



EU-WISE Project FINAL REPORT

Grant Agreement number: 279081

Project acronym: EU-WISE

Project title: " Self-care Support for People with Long Term Conditions, Diabetes and Heart Disease: A Whole System Approach "

Funding Scheme: THEME [HEALTH.2011.3.3-2] Collaborative Project

Project Start Date: 1 January 2012.

Project End Date: 31 December 2015.

Name, title and organisation of the scientific representative of the project's coordinator:

Prof Anne Rogers, University of Southampton.

Tel: + 44 (0)23 8059 6830

Fax: ++44 (0)23 8059 7900

E-mail: A.E.Rogers@soton.ac.uk

Project website address: www.eu-wise.com

Table of Contents

1. FINAL PUBLISHABLE SUMMARY REPORT	3
1.1 EXECUTIVE SUMMARY	3
1.2 A SUMMARY DESCRIPTION OF PROJECT CONTEXT AND OBJECTIVES	5
1.2.1 BACKGROUND	5
1.2.2 THE EU-WISE APPROACH	5
1.2.3 EU-WISE AIMS AND OBJECTIVES	6
1.2.4 REFERENCES	7
1.3 A DESCRIPTION OF THE MAIN S&T RESULTS/FOREGROUNDS	8
1.3.1 INTRODUCTION	8
1.3.2 WP2 STRUCTURE AND GOVERNANCE OF HEALTH AND WELFARE SYSTEMS	8
1.3.3 WP3 PERSONAL NETWORKS	10
1.3.4 WP4 VOLUNTARY AND COMMUNITY GROUP NETWORKS	17
1.3.5 WP5 IN-DEPTH EXPLORATIONS	21
1.3.6 WP6 SURVEYS	28
1.3.7 WP7 DEVELOPMENT OF RESOURCES	35
1.3.8 WP1 THEORETICAL AND METHODOLOGICAL BACKGROUND OF SYSTEMS OF SUPPORT	40
1.3.9 CONCLUSION	46
1.4 IMPACT, DISSEMINATION AND EXPLOITATION	48
1.4.1 EU-WISE IMPACT AND FUTURE USE	48
1.4.2 EU-WISE DISSEMINATION	52
1.5 WEBSITE AND CONTACT DETAILS	64

1. Final publishable summary report

1.1 *Executive Summary*

The increasing prevalence of people living with long term conditions (LTCs) and associated costs, have meant that seeking out and implementing effective self-care support is a key consideration for health care policy. The overall aim of EU-WISE has been to develop a better understanding of innovative approaches to supporting people in the management of LTCs. We aimed to study how health care systems, personal networks and local organisations can improve self-care in order to assess how best to develop a broader system of self-management support which extends beyond the scope of individualised patient education and traditional self-management programmes. We aimed to focus on socially disadvantaged or marginalised groups.

The key work undertaken and results achieved in EU-WISE include the following:

- We have provided insights into the nature and differences in the role that healthcare systems and welfare regimes play in the experiences and systems of support for people with LTCs.
- We conducted substantive analysis of the nature, importance and underlying mechanisms of personal and social networks of support relevant in partner countries.
- We explored the support mechanisms that operate at the meso level (non-governmental, voluntary organisations and community groups (VOCGs)) and examined the role that VOCGs play in the self-management of long term conditions.
- We carried out qualitative empirical investigations into self-management of LTCs, conducting 90 key informant interviews, 175 biographical interviews, 285 interviews with NGOs and voluntary groups and 32 focus groups (and 11 related interviews).
- We completed quantitative empirical investigations, involving a survey in a sample of 1,861 patients (18 years or older) with (diagnosed) diabetes mellitus type 2 and 877 members of community organisations.
- We analysed existing self-management interventions and designed a new intervention (EU-GENIE), involving participatory methods of social network mapping to encourage patient reflection on self-management supports, to inspire positive change and (in many cases) to link patients with useful resources. EU-GENIE was piloted across 6 partner countries and was positively received by participants. The visualization of their network was important to users and helped them reflect on support, reciprocity and availability of resources.

Our work has resulted in 25 project publications to date, with 3 more articles accepted for publication/in press and approximately 12 more publications planned.

In EU-WISE we have generated new knowledge about self-management support (SMS) and macro level influences, the role of personal networks, the importance of VOCGs and the position of healthcare professionals. We have also opened up avenues for further research, particularly in the VOCG sector. Significantly, our findings on networks suggest that policy and interventions should be extended to include: (i) raising awareness about the structure and organisation of personal communities; (ii) building individual and network capacity for navigating and negotiating relationships and (iii) maximising the possibilities for social engagement. We believe that the findings of EU-WISE will provide policymakers with a sound basis on which to shape future health policy, self-management supports and interventions. We have identified a clear need to focus the future direction of self-management policies on the role of social networks and community organisations. In our view, the future of self-management support must concentrate on looking outwards to links and connectivity to resources, relationships and community.

As part of the project we also delivered a new self-management support intervention for people living with long term illness, which has potential for use in different contexts and populations. Our work on EU-GENIE suggests a face to face network-based intervention works as a positive disruption to the established ways in which people self-manage, which opens up new possibilities for people to consider how they might do things differently.

We believe the ultimate legacy of EU-WISE will be to help improve self-management and health outcomes, increase patients' wellbeing and foster enhanced communities, while also reducing the burden on the health sector and delivering related social and socioeconomic benefits.

1.2 A summary description of project context and objectives

1.2.1 Background

The increase in the number of people living with long term conditions and the associated rising costs have highlighted the need for policy makers to make self-care support a central part of the management of long-term conditions. Self-care has been defined as *“the care taken by individuals towards their own health and well being: it comprises the actions they take to lead a healthy lifestyle; to meet their social, emotional and psychological needs; to care for their long-term condition; and to prevent further illness or accidents”* (DH 2005). Self-care has been estimated as beneficial for 70-80% of people with LTCs, and forms part of a wider agenda about public health, health promotion and patient involvement in different health systems across Europe (DH 2006, Hadjiev, Toneva, Short 2007).

The potential benefits of better self-care support are substantial; they include improvements to subjective well-being, patient empowerment, increased self-efficacy, changes to lifestyle and health behaviour and a reduction in the utilisation of health care services. However, evidence for the effectiveness of implementation and outcomes within and across countries remains equivocal. Whilst there is evidence of behavioural change, using psychological approaches, there have been calls for the inclusion of a broader focus on the psycho-social influences and the structure and environment of long term illness management, in order to fully realise the potential of self-management initiatives.

It is in employment, domestic and community settings where health-related behaviours are influenced by personal, economic, and institutional contexts. Current questions about devising and implementing effective self-care practices and health behaviour change implicate a broad range of ideas in academic and policy debates about self-management. The latter includes developing alternatives to a ‘one size fits all’ approach to self-management (which have proved limiting in terms of reach), and the need to devise and implement workable, context sensitive strategies for self-management that use effectively the full range of available technologies (e.g. eHealth), and personal, community and institutional networks and resources.

The importance of social networks for people’s health is well established. Not only do economic and cultural resources interact with social networks to determine people’s health chances, choices, and the unequal distribution of health outcomes (Abel 2008), there is evidence that social networks have an independent influence on health. In a systematic review Holt-Lunstad, Smith, Layton (2010) argued that the influence of social relationships on risk for mortality was comparable to well established risk factors such as smoking and alcohol consumption and exceeded the influence of risk factors such as physical inactivity and obesity. This supports the argument for placing a stronger emphasis on the role of social networks and everyday contexts in research on self-care support, and the need to better understand the relationship between informal support and formal provision of healthcare in different countries. Cross country, international research can provide more robust insight into the mechanisms implicated in the operation of social networks than studies in single countries. There is also a need to focus on the translation of efforts within individual countries to multiple health systems.

1.2.2 The EU-WISE Approach

In order to address the above questions, which extend beyond an individual capacity model, EU-WISE builds on a number of conceptual approaches. First, we have extended and applied the Whole System Approach to self-care support (Kennedy, Rogers, Bower 2007) to a range of countries to identify the processes implicated in illness management operating at different system levels (professional, organizational, and patient), and identify gaps in existing support for people with LTCs. We have also drawn on Normalization Process Theory (May et al. 2007), social network analysis (Pescosolido 1992, Stoller and Wisniewski 2003, Vassilev et al. 2010) and the sociology of chronic illness (Corbin and Straus 1985).

Our starting point has been that a variety of concepts are necessary to deal with relationships and mechanisms operating on a variety of levels which impact on self-care support. In order to uncover the variety of processes implicated in self-care there is a need to explore influences operating at a macro, meso and micro levels. At the

macro level we have explored different long term illness health care structures and governance arrangements within welfare and health care systems across partner countries. Meso level factors investigated include the services and support provided by voluntary, community and local organizations and inter-organizational networks. At the micro level we focussed on the structure, content, and function of people's social networks and resources and the processes involved in the normalization of health behaviours and illness work within everyday life.

To achieve its aims EU-WISE has combined literature and systemic reviews with empirical research. Our empirical research has included qualitative and quantitative investigations. The project has featured key informants interviews, biographical interviews, interviews with NGOs and VCOs (voluntary & community groups) and Focus Groups (people with diabetes, representatives of voluntary and community groups, and health professionals). In addition, we conducted comprehensive surveys of diabetes patients, members of community organisations and network members in each partner country.

EU-WISE has focused on developing alternatives and supplements to a 'one size fits all' approach to self-management and on workable, context sensitive strategies for self-management, that avail of the full range of available technologies, as well as personal, community and institutional networks and resources. EU-WISE has an emphasis on socially disadvantaged, marginalised or vulnerable people (among whom the prevalence of long term illness is higher than the population average across Europe), who have some of the lowest levels of uptake of existing interventions and are likely to benefit the most.

1.2.3 EU-WISE aims and objectives

The main objectives of EU-WISE have been to:

- Shift the emphasis on self-care support to take account of domestic and social contexts which act as a complementary focus to the delivery of self-care support by formal health care agencies.
- Understand the illness related work undertaken in people's everyday lives.
- Consider the challenges faced by deprived populations in adopting, adapting and engaging with illness management strategies.
- Describe the contexts and settings in which the common European concern of providing healthcare for people with long term conditions is addressed.
- Review the emerging strategies and interventions being developed and deployed in different countries.
- Informed by the above points, to develop and test a set of interventions centred on social networks and integrated within broader systems of support within partner countries (taking into consideration differently structured healthcare systems and welfare regimes).

The EU-WISE approach differs from existing approaches to self-care and illness management in the degree to which it puts an emphasis on:

- i. management in informal every day domestic and community contexts and lives of people as opposed to healthcare settings;
- ii. the dynamics and opportunities inherent in social and personal networks and the capacity to leverage and mobilise resources needed for support networks as opposed to individuals;
- iii. the potential of voluntary and community groups to make a contribution ;
- iv. locating illness management within 'whole systems' as opposed to primarily links to and interactions with health professionals;
- v. the role of new technologies and eHealth as carrying substantial promise for the management of LTCs if considered as an element of broader systems of support (rather than as a ready-made set of solutions that can automatically replace existing provisions);
- vi. person-centred priorities such as well-being and sense of normality in everyday life that work in parallel to professionally defined ones; and
- vii. building repertoires for behaviour change and illness management that are sustainable over the longer term (in contrast to approaches and interventions that expect to achieve behaviour change over the short-term, yet often with limited impact over the longer term and for disadvantaged people).

There is a specific emphasis in EU-WISE on developing multi-level (individual, community, organisational, and system levels) approaches to behaviour change that take into account a variety of contexts. In addition, the strong emphasis on social networks and everyday practices carries potential for facilitating sustainable behaviour change, including for disadvantaged groups.

The overall aim of EU-WISE is to develop a better understanding of the mechanisms involved in the management of key long term conditions (diabetes type 2 and risk of heart disease), with a specific focus on socially disadvantaged people and on enhancing better self-management in peoples' everyday lives and local communities, within and across different contexts.

1.2.4 References

Department of Health (2005) Self-care – A Real Choice: Self-care support – practical option. DoH. London.

Department Health (2006) Our Health, Our Care, Our Say, DoH, London.

Hadjiev, V, Toneva, Z., and Short, S. (2007) 'On the inequitable impact of universal health insurance: the experience of Bulgaria in transition', Health Sociological Review, 16:2, pp. 130-145.

Abel, T. (2008) 'Cultural capital and social inequality in health', J Epidemiol Community Health, 62, (7), e13.

Holt-Lunstad J, Smith TB, Layton JB (2010) Social Relationships and Mortality Risk: A Meta-analytic Review. PLoS Med 7(7): e1000316. doi:10.1371/journal.pmed.1000316.

Kennedy, A., Rogers, A., and Bower, P. (2007) 'Support for self-care for patients with chronic disease', BMJ, 335, (7627), 968-970.

May, C., Finch, T., Mair, F., Ballini, L., Dowrick, C., Eccles, M. (2007) 'Understanding the implementation of complex interventions in health care: the normalization process model', BMC Health Services Research, 7:1, 148.

Pescosolido, B. (1992) 'Beyond Rational Choice: The Social Dynamics of How People Seek Help', American Journal of Sociology, 97, 1096-1138.

Stoller, E. and Wisniewski, A. (2003) 'The Structure of Lay Consultation Networks: Managing Illness in Community Settings', Journal of Aging and Health, 15: 482-507.

Vassilev, I, Rogers, A, Sanders, C, Kennedy, A, Blickem, C, Protheroe, J, Bower, P, Kirk, S, Chew-Graham, C, Morris, R (2011) 'Social networks, social capital and chronic illness self-management: a realist review' Chronic Illness March 2011 7: 60-86.

Corbin, J. and Strauss, A. (1985) 'Managing Chronic Illness at Home: Three Lines of Work', Qualitative Sociology 8.

1.3 A description of the main S&T results/foregrounds

1.3.1 Introduction

The scientific work of the project was divided into the following work packages:

- WP1: Theoretical and methodological background of systems of support for people with diabetes and heart disease.
- WP2: Structure and governance of health and welfare systems.
- WP3: Personal networks, relationships and systems of support.
- WP4: Voluntary and community group networks.
- WP5: Methods 1: In-depth Explorations.
- WP6: Methods 2: Surveys.
- WP7: Development of resources.

The main work undertaken and results achieved in each work package are described below. Commentary on WP1 is reserved to the end, given its role drawing together, analysing and synthesising the themes that emerged across the project.

1.3.2 WP2 Structure and Governance of Health and Welfare Systems

1.3.2.1 Overview

WP2 has provided theoretical insight into state functions and structures and has delivered a comparative perspective on the impact that different health systems and welfare regimes have on the experiences and structure of systems of support for people with long-term conditions. This WP offers a macro –meso perspective on the systems of support operating in different countries of the EU and addresses questions about the specific regulatory emphasis that exists, and the role that different professional groups play, in providing support for people with long term illness. WP 2 also explored links between the formal governance and regulatory framework, and the structure of other forms of support for people with diabetes and heart disease that operate on the meso (WP4) and micro (WP3) levels.

The specific objectives of WP2 were to:

- Identify relevant official data sets with which to locate the focus of self management support.
- Explore the overarching institutional and funding structure of different health care systems in Europe, including government initiatives and adopted self-care and behaviour change interventions.
- Identify the literature on long term illness management arrangements of health systems of the different partner countries.
- Ask what are the key government objectives and directions of change in the provision of health care in general and self-care and behavioural change in particular.
- Identify the key professional groups involved in chronic illness management (CIM) and how support is distributed between health and non-health sector providers and how the role of health care professionals is changing.

The work of WP2 was conducted in stages. First, the lead partners carried out a review of relevant qualitative and quantitative literature. Second, country specific reports were written by all partners. Third, the findings of the review and the reports informed the development of an interview schedule for the key informant interviews (WP5). The preliminary analysis of the findings from key informant interviews, country reports, statistics and reviews all fed back into writing the final WP2 report. As with the other thematic WPs in the project, the findings from WP2 helped inform the development, implementation and assessment of the EU-GENIE intervention adapted to specific national contexts in WP7.

1.3.2.2 Key Results

WP 2 has delivered insights into the different welfare policies, systems provision, structure and reforms of partner healthcare systems and the association that exists, through direct and indirect impact, on the configuration of support for people with LTCs, with a focus on those with Type 2 Diabetes. In this WP we succeeded in identifying and reviewing policy documents and background information for each participating country, as well as integrating this information for summarizing and mapping. Specifically we provided an overview of:

- the current policies and understanding of changes in health and welfare systems;
- the existing knowledge, practices and health care professionals roles in relation to long term illness management;
- the emergence and growing significance of new providers of illness related services;
- the use of IT based interventions telemonitoring, remote consultations, online resources etc. for supporting self-care (world wide web);
- context, trends and the politics of health policy and service delivery in different European countries.

The following are some of the key learning points that emerged from WP2:

- There is variation in the organizational and funding structure in the governance and welfare systems in the EU-WISE partner countries; different funding models and payment systems with GPs as gate keepers in some of them and various governance schemes.
- The natures of healthcare systems are indirectly implicated in the emergence of new forms of support for self-care. The focus on secondary care reflects a tendency for healthcare systems to follow an exclusively bio-medically defined health outcomes agenda, which operates in relative isolation from broader well-being objectives.
- One of the most important changes in terms of diabetes self-management support has been the transition from secondary to primary care and the recognition of lay knowledge, and a normative drive towards patient involvement and patient empowerment. The revision of professional roles into multi-disciplinary clinical teamwork in primary care seems to be an urgent need in certain EUWISE partner countries.
- The potential for eHealth and telemonitoring to play a key role in supporting SMS is recognized in all EU-WISE partner countries.
- Prevention, and health promotion measures that invest on building and sustaining of health environments, while acknowledged as important for the management of diabetes mellitus (DM), are in practice relegated to being of secondary importance and/or left to individual choices and to the self-regulating mechanisms of markets.
- The financial crisis in Europe has had an impact on SMS in all EU-WISE countries to different degrees. Within countries, even where the politics of austerity have had a more limited impact, social inequalities and living in deprived circumstances have a significant impact on illness management.

Our work in WP2 has led to 2 key publications to date: *“Diabetes self-management arrangements in Europe: a realist review to facilitate a project implemented in six countries”* (Antonis A Kousoulis et al) BMC Health Services Research Vol. 14/Issue 1 page 453. DOI 10.1186/1472-6963-14-453 and *“Connectivity, contest and the ties of self-management support for type 2 diabetes: a meta-synthesis of qualitative literature”* (Christina Foss et al) Health and Social Care in the Community DOI:10.1111/hsc.12272.

The work performed in WP2 and elaborated in the published articles above, has impacted on subsequent WPs, especially in synthesizing both formal and informal self-management support with particular reference to the relevance and influence of the social context operating at different levels.

1.3.3 WP3 Personal Networks

The main focus of WP3 was to explore long term illness management in the context of personal networks and to contribute to developing approaches and interventions that go beyond the currently dominant focus of individual behaviour change. The findings of this WP draw on literature reviews and the analysis of the qualitative and quantitative data collected as a part of the EU-WISE project. The key findings can be summarised in four closely interrelated themes: 1) social network mechanisms, 2) links between macro level processes and processes operating on the level of social networks, 3) factors relevant for individual and network engagement with online resources, 4) typology of networks.

1.3.3.1 Social network mechanisms relevant for the management of long-term conditions

A qualitative metasynthesis was undertaken in order to focus on identifying the mechanisms linking social networks with CIM (Vassilev et al 2014). A systematic search of qualitative studies was undertaken on Medline, Embase, and Web for papers published between 1st January 2002 and 1st December 2013. Eligible for inclusion were studies dealing with diabetes, and with conditions or health behaviours relevant for diabetes management; and studies exploring the relationship between social networks, self-management, and deprivation. 25 papers met the inclusion criteria.

The main themes identified were: 1) sharing knowledge and experiences in a personal community; 2) accessing and mediation of resources; 3) self-management support requires awareness of and ability to deal with network relationships. These translated into line of argument synthesis in which three network mechanisms were identified. These were network navigation (identifying and connecting with relevant existing resources in a network), negotiation within networks (re-shaping relationships, roles, expectations, means of engagement and communication between network members), and collective efficacy (developing a shared perception and capacity to successfully perform behaviour through shared effort, beliefs, influence, perseverance, and objectives) (see Figure 1).

