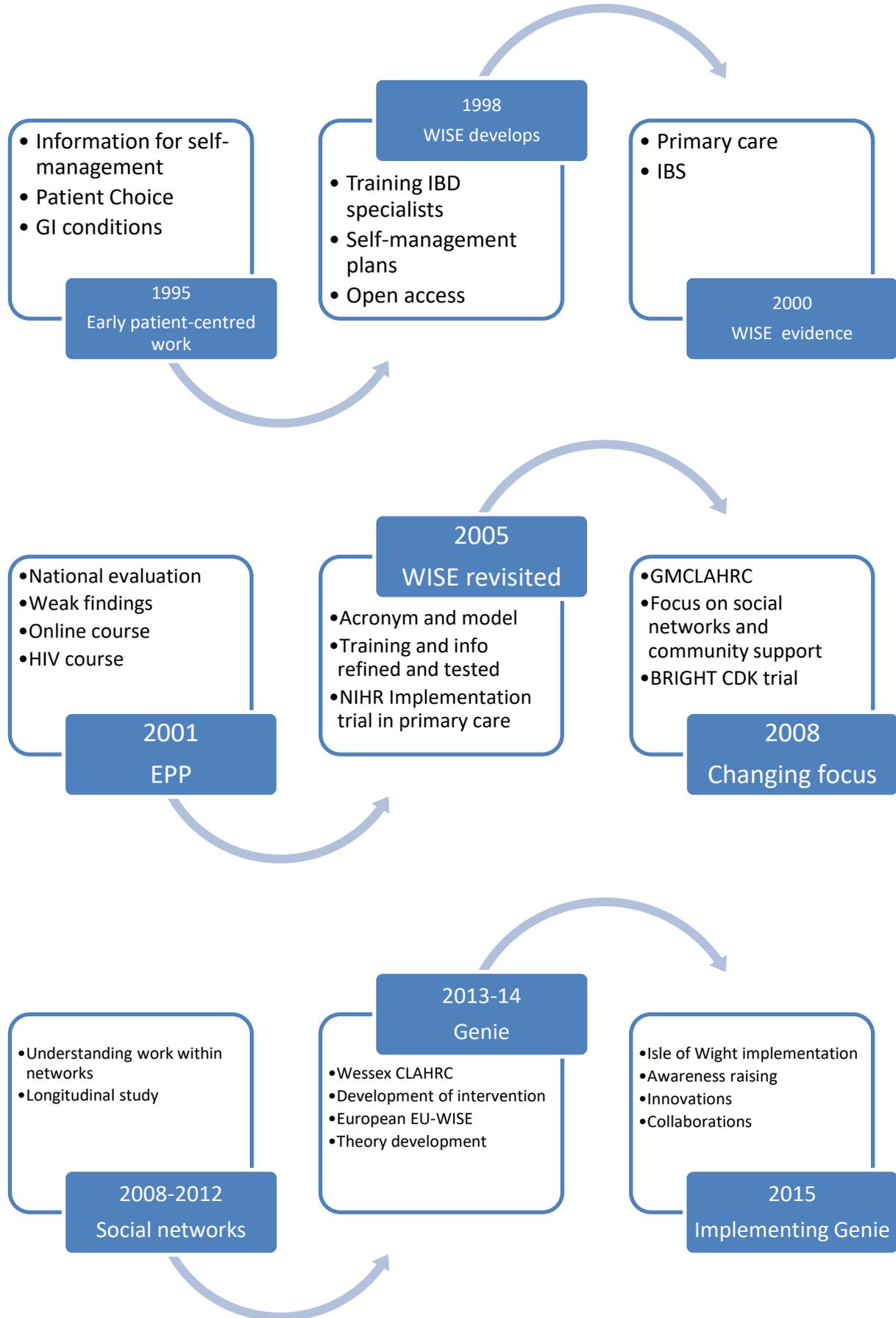
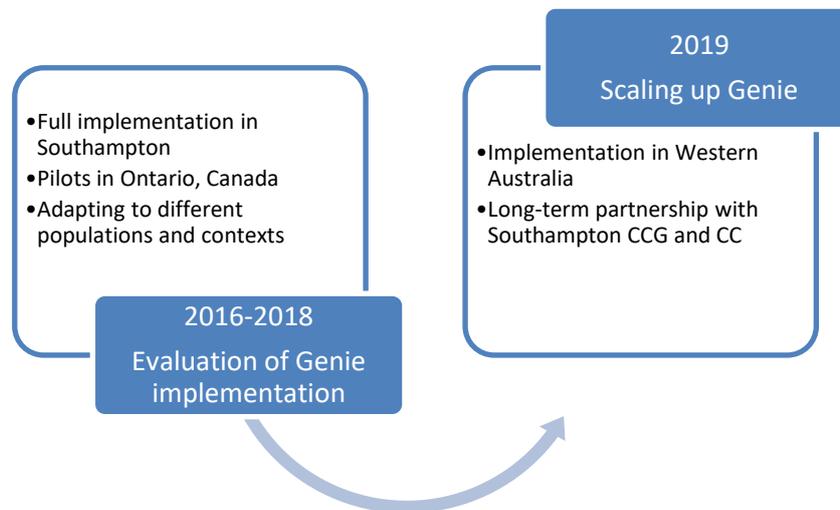


