Where have we come from and where did we get to: the EUWISE Journey

Professor Anne Rogers

UNIVERSITY OF Southampton

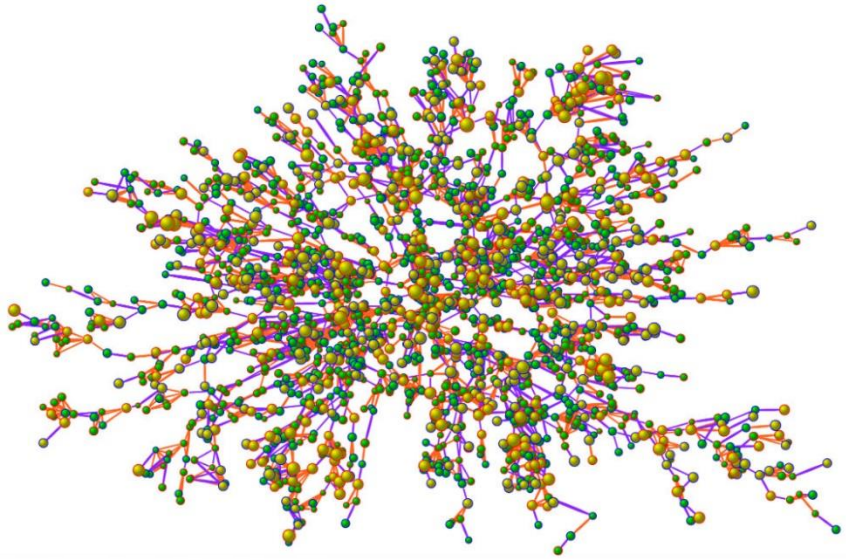
NHS National Institute for Health Research

CLAHRC Wessex
Collaboration for Leadership in Applied Health Research and Care

The EU-WISE intervention

- Where we started
- What we ended up with
- How we got there
- A model

Where we are coming from and going to



Where we started

- Individualised models of self-management support produce equivocal evidence for progress they promote isolation and ignore reciprocity.
- Support for self-management with potential for desirable outcomes seen **less** as an individualised set of actions and behaviour **more** as a social network phenomenon.
- Replace vision of activated **individuals** with activated **networks.**

What we knew about Personal Communities & Outcomes for LTCM

1. Social involvement with a wider variety of people and groups supports personal self-management physical & mental well-being.
2. Support work undertaken by personal networks expands in accordance with health needs, helping people to cope with their condition.
3. Network support substitutes for formal care and can produce substantial saving in traditional health service utilisation costs. Health service costs significantly ($p<0.01$) reduced for patients receiving greater levels of illness work through their networks.

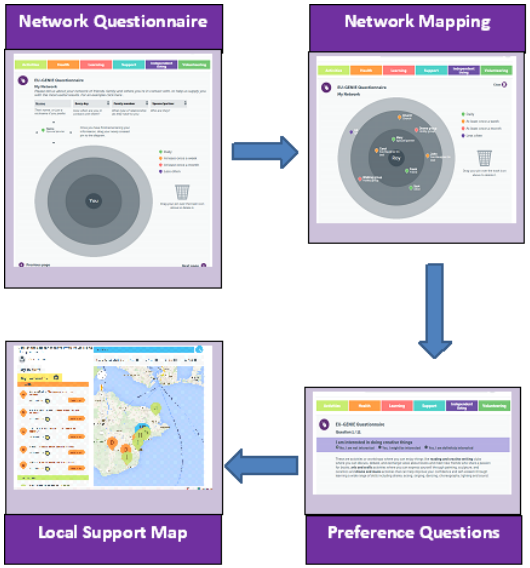
Reeves D, Blickem C, Vassilev I, Brooks H, Kennedy A, Richardson G, et al. (2014) The Contribution of Social Networks to the Health and Self-Management of Patients with Long-Term Conditions: A Longitudinal Study. PLoS ONE 9(6): e98340. doi:10.1371/journal.pone.0098340http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0098340

Genie Tool: The Four Elements

- Network mapping – Preferences – Resources Facilitation/Mediation

Genie: How does it work?