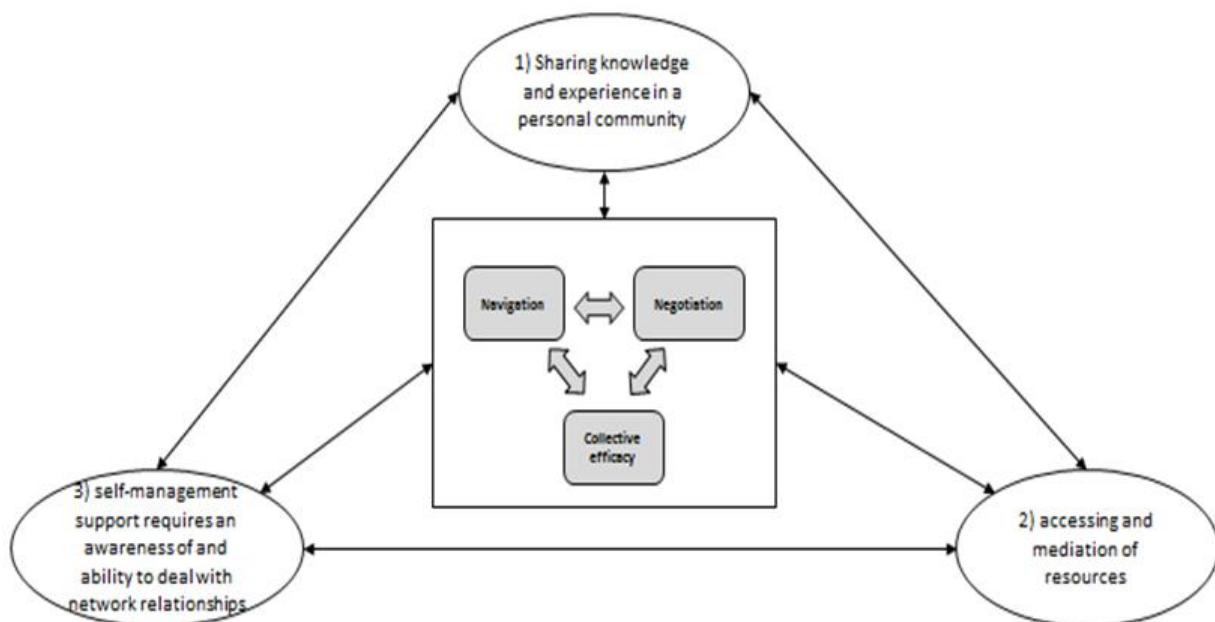


Figure 1 Illustration of Themes from Qualitative Metasynthesis

Identifying the significance of collective efficacy brings with it a set of continuities and tensions with the current normative and policy emphasis on self-efficacy as a way of improving illness management (see Figure 2). Four broad scenarios for illness management can be identified: low self-efficacy/low collective efficacy, high self-efficacy/low collective efficacy, high collective efficacy/low self-efficacy, and high self-efficacy and high collective efficacy.

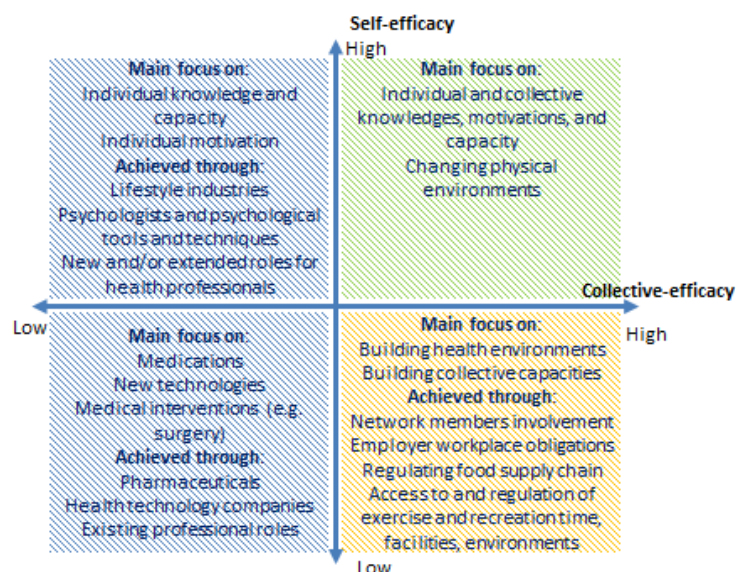


Figure 2 Self-efficacy and collective efficacy

The four possible scenarios modelled above illustrate that making a choice about illness management policy and interventions involves nuanced political and value choices, and affects differently the interests of stakeholders. For example, interventions focused on improving motivation and individual knowledge tend to work best for people who are already motivated and knowledgeable, and to be less effective in deprived populations.

1.3.3.2 Links between individual experiences and relations within social networks, and macro level processes

It has been argued that the shift from social democratic to a neoliberal consensus within modern welfare capitalist states has been characterised by a growing emphasis on individual responsibility, consumer choice, market rationality, and associated with growing social inequalities. There is however variation in how neoliberalism has played out across nation-states and shaped the contexts where long term illness is experienced and managed. For example, we explored the different articulations of neoliberalism in Bulgaria and the UK in order to illuminate the new illness management environments that have emerged as a consequence of contemporary neoliberal shifts. Specifically, the UK, traditionally considered as one of the most liberal European economies (Bambra 2007), and a pioneer of neoliberalism, adopted neoliberal policies as a relatively slow process. By contrast the process of neoliberalisation in Bulgaria has been both rapid and comprehensive resulting in a much smaller and less interventionist state (see Table 1).

Table 1 Macroeconomic indicators for Bulgaria and United Kingdom

	BG	UK
State expenditure		
<i>Expenditure on social protection % GDP (2012)*</i>	17.4%	28.8%
<i>Government cash payments as % GDP (2012)**</i>	31.3%	42.1%
Size of the public and private sectors		
<i>Private sector share of employment % (2010)‡</i>	89%	81.2%
<i>Public administration employment % of population (2010)‡</i>	1.9%	3.1%
Distribution of tax burden		
<i>Corporate tax rate %††</i>	10%	21%
<i>Income tax rate %†</i>	10%	Progressive up to 45%
Macro-economic conditions		
<i>Deficit % GDP (2014)*</i>	2.8%	5.7%
<i>Debt % GDP (2014)*</i>	27.6%	89.4%

* Eurostat (2015); ** World Bank (2015); † KPMG (2015); ‡ EU Presidency (2010); †† Trading Economics

Drawing on 60 qualitative interviews conducted in Bulgaria and UK (WP5) and the findings of the stakeholder interviews (WP2) we explored the experiences of people with diabetes type 2 in the context of politics of austerity. The analysis drew on a chronological narrative approach and aimed to elicit personal explanatory accounts of events, people, places and situations (Roberts 2002). Participants were identified through purposive and snow-balling sampling techniques drawn from networked contacts and personal knowledge. Recruitment was done in deprived and marginalised settings and focused on identifying information rich cases of respondents of different age, gender, health and socio-economic status who were likely to report a wide range of experiences of living with LTCs.

We found that people with diabetes discussed their experiences of illness management in terms of *struggling with diet; diabetes as a personal failure; integrating illness management and valued activities; trust and trustworthiness of the healthcare system*. While respondents in both countries faced challenges related to failures of consumer and healthcare markets, there were differences in how these markets were regulated, what stakeholder and interest coalitions emerged, and how users navigated markets, and experienced, expected, and adapted to market failures in their everyday illness management practices. We argue that the articulations of neoliberalism in UK and Bulgaria can be described as logic of managed choice and logic of unmanaged consumerism.

1.3.3.3 Factors and processes relevant for individuals and network engagement with online resources

In a realist review of telecare (Vassilev et. al 2015) we aimed to identify the core mechanisms associated with optimal design, deployment, and sustainable implementation of telehealth interventions for supporting people with long-term conditions. We reviewed qualitative papers focused on COPD, heart failure, diabetes, and behaviours and complications associated with these conditions, published 2009 to 2014, and adopted a two-stage realist synthesis approach.

Three concepts were identified, which suggested how telehealth worked to improve health and likely engagement with technology. The first refers to *relationships*: consideration must be given to whether and how a telehealth intervention enables or limits the possibility for relationships with professionals and/ or peers. Specifically, there was evidence about telehealth reshaping and extending existing relationships, as well as potentially acting as a partial substitute to the role of health professionals. The second is *fit*: successful telehealth interventions are those that can be well integrated into everyday life and health care routines and therefore need to be easy to use, simple, compatible with patients' existing environment, skills and capacity and do not significantly disrupt patients' lives and professional routines. The third is *visibility*: visualisation of symptoms and feedback has the capacity to improve knowledge, motivation and sense of empowerment. Visualisation can engage network members and reinforce positive behaviour change e.g. prompts for action, elements of surveillance and monitoring.

Technologies used to support CIM are most likely to be successful if they are simple and familiar to users. They can only be successfully embedded if they take into consideration how they enable or limit the possibility for relationships with professionals and or peers; how they fit with existing environment and capacities to self-manage and if they enhance the visibility of symptoms.

1.3.3.4 Network typology: dynamics and structure

Building on the network mechanisms identified in the earlier metasynthesis we analysed biographical interviews which included personal network maps in order to explore the experiences, self-care support needs and resources that individuals draw on in responding to living with LTCs. We distinguished between two interrelated but distinct dimensions of networks: *network dynamics* and *network structure*. *Network dynamics*, which we explored in a qualitative paper (Kennedy et al. 2014) refers to type of support available and form of network engagement. *Network structure*, which we explored in a quantitative paper (Vassilev et al. to be submitted) refers to the key structural characteristics of networks that could be captured through factors such as number of links, types and mix of relationships, frequency of contact with different network members, and their proximity.

Network dynamics

We analysed biographical interviews (from WP5) in order to explore the experiences, self-care support needs and resources that individuals draw on in responding to living with long term illness (dynamics). The six partner countries

were asked to provide case summaries in English for each of the 25-30 biographical interviews which described how the participant navigated and negotiated their networks and to what degree there was collective efficacy. Quotes were then translated into English from up to five of the case studies in the data set which best exemplified these properties. The broad coding regarding network mechanisms was then subjected to further analysis. Firstly the data from all partner countries was scrutinised to elucidate whether network support mechanisms were similar across the whole data set and to explore the differences. This was achieved at a data workshop which involved three of the partner countries (UK, Norway, Bulgaria). At this workshop, the data relating to navigating, negotiating and collective efficacy was then discussed in more depth to explore and generate themes around the dynamics and nature of support for self-management within social networks.

We identified four types of network dynamics:

- generative – diverse and beneficial to individuals;
- proxy – network members undertook diabetes management work;
- avoidant – not engaged with network supports, but with some capacity for self-management and
- struggling – support not effective and individual capacity for diabetes management a struggle and/or not prioritised.

Network structure

We analysed the survey data collected within WP6 in order to identify the properties of the networks most likely to provide resources and support for those with a long-term condition. We used k-means clustering analysis to derive the types of network structure, and one-way analysis of variance and multivariate logistic regression analysis to explore the relationship between network type socio-economic characteristics, self-management monitoring and skills, well-being, and network work. Five types of networks were identified by applying the k means cluster analysis (see Table 2).

People with a *diverse* type of network had a large number and diverse type of network members (including family, friends, acquaintances, and groups), and were in frequent contact with them. Compared to other types of networks people with diverse networks had a much higher frequency of contact with friends and frequently attended voluntary and community groups.

The network type labelled *acquaintances* or *weak ties* was characterised by diverse types of relationships. A defining characteristic of the *weak ties network* type was that people were in very frequent contact with network members who were neither family members nor friends and included voluntary and community groups, health professionals, and acquaintances such as neighbours, colleagues, wardens, taxi drivers.

Two other network types that we identified were identifiable by relations with family members. We called them '*family*' and '*limited family support*' networks. Respondents clustered in the *family network* were in regular contact with network members and had large networks. However, unlike the other two network types we discussed above their contacts were less diverse, predominantly with family members and engagement with friends and acquaintances was limited.

People with *limited family support* networks had most of their contacts with family members and in that, their networks were similar to the *family network*. However, unlike *family networks* they had fewer network members and were not in very frequent contact with them. Additionally, the contact that people with *limited family support* networks had with non-family network members was minimal.

The '*restricted*' network type was lowest on most characteristics used in the typology. Numbers of network members were very small and their contact time with network members of all kinds was similarly low. People in such networks were likely to be isolated with contact to others likely to be limited to contact with a partner and/or with a live-in child.

Table 2 Network type by delineating characteristics*

	Married	Number of children	Number of network members	Contact with network members	Frequency of contact-Family	Frequency of contact-Friends	Frequency of contact-Other	Frequency of contact-Groups	Frequency of contact-Professionals	Pets
Diverse	.63	<u>.25</u>	4.6	220	78	123	<u>6</u>	34	13	.26
Weak ties	.62	.26	2.7	211	72	24	55	42	54	.28
Family	.78	.57	4.5	252	204	20	12	<u>21</u>	<u>7.3</u>	.40
Limited family contact	.72	.41	3.0	128	109	<u>10</u>	<u>4</u>	<u>16</u>	<u>4.8</u>	.40
Restricted	.62	.37	<u>1.5</u>	<u>38</u>	<u>28</u>	<u>4</u>	<u>1</u>	<u>20</u>	<u>4.4</u>	.35
SAMPLE MEANS	.66	.39	2.4	98	73	12	5	20	7	.37

* We performed post-hoc Tukey HSD test on each of the variables used in the typology and the results are included in the table (underlined italics is the subset for lowest values, and bold italics for highest values).

We found that restricted networks represented those with the poorest self-management skills and were associated with least support from social network members. Diverse networks reported the best self-management skills, received most emotional and information support from network members, and reported the lowest level of healthcare service utilisation, thus indicating that diverse networks constitute the optimal network type and a clear target for policy (see Table 3).

Table 3 Network type, self-management, network work and well-being: Logistic regressions

Variables	Categories	Self-management				Network work						Well-being			
		Skills		Self-monitoring		Information		Emotional		Practical		MCS (SF-12)		Happiness	
		OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI	OR	95% CI
Network type	<i>(Restricted)</i>														
	<i>Limited family support</i>	1.22	.95-1.57	1.51	.98-2.31	1.56**	1.21-2.02	8.70***	6.42-11.80	6.03***	4.47-8.14	.89	.68-1.17	1.03	.78-1.35
	<i>Family</i>	1.02	.66-1.59	.81	.38-1.74	.95	.60-1.50	12.28***	6.24-24.17	13.43***	7.58-23.77	1.55	.96-2.49	1.50	.92-2.47
	<i>Acquaintances</i>	1.36	.69-2.69	1.97	.44-8.82	2.10*	1.04-4.23	24.84***	8.05-76.68	6.64***	3.04-14.51	1.02	.49-2.09	.65	.29-1.42
	<i>Diverse</i>	3.50**	1.72-7.11	2.17	.49-9.69	1.61	.87-2.96	18.70***	5.50-63.43	4.49***	2.33-8.68	1.05	.57-1.94	.86	.45-1.65
Age	<i>(Up to 59)</i>														
	<i>60-74</i>	1.65***	1.26-2.14	1.49	.95-2.36	1.10	.83-1.44	1.20	.87-1.66	1.20	.89-1.61	1.79***	1.35-2.37	1.36*	1.02-1.81
	<i>75 and over</i>	1.06	.77-1.45	.95	.58-1.56	.98	.70-1.36	1.05	.71-1.55	1.09	.76-1.57	2.03***	1.43-2.87	1.28	.91-1.81
Gender	<i>(Men)</i>														
	<i>Women</i>	1.22	.98-1.52	1.41	.98-2.03	.94	.75-1.18	1.35*	1.03-1.76	.44***	.34-.58	.76*	.60-.97	.91	.72-1.16
Country	<i>(Bulgaria)</i>														
	<i>Greece</i>	1.50*	1.01-2.22	2.70**	1.45-5.02	.22***	.14-.33	.14***	.09-.23	.47***	.28-.80	.58***	.38-.90	2.41***	1.59-3.64
	<i>Netherlands</i>	2.90***	1.80-4.78	2.14	.94-4.86	2.06**	1.21-3.51	1.84	.85-3.97	.86	.42-1.76	3.97***	2.28-6.90	15.41***	8.64-27.47
	<i>Norway</i>	3.26***	2.23-4.77	3.22**	1.64-6.31	.59**	.040-.86	.31***	.19-.51	.80***	.05-.13	2.20***	1.48-3.26	.44***	.29-.67
	<i>Spain</i>	2.84***	1.85-4.36	2.72**	1.44-5.14	1.30	.84-2.01	.72	.43-1.12	.29***	.17-.49	2.85***	1.80-4.52	7.21***	4.60-11.56
	<i>United Kingdom</i>	3.60***	2.43-5.33	4.75***	2.30-9.84	1.21	.81-1.79	.32***	.19-.53	.22***	.13-.36	2.69***	1.77-4.07	6.39***	4.24-9.64
Network members	<i>(No network members)</i>														
	<i>1 to 3</i>	.84	.56-1.27	1.07	.54-2.13	5.61***	3.52-8.91	12.12***	6.03-24.34	14.40***	7.83-26.47	2.23**	1.42-3.51	1.23	.79-1.94
	<i>4 or more</i>	.73	.67-1.78	1.72	.70-4.22	21.92***	12.45-38.58	48.08***	21.74-106.32	15.84***	8.00-31.66	1.69	.99-2.88	1.23	.72-2.09
Education	<i>(No education)</i>														
	<i>Primary school</i>	1.79	.95-3.38	1.97	.94-4.14	.76	.40-1.45	1.08	.50-2.29	.57	.26-1.24	1.10	.60-2.42	1.58	.84-2.98
	<i>Secondary school</i>	1.68	.85-3.31	2.30	1.00-5.31	1.14	.57-2.26	1.58	.70-3.53	.77	.38-1.77	1.17	.81-3.63	1.99	1.00-3.97
	<i>College</i>	2.37*	1.19-4.73	3.84**	1.60-9.20	1.20	.59-2.41	1.91	.84-4.33	.80	.35-1.86	2.20*	1.03-4.71	2.02*	1.00-4.08
	<i>University</i>	3.00**	1.46-6.18	9.19***	2.90-29.12	.88	.42-1.83	1.48	.63-3.49	.61	.26-1.46	1.64	.74-3.62	2.06	.99-4.31
Parents	<i>(Born in country)</i>														
	<i>Not born in country</i>	.87	.60-1.25	.70	.37-1.30	.62*	.42-.93	.57*	.36-.90	.97	.67-1.49	.57**	.38-.84	.60*	.40-.89
Income	<i>(Lower)</i>														
	<i>About average</i>	1.18	.86-1.56	1.25	.75-2.08	.94	.69-1.27	1.21	.86-1.72	.70*	.51-.96	1.10	.80-1.50	1.32	.96-1.81
	<i>Higher</i>	1.53**	1.15-2.14	1.47	.82-2.64	1.10	.80-1.51	.85	.58-1.22	.78	.55-1.10	1.45*	1.04-2.02	1.36	.97-1.91
Health	<i>(Poor health)</i>														
	<i>Good health</i>	1.71***	1.37-2.14	1.90**	1.27-2.83	1.13	.89-1.42	1.01	.77-1.33	.79	.61-1.02	4.78***	3.77-6.05	2.79***	2.19-3.55
Comorbidities	<i>(No comorbidities)</i>														
	<i>1 or 2</i>	.76	.56-1.04	1.49	.87-2.55	.89	.65-1.23	1.00	.69-1.46	1.13	.79-1.60	.97	.69-1.35	.75	.54-1.05
	<i>3 or more</i>	.86	.60-1.23	1.21	.68-2.18	1.23	.85-1.78	1.40	.91-2.16	1.16	.77-1.74	.71	.48-1.03	.68*	.46-1.00

1.3.3.5 Implications for the development and implementation of interventions

The network typology can inform the development of CIM interventions and the engagement of users (see Figure 3). Specifically, the structural characteristics of networks represent divergent affinities with network dynamics and thus can potentially be effectively used as way of assessing network support and positive direction of change. For example, people in struggling networks, with low levels of self-efficacy and collective efficacy, are likely to be most vulnerable, while a change towards a proxy or avoidant network can indicate a positive avenue for change. People embedded or introduced to generative networks, that is networks with high levels of self-efficacy and collective efficacy, are likely to be better placed in terms of increasing capacity to CIM. The point of personal action here might be encouragement to continue developing and maintaining contacts, flagging the benefits in terms of the mobilisation flow and outcome that generative mechanisms provide.

There are further implications of conceptualising illness management as an essentially collective process for the development of interventions that potentially take CIM strategies further than those that operate on the level of individual behavioural change mechanisms. Members of networks bring extra capacity that require building into interventions (e.g. navigation of specified network involvement, together with avoidance of some places and relationships, thereby enhancing access to those connections that are likely to have positive influences). Interventions could be more productively designed for building individual and network capacity for navigating and negotiating relationships and CIM environments and could be more productively designed to maximise the possibilities for social engagement, particularly through extending people's access to weak ties and the building of enabling environments that have relevance for illness management.

