

**CLAHRC Wessex**

Collaboration for Leadership in Applied  
Health Research and Care

**NHS**

*National Institute for  
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# Linking to networks and resources for illness management: implementing personal community mapping and analysis

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# Introduction and overview

- Social networks for self-management
- EU-WISE project and European partner countries
- Implementation and evaluation in UK
- Using NPT to makes sense of process
- What have we found?

# Properties of social networks for self-management support

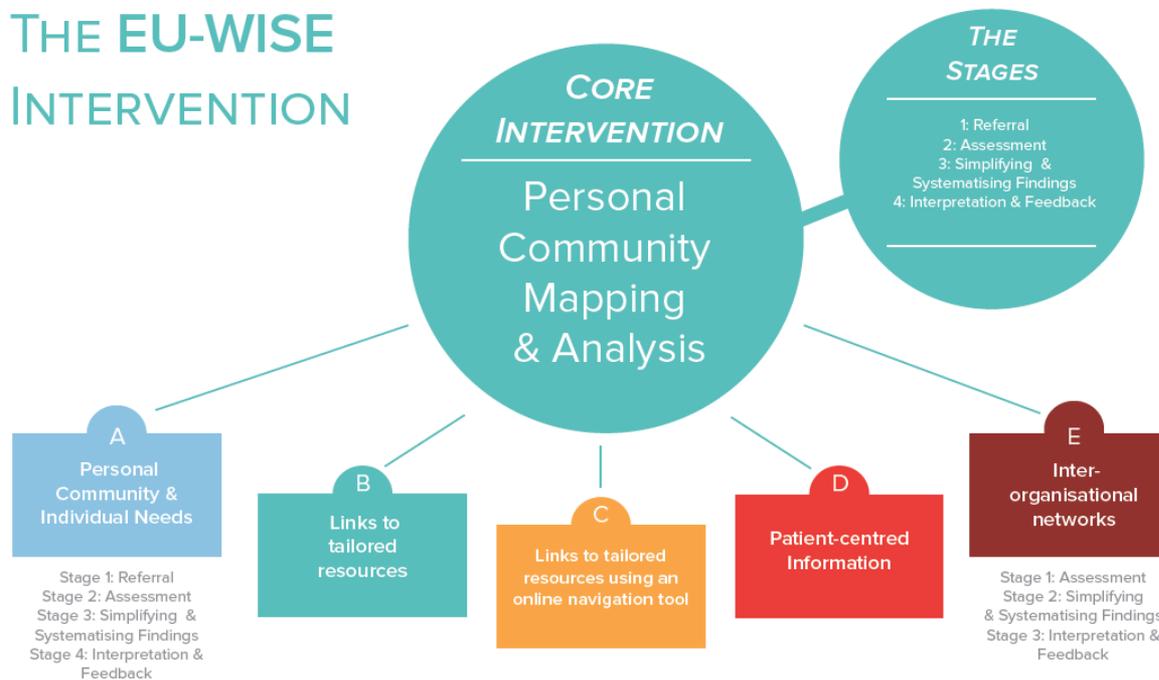
- Established that a workforce of network members are involved in self-management support
- Diverse networks are more likely to have better health and well-being
- Social involvement and participation in community groups related to better physical and mental health, and better individual capacity to self-manage

# EU-WISE: a social network approach to self-management support

## EUGENIE

### THE EU-WISE INTERVENTION

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[WWW.EU-WISE.COM](http://WWW.EU-WISE.COM) | [TWITTER.COM/EUWISE](https://TWITTER.COM/EUWISE)



## EU-WISE

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

Country	Format	Facilitator	Setting
UK	Mainly web-based	Health Trainers and Care Navigators	Community and people's homes
Netherlands	Paper-based	Researcher/GP	Hospital
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

## Implementation and Evaluation of EU-GENIE

- Normalisation Process Theory as sensitising framework for analysis
- Case study with 15 participants living with diabetes type 2
- Intervention facilitated in a community setting by non-health care professionals (such as Health Trainers, Care navigators, researcher)
- Two training days with Health Trainers, Care Navigators and managers
- Video recording of intervention, researcher observation, post-intervention interview
- Face to face interviews with participant at 6 and 12 months (researcher)
- Notes on intervention video and evaluation interview entered using NPT



# EU-GENIE Questionnaire

## My Network

Close



- Daily
- At least once a week
- At least once a month
- Less often



Drag your pin over the trash icon above to delete it.

Please tell us about your network of friends, family and others you're in contact with, to help us supply you with the most useful results.

