

Protocol for evaluation of a social network intervention GENIE (Generating Engagement in Networks Involvement)

Theme 5: Patient engagement with self-directed support for long-term conditions

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Background

The aim of NIHR CLAHRC Wessex is to improve the health of people in Wessex and the quality and cost-effectiveness of health care by undertaking, applying and implementing world class applied research for patient and population benefit. To realise the potential of self-management resources, attention needs to be directed to how best to encourage diffusion, engagement and integration in the contexts within which patients, professionals and people in their health care social network can best make use of them. This proposal forms part of a programme which aims to maximise the use of recently developed tools for self-management through adapting and embedding online and offline resources in a pathway of care which integrates with professional care provided in primary and secondary care and interfaces with informal care. The long-term aim of the programme is to develop and adapt resources relevant to the effective deployment and use of self-care support tools for people with long term conditions with priority needs. We aim to develop engagement and implementation strategies targeted at those who are most vulnerable and marginalised.

The specific aim of this study is to utilise knowledge transfer to implement an intervention developed to assess and develop people's personal networks so as to improve the support they get to manage their diabetes. Knowledge transfer will be done through training and access to online tools. This project aims to answer the following question: **Can an intervention to determine and enhance personal networks for self-care support which is acceptable and appropriate be designed and implemented across a health community?**

And secondly if it can **to what extent might learning and knowledge transfer occur from one locality to another within CLAHRC Wessex?**

This is a project which combines implementation with research and is informed by the principles of the PDSA (Plan do Study Act) cycle.

Working with our partners in the Isle of Wight: The Background

The Isle of Wight is the largest off-shore island in England with the only combined hospital, ambulance, community, and mental health services in the country.

- The Isle of Wight Clinical Commissioning Group, Isle of Wight NHS Trust and the Local Authority serve a population of 140,000

- The Clinical Commissioning Group has recently been established and gained authorisation, the Isle of Wight NHS Trust is applying for Foundation Status and the Isle of Wight Council is a unitary authority
- My Life a Full Life (MLAFL) is a coming together of these three organisations, in collaboration with the voluntary and private sector, to deliver a vision for integrated care and support on the Island. People were isolated, and care was duplicated and lacked co-ordination
- The MLAFL is designed to work with people to have greater independence, inclusion in communities and where care is co-ordinated .
- The MLAFL programme focuses on people with long-term conditions, older people and those with mental health needs, with three priority areas identified:
 - Self Care and Self-Management
 - Crisis Response
 - Locality Working
- MLAFL programme commenced in Dec 2012 with the Head of Commissioning for Adult Social Care being released to take up the position as Programme Director for Integrated Care funded by IWC, CCG and IW NHS Trust

The Isle of Wight was selected as an initial test location for the following reasons:

1. As an island, it forms a marginalised community. There are problems of such as access to resources, a higher than average elderly population and a reduction of health service funding at a time of increasing demand. Improving access to support for people from marginalised and deprived communities is likely to be an effective way to improve engagement with strategies for self-management and access to associated community resources.
2. The Isle of Wight has an ongoing programme which makes the intervention relevant to commissioners:

The My Life A Full Life (MLAFL) programme is a comprehensive integrated care programme being delivered on the Isle of Wight. It is a collaboration between the Clinical Commissioning Group (CCG), IWNHS Trust and the Isle of Wight Council. The new initiative works in partnership with local people, voluntary organisations and the private sector to build a more co-ordinated approach to the delivery of health and social care services for older people and people with long term conditions on the Island.

MLAFL aims to help services to work together to make a real difference to people, as well as making better use of the resources that exist, both within the care system and the wider community.

There are three tranches of work;

- 1) Self-care/self-management – enabling and supporting people to manage their long-term conditions in a more informed pro-active way,
- 2) Crisis response – emergency response support which can be accessed by phoning 111. The phones are manned by a range of specialist healthcare and social care staff and give advice to people or organise ambulance dispatch as appropriate.
- 3) Locality working – a range of health care and social care staff co-located at three venues across the Island. This enables people to access a wide range of health and social care support all in one place.