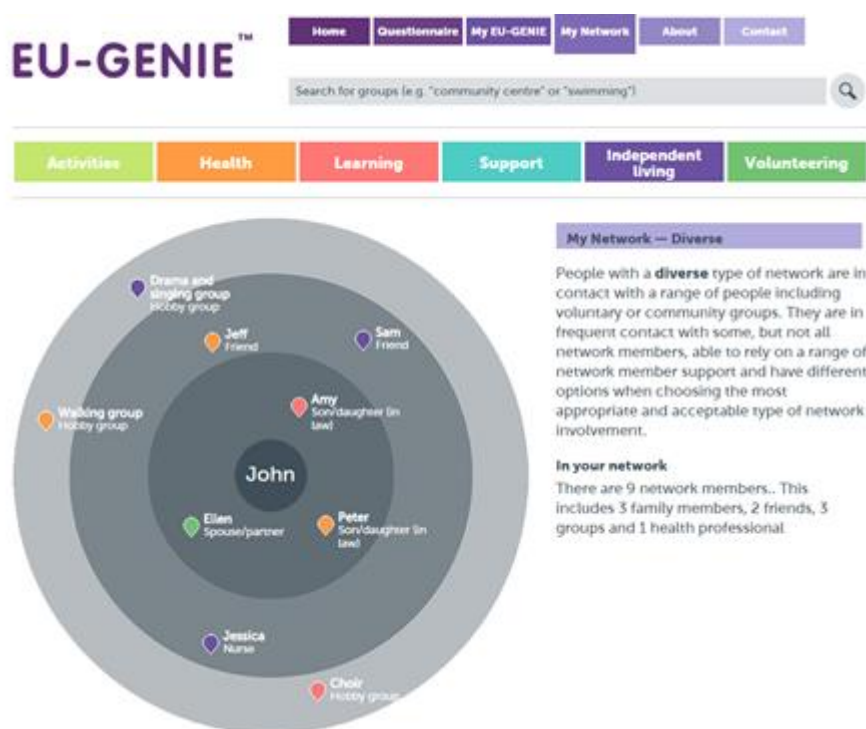


Figure 3 Sample Personal Networks Diagram from EU-GENIE intervention

The findings of WP3 fed into the EU-GENIE intervention where facilitation and visualisation of networks play a central role. More broadly, our work indicates that interventions and policy need to be better tailored so that they build additional capacity where it is most needed and where it is most likely to be effective and acceptable. One of the contributions of WP3 to this agenda is through identifying key network mechanisms, dynamics and structures. Focus on network mechanisms brings to the fore the close interdependence between social and psychological

processes in CIM, and the intertwining of practical and moral dilemmas in identifying, offering, accepting, and rejecting support. The affinities between self-efficacy, collective efficacy, structure and dynamics of networks are illustrated in Figure 4.

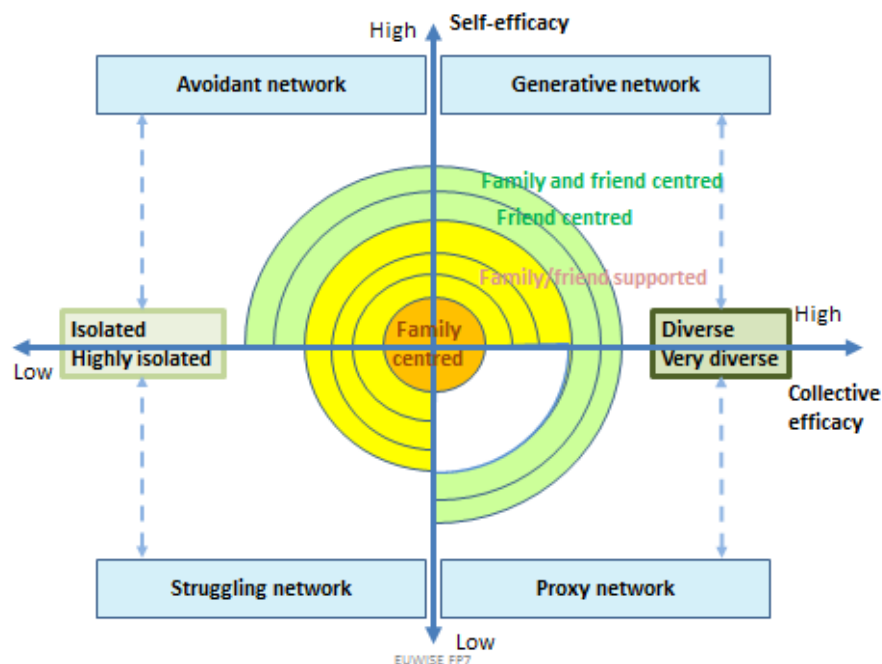


Figure 4 EU-WISE Networks Diagram

1.3.4 WP4 Voluntary and Community Group Networks

1.3.4.1 Role of WP4 in EU-WISE

WP 4 forms the third thematic WP in EU-WISE. Its main focus has been on describing and analysing the support mechanisms that operate on the meso level. This has complemented WP2 and WP3 by focusing on the support provided by a diverse set of organizations: non-governmental, voluntary and community groups. This WP has developed new knowledge about the specificities of this domain in different national contexts and the function and scope of its role in relation to illness management and behaviour change of people with diabetes and heart disease. An important aspect of developing such an understanding is that the WP has described and analysed the inter-organizational networks of such groups as well as describing the affinities between personal and organizational networks. The findings of this WP have also fed into the development of interventions in WP7, where it has informed the mapping and understanding of the functions of community resources within specific national contexts.

1.3.4.2 Objectives and research questions of WP4

The aim of this research theme was to explore the role of VCOGs, to identify the work that such organisations undertake, and to understand how they are integrated within a broader system of support.

More concretely, WP4 aimed to explore:

- the role that VCOGs play in the provision of support for people with diabetes and heart disease;
- how the structure of voluntary organizational networks' funding streams and type of support vary;
- how the type of voluntary organisation support is effectively delivered to deprived populations;
- how do these forms of voluntary organisational support vary across national contexts and
- how does the structure of inter-organisational networks (density, functions, levels on which they operate, e.g. national/local) vary between different areas (e.g. deprived and affluent) within countries.

1.3.4.3 Tasks of WP4

The tasks planned and developed in this WP were as follows:

1. Report outline: non-governmental, voluntary and community groups review
2. Guidelines for writing the country reports
3. Country specific reports
4. Summary of country reports
5. Final country specific reports
6. Typology (profiling) of inter-organisational networks
7. Cross national review and summary report: community groups. Review and data.

The conduct of these tasks gave rise to the following results.

1. A synthesis of country reports in relation to voluntary organisations, population with special needs and SM.

The country reports covered issues mainly related to:

- a. VCOGs which were available in the participating countries.
- b. SM programmes in which VCOGs were involved in the countries (especially The Netherlands and the United Kingdom (UK), missing in the other countries).
- c. The goals and objectives, and structural information on the organisations and community groups.
- d. Research and empirical evidence involving VCOGs.

Some general similarities and differences between VCOGs in the countries participating in EU-WISE have been found. There are similar organisations in all countries, but the users' level of involvement differs considerably. There is also an increasing tendency in these organisations to associate with the public administration and create common projects in which the fieldwork/interventions seem mainly developed by community agents and volunteers. Many activities of these organisations are funded by governments. However, since lately this source is not reliable in many countries, other alternative ways of funding are sought.

The main focus of volunteering is illness prevention, health promotion, increasing awareness of the role of these organisations and fighting societal prejudice against illness. Although a special interest in deprived populations is emerging in certain countries, especially in those affected by the austerity measures, the focus on self-management (SM) is still limited. In this regard, most activities are developed for the elderly population and advocating people's rights.

One of the main gaps identified on this subject across Europe was the lack of empirical evidence on long term illness management fostered by VCOGs. Furthermore, apart from some exceptions, SM is not being integrated in the activities developed by the voluntary sector in most countries. This consequently, has a negative impact on the empirical evidence available nowadays (which is mainly developed in the US and UK).

2. A Critical interpretative synthesis (CIS) of the literature.

A critical interpretative synthesis of the literature was undertaken as part of the conceptual development of our research. Evidence (2000-November 2014) was searched in databases, with the use of key terms, and limited to the languages of the participating countries. This was supplemented by an additional hand search and snowballing technique. A total of 21 articles were included in the review.

Evidence regarding the involvement of voluntary organizations in diabetes SM programs mainly related to: the nature and remit of their work, responsibilities, and attributes; key strategies of programs accounting for success; motivations/barriers for engaging in volunteering participation; relationships between volunteers and users; and connections/tensions with formal services.

Several facets of voluntary organizations and community groups relevant for supporting diabetes SM were explained such as the context within which they act and the nature of relationships developed with community and health services. The principles of "assistance, support, sharing, and link" seem essential for this voluntary initiative in SM to establish effective reciprocal collaboration with health professionals.

3. Cross-national synthesis of interview data from representatives of VCOGs (also involving work in WP5) .

The different types of organisations provided an amalgam of services and activities that contributed to meeting the needs of patients with LTCs.

Illness-related organisations appeared to be the type of organisation that dealt with the disease more overtly through the provision of disease relevant information, public awareness campaigns and also promoting the prevention of disease complications among others. The focus adopted in doing so and the explicit presence of SM varied across countries. The contribution of organisations mainly focused on healthy lifestyles to meet the needs of patients with LTCs, tended to take the form of the promotion of physical exercise and a healthy diet mainly, while wellbeing organisations often aimed to keep users active and connected with others, which was often done by offering a range of activities that could respond to their personal interests and hobbies. People's rights organisations also made a significant contribution to this. In addition, this latter type of organisation aimed to influence policy to protect the rights and needs of people. In most countries there seemed to be some differences between organisations working in affluent and deprived areas. As such, organisations working in deprived areas usually had a higher awareness of minority groups. Similarly, often the more formal an organisation was, the more efforts were put into identifying people in need, and State funding for example tended to be more frequent in organisations working with deprived populations.

While many organisations relied on membership fees for their budgeting, there were differences between organisations in terms of external funding. More formal organisations such as illness-related organisations were usually more likely to get funding than informal ones. As a consequence, these organisations seemed to have experienced more intensely the effects of the financial crisis, having to limit the activities or services offered in some cases due to cuts in the funding received. Most organisations acted on a local level, often in combination with a national representation. Bigger organisations (often national or international), that tended to be more likely to receive State funding and be project oriented, usually seemed better organised and more formal, with the potential of being less flexible to adapt to local needs.

Certain overlap might occur in the activities offered by the different types of organisations and their focus, which often varied. While illness-related organisations might have clear disease-related objectives, other types of organisations also promoted health, but in more general terms, SM not being a priority, to the extent that illness-related conversations might even be deemed inappropriate. This identifies an important gap in the voluntary sector across countries in terms of the definition of roles and competences, relationships and means of cooperation and social participation. In this regard, the development of a typology of VCOGs could provide further understanding about how these organisations operate and increase the effectiveness of their interventions and activities, which would be better defined and focused. Furthermore, the role that the different types of organisations played in fulfilling the needs of these patients was relevant and complementary, both between organisations and between the organisations and the micro and macro levels. However, in general there seemed to be room for improving collaborations between organisations and health services.

4. A proposed typology of inter-organisations networks.

For data collection purposes an initial typology was developed which was descriptive and had utility for the categorization of activities for users and identification of potential organisations who could participate in the individual interviews with representatives of organisations and in the survey of organisations. This typology ensured a comparison and integration of results and reports across countries. Initially, three main types of groups and organisations were identified:

- Diabetes related organisations
- Health and healthy lifestyle related organisations
- Wellbeing related organisations

However, this initial typology has been revised to understand how these organisations operate and establish relationships within meso level and with macro and micro levels of health care. As a result of the in-depth study, a

variation of this typology has been made in an attempt to illustrate other dimensions and subdimensions of the types of VOCGs, resulting in the following typology:

- Illness related organisations
- Healthy lifestyles related organisations
- Wellbeing organisations
- People’s and patients’ rights organisations
- Other community groups

To locate the position of the different types of VOCGs, and orientation to SM, a matrix has been developed as presented in Figure 5. This was important for distinguishing between pure and hybrid forms of VOCGs and trying to identify the different dimensions and types of VOCGs. A range of dimensions and subdimensions have been identified for this typology, two dimensions of the typology have been chosen to develop this matrix (strength of links and activities related to SM) as they were especially relevant for the research questions of WP4 and because they are considered the most defining dimensions, whereas other dimensions provide more information about the types of VOCGs, but do not really distinguish them.

Considering these two distinguishing dimensions, as illustrated in Figure 5, the organisations that seemed to have the strongest links with macro, meso and micro levels and the highest orientation to SM were the “illness related” type. In contrast, “other community groups” were organisations with the weakest links with other levels and organisations and with the lowest orientation to SM.

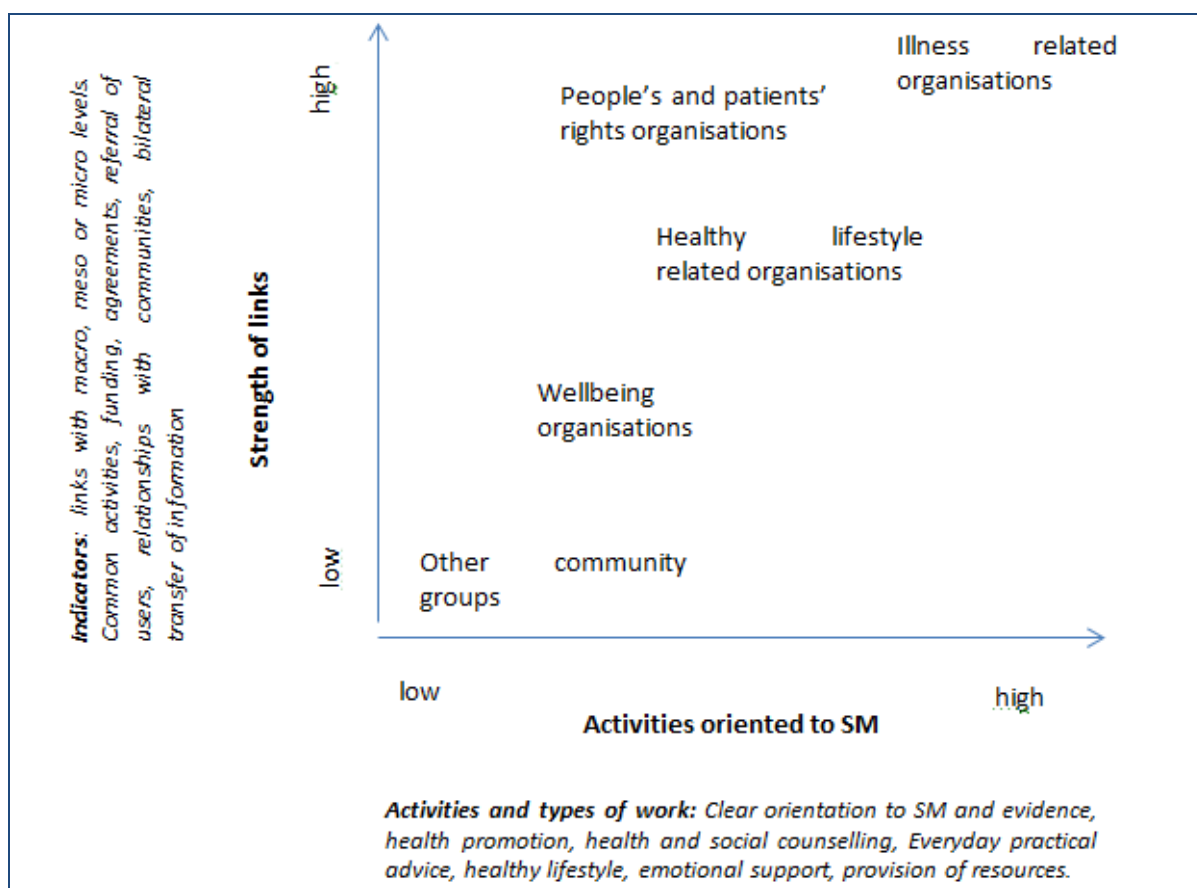


Figure 5 Matrix for types of VOCGs

1.3.5 WP5 In-Depth Explorations

1.3.5.1 Overview

The objective of WP5 was to develop qualitative empirical investigations to support the thematic work carried out in WPs 2, 3, and 4, to inform the interpretation and analysis of WP6 and to help with design and assessment of the intervention in WP7.

The process of data collection and collation together with the 'headline' findings are presented here under the following headings: key informant interviews; biographical interviews; interviews with representatives of voluntary and community groups and focus groups and interviews. A summary table of the collected data is provided in Table 4.

Table 4 Summary table of completed qualitative data collection

	Bulgaria	Greece	NL	Norway	Spain	UK	Total completed
Key informants							
	15	15	15	15	15	15	90
Voluntary and community groups							
	50	50	35	50	50	50	285
Biographical interviews							
	30	30	30	25	30	30	175
Focus groups and interviews							
Patients	2	2	2	2	2	2	12
Members of groups	2	2	2	2	2	2	12
Health professionals	2	2	2	2	6	5	8 11

1.3.5.2 Key informant interviews

The objective of conducting the key informant interviews was to inform the WP2 report analysis by drawing on the knowledge, experience and opinions of a community of experts. The latter included representatives of government and local authorities, academics, civil servants, representatives of the private sector/insurance and health professionals. The key informant interviews extended knowledge and understanding of SMS support for Diabetes by addressing the following themes:

- Development of past and recent policy and practice developments in the area of self- management and prevention and management of diabetes type 2.
- Policy design and implementation in food and eating, life style, drug and insurance companies.
- Policies around delivery of SMS tele-care primary care, public health and general practice.
- Changes in policy since reports in the literature review papers (elections, changes of administration, restructuring) the emergent crises and age of austerity.
- The impact of the fiscal crises on the ability of people to manage life with diabetes, (professional involvement, medication, emotional and social capital, diet life style opportunities etc.).
- Nature of clinical guidelines, practice and innovations in the area of diabetes.
- Changes in the environment about patient self-management for diabetes.

We conducted 15 interviews in each of the partner countries. The interviews were conducted between November 2012 and April 2013. Most interviews were recorded and transcribed. Where recording was not agreed to by the respondents extensive notes were kept during and after the interview. The interviews were done either face to face or over the phone and lasted between 20 and 90 minutes. Table 5 presents a summary of the interviews.

Table 5 Background and position of key informant interviewees

	Professionals			Policymakers	Academics	Managers/representatives of Drug Companies or Health Units
	Physician ¹	Nurse	Other			
Bulgaria	11	1	3	5	5	5
Greece	6	2	6	3	3	3
Netherlands	2	2	1	6	3	1
Norway	5	4	6	7	2	6
Spain	5	3	3	6	7	2
UK	6	1	6	3	9	3

1 The category "physician" states the level of education in medicine.

Note: The table indicates both position and professional education and thus adds up to more than 90 interviews.

The analysis was finalised in face to face meetings with leads for analysis for all partner countries. A summary of the key themes is presented in the WP2 report. From the data analysis undertaken three broad key themes emerged: 1) social environmental influences on diabetes SM (stigma, inequalities and food) 2) reluctance or inability of policy makers to regulate processes and environments related to long term illness management, 3) biomedical focus and gaps in provision of SMS in the healthcare system (for key themes and subthemes see Table 6).

Table 6 Key themes and sub-themes

	BG	GR	SP	UK	NO	NL
Social environmental influences on diabetes self-management	+	+	+	+	+	+
Social inequalities impact on resources for SM				+	+	
Public stigma and impact of portrayal of behavioural dispositions	+	+		+	+	+
Diabetogenic food environment	+	+		+	+	
Reluctance/ inability of policy makers to regulate processes and environments related to chronic illness management	+	+	+	+	+	+
Governments unable/unwilling to regulate the food supply chain	+			+	+	
Growing responsibility of local stakeholders: uncertainty of process and quality of service, reduction in resources, and ad hoc solutions			+	+	+	+
Challenges associated with the coordination, funding, and implementation of local commissioning of services				+	+	+
Extending the scope of voluntary and community groups and private provider involvement in SMS				+	+	
Few welfare recourses and impact of austerity on local supply and demand for SMS	+	+		+		
Bio-medical tendencies and incentives in primary care	+	+	+	+	+	+
Inconsistent support for shift in healthcare provision towards better SMS		+	+	+		
Prevention/ public health interventions have a role in SMS	+	+	+	+	+	+
Insufficient policy level commitment to implementing SMS policies	+	+	+	+	+	
Lack of incentives for SMS		+		+		
Insufficient SMS tools and infrastructure in the health service	+	+	+	+	+	+
Drugs companies interests as barrier to implementing SMS	+	+	+	+	+	
Professionals interests as barrier to implementing SMS	+		+	+		
Growing involvement of patient groups			+		+	+
Patient habitus, abilities, and skills capacity as a barrier to SMS	+		+			
Financial crisis as an opportunity for changes in the healthcare system		+	+	+		
System level crisis as a dominant policy concern	+	+				
Drug companies providing SMS in the absence of state capacity	+	+	+			

1.3.5.3 Biographical interviews

The biographical interviews data provided information for and fed into WP3 objectives. The interviews explored personal experiences of living with diabetes, the structure of personal networks and ability to access and mobilize resources. The interviews focused on eliciting and understanding narratives of events, people, places and situations about people's illness. Mapping of whole networks of support was undertaken using a network diagram and by exploring the nature of relationships, narratives of responsibility and the availability and acceptability of support. We aimed to maximise the diversity of the sample in terms of gender, marital status, age, stage of illness career and level of isolation. We explored types of illness-related-work undertaken by the person and by others; the economic, social, and cultural resources and influences that people with LTCs and members of their personal communities draw upon; the social network dimensions which impact on illness management and whether they differ according to the type of long term illness "work" and social inequalities.

The biographical interviews were conducted in two stages. During the first stage we conducted five pilot interviews, which were transcribed and the preliminary analysis as well as the process of data collection and the interview schedule was discussed and refined at meetings with all other partner countries. A further 25 interviews were conducted at the second stage. Most interviews were between 60-80 minutes long. All interviews were conducted face to face and were recorded and transcribed. Table 7 shows a summary of the interviews conducted across the EU-WISE partner countries.

