

Winter 2013/2014 Newsletter

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EU-WISE

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



Project Meeting

Photo of the project partners at Universidad de Navarra, on 19th October, 2013.

For further information on the project and its partners (including biographies and contact details) please see the Project website

www.eu-wise.com

You can also follow us on Twitter

twitter.com/EUWISE

This Edition

This issue looks at progress and results over recent months, with particular emphasis on the new EU-WISE intervention 'EUGENIE'.

Progress Update

The EU-WISE work plan consists of three stages: 1) Theoretical Framework, Developing Fieldwork; 2) Conducting Fieldwork; and 3) Intervention & Analysis. At this point in the project we have completed Stages 1 and 2. In Stage 1 we developed and refined the theoretical framework for the EU-WISE study and laid the foundations for the field work. In Stage 2 we conducted the fieldwork itself, across multiple healthcare contexts. We are currently in Stage 3 of the project, where our work is informed by the findings of Stages 1 and 2. Stage 3 is focused on the development, implementation and assessment of a new self-care management intervention and the final analysis of our core themes.

EU-WISE consists of 9 different work packages which span all the stages of the project, with WPs 2 to 7 delivering the core scientific research. We have made significant progress in these WPs over the past 12 months, working on Healthcare Systems, Personal Networks, Voluntary and Community Organisations, empirical research and developing the EU-WISE intervention.

Healthcare Systems: The final report from WP2 issued in June 2013. This report explored the different welfare policies, systems provision, structure and reforms of healthcare systems in the UK, Bulgaria, Norway, Greece, Spain and the Netherlands and how national differences impact on the support of people with chronic illness. Some of the key findings set out in the WP2 final report are summarised in Key Results below.

Personal Networks: The WP3 team have completed a literature review and produced an outline report on the content and dynamics of personal networks. Initial country specific reports have also been produced. The findings of our empirical research in WPs 5 and 6 will feed into the final report of WP3, due in December 2014.

Voluntary and Community Organisations: Interpretation and synthesis of literature relating to voluntary and community organisations is well underway in WP4 and country specific reports have been generated, analysed and summarised. The work of WP4 has helped to shape the empirical research of WPs 5 and 6. The results of WP5 and 6 will in turn inform the work of WP4, which will culminate in the WP4 final report in December 2014.

Empirical Research: WP5 (In-Depth Explorations) has delivered qualitative empirical investigations, providing support to WPs 2 – 4, 6, and 7. We have conducted four types of interview: key informants, biographical, NGOs and VCOs (voluntary & community groups), and Focus Groups (people with diabetes, representatives of voluntary and community groups, and health professionals).

3 STAGES OF EU-WISE

1

Theoretical
Framework,
Developing
Fieldwork

2

Conducting
Fieldwork

3

Intervention
& Analysis

WP5 - INTERVIEWS IN NUMBERS



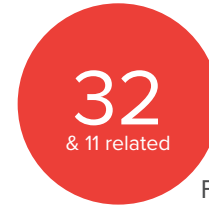
Key Informants



Biographical



NGOs & VCOs



Focus Groups

Findings from these investigations were synthesised and summarised in a key report, submitted to the EU in June 2013. Some of the main findings from the WP5 report are summarised below (see Key Results).

WP6 is also concerned with empirical research. Work in this WP over recent months has included surveys with (i) 300 adult patients with diagnosed diabetes mellitus type 2 and (ii) a sample of 150 members of community organisations across 6 European countries. The results of these surveys are reported in the final deliverable from WP6 (submitted in Dec. 2013) and provide empirical evidence about the practical realities of self-care management.

The EU-WISE Intervention: In WP7 a new EU-WISE intervention relating to self care management has been developed for implementation across a number of different sites. The work of WP7 has been informed by the research completed in WPs 2 to 6. The new EU-WISE intervention, entitled EUGENIE, is described in more detail below.

Next steps: Our work in the coming months will focus on implementation of the new EU-WISE intervention. The final phase of the project will involve assessment of the pilot intervention(s) delivered and final analysis of our core findings and themes.

WP6 - SURVEYS IN NUMBERS



Adult Patients w/ diagnosed diabetes mellitus type 2



Members of community organisations in 6 EU countries

Key Results

Some of the key results of our research to date have been included in the WP2, WP5 and WP6 reports. Our work in WP2 has focused on understanding health care systems in each partner country and how systems impact on chronic illness management. **Some key learning points from WP2 include:**

- The nature of each healthcare system is indirectly implicated in the emergence of new forms of support for self care.
- 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.
- 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.
- Prevention and health promotion measures that invest in building and sustaining health environments are often afforded secondary importance.
- The potential for eHealth and telemonitoring to play a key role in supporting SMS is recognized in all EU-WISE partner countries.
- The financial crisis in Europe has had an impact on SMS in most EU-WISE countries. In all countries, social inequalities and living in deprived circumstances has a significant impact on illness management.