Self-management support is recognised as a central element of chronic disease management and is promoted by health policy.¹ There is a need to devise workable strategies for self-management support which are able to address the needs of socially disadvantaged people through making use of available technologies, personal, community and institutional resources.² Social network research is needed to re-dress the balance between individual and wider social influences in the management of health conditions.³⁻⁵ Specifically, it brings into view how social support and network ties can be harnessed to bring new resources and relationships into self-management support. The CLAHRC programme was developed with the ambition to draw on social network approaches to help understanding of chronic illness management and to translate the generated new knowledge into interventions. The programme of work draws on relationships and societal influences to offer a deeper understanding of the different mechanisms involved in the management of chronic conditions.

At the micro level we propose to use a network mapping technique in order to explore the meaning and contribution of relationships to networks, the nature of the context, and content of illness work undertaken. We know that 'habitus', different types of capital, and relational positioning are relevant to illness management in a broad sense particularly in terms of gaining access to primary care. As well, we want to highlight how broader cultural structures can be worked into personal narratives to illustrate how self-management support is enacted according to different habitus, critical moments and changes over time in connection with available health and social care resources.

On the meso level we are using social network analysis in order to explore the contribution and potential of the voluntary sector to provide self-management support. There is at present an expanding role for voluntary and community groups in operationalising health and social policies. However, while the potential of the voluntary sector to provide resources, emotional, social and practical support for people with long-term conditions is widely acknowledged it is poorly understood and specified.^{6;7} We will address this by mapping and analysing the structure and functions of inter-organisational networks in a comparative context. This is likely to offer insight into the ability of VCOs to access, modify, and tailor self-management resources to individual needs and enhance our understanding of the sustainability and outreach of different local organisations. The latter is particularly relevant in a context of austerity politics where the provision of funding for local and voluntary initiatives is treated as a low level priority.

Aims

The main aim is to increase capacity in the NHS by the transfer of knowledge and skills concerning self-management support through training in the use of a participatory method designed to engage health workers, peers and lay people in both use and administration.

Our work aims to identify whether and how the use of training in social networking methods can enhance or change existing approaches to self-management which can fruitfully be implemented across a health community. The GENIE intervention aims:

- to raise awareness of social networks (both at the level of personal communities and community organisational level),

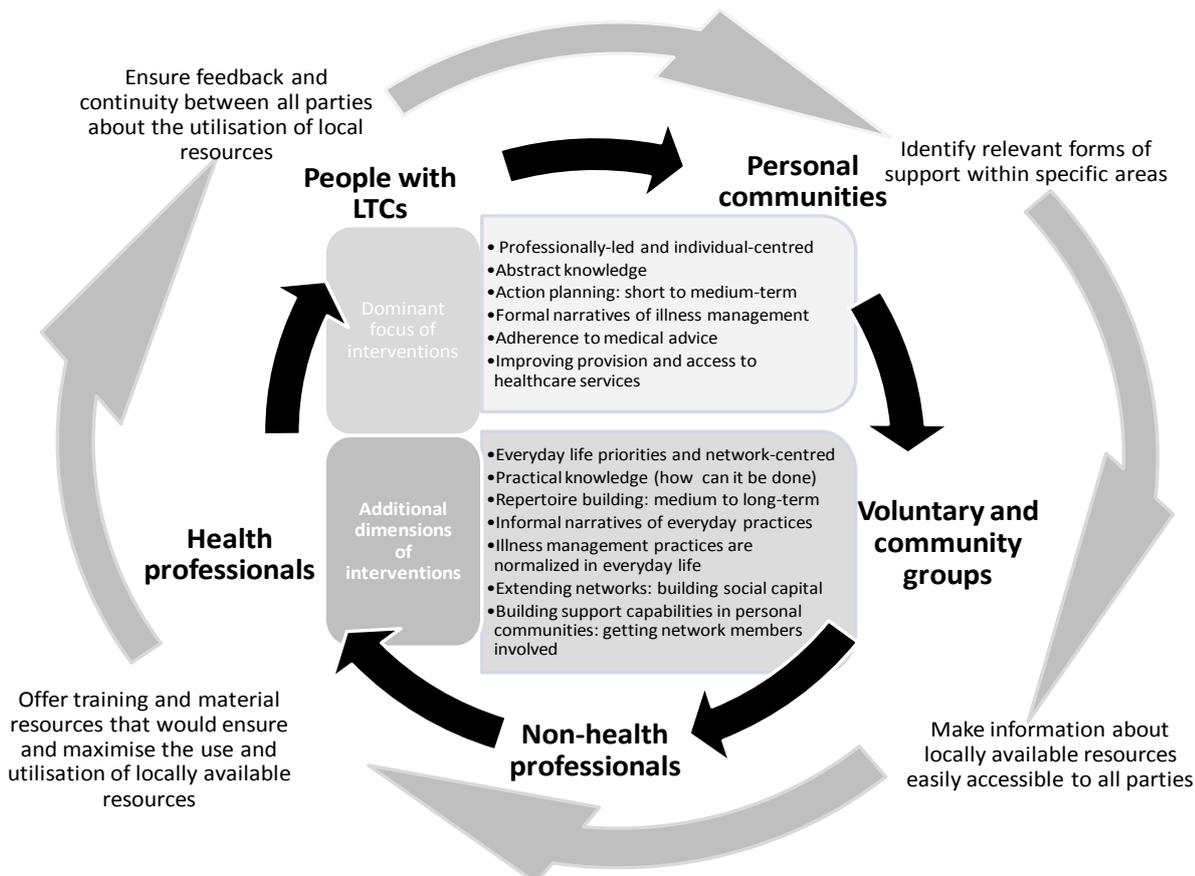
- to use social networks to engage patients in reflecting on their needs and support, help them access further resources and knowledge and introduce practices related to lifestyle, illness management, and behaviour change,
- to strengthen existing individual and community networks and improve patient engagement.

