean that financial transfers to informal carers can be seen as substituting for income from employment. In Denmark they are offered for six months (Riedel 2012) although financial support is available to take care of a dying family member at home, as long as the carer is still in employment. In Poland, respite leave for carers is not provided but carers are eligible for carers leave (see Box 5).

Box 5: Support for informal carers in Poland

In Poland, care allowances aim to cover part of the costs of care. Care benefit instruments for informal carers who have left employment to care for a dependent person are also in place as in-kind services. There is no respite leave for carers but the carers are eligible for carers leave. Counselling, coordination and information services are sometimes provided by local municipalities. There is no remuneration to family carers apart from the care benefit.

A summary of the care and attendance allowance measures in SPRINT countries is presented in Table 2.

Table 2: Care and attendance allowances in SPRINT countries (adapted from Courtin *et al*., 2014)

Country	Care Allowances (Direct financial support)	Attendance Allowances (Indirect financial support)
Belgium	No	Yes
Denmark	Yes	No
England	Yes	Yes
Finland	Yes	No
Germany	Yes	No
Greece	No	Yes
Hungary	Yes	No
Italy	Yes	Yes
Lithuania	No	Yes
Poland	Yes	Yes
Portugal	No	Yes

5.3 Formal Care

Support for carers can also be indirect. In England, the Care Act 2014 pays special attention to ensuring that the needs of informal carers are assessed alongside those of the care recipient (Department of Health 2017). Home-based professional formal services are often provided to older person. In Scandinavian countries they are frequently also used to support informal carers. In some countries home support devices and home adaptations are also provided and partially funded (for example, in Denmark and the UK). In Germany, domestic help is available where the care burden is too great for the informal caregiver (Bauer and Sousa-Poza 2015).

Higher public funding for LTC services typically reduces the marginal costs of formal LTC for families (Yoo *et al.* 2004). It might follow that subsidising formal care provision can stimulate demand for formal care services, even where informal carers might be available. Evidence regarding this is mixed. In some cases, such as Japan, it is reported that the demand for formal care increases because of public funding (Shimizutani and Noguchi 2003). This demand may be to complement the provision of informal care, rather than to substitute for it completely (Yoo *et al*.

2004). Other studies show a reduction in hours spent on informal care (for example, Hollingsworth *et al.* 2017). Van Houtven and Norton (2004) show that informal care can reduce medical expenditures if it substitutes for formal care and delays nursing home entry. The substitution effect depends on the level of disability (Bonsang 2009) and (associated with this) the nature of care needs. Bolin *et al*. (2008b) present data demonstrating that informal and formal home care are substitutes, while informal care is a complement to doctor and hospital visits.

While there are a few exceptions, most research studies show that the provision of formal care increases the participation of informal carers in the labour force (e.g. Geyer and Korfhage 2015, Haberkern and Szydlik 2010, Heger 2014, Lamura *et al*. 2008, Pickard *et al*. 2018, Viitanen 2007), with the potential to reduce the associated individual and societal costs of carers not being in employment (Pickard *et al*. 2018).

5.4 Care Leave

Policies which reduce the dual pressures for informal carers caused by both working and providing care might assist them to remain in formal employment, as well as making caring a viable option for more individuals. Even if instruments such as family leave and flexible working hours can impact positively on the propensity of women to stay in work, the effect they may have on the overall level of employment is not clear as these policies may affect the potential employment opportunities for people who are currently providing care and not working (Colombo *et al*. 2011).

Many countries provide flexible working time arrangements for informal carers. Two-thirds of the OECD countries allow informal carers to take temporary leave periods from work. In some countries one or more years of leave are permitted, for example, in Belgium, where there are extensive provisions for family carers to combine work and care, with regulations mandating various forms of leave. In English-speaking countries and the Netherlands, shorter periods of leave (less than three months) are available. In countries such as Germany and Austria medium-term leave (six months) can be requested (EU 2014). There is very little available evidence on what effect care leave has on substitution between informal and formal care. The limited evidence there is, in the US, shows that it leads to small increases in informal care provision, with paid leave generating larger increases (Skira 2015). The substitution effect depends on care needs and caring duration (Colombo *et al*. 2011). Care leave may also enable informal carers to remain in employment (Bouget *et al*. 2016, Ikeda 2017), again dependent on care need and caring duration.

5.5 Respite Care

Respite care consists of services to allow the informal carer to take a temporary break from their caring responsibilities and is usually provided to the person with care needs (see Table 3). In several countries (Belgium, Finland, Italy, Lithuania, Portugal) its purpose is to support family caregivers using professional care. However, the generosity of these services often varies according to age group (European Commission 2016).