- Positive Disruption of existing practice (externalising away from self).
- Visualisation, Reconstruction, Mobilisation of network resources.
- Engagement with new or renewed activities.
- Mediation (facilitation/web).



Where did we start?: Existing Interventions WP2

- Most (11/21, 52%) of the interventions were designed to fit within the context of primary care.
- Most (11/21, 52%) highlighted behavioural change as an important goal.
- Some (5/21, 24%) referred explicitly to Internet-based tools.
- Socio-economic circumstances relevant to capacity to self-manage. Gains and progress will be hard to maintain during economic austerity.

- Kousoulis AA, Patelarou E, Shea S, Foss C, Ruud Knutsen IA, Todorova E et al.. Diabetes self-management arrangements in Europe: a realist review to facilitate a project implemented in six countries. *BMC Health Serv Res*. 2014; 14:453

Meso and Policy Influences

- Social environmental influences on diabetes SM: inequalities, stigma, food.
- Reluctance/inability of policy makers to regulate processes and environments related to chronic illness management.
- The focus of healthcare system governance and gaps in provision of self-management support (SMS).

- Rogers A, Vassilev I, Purmar M, Todorova E, Portillo MC, Foss C, et al. Meso level influences on long term condition self-management: stakeholder accounts of commonalities and differences across six European countries. BMC Public Health. 2015. http://www.biomedcentral.com/1471-2458/15/622

Personal Networks an environment for the negotiation of central aspects of SMS

- There are complex negotiations that influence self-management and food, including support, knowledge, and relationships within families Knutsen et al (2015) http://qhr.sagepub.com/content/early/2015

- Meta-synthesis indicates a need to heed the notion of connectivity as a means of mobilising and supporting the self-management strategies of people with type 2 diabetes in everyday life Foss et al (2015) http://onlinelibrary.wiley.com/doi/10.1111/hsc.12272/ (abstract).

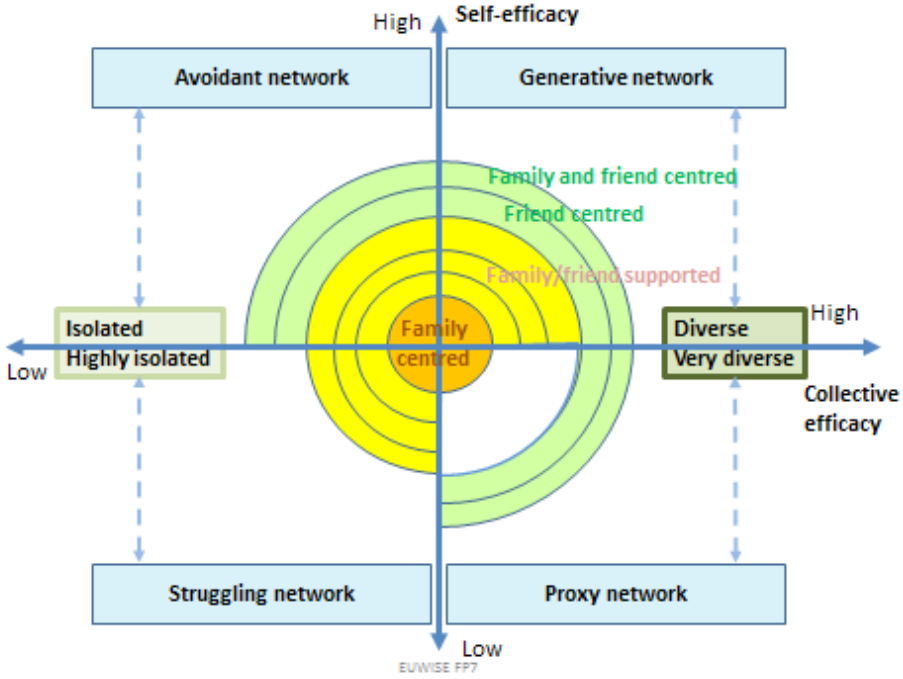
Personal Communities Composition a focus for network interventions

- *"…health interventions that harness the distributive properties of social networks could be made more effective and efficient than those that do not…" Kim et al Lancet (2015).*

- Membership: partners, family, professionals, weak (friends & neighbours), groups, pets.
- Generative & diverse beneficial to individuals?
- Avoidant, Struggling, Chaotic or SMS not prioritized.