Table 7 Characteristics of participants in the biographical interviews.

		Bulgaria	Greece	Netherlands	Norway	Spain	United Kingdom
Age							
	0-59	3	7	5	15	10	4
	60-74	22	17	13	9	14	16
	Over 75	5	6	7	1	6	10
Multimorbidity							
	Yes	18	13	11	n.a.	19	20
	No	12	17	14	n.a.	11	10
Ethnicity							
	Majority	30	30	20	19	28	28
	Minority	0	0	5	6	2	2
Gender							
	Male	13	11	11	13	18	16
	Female	17	19	14	12	12	14
Civil status							
	Married	16	26	12	16	20	21
	Widowed	9	3	7	0	5	5
	Divorced	4	1	1	4	2	1
	Never married	1		2	5	3	3
Socioeconomic status							
	Low	28	25	11	11	17	9
	Medium or high	2	5	14	10	8	21
General health							
	Very good	3	0	2	4	12	0
	Good	18	18	10	13	8	8
	Poor	9	12	13	4	5	22

Note: This table includes 170 of the interviews.

A detailed discussion of the biographical interviews analysis is presented in the relevant WP3 report. In summary we found there are a wide range of relationships that are involved in illness management. We found similarities between countries in terms of peoples' perceptions on the role of diabetes genetic disposition, knowledge and awareness of prevention of co-morbidity etc. and differences between countries in relation to sharing information about diabetes diagnosis with acquaintances or other patients. The main focus of self-management in everyday life is characterized by having a sense of normality, and is directed towards making self-management 'fit' into everyday life. Self-management support that interrupts daily routines is not seen as appropriate. Lack of economic resources is a factor in hindering patients from adequate self-management and to a lesser degree also lack of time. In most countries patients do not tend to join illness-related groups. Exceptions are Norway and UK. Health professionals (doctors and nurses mainly) play a key role in providing disease related support. However, the relationship between patients and health professionals varies between countries.

Networks are perceived as being important. Family and friends often support self-management, but they might also hinder it. Ties with local or voluntary groups tend to be valued but not directly associated with illness management and are preferred for association and leisure/pleasure. Weak ties such as acquaintances, especially with other people with LTCs, play an important role for information exchange about illness management. The networks of elderly people are often limited, which makes them more vulnerable.

1.3.5.4 Voluntary and community group interviews

Voluntary, community and local organisations can potentially play a key role in long term illness management, although this varies from country to country. The analysis of our findings in these interviews primarily contributed to the work of WP4. Our objectives were to explore the role of voluntary and community organisations, to identify the work that such organisations undertake, and to understand how they are integrated within a broader system of support for people with LTCs. The key questions were: What is the role that community groups and voluntary organisations play in the provision of support for people with diabetes and heart disease? How do the structure of voluntary organizational networks, funding streams/type of support vary? How is voluntary organisation support effectively delivered to deprived populations? How do forms of voluntary organisational support vary across national contexts? How does the structure of inter-organisational networks (density, functions, levels on which they operate, e.g. national/local) vary between different areas (e.g. deprived and affluent) and within countries? What are the types of health-relevant voluntary, community and local organisations available to people with diabetes and heart disease, and in what ways do they meet needs? How do organisations differ in purpose, style, content and composition and how are they associated with formal health provision? What are the types and extent of support provided by voluntary, community and local organisations and do they act as substitutes or are they complementary to relationships with family, friends and health professionals? What is the structure of inter-organizational networks of providers of health-related support and how do these networks differ across countries?

The interviews were conducted either face to face or over the telephone. We aimed to recruit a wide range of voluntary and community organisations that offered illness specific support or were involved with activities that related to people's well-being more broadly. We sampled organisations according to type, size, affluent and deprived, urban and rural or semi-rural areas, and distinguished between four types: diabetes related organisations, health and healthy lifestyle related organisations, wellbeing related organisations and people's or patient's rights organisations (50 organizations in each country). The interviews lasted between 15 and 90 minutes.

Table 8 shows a summary of the interviews conducted across the EU-WISE partner countries.

Table 8 Voluntary and community group interviewees

	<i>Bulgaria</i>	<i>Greece</i>	<i>Netherlands</i>	<i>Norway</i>	<i>Spain</i>	<i>UK</i>
Illness related	14	47	1	6	5	7
Healthy lifestyle	12	3	6	21	7	16
Well-being	14	24	14	19	17	28
People's/Patients' rights	10	3	5	4	12	15
Other Community groups					9	

An organisation may be listed under more than one category. Table does not include all interviews from the Netherlands.

A detailed discussion of the voluntary and community interviews analysis is developed in the relevant WP4 report. Preliminary findings show that most voluntary and community groups are familiar with self-management, but tend to define it differently. The health effects of voluntary groups are often indirect, but respondents find that they are important contributors to health as well as to avoiding isolation. Within illness related organizations there appears to be a sharp distinction between formal and informal organizations influenced by different access to funding. Formal and informal organisations tend to be linked, but the ties are often weak (more so in counties with a weaker voluntary sector such as Norway and Bulgaria). Voluntary and community groups find it difficult to reach deprived populations even where they have a specific policy to do so and economic constraints often hinder the activity of organisations. Many organisations struggle with the bureaucracy associated with applying for funding but most formal organisations get funding from local or national public entities. However, there are other ways of getting funding such as collaborating with food companies. The role of voluntary and community groups is seen as complementary to health professionals and public administration. Nevertheless, willingness to improve the connections with formal health services is expressed. Deprivation and social inequalities are often not central objectives in the work of voluntary and community organizations.

1.3.5.5 Focus Groups

The main objective of conducting the focus groups was to inform WP4. Using focus groups offers additional insights into peoples' attitudes and opinions, but also enables exploration of other dimensions of the way in which social networks and capital are related to health and illness and the concrete challenges faced by different stakeholders. Questions addressed were e.g. the value of voluntary and community groups for patients with diabetes; the reason why people do or don't join groups; the impact of economic change on the way diabetes is perceived and managed and the role of voluntary and community groups in moderating or ameliorating this. These questions were explored with three types of groups: 1) Patients with type 2 diabetes with experience of some level of deprivation; 2) Representatives of local voluntary and community groups or organisations; 3) Health care professionals. The questions and the additional prompts were adapted for each group.

We organised two focus groups with people with diabetes and two focus groups with representatives of voluntary and community groups. We found that organising focus groups with health professionals was not feasible in all countries due to the heavy workload and time constraints on health professionals. In such cases we conducted face to face and telephone interviews with health professionals. All focus groups and interviews were recorded and transcribed. The focus groups lasted between 45 and 85 minutes, and the interviews lasted between 30 and 60 minutes. Table 9, Table 10 and Table 11 show a summary of the interviews conducted across the EU-WISE partner countries.

Table 9 Participants in focus groups: people with diabetes

		Bulgaria	Greece	Netherlands	Norway	Spain	United Kingdom
Age							
	0-59	5	4	5	8	6	6
	60-74	8	5	5	3	10	7
	Over 75	1	0	3	0	0	0
Multimorbidity							
	Yes	8	6	n.a.	8	6	6
	No	5	3	n.a.	3	2	7
Gender							
	Male	2	4	10	5	10	9
	Female	12	5	3	6	6	4

Table 10 Participants in focus groups: voluntary and community groups

	Bulgaria	Greece	Netherlands	Norway	Spain	UK
Illness related	6	7	1	5	1	2
Healthy lifestyle	1	0	2	3	3	5
Well-being	5	3	2	4	3	6
People's/Patients' rights	2	7	0	5*	5	3

*The Norwegian Diabetes Association is registered as both illness related and a patients' rights organisation

Table 11 Participants in focus groups/interviews: health professionals

		Bulgaria	Greece	Netherlands	Norway	Spain	United Kingdom
Position							
	Nurse	8	1	6	2	6	5
	Medical Doctor	6	4	2	2	5	0
	Other health professional	0	0	1	6	0	0
Gender							
	Male	2	1	1	2	4	1
	Female	12	4	8	8	7	4

A detailed discussion of the focus group interviews analysis is developed in the relevant WP4 and WP7 reports. In broad summary, findings showed that there is growing public awareness and understanding of long term illness and diabetes. The experiences of receiving education and information sessions about diabetes are generally unsatisfactory at health care establishments but voluntary and community groups could be a source of information, self-esteem, exchange of experiences and advocacy for protecting patients' rights. In several countries, there is poor participation of patients in voluntary groups. This is caused sometimes by the lack of patients' awareness of the groups, the poor dissemination by the organisations themselves and the lack of referral from professionals (lack of interest or knowledge). The functioning and sustainability over time of voluntary and community groups is often dependent on qualities of the key people running them, as well as on their networks with other organisations and funding bodies. There is agreement among stakeholders that voluntary and community organisations can play an important role in wide ranging support for people with diabetes, exerting pressure even on changes which concern health professionals themselves. The links between GPs and nurses, and voluntary organisations tend to be more sustainable if the voluntary group provides services that are immediately illness related. The barriers to access to what is locally available need to be discussed in relation to the diverse needs about what is acceptable to people with long term conditions. Building a highly versatile sector with differentiated offering of type and form of delivery of services is most likely to address the needs of local people, and especially of deprived groups. The state of the economy has variable influence on self-management and self-management support, but is always an important factor, while the financial crisis has a complex, almost exclusively negative, impact on self-management support. The impact however varies across countries, but even where the impact has so far been only small it is expected to be felt much more strongly over the coming years. The overwhelming perceptions among different stakeholders is that support by health professionals and representatives of voluntary groups should be complementary. There are however many tensions that are played differently across national contexts between statutory providers, voluntary groups and representatives of the private sector.

1.3.6 WP6 Surveys

1.3.6.1 Overview

The survey studies in WP6 documented key aspects of social systems of support in 18 geographic regions in 6 countries. Concepts that were identified and elaborated in qualitative research and literature analysis (EU-WISE work packages 1 to 5) have been tested, using quantitative methods, including social network analysis. This way we captured the composition and structure of inter-organisational networks (whole networks in a region) and described the support available to people with LTCs (ego-networks). The survey of the systems of support of people with diabetes related to WP3 and the survey of the networks of organisations related to WP4. Taken together, WP6 has provided in-depth insight into the role of social systems of support in self-management of people with diabetes. The findings of this WP6 were also used to inform work in relation to the EU-WISE intervention(s), designed, implemented and analysed in WP7. Also, the findings of WP6 have been published in open access peer reviewed journals.

1.3.6.2 Aims

Our main objectives in this WP were:

- To describe social networks, social support and self-care in adults with diabetes with varying degrees of socioeconomic deprivation.
- To examine associations between social networks, social support, self-care, and health status in adults with diabetes, with a particular focus on socioeconomic deprivation.
- To describe organisations that support self-care in adults with diabetes, and to map out the connections between these organisations.
- To examine associations between social networks, social support and self-care on the one hand, and characteristics of geographic areas, support organisations (including primary care practices) and their organisational networks on the other hand, with a particular focus on socioeconomic deprivation.

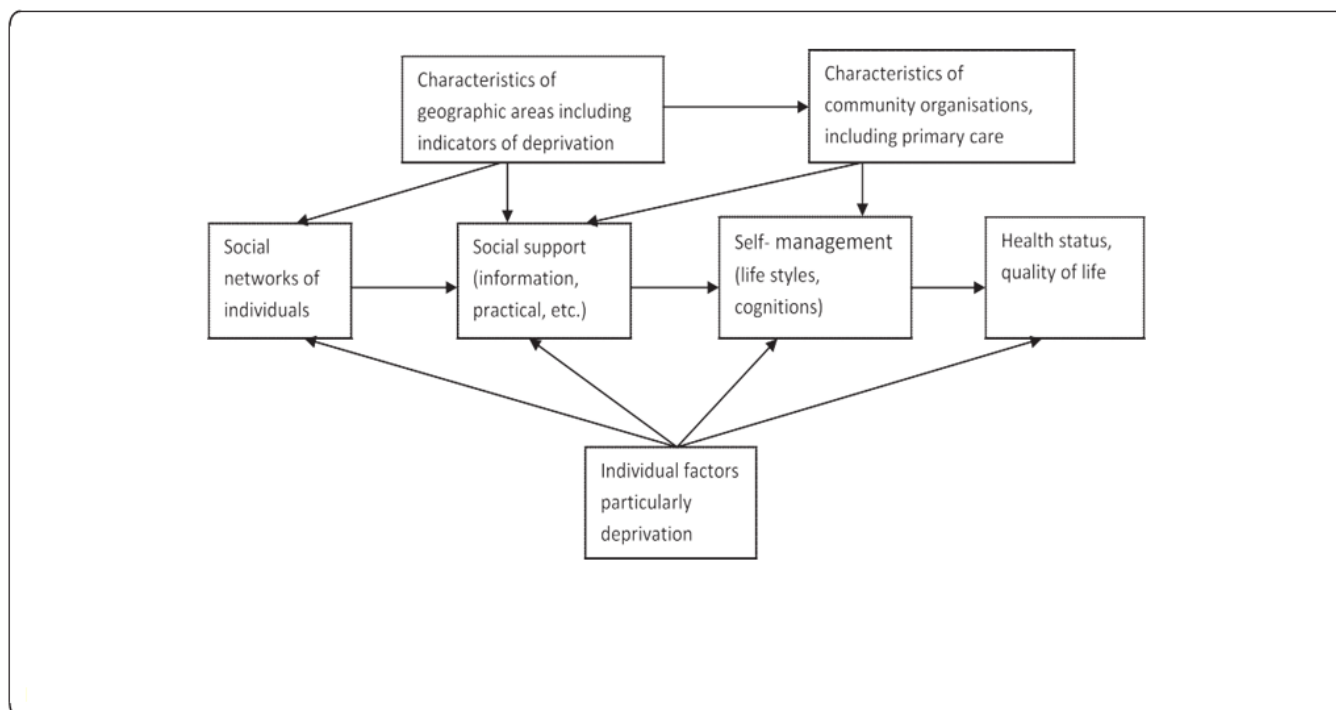


Figure 6 Conceptual framework for the study. Legend: Blocks refer to cluster of variables and arrows refer to expected causal effects.

Figure 6 provides the conceptual framework for EU-WISE work package 6, and a schematic overview of the main domains (blocks) and their relationships (arrows), that were explored in this work package. A range of factors and mechanisms related to social networks may influence self-care and health status, such as: contagion mechanisms, (e.g. access to/transfer of knowledge and other support, social influence/comparison principles); cooperation mechanisms, (e.g. mandated coordination, game theoretical principles); social capital mechanisms (e.g. perception of having access to resources in a social network). Self-care and health status are obviously also directly influenced by individual deprivation and characteristics of the disease, and may further be influenced by characteristics of healthcare, support organisations, the region and the country.

1.3.6.3 Development of study protocol and survey tools

We developed a detailed study protocol in 2012 to guide the data collection for WP6. In this protocol we described the background of the studies, structure of the project and especially WP6 and the aims and objectives of WP6. Second, the study design, geographical areas, sampling, data collection and measures were described. Third, the structure of the collected data was described to ensure the creation of a harmonized dataset. Survey tools were selected or developed in 2012.

The patient study used a pre-structured questionnaire, which utilized both established and purposefully constructed measures in order to explore a range of domains. We used a questionnaire which consisted of two parts; a written questionnaire with demographic variables, health and wellbeing items, self-care, received care and participation in local organisations. The face-to-face or telephone interview provided information on the social networks and support of the respondents. We used the SF-12 (version 2) to measure functional health status, both a physical and mental component. To assess self-management behaviour we used 3 indicators: physical activity, healthy diet and non-smoking. These indicators were measured by 2 validated scales: the Summary of Diabetes Self-Care Activities (SDSCA) and the Rapid Assessment of Physical Activity (RAPA). The SDSCA assesses self-care behaviour and lifestyle, including diet, smoking, physical exercise, blood sugar testing and foot care. The SDSCA was used for diet (2 items measuring general diet) and smoking. Medication adherence as a self-care behaviour was assessed using the Morisky Medication Adherence Scale (MMAS-4). Self-care cognitions were measured by two domains from the HEIQ V3.0: the self-monitoring and insight domain and the skill and technique acquisition domain. As intermediate variables we retrieved data on the medical and social care received in the past six months with the use of the Diabetes Health Care Utilization questionnaire. Furthermore we collected demographic data, including patients' age, sex, family situation, education, employment status, sick leave, ethnicity, housing, global household income and comorbidities. In order to map out affiliation networks we also measured involvement in regional or national support organisations.

To measure community organisation characteristics we purposefully developed a questionnaire that covered the following domains: descriptive information on the organisation and its activities; reach in target group in terms of users of information, participants in activities; collaboration with other support organisations in the local area, including primary care healthcare practices; contact/collaboration with other organisations in domains that are relevant to self-management behaviours. Telephone or face-to-face interviews were conducted with individuals who represented a support organisation.

Although all measures were chosen based on proven validity and reliability and often already were translated into other languages, not all measures were available in all countries. In Bulgaria, the SCSCA, RAPA, and, SF-12 were translated independently by two researchers into the Bulgarian language. The procedure for the heiQ translation followed the same process, and also included an extensive discussion with the developer of the heiQ (Richard Osborn, Deakin University), so that the Bulgarian team and UK team received an official license to use in Bulgaria. In Greece, the RAPA was also translated independently.

1.3.6.4 Results of patients with long term conditions study

In total 1,861 patients completed the written questionnaire, of which 1,692 also participated in the interview. Average age was 66.1 years, men and women were equally present (50.0% female) and about 10% had a non-native origin. The majority (61.3%) had an income that was below the country average, which reflects the focus of the study on deprived populations. They reported 5,433 connections with individuals providing some kind of support (a mean

of 3.2 connections per patient and a median of 3 connections per patient). Nearly half (48.3%) had health professionals in their extended network and about a third (34.6%) participated in community organisations. Regarding self-management behaviour, a physically-active lifestyle was reported by 35.3%, 50.8% followed a healthy diet and 85.8% were non-smokers (Table 12).

Table 12 Description of Patient Samples

	<i>Total</i> (n=1692)	<i>Bulgaria</i> (n=283)	<i>Greece</i> (n=302)	<i>Nether-lands</i> (n=245)	<i>Norway</i> (n=291)	<i>Spain</i> (n=290)	<i>UK</i> (n=281)
Individual characteristics							
<i>Sex (% female)</i>	50.0	61.1	57.3	43.8	38.5	55.9	40.0
<i>Age in years (mean)</i>	66.2	65.2	69.0	68.4	59.8	69.3	65.5
<i>Parents born in other country (%)</i>	6.3	0.4	8.6	13.9	14.4	1.0	- †
<i>Pet in household (% yes)</i>	38.0	55.0	53.5	29.1	30.7	30.5	27.3
<i>Education (mean years)</i>	10.3	10.5	7.8	11.0	11.1	9.0	12.7
<i>Pensioner (%)</i>	62.3	70.9	72.7	60.6	29.7	75.3	64.4
<i>Low income</i>	61.0	69.3	55.5	47.5	46.2	81.1	65.6
Comorbidities							
<i>0 comorbidities</i>	14.8	7.4	7.6	13.5	15.1	19.3	26.3
<i>1-2 Comorbidities</i>	57.4	52.7	60.6	61.2	51.2	59.7	59.4
<i>> 2 Comorbidities</i>	27.8	39.9	31.8	25.3	33.7	21.0	14.2
Physician/nurse visits last 6 months							
<i>0-2 visits</i>	35.0	14.5	1.0	67.9	39.7	40.9	53.9
<i>3-5 visits</i>	51.4	56.0	93.7	29.2	45.2	43.0	34.9
<i>> 5 visits</i>	13.5	29.4	5.3	2.9	15.2	16.1	11.2
Social support							
<i>Spouse (% yes)</i>	70.5	62.1	70.9	74.7	65.6	81.2	71.0
<i>Household members (mean)</i>	2.3	2.6	2.3	1.9	2.0	2.6	2.0
<i>Network members (mean)</i>	3.2	2.7	2.2	4.1	3.3	3.0	4.1
<i>Network members providing:</i>							

<i>Information support</i>	1.9	1.9	0.9	1.6	1.9	2.2	2.8
<i>Practical support</i>	1.5	1.8	1.2	1.2	1.2	1.6	1.8
<i>Emotional support</i>	2.5	2.7	2.1	2.5	2.6	2.6	2.8
<i>Health professional in wider network (%)</i>	48.3	54.8	57.6	47.8	49.8	31.4	48.0
<i>Attending community organisations (%)</i>	34.6	37.8	24.8	44.1	23.7	41.4	38.1
<i>Residential area</i>							
<i>Urban deprived</i>	35.9	35.3	32.8	37.6	35.4	33.1	42.3
<i>Urban affluent</i>	39.1	32.2	32.8	21.6	30.6	32.8	57.7
<i>Rural deprived</i>	25.0	32.5	34.4	40.8	34.0	34.1	-*
Health and health related behaviours							
<i>Health related QOL (SF-12)</i>							
<i>Physical (mean)</i>	50.0	48.0	48.0	51.3	51.8	49.9	50.5
<i>Mental (mean)</i>	50.0	48.1	46.9	52.5	51.0	50.7	50.7
<i>Self-management</i>							
<i>Physically active (%)</i>	35.3	40.1	19.5	49.8	42.9	30.9	31.2
<i>Healthy diet (%)</i>	50.8	33.1	56.8	53.1	45.0	67.2	48.9
<i>Non-smoking (%)</i>	85.8	80.4	89.0	89.8	77.2	89.2	89.5

*Not included in sampling, † Not recorded.