Timeline





User and stakeholder engagement at each stage of the research, development and implementation of Genie.

In this document, we briefly explain the research and thinking which led to the development of a social network intervention and provide links to the papers which give more detail.

Before 2008 work: self-management

Early work

A method for developing patient-centred information was initiated which has been used in many interventions.

1. Kennedy AP, Robinson A, Thompson D, Wilkin D: 1999 Development of a Guidebook to Promote Patient Participation in the Management of Ulcerative Colitis. *Health and Social Care in the Community* 7(3) 177-186
2. Kennedy AP & Rogers A. 2002, "Improving patient involvement in chronic disease management: the views of patients, GPs and specialists on a guidebook for ulcerative colitis", *Patient Education and Counseling*, 47(3): 257-263.
3. Kennedy A, Robinson A, & Rogers A. 2003, "Incorporating patients' views and experiences of life with IBS in the development of an evidence based self-help guidebook", *Patient Education Counseling*, 50(3): 303-310

A process to train professionals in providing self-management support was developed as part of a whole systems approach to self-management.

1. Kennedy AP and Rogers AE: 2001 Self-management, a whole systems approach. *British Journal of Nursing* 10(11): 734-737
2. Kennedy A, Gask L, Rogers A. 2005, Training professionals to engage with and promote self-management. *Health Education Research* 20(5), 567-578.

This was successfully tested in a series of randomised controlled trials which provided an evidence base for the whole systems approach.

1. Kennedy AP, Robinson A, Hann M, Thompson DG, & Wilkin D. 2003, "A cluster-randomised controlled trial of a patient-centred guidebook for patients with ulcerative colitis: effect on knowledge, anxiety and quality of life.", *Health and Social Care in the Community*, 11(1): 64-72.
2. Kennedy AP, Nelson E, Reeves D, Richardson G, Robinson A, Rogers A, Sculpher M, & Thompson D. G. 2004, "A randomised controlled trial to assess effectiveness and cost of a patient orientated self-management approach to chronic inflammatory bowel disease", *Gut* 53(11): 1639-1645
3. Robinson A, Lee V, Kennedy A, Middleton E, Rogers A, Thompson D, Reeves D. 2006 Randomised Controlled Trial of Self-Management Interventions in Patients with a Primary Care Diagnosis of IBS. *Gut* 55:643-8

National evaluation of a self-management programme

We have found that highly directed approaches to self-management such as the Expert Patients Programme tend only to reach a small minority of people (white middle class women) and not the deprived populations most likely to need such support, it also tends to only have small to moderate effects and what was liked most was not the content of the programme itself, but getting in contact with people in similar situations. It worked well when run in conjunction with a supportive local organisation. Any small positive effects were not sustained after the end of the programme and there was a poor fit with existing NHS services.