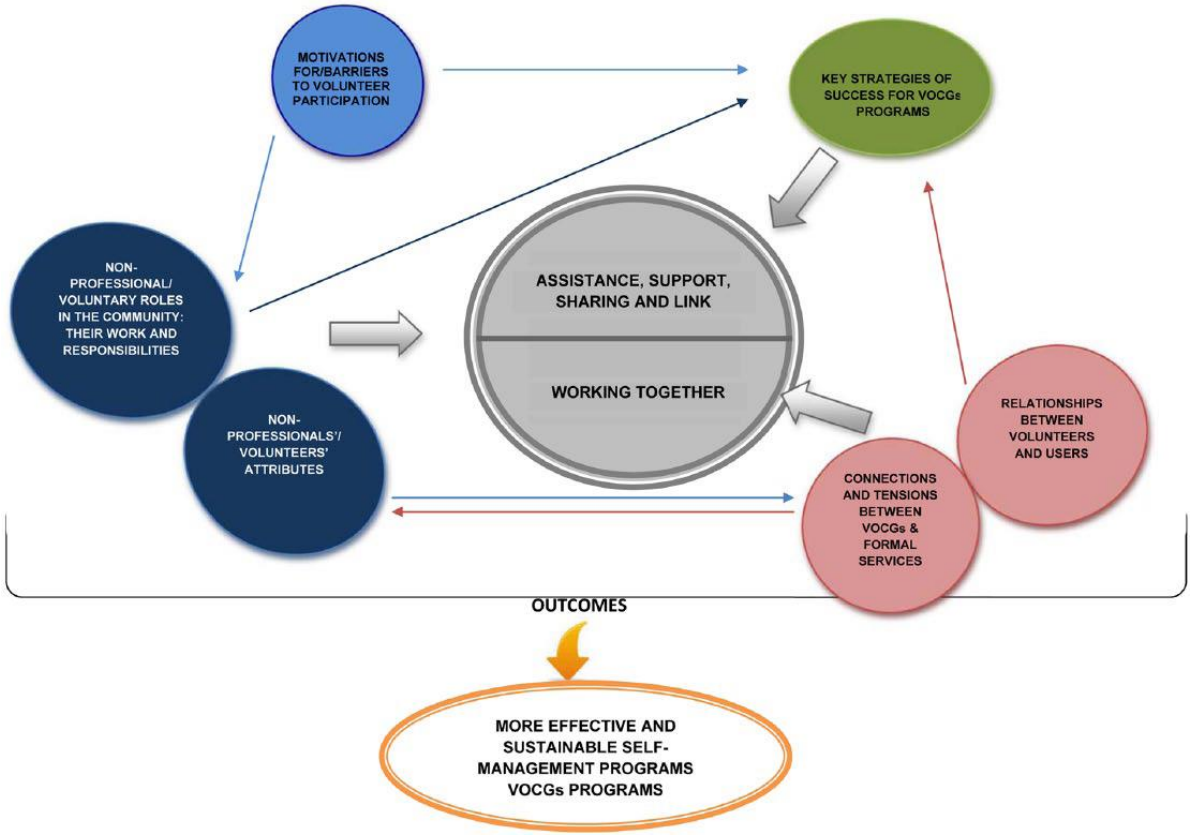
Personal Communities: Mechanisms for the mobilisation of resources

- Navigation
- Negotiation
- Collective Efficacy
- Need Diverse network for SMS skills (weak ties rule)
- Cost efficiency



Community & Voluntary Orgs - Composition

- Support & Assistance
- Sharing
- Links
- ‘Logics’ of healthy appearance and mind-set, fellowship and moral responsibility



Community & Voluntary Orgs Mechanisms for SMS

- Participation in community organizations associated with better physical and mental health and, in patients with low income, with more physical activity.
- Confirms: Greater involvement significantly related to better self-management ability & well-being a clear target for interventions and policies.