We found that controlled for other patient characteristics and comorbidities, lower income was related to worse physical and mental health status ($B = -1.87$ and -1.38 , respectively). Individual network characteristics were inconsistently related to physical quality of life. Having a spouse was associated with a better physical health status ($B = 1.01$), especially for patients with a high income, whereas receiving more practical support was associated with a worse physical health status ($B = -0.46$). Controlled for patients characteristics and comorbidities, attending community organisations was related to better physical health status ($B = 1.39$). Similar linkages were found for mental health status; having a spouse and visiting community organisations were related to better health status and practical support to worse health status ($B = 0.88$, 1.22 and -0.27 , respectively). In addition, having more health professionals in the wider network was associated with better mental health status ($B = 0.67$), mostly for patients with a low income ($B = 0.76$). Patients living in an urban deprived area had worse mental health status compared to patients living in an urban affluent area ($B = -0.84$), but this effect was only present for patients with a low income ($B = -1.29$ versus $B = -0.11$ for high incomes).

Lower income was related to less physical activity (OR = 0.75), but not to diet and smoking. Regarding individual network characteristics a higher number of practical support connections was associated with less physical activity. However, focusing on differences in level of income, the negative relationship between practical support connections and physical activity only applied to higher incomes (OR = 0.70), whereas for lower incomes no relation was found (OR = 1.00). Higher numbers of information and emotional support connections were related to more physical activity, however only for higher incomes (OR 1.20 and 1.30, respectively). Attending community organisations was positively related to physical activity, however only for patients with a low income (OR = 1.53). A healthy diet and non-smoking were less related to the social support indicators, with some exceptions. The number of household members was negatively associated with a healthy diet (OR = 0.91) and having a spouse was related to a more healthy diet in the high income group (OR = 1.67). Having more emotional support members in a network was negatively related to non-smoking (OR = 0.87). Living with more household members was positively associated with non-smoking, however only for the low income group (OR = 1.21) and attending community organisations was positively related to non-smoking, but only for higher incomes (OR = 1.72).

Focusing on self-management capabilities using the heiQ, we found that low-education was negatively related to self-management capabilities, for both self-monitoring and insight and skill and technique acquisition status (B = -0.10 and -0.11, respectively). Regarding the social factors, the number of information support members has a positive effect on both of the self-management capabilities scales (B = 0.02 and 0.03, respectively) and these effects are the strongest in the low-education group. In addition, practical support and attending community organisations was related to better self-monitoring and insight. Having a spouse was related to better skill and technique acquisition, but only for patients in the high-education group.

1.3.6.5 Results Organisational Network Study

In total 877 respondents were interviewed, representing several hundreds of community organisations and local departments. Respondents were volunteers, paid employees, or linked to the organisation in other ways. In Norway, the Netherlands and the UK, the interviewed members were predominantly paid employees, whereas in Bulgaria, Greece and Spain most were volunteers. Table 13 presents information on the organisation characteristics. The majority were locally active (55 to 95%), while the remaining were active at regional or national levels. On average, the organisations existed for 20 years or more. They had a range of primary goals, which differed across countries. The number of users of their services varied widely, with averages ranging from 464 in Norway to 4,679 in Greece, but also within countries (from few users to ten thousands). Most depended on grants and/or contributions of users. They also depended on volunteers, who comprised the large majority of workers in all community organisations. Nearly all organisations cooperated with other organisations. The number of organisations they cooperate with varied between 3.4 (Spain) and 5.0 (Norway). The contact frequency varied between countries, but in nearly all countries most organisations indicated that they have at least 'once a month' contact with each other. Participation together in projects was the most important reason to cooperate in four countries (Greece, Netherlands, Norway and Spain), while receiving information from other organisations seemed to be the most important reason to cooperate in the UK and Bulgaria.

Table 13 Organisation Characteristics

	Country					
	<i>Bulgaria</i>	<i>Greece</i>	<i>Nether-lands</i>	<i>Norway</i>	<i>Spain</i>	<i>UK</i>
<i>Geographical focus (%)</i>						
<i>Local</i>	64.0	68.7	55.3	54.7	60.7	94.7
<i>Regional</i>	10.7	18.0	34.2	6.0	17.3	5.3
<i>National</i>	21.3	9.3	5.3	3.3	8.0	0.0
<i>Local department</i>	4.1	4.0	2.6	32.0	0.7	0.0
<i>Other</i>	0.0	0.0	2.6	4.0	13.3	0.0
<i>Average years of existence</i>	20.1	20.0	21.2	21.2	28.0	25.7
<i>Main goal of organisation (%)</i>						
<i>Providing information</i>	79.0	33.3	18.4	18.0	11.3	7.9
<i>Practical support</i>	7.2	18.7	15.8	2.0	26.0	27.6
<i>Medical care</i>	0.0	9.3	15.8	11.3	12.0	0.0
<i>Providing physical activities</i>	10.1	3.3	28.9	30.0	9.3	9.4
<i>Providing social activities</i>	3.6	8.0	10.5	26.7	32.0	22.0
<i>Other</i>	0.0	27.3	10.5	12.0	9.3	33.1
<i>Average number of users</i>	1591	4679	2676	464	2091	3790
<i>Sources of funding (multiple categories possible)</i>						
<i>Charity</i>	31.3	14.6	21.4	18.7	26.0	17.3
<i>Grants</i>	0.7	53.0	60.0	72.7	75.3	39.4
<i>Contributions</i>	79.3	50.3	62.9	55.4	74.5	48.8
<i>Other</i>	14.2	61.0	65.7	16.7	26.6	28.3
<i>Average number of workers</i>						
<i>Volunteers</i>	179.6	31.2	1259.8	29.4	1471.8	21.8
<i>Paid employees</i>	5.2	74.5	119.4	6.6	279.0	18.2
<i>Other</i>	0.8	20.5	13.9	11.2	1.5	6.5
<i>Total</i>	185.6	126.2	1393.1	47.2	1752.3	46.5

1.3.6.6 Significant Results

This study found that across Europe patients with a diagnosis of diabetes reported variable availability of social support from individuals and community organisations. Participation in community organisations (reported by about a third of the population) was most consistently related to better health status and health-related behaviours,

especially in low income populations. Individual support network characteristics had mixed effects on health and behaviours, while living in a deprived urban neighbourhood had a negative impact on mental health status. These linkages were influenced by individual income, which itself had a (positive) effect on health and health-related behaviours. In low income populations, some of the positive impacts of a large individual support network were not found.

Our findings are consistent with other studies that focus on identifying the influences of social support and social networks. The mixed effect of individual support networks was also found in a systematic review which indicated tentative evidence for informal support. The ‘contagion’ of health-related behaviours (such as smoking) as found by Fowler and Christakis in the Framingham cohort may have to be reconsidered in the light of our finding that some of the protective impacts of a large individual support network were only found in patients with high income. This suggests that deprived patients benefit less from a large network than those with high income. Regardless of the hypothesized mechanisms of social support, this finding raises important concerns about the potential untapped resources in individual networks to compensate for austerity measures, particularly in people with low income.

On the other hand, participation in community organisations had a consistently (small) positive effect on health status and physical activity, especially in people with low income. Besides directly providing information, practical help and emotional support, or navigating to sources of support, these organisations can fulfil a range of functions including enhancing feelings of social integration and individual identity. Interestingly, qualitative interviews with individuals with diabetes suggested that providing support to others was one of the key mechanisms of support that contributed to better health status.

A strong and novel aspect of this study is that the involved countries reflect a variety of health and welfare systems and policies in response to austerity in Europe. The focus on regions made it possible to combine various types of social support (from individual networks, community organisations, and neighbourhoods) in one analysis. The cross-sectional design of the study did not allow causal inferences, so we could only speculate about mechanisms underlying social support. While we used previously validated measures and methods, the study has a risk of bias due to non-identified differences in national health systems and cultures.

1.3.6.7 Practical implications

Although the overall variance in self-management capabilities explained by the regression models was small, some guidance to strengthen self-management support interventions can be provided. The positive effect of participation in community organisations reflects the supportive function for self-management in people with LTCs. Therefore, an important implication of this study for health professionals and policy makers is that they may need to give consideration to the provision of (increased) support to community organisations, which offer activities that are relevant for the self-management of health in people with long term diseases. Although our study was not designed to provide nationally representative samples, it also suggests that there is room to increase the participation of relevant groups in these organisations.

Many diabetes patients reported receiving support from family members, friends and others. The relevance of having a large number of connections was mixed and overall of limited value, particularly in low-income groups. Therefore, interventions to increase the size of individual support networks need to be applied on the basis of individual assessments rather than taken as the given goals of public health policies. Only enlarging the number of network members providing information support provided an opportunity to compensate for the adverse effects of deprivation. Therefore, interventions with an information support component should not only focus on the individual patient, but also involve his/her social network to maximize this effect, especially in low education groups. This supports the involvement of patients’ partners and groups in self-management support interventions.

1.3.7 WP7 Development of Resources

1.3.7.1 Introduction

WP7 was focused on the development and testing of a novel intervention(s) to support self-management of long term conditions (with an emphasis on type 2 diabetes mellitus). Our aim was to develop a community based strategy for the creation of illness management resources and draw on knowledge generated about personal and inter-organizational networks, in order to offer a targeted and contextually sensitive intervention(s).

When designing the EU-WISE intervention, we took the techniques developed within the WISE approach and the CLAHRC programme (in particular the PLANS intervention) as our starting point. We also undertook a review of interventions, included in WP2, which identified appropriate interventions focussed on type2 diabetes for use in primary and community settings. This review was aimed at identifying the limitations and the barriers in the implementation of the key intervention(s). Finally, we assimilated the knowledge emerging from other WPs within EU-WISE (e.g. about the importance of social networks, the potential for an expanded role for voluntary and community groups and country specific contexts).

1.3.7.2 The EU-GENIE Intervention

The intervention developed was called EU-GENIE (European Generating Engagement in Networks Involvement). The intervention uses participatory methods of social network mapping to encourage patient reflection on self-management supports, to inspire positive change and (in many cases) to link patients with useful resources. The core of the intervention is personal community mapping and analysis. Additional, optional aspects are:

- A. An additional assessment of patient needs, interests and supports.
- B. Provision of links to resources tailored to meet the patient's needs.
- C. Use of an on-line navigational tool.
- D. Providing patient centred information about chronic illness management.
- E. Analysis of inter-organisational networks.

The intervention is guided by a facilitator and can be completed online, or in paper version. The core of the intervention involves the participant completing a circles diagram, into which they place the people and contacts that are important in their lives, who help them on a day to day basis and with the management of their condition. Depending on the setting, the intervention may then involve additional needs assessment, provision of links to tailored resources, use of the online tool and/or provision of information about the patient's condition.



Figure 7 Graphic showing the EU-GENIE intervention and its components

EU-GENIE was adapted and contextualised for pilot studies in the UK, the Netherlands, Bulgaria, Greece, Norway and Spain. The core intervention was delivered in each country, with some or all of the additional components, depending on needs analysis and feasibility in each setting. Once the format for the intervention was devised, we identified suitable sites in each partner country as test sites for the intervention(s) and the resources for the intervention were adapted to local conditions. For the implementation, we developed a workbook translated into partner languages. A patient-centered, diabetes self-management guide previously developed by the University of Southampton team was translated into Greek and Bulgarian and was used as a part of EU-GENIE in those countries. The online EU-GENIE tool was made available in English, Spanish, Greek and Bulgarian.



Figure 8 The Diabetes Guidebook in English, Greek and Bulgarian



Figure 9 Screenshot from EU-GENIE online English version

A database with local resources was built for each partner country, as required, including information about local diabetes associations, health and lifestyle organizations, voluntary groups, wellbeing related organizations, professional groups, community groups and patient's and people's rights groups. Table 14 illustrates the number of organizations that were included within each country and which countries used the online version and paper based database as part of the implementation of the EU-GENIE intervention.

Table 14 Online and paper based database of local organizations used as part of EU-GENIE

	UK	BG*	NO*	SP	GR	NL**
Paper based EU-GENIE (number of organizations included)	210	28	31	24	95	--
Online EU-GENIE (number of organizations included)	210	--	--	24	95	--

*Only paper based intervention used

**Only network mapping part of EU-GENIE (A) used

The members of the University of Southampton team who developed the PLANS intervention, and had the most relevant experience with the implementation process, developed a training session for EU-GENIE and delivered the training to the intervention team in each country.

EU-GENIE was delivered to 15 participants in each site. The format of delivery was chosen to suit the specific country context. Table 15 summarises implementation in each country.

Table 15 Implementation of EU-GENIE across different sites

Country	Format	Facilitator	Setting
UK	Mainly web-based	Health Trainers and Care Navigators	Community and people's homes
Netherlands	Paper-based	Researcher/GP	Primary Care
Greece	Web-based and paper based	Nurse & social worker	Rural GP practice
Bulgaria	Paper-based	Researchers	Rural community; people's homes
Spain	Web-based and paper-based	Researcher	Community, and GP practice
Norway	Paper-based	Nurse specialists	Health House

1.3.7.3 Assessment of Intervention and Results

We carried out an assessment of the intervention to ascertain the feasibility (including acceptability and practical implications). The evaluation was carried out using qualitative and process research methods based on an NPT (Normalization Process Theory) theoretical framework (May et al., 2010).

All pilots were observed by a trained evaluator and were either video or audio recorded. The evaluators took notes during the intervention using an NPT framework as a sensitizing coding framework used in situ. After the delivery of the intervention, the user was interviewed following an NPT framework. A separate set of questions were designed for a two week and three months follow up (although in order to address the specificities in how the intervention was tailored to each local context there was some variation in the procedures followed). The core assessment interviews were audio-recorded and guided by key questions. An NPT framework was used to assist coding of transcripts and to give insights into how feasible the intervention is in practice.

The application of NPT constructs (as above) helped us to analyse and synthesise our results.

We found that the intervention (EU-GENIE) was positively received and accepted as an important potential SMS intervention in the implementation sites. In overall terms we were able through testing, to uncover the key elements necessary to answer the question of *what is likely to assist with the implementation of self-management support through a network based intervention*:

- Visualise and raise awareness of the structure and organisation of personal communities.
- Improve individual and network capacity for navigating and negotiating relationships and roles.
- Focus on user-preference in order to maximise possibility of social engagement.
- Professional endorsement is important, but delivery of SMS interventions should be outside primary care.
- Facilitator as a co-traveller in the process of re-framing CIM.

An important aspect of the intervention was the nature of the facilitation utilised to engage people with the intervention. In Greece, Norway and Spain the facilitation worked optimally if undertaken by health professionals, as the users felt more confident and comfortable with them due to their background of medical expertise and the already existing relationship as a patient. By contrast, in Bulgaria, the United Kingdom and the Netherlands the facilitation work worked best if undertaken by non-health professionals, as this was seen as more likely to lead to an open discussion - respondents did not expect a high level of expertise from facilitators and were happy to navigate the EU-GENIE options together. This suggests that a wide range of volunteers and service providers could be trained as facilitators in some countries. Training the facilitators is an important part of implementation. Our results suggest that exclusively self-directed facilitation may not be optimal and could result in lower levels of engagement than including some form of guided facilitation via a dedicated facilitation agent.

The visualization of network members as part of the mapping process seemed to be a relevant aspect of both disruption to existing normative thoughts about who provides support and imagined positive reconstruction of the individual's social network. Further, in Bulgaria, Greece and Spain the visualization in SMS of their network seems to be family-centred.

The diabetes guided self-management book was important in Bulgaria and in Greece – where informational needs are high and patient orientated materials less available than in other settings. Suggestions included to expand by adding further information on dietary guidance and medical advice for patients.

In Greece the online version of EU-GENIE seems, comparative to other settings, unsuited to some people with low computer literacy, while technical issues also impeded the use of the online version of EU-GENIE.

Users with diverse networks felt motivated as they visualized their social network – which illuminated substantive sources of assistance from a range of connections. This seems to engender and accelerate the process of decision making in terms of self-management. Some users with isolated networks experienced the process of visualizing of their network as more challenging, since it involved coming to terms with an absence of support and membership. The facilitated discussion and the referral to possible activities in general terms opened up a space for reflection and offered alternative pathways for individuals to reconstruct CIM in a new and refreshed way. Again, the facilitator played a seemingly central role in this process.

The question of long-term sustainability for the system emerged as one of the questions which will be addressed in follow up work. Possible solutions include implementing multi-layered administrator access to the database - local champions, facilitators, and central administrators, each with a different level of access for making and approving changes to the system.

Key themes identified as a result of applying NPT included:

- EU-GENIE as a catalyst for positive disruption of existing practice that opens space for reflexive engagement.
- Buy-in framed and legitimised in a variety of different ways.
- Country Specific Themes (e.g. Diabetes Booklet).
- A focus on practical solutions of immediate relevance to the user.
- Facilitation can create equal partnership working.
- Perspectives on facilitation by health professionals/non-health professionals.
- A limited network may be related to felt stigma.
- Skill diffusion for individual and communal appraisal.

1.3.7.4 Expert Consensus Panel

On 24 November 2016, the EU-WISE partners held a round-table discussion with external experts where we gathered valuable feedback about the project and the EU-GENIE intervention. The key lessons and themes arising from the regional workshops, final conference and expert consensus panel are set out in D1.1 and included learnings about (i) adapting EU-GENIE for different settings, (ii) EU-WISE and policy and (iii) EU-WISE, primary care and education. These themes fed into the final synthesis of project results carried out in WP1.

1.3.7.5 Conclusion

The aim of WP7 was to develop a community based strategy for the creation of illness management resources and to draw on knowledge generated about personal and inter-organizational networks, in order to offer a targeted and contextually sensitive intervention. Thus, the EU-GENIE intervention was developed to raise awareness of social networks (both at the level of personal communities and community organisational level), to improve patient engagement and outcomes as well as outcomes for professionals and voluntary groups. EU-GENIE uses participatory methods of social network mapping to encourage patient reflection on self-management supports, to inspire positive change and (in many cases) to link patients with useful resources. EU-GENIE was adapted to each partner's site according to local requirements and cultural differences and has contributed to capacity building, by leaving trained personnel, tools and resources for suitable use and implementation in the local settings.

The intervention was positively received in each of the implementation sites. The visualization of their network seems to be important to users and helps them reflect on support, reciprocity and the availability of resources. The visualization and the discussion of network members seem to operate as a useful disruption to what individuals have normalised in terms of CIM. The facilitated discussion that follows and the referral to possible activities opens space for reflection and offers alternative pathways for individuals to reconstruct CIM in a new way. The facilitator plays a central role in this process.

1.3.8 WP1 Theoretical and Methodological Background of Systems of Support

This work package was designed (i) to provide a theoretical and methodological framework with which to guide the EU-WISE programme of work, and to ensure that terminology and interpretation of methods and findings would be undertaken consistently across WPs and partner countries and (ii) at the end of the project, to produce a theoretical model, drawing on the work emanating from other WPs and to analyse and synthesise the themes that emerged across the project.

At the outset of WP1, we achieved a very good collective understanding of the key components of the values, knowledge, methods and theory underpinning this novel and complex area of self-care support. This laid solid foundations for our work and ensured project-wide norms prior to data collection and reviewing, which helped to improve the quality of the data collection, analysis and reporting. We complemented this initial work with ongoing theorising, giving rise to new concepts and analysis, from which a robust framework has now emerged.

The focus of our work in WP1 in the latter stages of EU-WISE has been on producing a theoretical model, drawing on, and together, the work emanating from other WPs, and analysing and synthesising the themes that emerged across the project as a whole. Here we outline the synthesis of our findings by presenting a final working model (Figure 10) which draws on the work and results from all work packages. We also expand on the four elements of the model.

The final framework devised in WP1 (the EU-GENIE theoretical networks mechanisms model) is represented in Figure 10 below and contains 4 key elements:

1. Macro and Meso Influences (policy, industry, environment).
2. Personal Communities ('ego' and network membership influence).
3. Community and Voluntary Organisations (social involvement potential).
4. Mechanisms of Social Network Intervention EU-GENIE.