The quality of public direct care provision and financing of respite care services is different across European countries (Colombo *et al*. 2011). Legal entitlements to respite care exist in some European countries. For instance, in Finland carers can take a few days off each month; in Germany the respite care leave is four weeks per year. In some studies, respite care is assumed to be the most effective way to lighten caregiving responsibilities (Lopez-Hartmann *et al*. 2012). Despite this, two recent meta-reviews of support for informal carers (Parker *et al*. 2010, Thomas *et al*. 2016) found no evidence that respite care improved carers' mental or physical health, with some evidence of a negative effect. However, carers often highly value such services, although few carers use this opportunity for respite care (Van Exel *et al*. 2008), possibly because of lack of availability of publicly-funded services.

Table 3: Respite, counselling and information services for carers in SPRINT countries (adapted from Courtin *et al*., 2014)

Country	Respite care	Counselling	Information	Training
Belgium	Yes	No	No	Yes
Denmark	Yes	Yes	Yes	Yes
England	Yes	Yes	Yes	Yes
Finland	Yes	Yes	Yes	Yes
Germany	Yes	No	Yes	Yes
Greece	Yes	Yes	Yes	No
Hungary	Yes	No	Yes	No
Italy	Yes	Yes	Yes	Yes
Lithuania	No	No	Yes	Yes
Poland	No	Yes	Yes	No
Portugal	Yes	No	Yes	Yes

5.6 Training, Information and Psychosocial Support

Other benefits sometimes offered to informal carers are counselling, training and information. As reported in Table 3, training and information are provided in most of the European countries, but counselling is not as widely available. Local and voluntary organisations are heavily involved in the provision of social support services and training. Developing innovative organisational solutions, such as 'one-stop shops' for carers and families, could improve the provision of information. In addition, care managers could be a solution to support informal carers with administration. Implementing care management processes could also impact on the quality of the service provided (European Union 2014). Collaboration between formal and informal providers should also be fostered. Finding information about the services available and the procedures and conditions for applying for them is one of the most urgent needs of informal carers, but in many countries a satisfactory level of information is not provided. The same problem is reported for support services such as counselling, which might be very useful in guiding carers in their choices as well as providing psychological support. Self-help and peer support groups could also be of great benefit to some carers, but evaluation of their effectiveness is still scarce. Vandepitte *et al*. (2016) have recently shown that designing tailored policies for individual caregivers can have successful results, with positive effects not only for the care recipients and the caregivers' quality of life but also for society as a whole. Other research has shown psychological therapy, training, education and support groups to be effective in supporting carers' wellbeing (e.g. Thomas *et al*. 2016). The third sector and social enterprises could play a role in providing these services. For example, in Portugal, there is no widespread training for carers, but some NGOS are providing it, especially for carers of people living with dementia.

It would be expected that policy options to support informal care should be fiscally sustainable, with a manageable effect on the national budget and at the same time should foster social (including inter-generational) cohesion. This also applies to measures to improve the working conditions of the informal carers (Triantafillou *et al*. 2010). In many countries, especially in southern Europe, the family alone is responsible, from the financial and operative point of view, for the provision of care to the members of the family. In contrast, in Scandinavian countries, state or local levels of administration are formally responsible for the design and implementation of care services. A mixed approach exists in Germany where the person in need can access care through mandatory LTC insurance. Families often employ migrant care workers in many southern European countries (notably Italy), but also in central Europe (Germany, for example) (Triantafillou *et al*. 2010).

Specific support policies involving NGOs are often part of national LTC policies. Indeed, the NGOs involved sometimes take on a role in place of the state, often directly funding and delivering the

services. This occurs for instance in Greece, where NGOs are the only actors providing of support services to informal carers (Courtin *et al*. 2014).

In many other countries (for example, in Italy and Portugal), NGOs are important actors in the direct provision of LTC, in some cases even supplementing, or substituting, other forms of formal provision. NGOs also play a pivotal role at the level of communities, supporting the activities of informal carers and providing services including respite care, psychological support and information. NGOs frequently support immigrants to enter the labour market, providing legal coverage and organising training activities. In addition, they are often able to play a facilitating role in the management of the network relations between informal and formal carers and the public and private actors operating in a specific community. They are also engaged in advocacy and lobbying activities.