We will monitor how the Isle of Wight transfers the training skills to others. Diabetes is the exemplar condition used for the initial training, but the approach is generic and conditions of interest can be determined by local health organisations. Again, we will monitor to evaluate how other conditions are incorporated.

Co-design and co-working

The intervention will work on the premise that finding out about and enhancing network support can be undertaken by a variety of people (e.g. social network members, members of local community groups, health professionals) in a variety of situations (e.g. at home, work, in public and healthcare settings) (Figure 1).

Figure 1 Whole system approach to illness management: extending interventions and building a meta-level support for the utilisation of existing resources³



Methods

Intervention

The core intervention of GENIE consists of six stages.

Stage 1: Building capacity to carry out the study in partnership through training using network tool and PLANS

Stage 2: Referral

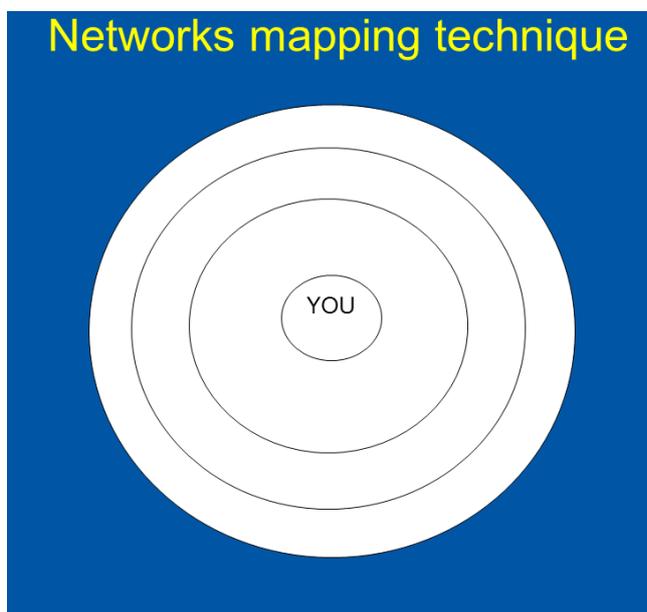
Users will be referred to GENIE through different channels including from: GP practice, secondary care, Voluntary and community groups, self-referral.

Stage 3: Assessment

The user will complete a questionnaire on paper or online. The participants will be asked to name the important people in their network, type of relationship and frequency of contact.