Key Results Cont.

Our work in **WP5** has focused on gathering qualitative empirical evidence about self care management from patients, professionals, government agencies and voluntary/community groups. **Key lessons from the research carried out in WP5 include:**

- 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 chronic conditions, play an important role for information exchange about illness management. The networks of elderly people are often limited, which makes them vulnerable.
- 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. Receiving education and information sessions 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. In most countries patients do not tend to join illness-related groups. Poor participation of patients in voluntary groups can be caused by the lack of patients' awareness of groups, poor dissemination by the organisations themselves and/or the lack of referral by professionals.
- The benefits of voluntary groups are often indirect, but respondents find that they are important contributors to health, as well as to avoiding isolation. Formal and informal organisations tend to be linked, but the ties are often weak.
- Lack of economic resources is a factor in hindering adequate self-management and restricts the activity of voluntary organisations.
- Voluntary and community organisations find it difficult to reach deprived people, even where they have a specific policy to do so.
- Perceptions among stakeholders is of significant external politics in health policy.

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*Voluntary and community organisations find it difficult to reach deprived people, **even where they have a specific policy to do so.***

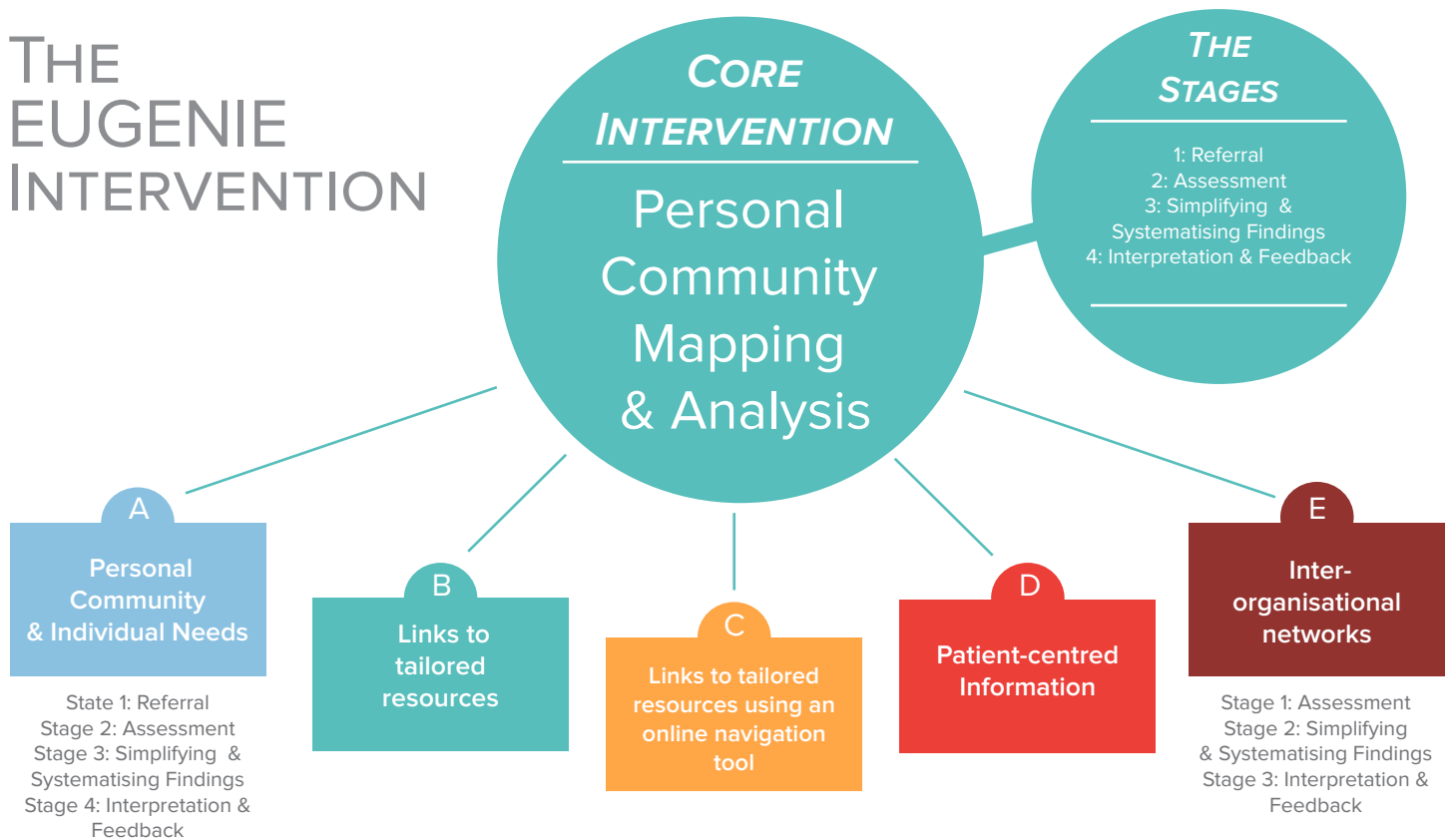
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*Family and friends often support self-management **but they may also hinder it.***

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Weak ties...especially with other people with chronic conditions, play an important role.