<b>Karen</b>	<b>Every day</b>	<b>Family member</b>	<b>Son/daughter (in law)</b>
<i>Their name, or just a nickname if you prefer.</i>	<i>How often are you in contact with them?</i>	<i>What type of relationship do they have to you</i>	
<b>Karen</b> Son/daughter (in law)	Once you have finished entering your information, drag your newly created pin to the diagram.	GP Nurse Specialist Other health professional Other	

Top Results

Social clubs

Swimming

Walking and outdoor activities

Reading and creative writing

Support for carers

Education and learning

Weight management

Volunteering opportunities

Diabetes

Print Your results

Top Results

Activities

**A** Bridge Club - Social clubs

Favourite This

[Read More](#)

Jill + Dave like this

**B** The Riverside Centre - Reading and creative writing

Favourite This

[Read More](#)

Jill + Dave + Carol like this

**C** Newport (I.W.) Scrabble Club - Social clubs

Favourite This

[Read More](#)

Jill + Dave like this

Health

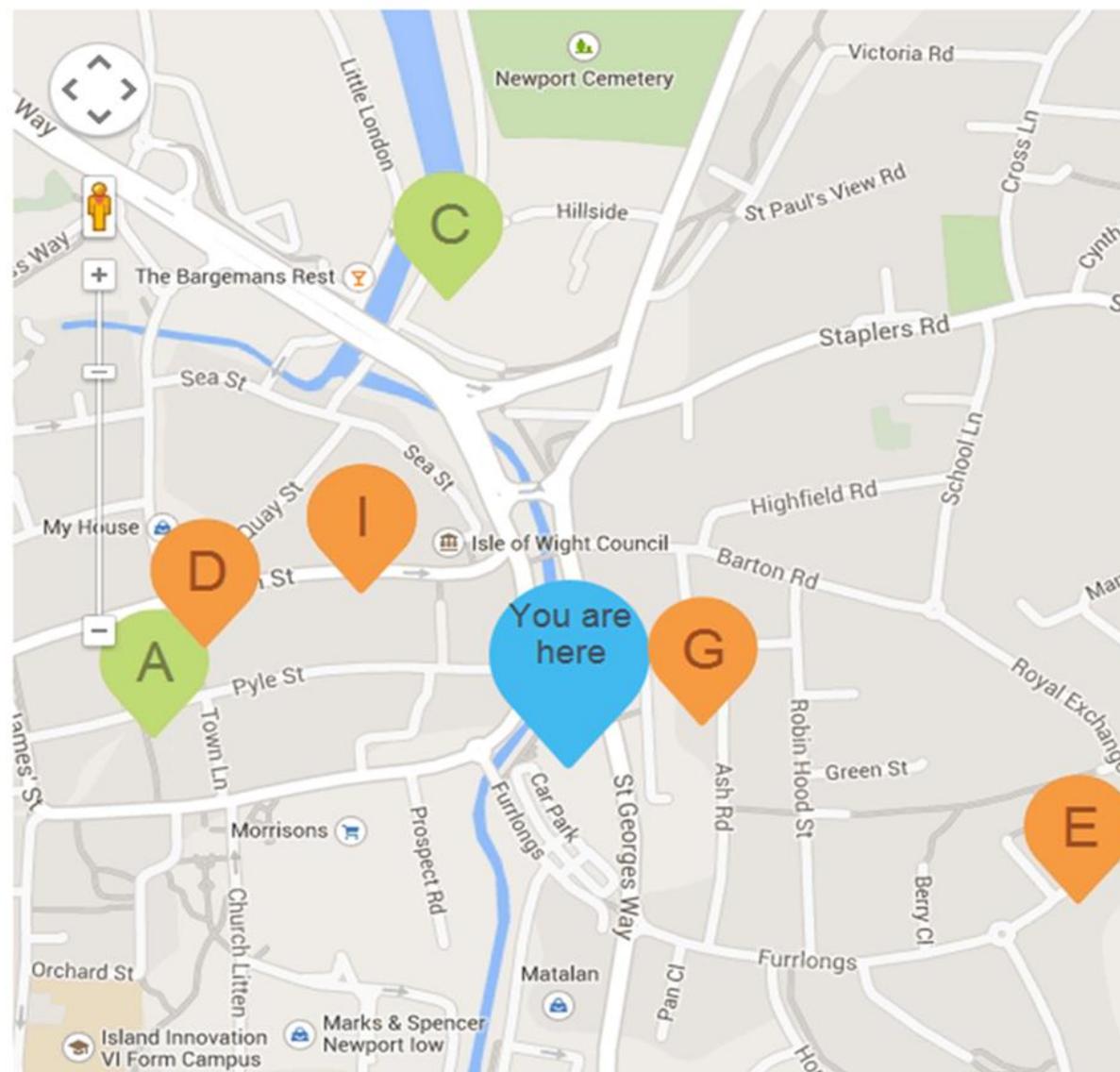
**D** Newport PH Club - Walking and outdoor activities