This will be done using the concentric circles diagram.⁸ For each network member we will then collect additional information about type of relationship and frequency of contact.

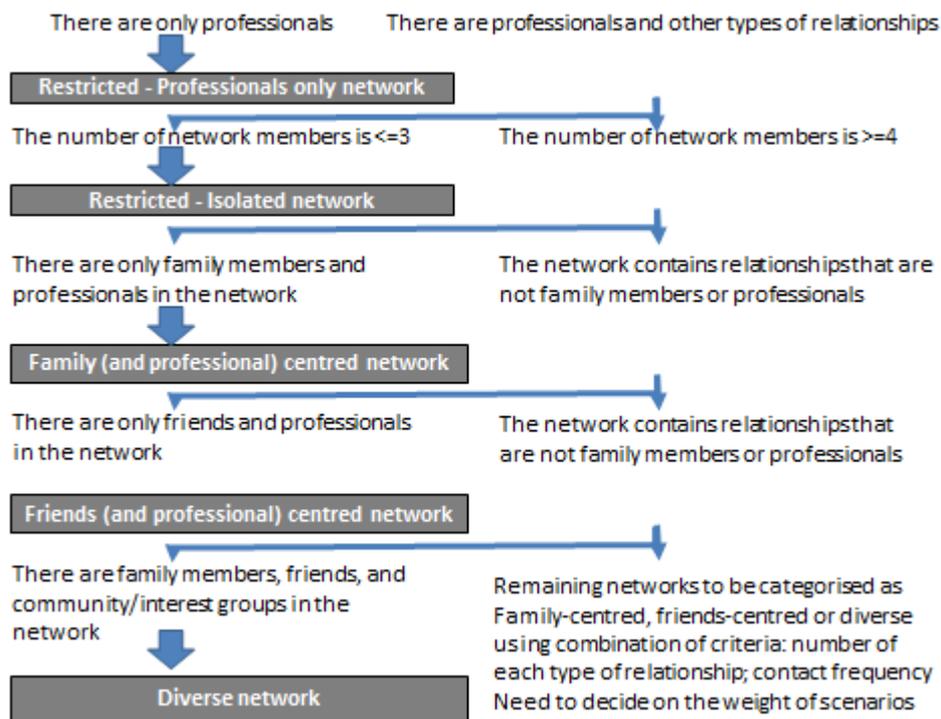
Figure 2 Concentric circles used for mapping personal networks



Stage 4: Simplifying and systematising findings

The collected assessment data will be linked to a network type: 1) restricted, 2) family centred, 3) friends centred, 4) diverse. A possible way of linking these broad types to actual configurations of networks is shown in figure 3.

Figure 3: Typology of personal communities



Stage 5: Interpretation and feedback

The feedback will contain a short description of the network and its relevant features e.g. what is most typical about people with such networks, who are the key members of the network, possible action to be taken. Feedback will be discussed with the user in the context of the intervention, a separate feedback form will be developed for stakeholders such as GPs, practice nurses, other health professionals. The feedback will be more a detailed version of the feedback provided by the core intervention and could also include structured notes, interpretation and recommendations by the facilitator.

Stage 6: Personal community and individual needs

In this component we will use a more in-depth questionnaire to first assess the needs and interests of users and second to link needs and preferences to engagement with network members (who among the network members is relevant for each domain) (see **Error! Reference source not found.**). We will add a weighting criteria based on user preference. For example, if questions 4, 5 and 6 have yes answers we can ask respondents to rank those in order of importance. This ranking could also feed into priorities to address in terms of key gaps in support. For those who want to learn more about their health, a booklet based on patient experiences of living with diabetes will be available.⁹

Table 1: Needs and interests assessment questionnaire

		Yes or no	Who helps you with this or who could you do this with
1	I am interested in doing creative things		
2	I would like to know more about social		

	activities		
3	I would like to learn more about my health		
4	I would like to lose weight		
5	I would like to get fitter		
6	I would like to learn new skills or complete a course		
7	I look after someone e.g. a relative		
8	I don't see other people very often		
9	I would like to know more about things that will help me remain independent		
10	I would like to know more about community transport		
11	I would like to help other people		