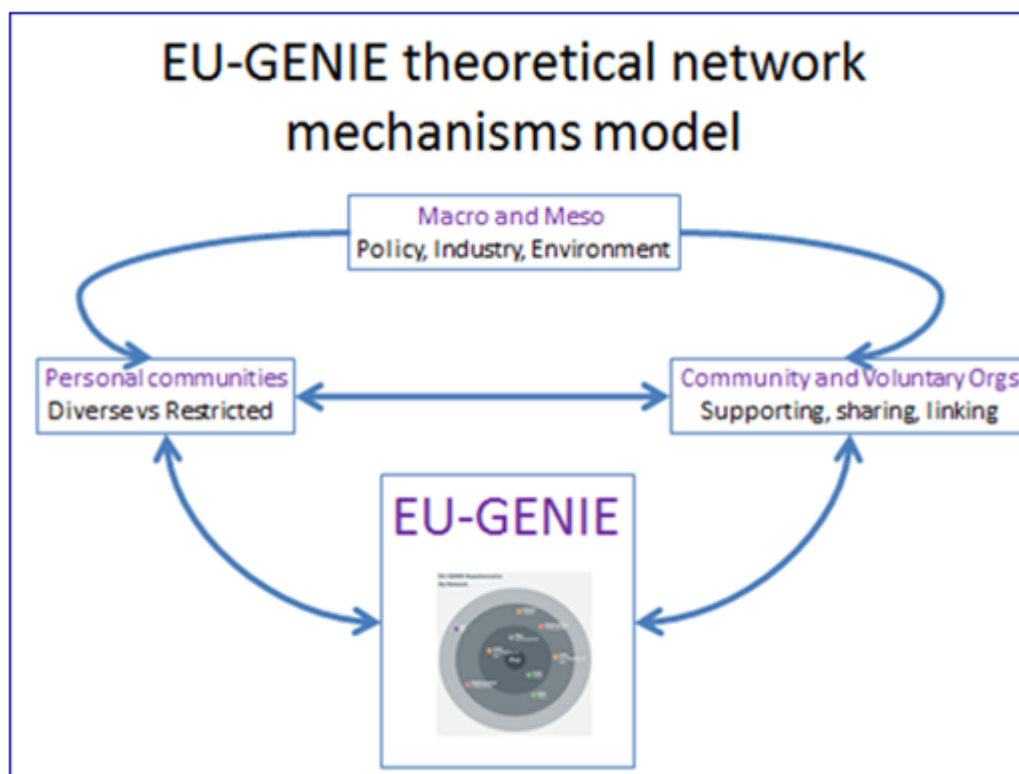


Figure 10 EU-GENIE network mechanisms model

1.3.8.1 Macro, Meso influences policy industry environment

Looking beyond the overarching notion of political economy, we identified some key themes that emerged across work-streams in relation to macro and meso influences.

From our exploration of diabetes self-management arrangements, interventions and programmes in Europe (Kousolis et al 2014), we identified a European wide policy shift towards patient-centred self-management of diabetes in a primary care context (although the form and content varied between settings). The professional role of diabetes specialist nurses, the need for multidisciplinary approaches and a focus on patient education emerged as fundamental principles in the design of relevant illness management programmes. Whilst these were important meso (relating to micro) facets of facilitating self-management support, macro influences were also important outer setting contextualising factors. We found that the infrastructure and culture for supporting self-management practice is viewed as being driven by political decision-makers, the socio-economic and policy environment and the ethos and delivery of long term illness management in formal health care systems. Key themes that emerged during the analysis of data elicited from stakeholder accounts included:

1. socio-environmental influences on diabetes self-management;
2. reluctance / inability of policy makers to sufficiently regulate processes and environments for long term illness management and
3. healthcare system governance and gaps in provision of self-management support (SMS).

The fiscal and financial crisis in Europe has impacted on SMS in most EU-WISE countries, to varying degrees. Socio-economic circumstances are relevant to the capacity to self-manage and suggest that any gains and progress will be hard to maintain during economic austerity and by implication in settings characterised by groups who suffer from chronic economic deprivation.

At a macro level we have seen that responses to symptoms and potential engagement with self-management activities in relation to diabetes are overlain by economic and policy nuances imperatives and corporate forces.

Cross-country comparison of biographical experiences provided a means of arriving at an integrated analysis of the impacts on long term illness management, through comparing system level differences and illuminating how macro level factors contribute to shaping practices and experiences in countries that are at different stages of implementing neo-liberal and economic reforms. We saw that the contexts of partner countries differ in terms of the resources available to individuals and the state, as well as the capacity, organisational and funding structures, and patient outcomes for respective healthcare systems. In considering the range of meso level considerations we found that they included the manner in which health care systems were organised and delivered and the influence of commercial interests and particularly drug companies and their salience. Additionally, of increasing importance as a meso level factor were ehealth interventions. Key theme similarities and differences between partner countries are set out in Table 16.

Table 16 Key theme similarities and differences between partner countries

	Low and medium income countries			High income countries		
	BG	GR	SP	UK	NO	NL
Adequately funded health care infrastructure				++	++	++
Existence and impact of dedicated SM policies, services, and resources			+	++	++	++
Emphasis on nuances in SMS policies, resources, and delivery		+	+	++	++	++
Absence of dedicated and enacted policies related to inadequate provision, austerity, and lack of resources	++	++	+			
Drug companies viewed in terms of playing an explicit role in SM	++	++	++			
Drug companies in strong position to reinforcing biomedical focus in SM	++	++	++			
Focus on promoting SM at an individual level				++	+	++
Behavioural interventions introduced by primary care services				++	++	++
Presence of cycling-friendly physical and social environment					++	++
Expressed concerns with social rights & socialising healthcare cost		++		++	++	

Key: '++' the statement is fully valid for this country; '+' the statement is only to some extent valid for this country.

Please note that each country is assessed in relation to all other countries in the sample. Regional differences exist within all countries in the sample, but they are relatively small (except for those in Spain, partly due to their autonomous status) (Rogers et al 2015).

1.3.8.2 *Personal Communities and Systems of Support*

Element 2 reflects our elaboration of knowledge and understanding about the properties of personal networks, highlighting their complexity and key relevance as sources of support. Ascertaining the types and characteristics of personal networks is relevant for understanding the inter-personal environments that can restrict or enable long-term condition self-management.

A wide range of relationships have been identified from our research as being involved in illness management. Family and friends often support self-management, but they can, under certain circumstances, also hinder it. Our research findings provide confirmatory results of weak ties such as acquaintances (especially other people with LTCs), playing an important role for information exchange about illness management.

In terms of key identifiable properties in illness work - we have arrived at a better understanding of personal networks by considering network dynamics and structures. We identified three network mechanisms:

- *network navigation* (identifying and connecting with relevant existing resources in a network);
- *negotiation within networks* (re-shaping relationships, roles, expectations, means of engagement and communication between network members) and
- *collective efficacy* (developing a shared perception and capacity to successfully perform behaviour through shared effort, beliefs, influence, perseverance, and objectives).

We found that losses and gains in personal networks impacted on diabetes management, testifying to the need for recognition of a dynamic rather than static model (Kennedy et al 2015). Contextual differences in narratives of personal experience related primarily to a country's economic situation. Gaps in a person's network caused by death, divorce, retirement, loss of work, partner's sickness or moving led to effort and struggle to re-navigate and renegotiate the support or work performed by the missing element. Death or divorce often meant other family members stepped in and imposed more control over the individual. In contrast, individuals outlined purposive strategies to include or exclude certain network members who were perceived as being more or less helpful. Collective efficacy was most frequently obtained through a respondent's partner changing their lifestyle, especially in cooking and eating, to make life easier for the partner with diabetes. In relation to diet (a central aspect of disease management), our empirical research indicated that in all partner settings there were complex negotiations which influence self-management and food including support, knowledge and relationships within families; attention and openness in social situations and the premises and norms of society (Ingrid Rudd Knutsen et al 2015).

Key analysis and findings point to how different types of network are associated with differing capacities to undertake diabetes management work – from diverse and generative networks, to struggling networks, where self-management may not be prioritized (see Figure 11).

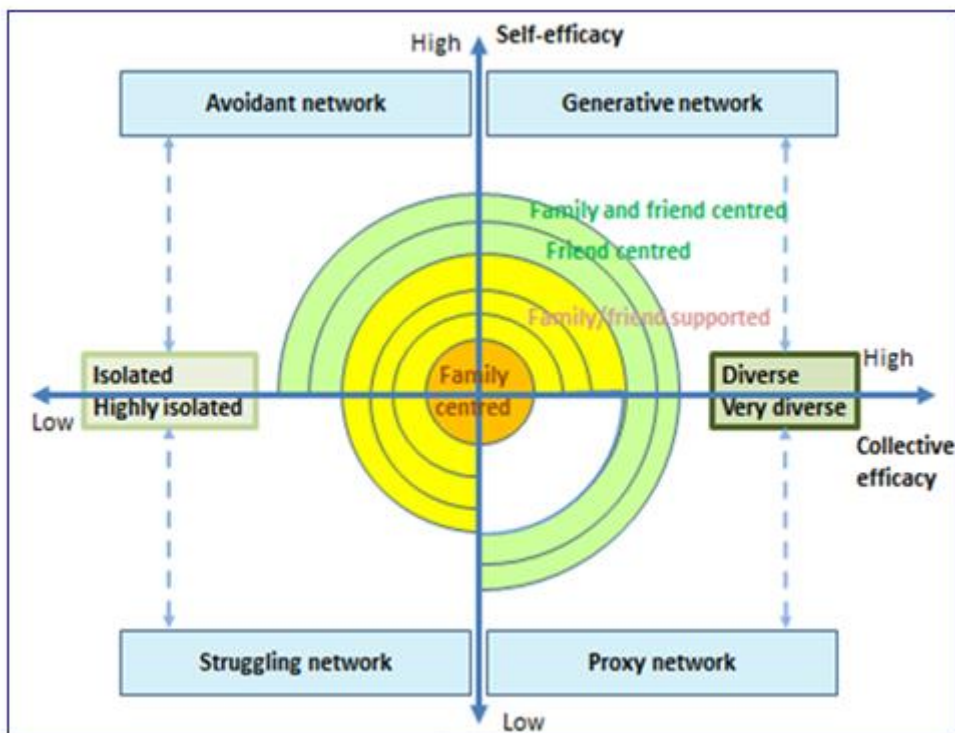


Figure 11 Graphical Representation of Personal Networks

Analysis of empirical studies in WP6 revealed that restricted networks represented those with the poorest self-management skills and were associated with least support from social network members. Diverse networks reported the best self-management skills, received most emotional and information support from network members, and reported the lowest level of healthcare service utilisation than other network types. Restricted networks were worst on all indicators: self-management capacity, network support, and well-being (Vassilev et al in submission).

Thus, diverse-friendship networks represent the most likely optimal network types in terms of long term illness management, due to their high self-management capacity and low cost to the healthcare service. This suggests the need to design interventions focussed on constructing personal networks for those with long term conditions in order to promote better access to and engagement with self-management support and resources.

1.3.8.3 Community Organisations as a target for interventions

Evidence feeding into the meta synthesis included in WP4, which explored the involvement of voluntary organizations in diabetes self-management programs, mainly related to: the nature and remit of their work, responsibilities, and attributes; key strategies of programs accounting for success; motivations/barriers for engaging in volunteering participation; relationships between volunteers and users and connections/tensions with formal services. The principles of **“assistance, support, sharing, and link”** emerged as key characteristics for voluntary initiatives in self-management to establish effective reciprocal collaboration with health professionals. We found in the meta-synthesis (Portillo et al 2015) that community support groups contribute to the construction of an illness-dignity, and group-processes are characterised by negotiation of a worthy identity, through allocating responsibility for management, confirming the complexities of a long-term condition and normalising illness-severity.

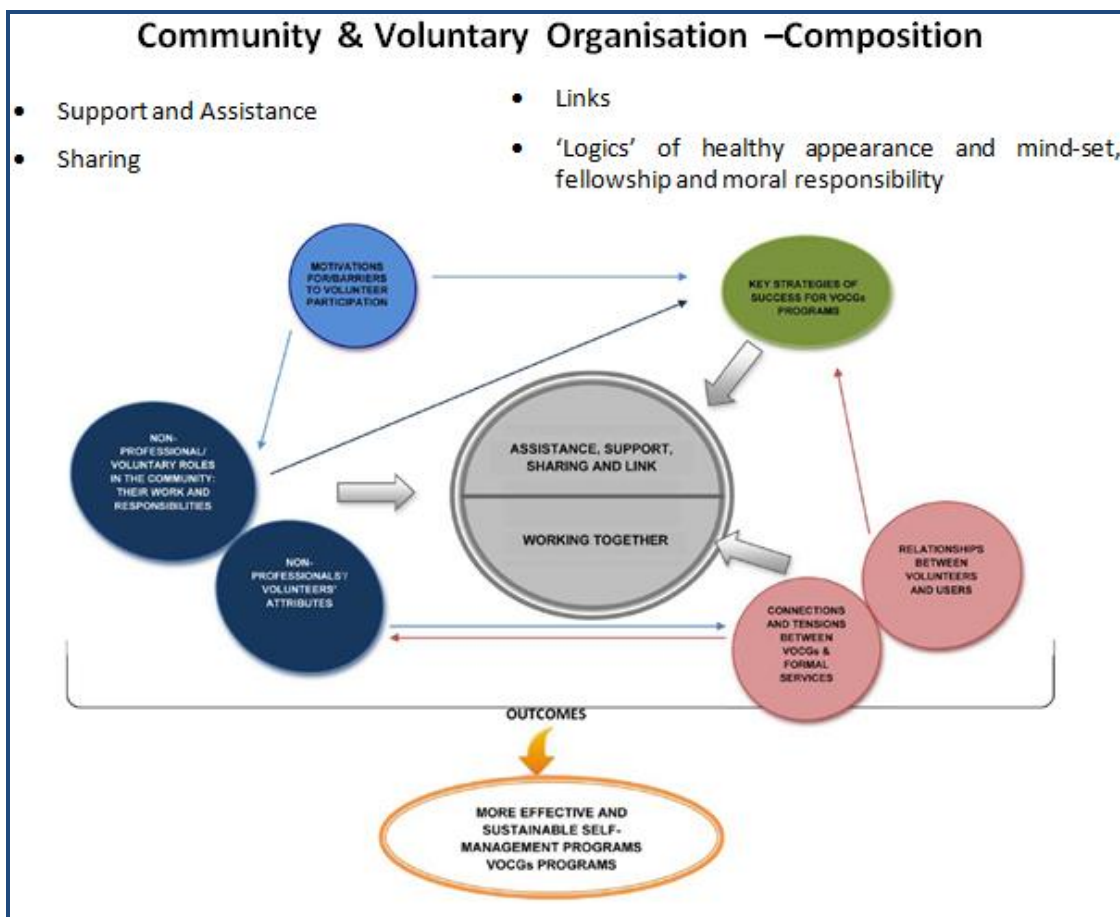


Figure 12 Element 3 of the theoretical model

The quantitative analysis of networks from the studies conducted in WP6 indicated that social involvement with community organisations might be relatively more important in terms of its impact on self-efficacy and the undertaking of positive health care practices. Participation in community organizations was associated with better physical and mental health and, in patients with low income, with more physical activity (Koetsenruijter et al 2015). The consistent association between participation in community organizations and health status provides a clear target for interventions and policies.

1.3.8.4 Social Network Intervention EU-GENIE

The social network intervention EU-GENIE is the fourth element of our network mechanisms model. EU-GENIE has been described already in section 1.3.7 above.

In our analysis of the intervention we found that the discussion of network members operates as a useful disruption to what individuals have normalised in terms of CIM. The facilitated discussion that follows and the referral to possible activities opens space for reflection and offers alternative pathways for individuals to reconstruct CIM in a new way.

It is a key strength of EU-GENIE that it can be adapted to suit local requirements and preferences whilst at the same time retaining key generalizable principles.

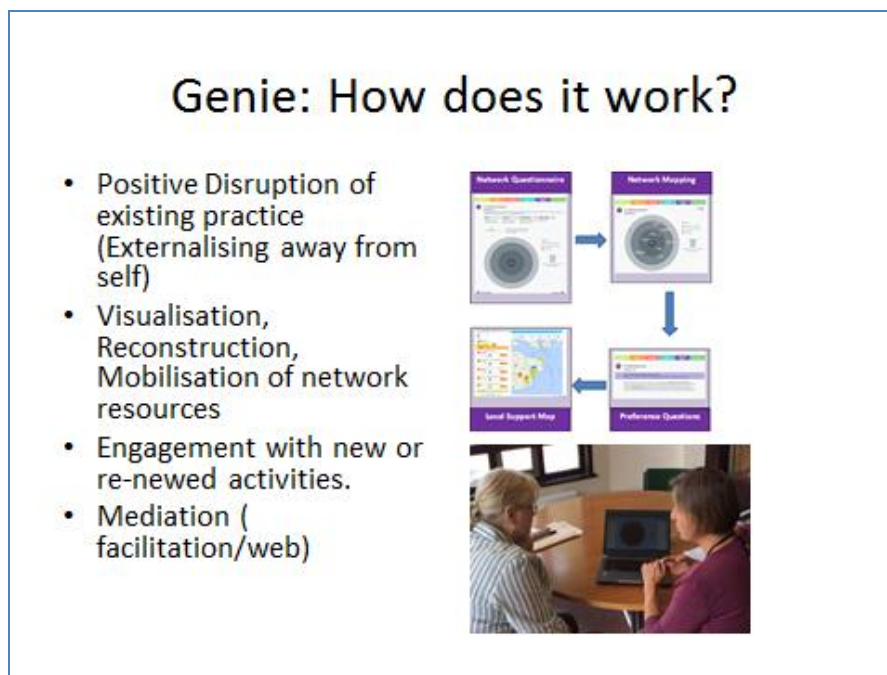


Figure 13 How EU-GENIE Works

1.3.8.5 Findings from Regional Workshops and Final Conference

During the project the EU-WISE team organised a series of regional workshops in order to discuss project results, implementation of interventions and potential impact in a regional context. Different formats were used for the workshops in each region, so that each partner could match local requirements. We also held the project's final conference in Southampton on 23 and 24 November 2015.

Overall the regional workshops and final conference proved very effective, allowing the EU-WISE team to engage at a local level with the issue of long term illness management, gathering feedback from external experts and furthering our insights into what works for who and why.

The key lessons and themes arising from the regional workshops and final conference are set out in D1.1 and included learnings about (i) adapting EU-GENIE for different settings, (ii) EU-WISE and policy and (iii) EU-WISE, primary care and education.

1.3.8.6 Summary

Our early work in WP1 set the foundations on which our theoretical and empirical research was built. In our later work we analysed and synthesised the findings from the other work packages running throughout the 4 years of the project. That synthesis culminated in production of the final working model above (Figure 10).

1.3.9 Conclusion

Over the course of the project, EU-WISE has conducted both systematic reviews and broad based empirical research, using a variety of methods. Our researchers (working across 6 countries) carried out qualitative and quantitative empirical studies, including capturing data from 90 key informant interviews, 175 biographical interviews, 285 interviews with NGOs and voluntary groups and 32 focus groups. In addition, a survey was conducted of 1,861 diabetes patients and 877 members of community organisations. In addition to empirical research, WP9 dissemination, workshops and our final conference have served to spread the message about EU-WISE and have also contributed important feedback to the group, in particular allowing us to formulate key themes about the future for EU-GENIE and for self-management support within health care policy.

The synthesis of our findings culminated in the production of a final working model (the EU-GENIE theoretical network mechanisms model set out at Figure 10) which draws on the work and results from all work packages. A comprehensive synthesis of our results is described in D1.1 (submitted 21 December 2015). Much of the work referred to in D1.1 is further elucidated in EU-WISE publications appearing in 2014-2015. These publications contribute to the state of the art literature and to the debate on health policy.

EU-WISE has gained valuable insight into the impact of different health care systems and welfare regimes on people with long-term conditions and the level of support available. We have successfully illuminated deficiencies in self-management support policies – particularly where austerity measures have hit hardest and where there is a failure to recognise, and engage with, the power of social networks and resources.

Our final interpretative synthesis represents an achievement in terms of moving on the discourse and field of behavioural change in a way which extends beyond individualised self-management support. For people with long-term conditions, the social networks approach is a different way of considering the support they have. The building of individual and network capacity is needed to navigate and negotiate relationships and health-related environments to gain self-management support. Findings from this EU WISE interpretative analysis illustrate the cyclic and temporal nature of network relationship negotiation, which requires persistent cognitive and emotional effort to generate collective efficacy. We have shown in WP7 that engagement with the circle diagrams provides a means of mobilising resources that people can intuitively transpose into real-life relationships in order to help them prioritise and make best use of available support. This new way of thinking – that illness management is more about network relationships and support than personal responsibility - disrupts existing patterns of coping in a non-threatening but powerful way, enhanced by having a visual network image which people can control and alter. Externalisation which does not focus on the self exclusively enables reflections that are missed or inhibited through introspections. WP7 findings also allowed us to capture change, for example, over time health professionals had less of a central role and weak ties and enjoyed activities came more to the fore.

Significantly, our findings on networks suggest that policy and interventions should be extended to include: (i) raising awareness about the structure and organisation of personal communities; (ii) building individual and network capacity for navigating and negotiating relationships and (iii) maximising the possibilities for social engagement. Our work on EU-GENIE suggests a face to face network-based intervention works as a positive disruption to the established ways in which people self-manage, which opens up new possibilities for people to consider how they might do things differently.