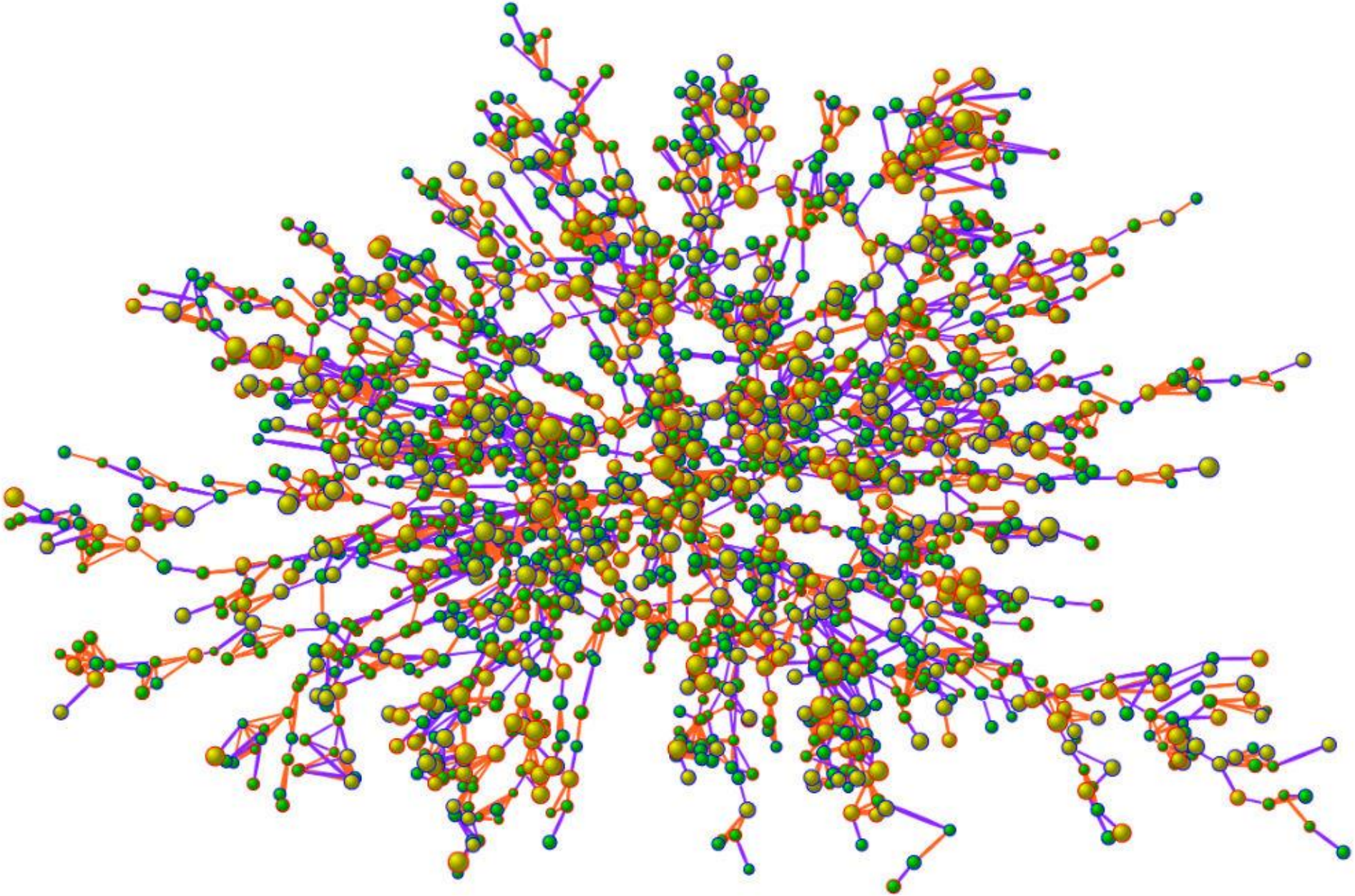
Koetsenruijter J et al (2015) Social Support and Health in Diabetes Patients: An Observational Study in Six European Countries in an Era of Austerity. PLoS ONE 10(8): e0135079.

The model (so far)

Macro and Meso
Policy, Industry, Environment

Personal communities
Diverse vs Restricted

Community and Voluntary Orgs
Supporting, sharing, linking

EU-GENIE

euwise
UNIVERSITY OF Southampton
NHS National Institute for Health Research
CLAHRC Wessex
Collaboration for Leadership in Applied Health Research and Care