Training

Training will be delivered by the team who developed the GENIE intervention. The session will take place over a day

1. Background

- Traditional self-management support delivered through primary care
- Role of social networks
- Evidence and background for interventions to enhance network support

2. Overview of the GENIE approach and aims

- Personal networks
- Identification of needs and personal interests
- Link to local resources using PLANS website and tailoring to needs and interests

3. Activity – creating a database

- Categories for the database are: Activities, Health, Learning, Support, Independent living, Volunteering
- Using the document '*Creating a PLANS database*'

4. Overview of Personal networks mapping

- Typologies of networks and what this means for support needs
 - i. Restricted, family, friend, diverse

5. Activity – using concentric circle tool for mapping personal networks

6. Activity - Working through PLANS questions using the workbook.

- Key questions
- How to develop rapport
- Looking for clues and working with personal preferences and need

7. Feedback and examples

8. Group discussion

Following the training, the participants will be given the tools required to roll out the intervention

- Paper and web-based concentric circles with typologies and support suggestions
- Access to the website <http://www.plansforyourhealth.org/> and the ability to create a database of local organisations which can be added to the website
- Guidebook on how to deliver GENIE

Evaluation

The evaluation will focus on the knowledge transfer related to the GENIE intervention. This will be done using qualitative and process research methods based on a normalisation process theory framework.¹⁰ The research questions will concern: Is it acceptable and to whom; does the approach make sense; what is entailed in doing the mapping and linking work; what sort of skills are needed or demonstrated; what are the reactions when people are given information about networks; what knowledge or links do individuals or organisations have with other organisations and does the intervention impact on this; what are the practical requirements for applying the intervention in terms of time and logistics.

Case evaluations will be done with 15 participants and the person who facilitates the intervention (a trained volunteer or health professional). The interviews will be audiotaped and may be done face to face or by telephone. Additional assessments include: observation of the delivery of the intervention by a researcher using note-taking or video-recording; pre- and post-questionnaires to ascertain knowledge of local organisations of the relevant health care professionals or voluntary organization managers.

Methods

Purposively selected cases for the study will be selected to try out the intervention in different settings including, for example: a GP practice, local community group, in the home of users. Ideally five individuals will be selected for each setting.

Measurements

The core assessment interviews will be audio-recorded and guided by some key questions:

- Was the intervention of relevance (e.g. 'What were your first thoughts when you were asked for a list of names?' 'Why do you think this might be helpful?')
- How acceptable was the mode of delivery and how easy was it to use (e.g. 'Did you understand what you were asked to do and how to do it?')
- What new insights were gained (e.g. 'Did you learn anything new about the patient/client?')
- How much use is this type of information (e.g. 'What do you think you will do now?')
- Who might benefit most from this type of intervention?

Additional assessments:

1. The researcher will observe the consultation or setting where the intervention is taking place. The observation will involve the researcher taking notes or filming the process^{11;12}. Immediately following the intervention, the researcher will go through the notes or video with those involved and talk through with them their thoughts on what was happening (video elicitation).¹³ This discussion will be audio-recorded. Following each observed case study, the researcher will write field notes and record their impressions of how the intervention was used and accepted.
2. Prior to the observation, the identified health professionals and voluntary and community groups who will be delivering the intervention will be sent a short questionnaire asking them to provide details of the organisations they know and could refer patients to. Following the observation and discussion, the same people will be re-contacted by phone to explore with them whether delivering the intervention has affected their knowledge and use of local organisations.

During the evaluation period, the health professionals and voluntary and community organisations involved will be asked to keep a record of the number of people they have used the intervention with.

Follow-up

Six months after the delivery of the intervention, the participant will be contacted to ascertain and record changes to their personal support network.

Knowledge transfer

A process evaluation will record how the knowledge transfer has been implemented in the local health community. Of interest will be what the expectations are for GENIE facilitators; how they are supported; the backgrounds of the facilitators (whether they are lay volunteers or health care professionals); what new conditions are included in the roll-out of GENIE; and to what degree GENIE improves and sustains the interaction of local voluntary organisations with health services.