In summary, we have gained significant insights into self-management support strategies and contexts through our work in EU-WISE and have identified a clear need to focus the future direction of self-management policies on the role of social networks and community organisations. In our view, the future of self-management support must concentrate on looking outwards to links and connectivity to resources, relationships and community.

1.4 *Impact, dissemination and exploitation*

1.4.1 EU-WISE Impact and Future Use

1.4.1.1 *Introduction*

We believe the EU-WISE project has the potential to impact significantly on future health policy and future research agendas in relation to the self-management of long term conditions. We also believe that the EU-WISE intervention EU-GENIE has the potential for use in a wide variety of settings and with different populations, to deliver better self-management, better long term health and better quality of life for people with LTCs and other marginalised/at risk groups, thereby also reducing associated healthcare costs. Some of the lessons we have learnt and their potential implications for the future are set out below.

1.4.1.2 *Lessons learnt about macro level influences on self management support*

In EU-WISE we found that the nature of each healthcare system is indirectly implicated in the emergence of new forms of support for self-care and that each system creates an environment which is more or less conducive to the facilitation of self management support. Some of the most important changes in terms of diabetes self-management support have been the transition from secondary to primary care, the recognition of lay knowledge and a normative drive towards patient involvement and patient empowerment. However, the revision of professional roles into multi-disciplinary clinical teamwork in primary care has emerged as an urgent need in certain EU-WISE partner countries. We also found that prevention and health promotion measures that invest in building and sustaining health environments have often been afforded secondary importance up to now. In all countries, social inequalities and living in deprived circumstances have a significant impact on illness management. These macro level influences should be taken into account in the design of new SMS policies and initiatives.

1.4.1.3 *Lessons learnt about personal networks and SMS*

Our findings about personal networks and SMS also have potential implications for designing future policies and initiatives.

We found that the main focus of self-management in everyday life is having a sense of normality and making self-management 'fit' into daily routines. Networks are hidden but important sources of support. There are a wide range of relationships involved in illness management. Family and friends often support self-management but they may also hinder it. Weak ties such as acquaintances, especially with other people with LTCs, play an important role for information exchange about illness management. The networks of elderly people are often limited, which makes them vulnerable.

Long term illness management is, we have established, a collective process and takes place in a context of multiple objectives and values that are interrelated. This requires developing interventions and CIM strategies that operate on the level of individuals and members of their networks, e.g. navigation of some network involvement, avoidance of places and relationships, enhancing those that have positive influences. We concluded that:

- Interventions should be more sensitive to, and raise awareness of, the structure and organisation of personal communities.
- Interventions should be more productively designed to build individual and network capacity for navigating and negotiating relationships in communities and other environments.
- Interventions should be more productively designed to maximise the possibilities for social engagement and involvement, particularly through extending people's access to weak ties and the building of enabling environments that have relevance for illness management.
- The network types that we identified can be used as a way of assessing network support and positive direction of change.
- People with diverse-friendship networks represent the most likely optimal network types in terms of long term illness management, due to their high self-management capacity and low cost to the healthcare

service. This suggests the need to design interventions focussed on constructing personal networks for those with long term conditions in order to promote better access to and engagement with self-management support and resources.

- Interventions and policy should be better tailored so that they build additional capacity where it is most needed, where it is most likely to be effective and acceptable; such an agenda is likely to be advanced if it takes into consideration the types of ties and work involved, and the structures and dynamics of networks.
- Technologies used to support CIM are most likely to be successful if they are simple and familiar to users. They can only be successfully embedded if they take into consideration how they enable or limit the possibility for relationships with professionals and or peers, how they fit with existing environment and capacities to self-manage, and if they enhance the visibility of symptoms.

1.4.1.4 Lessons learnt about voluntary and community groups (VOCGs)

Our work on voluntary and community groups has allowed us to identify a number of themes which should be taken into account in future policy formation. The capacity of the role of VOCGs to support self management activity has to date been under-estimated and could potentially be exploited far more than hitherto.

The VOCGs sector can be regarded as an untapped or underutilised resource in terms of SM support strategies. This sector can contribute to the provision of holistic care to people with long term conditions (instead of restricting care to the formal healthcare setting) and can help provide a more sustainable approach to living with and managing a long term condition, as well as producing better health outcomes. The benefits of voluntary groups are often indirect, but patients find that they are important contributors to health, as well as to avoiding isolation. In our surveys we found that participation in community organisations (reported by about a third of the survey population) was most consistently related to better health status and health-related behaviours, especially in low income populations (though it is acknowledged by VOCGs that there are real challenges reaching deprived populations). Besides directly providing information, practical help and emotional support, or navigating to sources of support, these organisations can fulfil a range of functions including enhancing feelings of social integration and individual identity. Interventions with an information support component should not only focus on the individual patient, but also involve his/her social network to maximize this effect, especially in low education groups. An important implication of our study for health professionals and policy makers is that they need to give consideration to the provision of (increased) support to community organisations, which offer activities that are relevant for the self-management of health in people with LTCs.

In our view, collaboration between professionals and VOCGs is likely to enhance the sustainability of SM professional and open access approaches, which in the current socioeconomic panorama, cannot be dismissed. We believe that the involvement of VOCGs should be a clear requisite in future SM initiatives and the policy put in place should support and enhance this end. Initiatives should be built upon collaborative relationships between (i) the voluntary sector and community groups and (ii) health services. Furthermore, it is suggested that this reciprocal collaboration should be built very early on, starting from the development stage of programmes and interventions. This collaborative approach seems to be the key, and at the same time the challenge, in creating successful initiatives. We have found that applying the principles of assistance, support, sharing and link fosters a “working together” ideology that is likely to result in successful collaborations.

The politics and enactment of austerity are important when it comes to any consideration of the VOCG sector. Although deprived populations were being paid special attention in certain countries, especially in those affected more intensely by austerity, in general we saw austerity leading to less stable financing of VOCGs, therefore putting at risk their sustainability. According to our findings, organisations working with deprived populations tended to be more reliant on state funding. As a consequence, austerity measures introduced in several European countries are likely to impact most negatively upon those most in need. Future policy should pay special attention to social inequalities and people living in deprived circumstances.

As part of our work, we established a typology of VOCGs. This typology may help in the future with the classification of organisations, the assessment of the activities and resources available within a particular community and with

determinations about which resources and activities should be reinforced according to the population needs in that area.

We anticipate that the demands on the VOCG sector are likely to increase in the future. The opportunities that the VOCG sector can offer may carry with it a requirement to pay more attention to the imperatives that this may impose on the VOCGs themselves. If future policy is to involve funding for VOCGs and reliance on their collaboration, there should also be an awareness of fostering appropriate structures, roles and interrelationships.

Finally, in order to ensure we apply future resources in the most efficient and productive way, further research may be required. In our review, we found a dearth of empirical evidence on long term illness management and VOCGs across European countries, pointing out a need to foster and make progress in research terms in this area at the European level. For example, we found gaps in the literature in relation to voluntary roles; the context in which volunteers act; relationships with the community and health services and connections between voluntary and community groups. Further research may be required to ensure we continue to build a comprehensive theoretical and empirical basis for future investment in the sector.

1.4.1.5 Lessons learnt about the role and education of health professionals

Our research indicates that health professionals (especially doctors and nurses) play a key role in providing disease related support, particularly in relation to SMS closely connected to bio-medically orientated outcomes. However, relationships between patients and health professionals vary between countries. We believe that the patient's experience of receiving education and information about diabetes at healthcare establishments could be enhanced significantly. The role of voluntary and community groups is complementary to health professionals and public administration, but can play a much larger role than commonly assumed.

Our findings about personal networks and VOCGs have implications for health professionals' practice and education. If we are to promote the self-management of long term conditions, the importance of social networks and the untapped potential of collaboration with VOCGs, we need to spread these messages to health professionals and ensure new approaches are embedded into continuing professional development and into primary professional education, so that we can impact clinical practice and attitudes within the health professions.

1.4.1.6 Impact and the EU-WISE intervention EU-GENIE

The EU-WISE intervention developed during the project uses participatory methods of social network mapping to encourage patient reflection on self-management supports, to inspire positive change and (in many cases) to link patients with useful resources. The core of the intervention is personal community mapping and analysis (with additional, optional components providing a deeper needs analysis and links to appropriate resources).

There is potential for the impact of the EU-GENIE intervention to be felt on a number of different levels:

- *The Health care services level:* EU-GENIE provides a tool and an approach with the potential to improve access to services, capacity for self-management, patient health and quality of life. We anticipate potential to reduce healthcare costs and deliver social and wider socioeconomic benefits.
- *VOCGs and other stakeholders:* EU-GENIE highlights the importance of VOCGs and other organisations and can help increase access and participation in these groups and foster links between community organisations and the formal healthcare sector.
- *Primary care practitioners' level:* The findings from the professional perspective showed a lack of understanding of the issue of self-management for patients with LTCs in some cases, as well as a lack of technology and training materials. EU-GENIE now provides health professionals with an electronic platform and tools that can be used by primary care practices to support self-management of long term conditions.
- *At the patients' level:* our findings indicate that there is scope for significant improvement in the approach to self-management of long term conditions in the community. EU-GENIE provides a tool which can be used with patients to help them assess current supports and to action positive change. Our results show health benefits for people who participate in community organisations, especially for low income populations. EU-

GENIE has the potential to offer improvements in health and quality of life for patients who are living with an LTC.

EU-GENIE constitutes an effective and context sensitive intervention to promote self-management of long term conditions, with scope for application in a wide variety of settings and with different populations. Specific examples of adaptations and potential future uses include:

- The team from the University of Southampton have been liaising with researchers from McMaster University, Canada. This has already resulted in the adaptation of the EU-GENIE intervention for use in 2 Canadian projects (Health TAPESTRY and Health Links).
- In the UK there is recognised potential for use of EU-GENIE with groups at risk of social isolation (e.g. older people in the community), for people with mental health concerns and for patients with a range of specific conditions (e.g. kidney disease) as part of broader programmes of illness management. Outline discussions are already taking place with representatives from the NHS about some possible practical applications, which include the use of EU-GENIE to facilitate people with respiratory disease from maintenance clinics to community based resources, and older people experiencing idiopathic dizziness and ongoing pain. We are exploring the use of EU- GENIE together with a Health Literacy tool in terms of enhancing the elements of a network intervention for supporting health literacy efforts.
- In Bulgaria there are possibilities of engagement with pharmaceutical companies e.g. in relation to the provision of tools to patients on admission to hospital in a pharma led pilot programme.
- In Spain, partner EHSF is working with the Public Health Council and Civil Social Council to construct a database to geolocalise resources for diabetes type 2 patients in Murcia, as a precursor to the possible future use of EU-GENIE in that region.
- In Norway, engagement with 3 municipals about the possible use of EU-GENIE suggests potential for spread in community agencies. As the piloting of the EU-GENIE intervention yielded positive results in Norway, a proposal has been delivered to the Norwegian Research Counsel (15 October 2015) for funding to try out an adapted version of EU-GENIE. If funded, the objectives of this project (SMIL-NET) will be to determine if enhanced use of social networks (personal and community networks) will significantly improve users self-management measured by specific patient outcomes, and to evaluate the process to appraise if such methods can fruitfully be adapted and implemented in different municipals. The planned project is developed together with, and will be carried out in collaboration with, three participating municipals.
- Independent of possible funding from the Norwegian Research Counsel (referred to above), a PhD position for 3 years has been funded in Norway. This position is attached to University of Oslo, and is related to further translation, adoption and testing of EU-GENIE in Norwegian language and conditions. The process will be planned and carried out in close collaboration with users (patients with chronic diseases, professionals and volunteers) in a Norwegian municipal. The process will also be described and evaluated with a focus on research practices that are based on cooperation between researchers and users throughout the process. The PhD position is to be announced in April and the PhD candidate will start working in August 2016.

1.4.1.7 Conclusion

In EU-WISE we have generated new knowledge about SMS and macro level influences, the role of personal networks, the importance of VOCGs and the position of healthcare professionals. We believe that this new knowledge provides policymakers with a sound basis on which to shape future health policy, self-management supports and interventions. We have also opened up avenues for further research and study, particularly in the VOCG sector.

As part of the project we delivered a new self-management support intervention for people living with long term conditions, which has potential for use in different contexts and populations. Our work on EU-GENIE suggests a face to face network-based intervention works as a positive disruption to the established ways in which people self-manage, which opens up new possibilities for people to consider how they might do things differently.

We believe the ultimate legacy of EU-WISE will be to help improve self-management and health outcomes, increase patients' wellbeing and foster enhanced communities, while also reducing the burden on the health sector and delivering related social and socioeconomic benefits.

1.4.2 EU-WISE Dissemination

The team undertook a comprehensive dissemination programme over the course of the project in WP9. Our target audience included academics and researchers, health professionals, voluntary organisations, policymakers, patients and the general public. Our aim has been to raise awareness about self-management support for long term conditions, the findings from our research and the EU-WISE intervention. Below we describe the dissemination activities undertaken including online, peer reviewed publications, conference presentations, project materials, regional workshops and the EU-WISE final conference.

1.4.2.1 Website and online

The project website is at <http://eu-wise.com/> and was established in July 2012. The website includes the following sections:

- Homepage (including a brief summary of the project).
- About Us (setting out more detail about the project's aims and objectives).
- Partners (details of each beneficiary, including the leads from each organisation).
- News (updates regarding recent developments and events).
- Resources (including project flyers and newsletters and links to articles, projects and materials relevant to the project).
- Work Packages (a description of the work, aims and objectives of the technical work packages).
- Contact us (a form for contacting the project and full contact details for the WP leaders).

The website has represented an important communication tool for EU-WISE and has been regularly updated throughout the project.

The screenshot shows the EU-WISE website homepage. At the top left is the EU-WISE logo. A navigation menu includes 'About Us', 'Partners', 'News', 'Resources', 'Work Packages', and 'Contact Us'. The main content area features a large article titled 'Selfcare for Long-Term Conditions in Europe' with a video player showing an elderly woman interacting with others. Below the video is introductory text about the project's goals and a 'Find out more about the Project' button. Further down is a section for 'EUGENIE - The EU-WISE Intervention' with two buttons: 'One page summary of the intervention' and 'Summary of the EUGENIE protocol'. The right sidebar contains an 'About' section, 'Recent News' with a small article snippet, and a 'EU-WISE Twitter' section listing several tweets with 'ReplyRetweetFavorite' options. At the bottom of the sidebar is a 'Follow @EUWISE' button showing 191 followers and a 'Project Information' section featuring the European Union flag and text about funding from the Seventh Framework Programme.

Figure 14 Screenshot of EU-WISE Homepage <http://eu-wise.com/>

Traffic to the website has grown steadily over the course of the project. Relevant details are set out below.

Table 17 Annual Summary of Visits to eu-wise.com in 2013, 2014 and 2015, taken from <http://eu-wise.com/awstats/>

Year	No of Visits	Unique Visitors
2013	6,552	5,080
2014	23,988	10,668
2015	33,032	19,864

In addition to our website, we have also maintained a strong presence on social media (twitter) throughout the project.

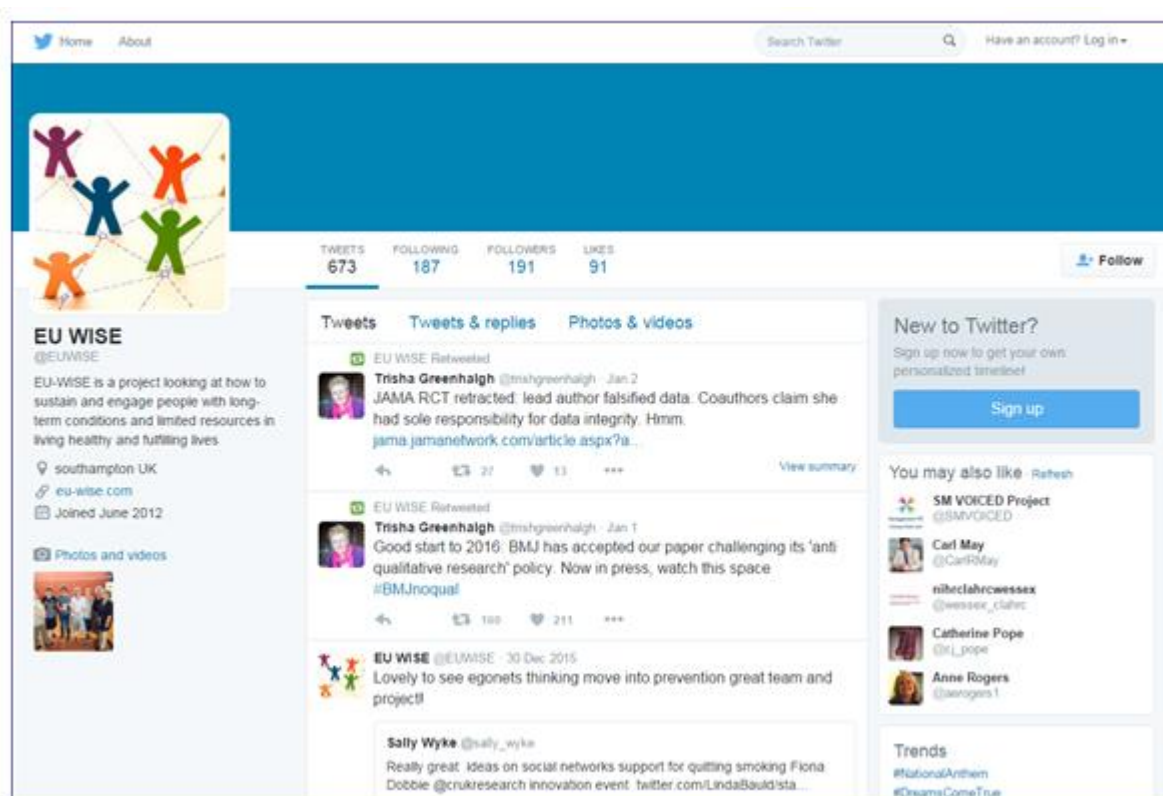


Figure 15 Screenshot from EU-WISE twitter account

1.4.2.2 Project materials

The project materials issued over the course of the project included the following:

- Leaflet and first newsletter issued to the project mailing list on 28 March 2013.
- Second project newsletter issued to the project mailing list on 10 February 2014.
- Summary of EU-GENIE intervention and one page “at a glance” EU-GENIE flyer issued to the mailing list on 21 February 2014.
- Third project newsletter issued to the project mailing list on 24 February 2015.
- Fourth project newsletter issued to the mailing list on 16 October 2015.

The project leaflets set out the project’s aims and objectives. The EU-GENIE leaflet and final leaflet also summarised the EU-GENIE intervention, with the final leaflet including a summary of some key project results and publications.

The EU-WISE newsletters were issued at key points in the project (generally shortly after scientific reports had been submitted) and provided updates on our research, summaries of latest findings and details of recent events and publications.

We built up a significant mailing list of over 80 contacts over the course of the project, including over 50 external researchers, academics, policymakers, stakeholders and medical professionals. In addition to circulating project materials to the mailing list, materials were uploaded to the website as they became available and were printed in hard copy and sent to partners for distribution locally. Project materials were also distributed to members of the EU EIP on Active and Healthy Ageing. The final leaflet and third and fourth newsletters were included in the conference packs distributed at the EU-WISE final conference. An EU-WISE roll-up banner (for display at the final conference) was also produced.



Figure 16 EUWISE Newsletter IV Autumn 2015



Self-care Support for People with Long Term Conditions, Diabetes and Heart Disease: A Whole System Approach

Overview of the EU-WISE Project

EU-WISE is an EU research project that is focused on how self-management of chronic illness is experienced by patients and those around them. Our research has explored the roles of:

- (i) family, carers, friends, neighbours and acquaintances;
- (ii) support organisations and non-government agencies and
- (iii) the formal health sector,

in the self-management of chronic conditions in different national settings.

EU-WISE has combined literature review, international best practice and empirical research (with stakeholders, voluntary organisations and patients). Our ultimate goal has been to devise workable, context-sensitive strategies for self-management which blend new technologies and personal, community and institutional networks and resources. We emphasise socially disadvantaged, marginalised and vulnerable people, where the need for effective self-management of chronic illness is greatest.

The EUGENIE Intervention

As part of our work in **EU-WISE**, we developed a new intervention (known as **EUGENIE**). This intervention uses participatory methods of social network mapping to encourage patient reflection on self-management supports, to inspire positive change and (in many cases) to link patients with useful resources. The core of the intervention is personal community mapping and analysis, with additional optional aspects (see diagram below). **EUGENIE** was adapted and contextualised for pilot studies in the UK, the Netherlands, Bulgaria, Greece, Norway and Spain. The core intervention was delivered in each country, with the additional components, depending on needs analysis and feasibility in each setting.



EU-WISE has received funding from the European Union Seventh Framework Programme (FP7) Health under grant agreement n° 279081

©EU-WISE 2015



EU-WISE - Preliminary Results

The synthesis of results in **EU-WISE** is ongoing, but already we have identified a number of key themes. Significantly, our findings on networks suggest that policy and interventions should be extended to include: (i) raising awareness about the structure and organisation of personal communities; (ii) building individual and network capacity for navigating and negotiating relationships and (iii) maximising the possibilities for social engagement. Our work on **EUGENIE** suggests a face to face network-based intervention works as a positive disruption to the established ways in which people self-manage, opening up new possibilities for people to consider how they might do things differently. In our view, the future of self-management support must concentrate on looking outwards to links and connectivity to resources, relationships and community. For further information and initial findings, see our Autumn 2015 Newsletter (available at www.eu-wise.com).