While there is a range of policies that directly or indirectly support informal carers, there is limited available evidence regarding the effectiveness of specific measures, or it is not conclusive. However, there is evidence that cash benefits and formal care policies affect the balance of informal and formal care, with fiscal, social and equity implications. There is a need for policy to be fiscally sustainable, equitable and supportive of informal carers' and care recipients' needs. A stronger system for routine data collection covering the provision of informal care is necessary, in addition to robust assessment of specific interventions.

Good evidence on the effectiveness and cost-effectiveness of measures to support informal carers is limited. Kendall and Knapp have suggested that appropriate indicators are needed to assess the effective performance of the voluntary sector and to analyse the impact of their activities on society. They propose eight domains of performance (economy; effectiveness; efficiency; choice/pluralism; equity; participation; innovation and advocacy) and 22 separate indicator sets (Kendall and Knapp 2000). There is certainly scope to build a better evidence base, using a framework of this kind, with a comparative dimension, for policy decisions on support for informal carers

6 Discussion and Conclusions

In determining strategies for LTC, policy makers may overlook or take for granted informal care provision since it occurs largely in a 'privatised' space, within family settings. This report draws attention to impacts, at personal, economic and social levels, of substituting formal care with informal care. Relying on the apparently low-cost informal system may neglect the wider but less visible costs.

There is no single definition of 'social investment' but definitions feature several common principles (Morel *et al*. 2012, Hemerijck 2015). Measuring the effectiveness of social investment focuses on outcomes, rather than on, for example, process measures. In investment terms, this can be regarded as the 'return' on investment. These outcomes are measured over the long term, rather than simply judging the immediate effects on the physical and mental health of the individual. Under a social investment approach, the focus also shifts from 'repairing' the physical, mental and emotional damage experienced by individuals to a focus on 'preparing' individuals and their families to manage disruptive and negative life events more successfully. Outcomes are also considered more broadly from the perspective of multiple stakeholder groups for social investment approaches.

For the individuals receiving informal care, outcomes from social investment under consideration may include broader quality of life benefits – for example, increasing social engagement and autonomy. For informal carers, quality of life outcomes may be improved by receiving financial, physical or emotional support for caring. These outcomes may result, for example, from reducing stress levels or by allowing the individual to continue in formal employment. Other stakeholders may experience positive outcomes - for example, as a result of measures to help balance caring roles with workplace obligations, employers may value retaining employees in the workplace rather than facing excessive recruitment and training costs to replace individuals who leave to become full-time carers. At a societal level, the outcomes may include an improved balance of labour market participation for the wider economy.

This report has highlighted several aspects of informal care policies which require consideration where governments wish to shift towards social investment strategies to support and manage long-term care provision. These aspects should be considered from two angles: first, they might provide governments with new policy options and opportunities to shape the nature of informal care; and second, the social investment perspective may encourage governments to consider policy decisions around informal care more actively. A social investment approach might enable and encourage governments to shape both the balance between informal and formal LTC, as well as the nature of informal care. For example, a new approach could address informal care in a more equitable way, moving away from the over-reliance of most countries on older female carers.

This report has discussed the impacts of providing informal care in three areas: the health and wellbeing of informal carers, employment and the labour market, and related to this, the fiscal implications of substituting formal care with informal care. With the longer-term and broader view associated with social investment, there are potential opportunities to consider these factors more actively than through traditional funding mechanisms. First, these new approaches would allow investors, whether government or non-government, to include the potential impact of policy interventions on the health and wellbeing of carers when designing interventions. Second, governments might employ new investment approaches to consider the returns for other parts of

the economy and public services – for example, health provision, welfare and disability provision, and taxation.

Finally, the report has highlighted some of the main policies and instruments in place in different European countries to support informal carers. Introducing a social investment approach may help to determine which mixes of policies are suitable for driving outcomes at both a macro and micro level. In the long term, therefore, social investment approaches may deliver new and innovative policy interventions to more actively balance the needs of a broad range of stakeholder groups. However, a proper evidence base is needed regarding the effectiveness of such measures.

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8 Annex 1: Survey Questions

1. Please give some information about the following items
   - financial support measures (i.e. care/attendance allowances) for informal carers
   - in-kind services for informal carers provided in your country
   - flexibility/parental leave/respite measures for informal carers
   - counselling, coordination and information services from health professionals to informal carers

2. Does the public sector provide remuneration to family carers who are formally employed or are means-tested allowances utilized? What is the overall cost of these measures?

3. Do peer-reviewed articles/books and/or statistical data (monitoring studies, quantitative indicators…) about the impact of informal care on LTC system in your country exist? If yes, please provide documents/web links.

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