Analysis

The aim of the analysis is to determine whether and how the work associated with knowledge transfer of the intervention occurred. An NPT framework will be used to assist coding of the transcripts and to give insights into how the intervention works in practice.

Details of sample and sampling strategy

People with type 2 diabetes will be purposefully sampled to obtain 15 cases to represent a range of ages and gender. Network types: isolated; family centred; friends centred; or diverse will be noted and reported on. Those charged with delivering MLAFL on the Isle of Wight will be asked to identify local organisations or venues where GENIE is to be delivered. A researcher will contact managers and ask them to find suitable participants and make

initial approaches concerning interest in the research. The researcher will then obtain informed consent. In addition, the research team will know those who have received training and will arrange through them consent for observation of the delivery of GENIE.

Participant inclusion and exclusion criteria

Inclusion criteria are adults over 18 with type 2 diabetes who can understand spoken English. Exclusion criteria are those receiving palliative care and who are unable to communicate in English.

Feasibility of recruitment, timetable of deliverables

March 2014: elaboration of protocol and materials for ethical committee

March 2014: first training for facilitators of GENIE

April 2014: recruitment of settings for administration of GENIE

May 2014: questionnaire data collection from organisations

May 2014: start of data collection and observations for case evaluations

July 2014: end of observations

October 2014: start of follow-up for case evaluations

October 2014: second round of questionnaire data collection from organisations

February 2015: end of follow-up

March – July 2015: analysis and publications; guidance for implementation submitted to the prioritisation committee

Milestones

August 2014: 15 case study observations completed

March 2015: 15 follow-up case evaluations completed

Patient and public involvement

There has been public involvement in the co-design of this project through the My Life A Full Life team on the Isle of Wight. Every research theme in Wessex CLAHRC has identified one or two members of the public who will work both with the research team and with the wider management group to set research priorities for Wessex CLAHRC. For this project, lay volunteers will be trained to deliver the intervention and it is the intention that we will identify early on individuals who are prepared to work closely with the researchers to help map the process of implementation and modify the intervention to suit the needs of the local community.

Summary of costs

Total for CLAHRC: £22,951

Total matched funding: £36,324 (Research assistant for 12 months)

Staff: Researcher 20% for three months £1,805

Training costs – venue, transport, refreshments £800

Development of website - £12,000

Travel expenses - £1096

Printing, stationery - £350

Transcription costs - £2,400

Dissemination costs, conference and open access - £4,500

Knowledge Transfer and Implementation

Protocol Final 22/5/14

Value/relevance to the NHS locally and nationally

- **for patients:** raises awareness of the importance of networks and encourages reflexivity of existing support and barriers; could be the basis for a discussion about available alternatives.
- **for professionals:** raises awareness of the importance of social networks, offers understanding about the social environment and potential for support or lack of such for specific individuals; offers a potential comparison between organisations through which to interpret and improve performance
- **for commissioners of services:** awareness of network structure of patients and the need for specific types of support; comparisons between localities, areas, regions.

Deliverables

- GENIE training package
- Online tool to map personal networks and to give feedback on network typologies

The programme will contribute to the achievement of the following objectives set out in our original plan

- support (SMS) tools and resources for long term condition management in the community and at the interface with formal service provision (1-2 years).
- Adapt a set of candidate tools and resources to meet pressing support needs for a range of conditions across a pathway of prevention and LTCM. (2-4 years)
- Model self-management pathways for using tools, applications and resources (2-3years)
- Evaluate use in practice and the implementation of self-management support strategies and resources through a programme of Implementation science using theories of implementation and social network analysis. (1-5)

It will also contribute to the generation of a cadre of Research and Implementation Associates.

Dissemination plans locally and nationally

The main aim of the study is knowledge transfer and local implementation, so local dissemination is of key importance. The purpose of GENIE is to build up awareness of local organisations and the support they provide.

Results will be shared on an ongoing basis with MLAFL to allow them to demonstrate the impact of their programme on their website and to local partners across the Isle of Wight. We will involve our PPI partners in local dissemination at the regular café clinics and community hubs.

Nationally, we will publish papers in peer reviewed open-access journals and present at conferences. Findings will also be disseminated on the Wessex CLAHRC website.

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