To find out more about **EU-WISE** visit www.eu-wise.com or follow us on Twitter (twitter.com/EUWISE). You can also read our project publications, including the following:

- “Social support systems as determinants of self-management and quality of life of people with diabetes across Europe: study protocol for an observational study” (Jan Koetsenruijter et al.) *Health and Quality of Life Outcomes* Vol. 12/Issue 1 page 29. DOI 10.1186/1477-7525-12-29.
- “The influence of social networks on self-management support: a metasynthesis” (Ivaylo Vassilev et al.) *BMC Public Health* Vol. 14/Issue 1 Page 719. DOI 10.1186/1471-2458-14-719.
- “Diabetes self-management arrangements in Europe: a realist review to facilitate a project implemented in six countries” (Antonis A Kousoulis et al) *BMC Health Services Research* Vol. 14/Issue 1 page 453. DOI 10.1186/1472-6963-14-453.
- “Dynamics and nature of support in the personal networks of people with type 2 diabetes living in Europe: qualitative analysis of network properties” (Anne Kennedy et al.) *Health Expectations* DOI 10.1111/hex.12306.
- “Assessing the implementability of telehealth interventions for self-management support: a realist review” (Ivaylo Vassilev et al.) *Implementation Science* 2015, 10:59 DOI 10.1186/s13012-015-0238-9.
- “Meso level influences on long term condition self-management: stakeholder accounts of commonalities and differences across six European countries”, (A. Rogers et al) *BMC Public Health* DOI 10.1186/s12889-015-1957-1
- “Voluntary Organizations and Community Groups as New Partners in Diabetes Self-management and Education: A Critical Interpretative Synthesis”, (M.C. Portillo et al) *Diabetes Educator* DOI: 10.1177/0145721715594026
- “Social support and health in diabetes patients: an observational study in six European countries in an era of austerity” (Jan Koetsenruijter et al) *PLOS ONE*, DOI: 10.1371/journal.pone.0135079.



EU-WISE has received funding from the European Union Seventh Framework Programme (FP7) Health under grant agreement n° 279081

©EU-WISE 2015



Figure 17 EU-WISE Final Project Leaflet Front and Back

euwise

Self-care Support for People with Long Term Conditions, Diabetes and Heart Disease: A Whole System Approach

EU-WISE is focused on how self-management of long term conditions is experienced by patients and those around them.

Our research has explored the roles of:

- family, carers, friends, neighbours and acquaintances;
- support organisations and non-government agencies and
- the formal health sector

in the self-management of long term conditions in different national settings.

EU-WISE has combined literature review, international best practice and empirical research to devise workable, context-sensitive strategies for self-management which blend new technologies and personal, community and institutional networks and resources.

Project findings suggest that in the future, self-management supports should pay greater attention to the power of social networks and the importance of resources in the community.

For more information visit us online:
www.eu-wise.com

The EU-WISE team

The EU-WISE project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement 101019152

Figure 18 EU-WISE roll-up banner produced for Final Conference

1.4.2.3 Regional Workshops

During the project the EU-WISE team organised a series of regional workshops in order to discuss project results, implementation of interventions and potential impact in a regional context. Different formats were used for the workshops in each region, so that each partner could match local requirements.

- In the **UK**, a regional workshop day, (combining training and dissemination objectives), was held on 14th July 2014 at the Innovation Centre, Newport, Isle of Wight. This was attended by a number of different stakeholder representatives who were included because of their strategic role in the future uptake and implementation of EU-GENIE. Attendees included managers, workers, care navigators and volunteers from Age UK (a key voluntary sector organisation operating in Hampshire). Public Health was represented, as was the local NHS and social care trust and health trainers and support workers operating in primary care.
- In **Bulgaria**, workshops were organised on 28 and 29 May 2014 in Suedinenie (town hall) and in Slivnitza (Diabetes Centre). The meetings were an introduction to EU-WISE and included also the launch of the new Bulgarian Diabetes Guidebook. The meetings were attended by patients with diabetes and family members, local authorities, health professionals and representatives of NGOs (including the President of the Sofia office of the National Diabetes Organization).
- The team in **Norway** hosted a seminar on Social Networks and Health in the University of Oslo on 11 November 2014. The event included presentations about EU-WISE and about social capital and voluntary work, social support for long term conditions, community organisations, network theory and the importance of social networks. The event was very well received by the 30 attendees (academics, researchers, students and healthcare professionals) who participated in some lively discussion.
- In the **Netherlands**, a meeting was arranged on 4 November 2014 between representatives from the Dutch College of General Practitioners and the RUNMC research team to exchange and plan in several domains, including self-management support. The meeting took place at Domus Medica, Utrecht (the office of the Dutch College of General Practitioners) and included 15 general practitioners involved in the development of guidelines, education and organisational support for general practice, including the head of department for implementation.
- In **Greece**, the research team held a workshop for local stakeholders at the University of Crete (8 December 2014). Among the participants were the Deputy Governor of 7th Health Region of Crete, the Regional Consultant of Public Health of 7th Health Region of Crete, the Director of the National Diabetes Centre (General Hospital of Heraklion), academics from the educational and research community, directors and health care providers from the local hospitals and rural health centres and a Board Member from the Association of Diabetes Crete. The meeting focused on the necessity of raising awareness regarding T2DM and the importance of self-management. The Crete team also led roundtable events at 2 key conferences aimed at academics, researchers, healthcare professionals, stakeholders and policymakers.
- An EU-WISE regional workshop was held in Murcia, **Spain** on 16 October 2015. The event was organised by Dr Manuel Serrano-Gil (EHSF Foundation), in collaboration with the Healthy Ageing Coalition (initiative of the public Health Council of the Murcia Region). In addition to presentations by members of the EU-WISE team (University of Southampton and EHSF), there were a number of external speakers, including Maria Jose Tormo (INCA Project), Jorge Martinez Olalla (TIC Biomed), Pilar Lopez Acuña (Foundation for Research and Education in Health (FFIS)), Maria Falcón (Medicine Law Department, School of Medicine, University of Murcia) and Jose Angel Martinez-Usero (International Affairs, Funka).

Overall the regional workshops proved to be very effective and allowed the EU-WISE team to engage at a local level with the issue of long term illness management. The regional events were used to disseminate information about EU-WISE, but they also proved instructive for the team, furthering insights into what works for who and why.



Figure 19 Regional Conferences in Norway, Bulgaria and Spain

1.4.2.4 Final Conference

The EU-WISE final conference was held in Southampton on 23 and 24 November 2015. The event was a great success with over 60 delegates in attendance. There were presentations from the EU-WISE team about the project, in addition to presentations by external experts. The day finished with some workshops where attendees got to try out the EU-GENIE intervention for themselves. The Conference offered the team a valuable opportunity to reflect on the project, what we have learned and next steps and to gain an external perspective from our expert guest speakers.



Figure 20 Picture from the EU-WISE Final Conference

Day 2 of the Conference (24 November) was designed to be more focused for a smaller group. The day began with a round-table discussion involving the EU-WISE PIs and some external experts, where we gathered valuable feedback

about the project, discussed the future for self-management support and considered next steps for the EU-GENIE intervention.

The key learning points and themes arising from the regional workshops and final conference are described in D1.1 under the following headings:

- EU-WISE in Different Settings (feedback confirms that there is scope for use of EU-GENIE in various different settings, some considerations that should be kept in mind are identified).
- EU-WISE and policy.
- EU-WISE, primary care and education.

1.4.2.5 Publications

Publishing in peer review journals has been a key aim of our dissemination strategy in order to reach academics, researchers and medical professionals. In total there are now 25 EU-WISE project publications (23 of these are entered on the EU portal, with the remaining 2 needing journal requests). Publications to date include the following:

- *“Social support systems as determinants of self-management and quality of life of people with diabetes across Europe: study protocol for an observational study”* (Jan Koetsenruijter et al.) Health and Quality of Life Outcomes Vol. 12/Issue 1 page 29. DOI 10.1186/1477-7525-12-29.
- *“The influence of social networks on self-management support: a metasynthesis”* (Ivaylo Vassilev et al.) BMC Public Health Vol. 14/Issue 1 Page 719. DOI 10.1186/1471-2458-14-719.
- *“Diabetes self-management arrangements in Europe: a realist review to facilitate a project implemented in six countries”* (Antonis A Kousoulis et al) BMC Health Services Research Vol. 14/Issue 1 page 453. DOI 10.1186/1472-6963-14-453.
- *“Dynamics and nature of support in the personal networks of people with type 2 diabetes living in Europe: qualitative analysis of network properties”* (Anne Kennedy et al.) Health Expectations DOI 10.1111/hex.12306.
- *“Assessing the implementability of telehealth interventions for self-management support: a realist review”* (Ivaylo Vassilev et al.) Implementation Science 2015, 10:59 DOI 10.1186/s13012-015-0238-9.
- *“Meso level influences on long term condition self-management: stakeholder accounts of commonalities and differences across six European countries”*, (A. Rogers et al) BMC Public Health DOI 10.1186/s12889-015-1957-1
- *“Voluntary Organizations and Community Groups as New Partners in Diabetes Self-management and Education: A Critical Interpretative Synthesis”*, (M.C. Portillo et al) Diabetes Educator DOI: 10.1177/0145721715594026.
- *“Social support and health in diabetes patients: an observational study in six European countries in an era of austerity”* (Jan Koetsenruijter et al) PLOS ONE, DOI: 10.1371/journal.pone.0135079.
- *“Connectivity, contest and the ties of self-management support for type 2 diabetes: a meta-synthesis of qualitative literature”* (Christina Foss et al) Health and Social Care in the Community DOI:10.1111/hsc.12272.
- *“Institutional logic in self-management support: coexistence and diversity”* (Dagmara Bossy et al) Health and Social Care in the Community DOI:10.1111/hsc.12277.
- *“Negotiating Diet in Networks: A Cross-European Study of the Experiences of Managing Type 2 Diabetes”* (I.R. Knutsen) Qualitative Health Research doi:10.1177/1049732315610318.
- *“Social support and self-management capabilities in diabetes patients: An international observational study”* (Jan Koetsenruijter et al) Patient Education and Counseling DOI: <http://dx.doi.org/10.1016/j.pec.2015.10.029> .
- *“Health care in challenging times of transition”*, (Portillo MC), Journal of Community and Public Health Nursing 2015, DOI: 10.4172/jcphn.1000e108).
- *“Doing the community maths”*, (Portillo MC), Primary Health Care, 2015 26, 1, 13-13. <http://dx.doi.org/10.7748/phc.26.1.13.s14>.

An article by Dr Mari Carmen Portillo (Associate Professor in Adult Nursing, University of Southampton and Invited Professor, University of Navarra) featuring EU-WISE was also published in the June edition of the Paneuropean Network Journal. The piece entitled *"In Illness and Health: Who Rules?"* puts the proposition *"As long term conditions are spreading throughout Europe, participating strategies to help patients take control of their health need to become a health agenda priority"*. This was a significant publication because of the journal's circulation among European policymakers.

As well as the articles that have already been published, 3 more have been accepted for publication/are in press and the team is working on several additional papers (circa 12 in total), many of which are already at an advanced stage.

1.4.2.6 Presentations

Since the beginning of the project, the EU-WISE team have recorded 111 dissemination activities (as per the EU portal and included in part 2 template A2 of this final report), including presentations at numerous key conferences and events. Some notable presentations are set out below:

- Prof Anne Kennedy (SOTON) and Dr Manuel Serrano Gill (EHSF) attended the 8th Annual World Health Care Congress held in Amsterdam, The Netherlands, on 23 May 2012 and presented on Implementing self-care and self-management.
- Dr Maria Carmen Portillo (SOTON/UNAV) presented at the International Nursing Research Conference on 2 April 2014 in Glasgow, Scotland. The presentation was entitled *"Patients' self-management of diabetes. The role of health professionals, personal networks and voluntary organisations"*.
- Prof Christina Foss and Ingrid Ruud Knutsen, PhD, post doc, from the University of Oslo presented at The 7th Diabetes Nursing Research Ph.d and Post doc conference, Bergen, Norway on 28th and 29th April 2014. Professor Foss presented the EU-WISE project with a specific focus on the social network approach in long term care. Dr Ruud Knutsen's presentation was entitled *"'A diabetes-free evening': Food and Diabetes type 2"*.
- Dr Manuel Serrano-Gil (from EU-WISE partner EHSF) presented the EU-WISE intervention EU-GENIE at the 8th European Patients' Rights Day in Brussels on 12 May 2014. The event was titled *"The role of citizens' organisations in the empowerment of patients with chronic diseases"*. Dr Serrano-Gil presented the EU-WISE intervention as one of the best practice examples of empowerment in long term diseases.
- Project Coordinator Prof Anne Rogers presented *"Understanding the Dynamics of Patient Systems of Implementation: a mixed methods study"* at The Biomed Central Health Services Research: Evidence-based practice Conference 2014, Kings College, London on 2 July 2014.
- Dr Ivo Vassilev from EU-WISE partner SOTON presented at the BSA Medical Sociology Conference 2014. The Conference was held on 10-12 September 2014 at Aston University UK. Dr Vassilev's presentation was entitled *"What is real about 'self-management: a mixed methods study of social network support and the value of 'strong' and 'weak' ties in the management of chronic illness."*
- EU-WISE partners UNWE and UniO made a presentation entitled *"Network processes and properties and how they impact on patient participation in diabetes self-management in six European countries"*, at the 12th International Conference on Communication in Healthcare (ICCH, 28 September - 1 October 2014) in Amsterdam (organised by the European Association of Communication in Healthcare - EACH).
- Members of the EU-WISE team from Southampton University presented at the Medicine 2.0 Conference, held in Malaga, Spain on 9 and 10 October 2014. The Conference was the 7th World Congress on social media, mobile apps and internet/web 2 in the health sector. The Southampton presentation was entitled *"Assessing the Implementability of Health and Telehealth Interventions for Self Management Support: a Realist Synthesis in a European Context"*.
- Prof Christos Lionis, from EU-WISE partner University of Crete presented at the 41st Annual Panhellenic Medical Conference, Athens (10th to 13th June 2015). The presentation was entitled *"Patient-centered approach. Is it feasible and what is required?"*. Prof. Lionis also presented at the 27th Panhellenic Conference of General

Practice, Athens (15th to 18th April 2015), Heraklion Crete. The presentation was entitled *“The patient-oriented medicine in the economic downturn; the role of General Practice”*.

- A number of project partners presented at the ISIH 6th Annual Conference, Palma de Mallorca, 10-12 June 2015. Oral presentations from the team included: *“Negotiating diet; Type 2 diabetes patients - rationale across Europe”* (Ingrid Ruud Knutsen et al., University of Oslo) and *“Understanding the influence of the socio-economic environment and social network mechanisms on self-management in Europe”* (Anne Rogers et al., University of Southampton).
- Researchers from RUNMC presented at the Sunbelt Conference of the International Network for Social Network Analysis (INSNA) in Brighton, UK on 25 June 2015. The presentation given was: *“Social Support and Health in Diabetes Patients: an Observational Study in Six European Countries in an Era of Austerity.”*
- Researchers from the University of Southampton presented at the 12th Conference of the European Sociological Association held in Prague on 25 August 2015. The presentation was entitled: *“The political and economic embedding of chronic illness management experiences: a comparison of lay accounts of people with diabetes in United Kingdom and Bulgaria.”*

1.4.2.7 Other

The EU-WISE team has also built connections with other stakeholders and initiatives over the course of the project.

EU-WISE has engaged with the European Innovation Partnership on Active and Healthy Ageing (EIP on AHA). As well as presenting the EU-WISE intervention EU-GENIE at the 8th European Patients’ Rights Day in Brussels on 12 May 2014 (noted above) and sharing project materials with EIP members, Dr Manuel Serrano (EU-WISE partner EHSF) attended the third annual meeting of the Murcia Consortium/Regional Coalition of the EIP on AHA on 1st July 2015. EU-WISE was featured at the meeting among a number of projects aligned with the objectives of the Coalition in Murcia. In addition, Dr Manuel Serrano Gil attended the 4th Conference of Partners of the EIP on AHA on 9-10 December 2015, in Brussels, engaging with colleagues and potential collaborators about EU-WISE and the EU-GENIE intervention.

On 27 January 2015 Prof Anne Rogers (SOTON) participated in a Workshop (DG Research, Public Health Research – Achieving Effective Management for Chronic Health Conditions), where Prof Rogers had an opportunity to disseminate information about EU-WISE and engage with other FP7 researchers and with policymakers.

Each project partner has their own relationship with regional and national stakeholders, in particular diabetes associations, and continues to engage with them locally e.g. re local meetings, guidebooks etc.

1.4.2.8 Conclusion

Throughout the EU-WISE project we have followed a targeted dissemination strategy. We have grown the EU-WISE presence online through the project website and twitter account. We have issued project leaflets and newsletters (uploading them to our website, issuing them to our mailing list and distributing them in hard copy). We held a series of regional workshops which allowed us to engage at a local level with the issue of long term illness management and learn more about what works for who and why. The EU-WISE final conference took place on 23/24 November in Southampton and provided a valuable opportunity for the team to engage with external experts, gather valuable feedback about the project, discuss the future for self-management support and consider next steps for the EU-GENIE intervention.

EU-WISE partners have achieved several significant publications, with many more in preparation. Researchers also presented on EU-WISE and the self-management of long term conditions at numerous key conferences.

We believe that our work on dissemination within WP9 has laid a solid foundation for increased awareness of the self-management of long term conditions and of self-management supports. The work undertaken will continue to bear fruit beyond the life of the project. We believe that our results and findings have real potential to impact on health policy in the future and that the EU-GENIE intervention has the potential to make a significant contribution to self- management support across a number of different long term conditions and at risk populations.

1.5 Website and contact details

The EU-WISE website is at www.eu-wise.com (see Figure 21).

Project partners and contact details are listed in Figure 22.

The screenshot shows the EU-WISE homepage with a navigation menu at the top: About Us, Partners, News, Resources, Work Packages, and Contact Us. The main content area features a large image of an elderly woman being attended to by healthcare professionals, with the title "Selfcare for Long-Term Conditions in Europe". Below the image is a paragraph describing the EU-WISE project as an integrated project under the 7th Framework Programme of the European Commission, focusing on understanding capabilities, resources, and changes in health-related practices in community and cultural context across Europe. It mentions a €2.9M research and development programme involving 6 European countries and 7 organisations. A "Find out more about the Project" button is provided. Below this is a section titled "EUGENIE - The EU-WISE Intervention", which describes a new intervention designed to help people with type 2 diabetes improve self-management. It includes two buttons: "One page summary of the intervention" and "Summary of the EUGENIE protocol". On the right side, there is a sidebar with "About" (research aims), "Recent News" (EU-WISE at EU EIP on Active and Healthy Ageing, 16 Dec, 2015), "EU-WISE Twitter" (three tweets with reply/retweet/favorite options), a "Follow @EUWISE" button (191 followers), and "Project Information" (European Union's Seventh Framework Programme funding, agreement no 279081, EU CORDIS).

Figure 21 Screenshot from the EU-WISE homepage at <http://eu-wise.com/>

Project Partners

 <p>UNIVERSITY OF Southampton</p>	<p>University of Southampton, England: Prof. Anne Rogers, Coordinator of EU-WISE, Prof of Health Systems Implementation. Email: A.E.Rogers@soton.ac.uk</p>
 <p>University of National & World Economy</p>	<p>University of National and World Economy, Sofia, Bulgaria: Prof Elka Todorova, Email: todrova_elka@yahoo.co.uk</p>
 <p>Universidad de Navarra</p>	<p>Universidad de Navarra, Spain: Dra. Agurtzane Mujika Zabaleta, Profesora Contratada Doctora, Department Of Community Nursing and Midwifery. Email: amujika@unav.es</p>
 <p>UiO : University of Oslo</p>	<p>University of Oslo, Norway: Prof I. Christina Foss, Institute of Health and Society, Dept. of Nursing, Email: i.c.foss@medisin.uio.no</p>
 <p>University of Crete</p>	<p>University of Crete, Greece: Prof Christos Lionis Professor of General Practice and Primary Health Care. Email: lionis@galinos.med.uoc.gr</p>
 <p>UMC St Radboud</p>	<p>Stichting Katholieke Universiteit (RUNMC), the Netherlands: Prof. Michel Wensing Email: Michel.Wensing@Radboudumc.nl</p>
 <p>FUNDACIÓN EDUCACIÓN, SALUD Y SOCIEDAD</p>	<p>Fundación Educación, Salud Y Sociedad (EHSF), Spain: Manuel Serrano-Gil (President), Email: manuel.serrano@globalalliancesms.org</p>
 <p>Pintail</p>	<p>Pintail Limited (PT), Ireland Ciaran Clissmann, Director Email: ciaran@pintailservices.com</p>

Figure 22 EU-WISE partners and contact details