THE EUGENIE INTERVENTION



EUGENIE - The EU-WISE Intervention

Over recent months the EU-WISE team have developed the EU-WISE intervention, drawing on the research and empirical studies conducted in the project to date. The intervention is focused on the role that social networks play in chronic illness management and aims to enhance access to resources and to improve support for health and well-being. The intervention is called EUGENIE (European Generating Engagement in Networks Involvement): focusing on network based interventions in supporting people with type 2 diabetes across Europe.

EUGENIE will be implemented between May and December 2014 in deprived or marginalised areas in the UK, Bulgaria, Norway, Spain, Greece and the Netherlands. It uses social network techniques as a way of engaging patients and providing feedback to different stakeholders. Each partner country will pilot the intervention in different settings including, for example: a GP practice, local community group, or in the home of users. The intervention is designed around a modular structure with a core intervention and five additional components that can be implemented independently. The core intervention will be delivered in each country and involves delivery of personal and community mapping and analysis. This will raise awareness of the importance of social networks, facilitate reflexivity of existing supports and barriers and encourage participants to consider positive change.

Each country will implement some or all of the additional components, depending on the needs analysis and feasibility for that country. The additional components of the intervention 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 and (E) analysis of inter-organisational networks.

After the intervention has been piloted it will be evaluated and analysed to ascertain the feasibility of its broader implementation and so that it can be adapted for future trials or dissemination. Evaluation will include in depth interviews with users and care providers. We will keep you updated on progress in our next newsletter, in Winter 2014/2015.

Project News

The project website is regularly updated with news, so please make sure you log on to keep up to date. Recent items include:



1. The third EU-WISE full consortium meeting took place in Pamplona on 19 and 20 September 2013. Members of the team from each project partner enjoyed a very successful and productive meeting. There was significant coverage of the event in the Spanish media (including news outlets such as El Mundo, Yahoo, and Telecinco).
2. The EU-WISE partners have been busy attending conferences and publishing material directly associated with EU-WISE and/or to chronic illness management generally; e.g. our partners in Bulgaria have just published a new article called “*The Impact of the Health Care System in Bulgaria on Diabetic Patients Self-Management and State*”, Todorova, E., P. Roukova, P. Balkanska. General Medicine journal, book 3, 2013, published by Medical University, Sofia.
3. The popular Norwegian newspaper “Bergens Tidende” recently published an article by Professor Christina Foss and Dr Ingrid Ruud Knutsen of Oslo University entitled “*Diabetes 2 care without governing*”. The piece addresses the problems arising from new Norwegian reform translating diabetes 2 care away from hospitals (Bergens Tidende, Søndag 24 November 2013).
4. Anne Kennedy and Anne Rogers from EU-WISE (Health Sciences at Southampton) led and worked with colleagues in Manchester, Keele and York to undertake one of the largest randomised controlled trials of self-management support in primary care ever completed. This has recently been published in the BMJ <http://www.bmj.com/content/346/bmj.f2882>.
5. The emergent findings have led to the establishment of a new generation of research to be carried out as part of the new NIHR CLAHRC Wessex – “patient engagement with self-directed support for long term condition management”. <http://www.clahrc-wessex.nihr.ac.uk/>
6. In April 2013 EU-WISE joined the EU EIP on Active and Independent Ageing. Membership will provide EU-WISE with an opportunity to engage with stakeholders and policymakers in the sector. The EU-WISE project newsletter and brochure were circulated on the Yammer intranet at the EIP A1 Action Group “Prescription and adherence action at regional level” where Dr Manuel Serrano, as President of EHSF, is an active member.

Spreading the Word

Dissemination of the EU-WISE message is important and there are a number of ways you can help:

- Make sure you are on the project mailing list and recommend colleagues add their name to the list (you can join the mailing list by using the contact form on the project website - eu-wise.com).
- Contact us to arrange hosting a link to the EU-WISE website on your own webpage.
- Contact us to arrange free delivery of our project flyer or printed copies of our newsletters.
- Follow us on twitter at twitter.com/EUWISE
- Contact us to express an interest in our 5 regional workshops to be held in Spain, the Netherlands, Bulgaria, Greece and Norway, in December 2014

Project Partners

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