Favourite This

[Read More](#)

Jill + Dave like this

Show Results Within: 1 Mile  2 Miles  5 Miles  10 Miles





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# EUGENIE DEMO



# Case Study

**COHERENCE: Meaning of practice: sense-making work; Does the practice make sense? What is the work involved?**

Components	EUGENIE 11
Differentiation	<p>Originally named those who support diabetes (daily proximity was important) – later added many more names of family, friends and acquaintances.</p> <p>There are many HCPs and HT on diagram as HT has already helped him make many changes to diet and alcohol intake and made links to eg exercise support.</p>
Communal specification	<p>Worked carefully with HT to populate circles, expressed surprise there were so many on the diagram. One close friend plus 2 regular drinking companions.</p>
Individual specification	<p>Important to have someone key to talk to (step-daughter next door).</p>
Internalisation	<p>Diagram important when it is merged with information obtained from others to give a wider picture of what is needed for experts to analyse – thus the logic of using a computer</p> <p>Not thought before about how other people could support him. Didn't take much notice of diabetes – until HT supported to make changes</p>

# COGNITIVE PARTICIPATION : Commitment & engagement: relational work; Who does the work?

Initiation	<p>Took time to move beyond thinking about HCP – then kept adding people</p> <p>Map with results very engaging</p> <p>The ‘used to do’ question reverberated through the discussions and interview.</p>
Enrolment	<p>Able to note currently relevant activities and those now lost to him because of physical deterioration.</p> <p>HT suggested Healthy Walks in the future as she knew they were going to start up 30 minute walks more suitable for him</p> <p>Wanted to know if results would appear on his computer so he could study them in more detail – surprised there were 9 pages</p>
Legitimation	<p>Beer/drinking a problem for health but important social activity – he also does voluntary (?) work at the social club – stocktaking.</p> <p>Biggest problem at night when he is on his own – since his wife died</p>
Activation	<p>Results of relevance mostly, though some not interested in eg swimming, group therapy. Did prioritising work on the paper version – but actual priorities set out in interview rather than during facilitation – walking and could do with best friend</p>

## COLLECTIVE ACTION: Interaction with already existing practices: operational work

### How does the work get done?

Interactional workability		HT struggled with web version of EUGENIE – patient helped to manage this and made suggestions (eg plug in computer to avoid losing data!) and was interactive and leading in where to place people on the circles.
Relational integration		HT was important and role to feed back findings to research team
Skill set workability		
Contextual integration		

## REFLEXIVE MONITORING: Understanding & assessing: appraisal work

### How is the work understood and assessed by actors implicated in it?

Systematization		Talking to HT important, wouldn't have thought of so many people without her – need prompting to help with diagram – reifies importance of diagram to others rather than himself, so key outcome is to get the diagram right.
Communal appraisal		Young people could do it online, but older people need help
Individual appraisal		
Reconfiguration		

# Opens space for reflexive engagement

- Not a single fixed way of thinking about CIM, but different sets of normalised practice
- The network diagram opens this up, de-naturalises it, and makes reflexive engagement, navigation and re-negotiation easier

# Buy-in happens in different ways

Buy-in is about engaging with the process of re-negotiation and navigation

- For outsiders to see if someone is isolated or needs support (1)
- A fixed point in time – need to use it to show change (6)
- For experts to accrue knowledge about what resources are being used locally and fill the gaps (11)
- Having diabetes one needs to look after oneself (10)
- Need to get fitter; once you've got people graphically it can serve as an aide-memoire; you can print it out and remind yourself who you can contact (4)
- To learn about activities that she didn't know about (7)
- To help prioritise in relation to need; finding others are supporting him rather than the other way around (13)

## Practical solutions of immediate relevance

- Mapping network members and discussing their roles offers reference points to where navigation and re-negotiation can take place
- Opening up of normalised CIM practice and network member roles feeds into the discussion of activities of immediate relevance
- Limitations: opening up is only happening on the cognitive level and actual negotiation of relationships still needs to take place outside the intervention discussion
- Focussing on user priorities means changes could be achieved indirectly through developing alternative forms of engagement (e.g. when network members have a negative impact on CIM)

## **What is likely to improve self-management and self-management support?**

- 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



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# Thank you to all our EU-WISE partners

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