1. Kennedy A, Reeves D, Bower P, Lee V, Middleton E, Richardson G, Gardner C, Gately C, Rogers A. The effectiveness and cost effectiveness of a national lay led self care support programme for patients with long-term conditions: a pragmatic randomised controlled trial. *J Epidemiol Community Health* 2007;61:254-61.
2. Reeves D, Kennedy A, Fullwood C, Bower P, Gardner C, Gately C, Richardson G, Rogers A. Predicting who will benefit from an Expert Patients Programme self-management course. *British Journal of General Practice* 2008;58:198-203.
3. Gately C, Rogers A, Sanders C. Re-thinking the relationship between long-term condition self-management education and the utilisation of health services. *Social Science & Medicine* 2007;65:934-45.
4. Rogers A, Gately C, Kennedy A, Sanders C. Are some more equal than others? Social comparison in self-management skills training for long-term conditions. *Chronic Illn* 2009;5.
5. Kennedy A, and Rogers A. The needs of others: self-management skills training and the differing priorities of gay men and asylum seekers with HIV. *Health Sociology Review* 2009; 18(2): 145-158
6. Kendall E, Rogers A: Extinguishing the social?: State sponsored self-care policy and the Chronic Disease Management Programme. *Disability and Society* 2007, 22: 129-143
7. Rogers A, Kennedy A, Bower P, Gardner C, Gately C, Reeves D, Richardson G. The UK Expert Patients Programme: results and implications from a national evaluation. *Medical Journal of Australia* 2008;189:S21-S24.

After 2008: social networks and Genie

Self-management support in primary care

Self-management interventions have been traditionally centred on professionals and health systems and prioritise what individuals can do. Policy drivers have been directed at providing support in primary care. We have tested this in a large trial called WISE conducted in north-west England where primary care teams were trained in how to provide self-management support and given resources and backing from the wider health management organisation. This approach had no effect on patient outcomes. We concluded that consultations with primary care based health professionals are not an appropriate place for delivering such services.

1. **Kennedy A, Bower P, Reeves D, Blakeman T, Bowen R, Chew-Graham C et al.: Implementation of self management support for long term conditions in routine primary care settings: cluster randomised controlled trial. *British Medical Journal* 2013, 346.**
2. Kennedy, A., Rogers, A., Bowen, R., Lee, V., Blakeman, T., Gardner, C., Morris, R., Protheroe, J., & Chew-Graham, C. 2014. Implementing, embedding and integrating self-management support tools for people with long-term conditions in primary care nursing: A qualitative study. *International Journal of Nursing Studies*, 51, (8) 1103-1113
3. Kennedy A, Rogers A, Blickem C, Daker-White G and Bowen R. Developing cartoons for long-term condition self-management information. *BMC Health Services Research* 2014, 14:60
4. **Kennedy, A., Rogers, A., Chew-Graham, C., Blakeman, T., Bowen, R., Gardner, C., Lee, V., Morris, R., Protheroe, J., & . 2014. Implementation of a self-management support approach (WISE) across a health system. A process evaluation explaining what did and didn't work for organisations, clinicians and patients. *Implementation Science*, 9:129**
5. Rogers, A., Vassilev, I., Brooks, H., Kennedy, A., Blickem, C. (2016) Brief encounters: do primary care professionals contribute to the self care support network for long-term conditions?: A mixed methods study, *BMC Family Practice*, 17(21), p.1.

A social networks approach

Building on our learning from previous work, we set out to develop an approach less reliant on health professionals for delivery, based in people's everyday lives, less focussed on individuals as isolated actors but focussed on what they do in relation to network members and network processes (see Rogers Imp Sci and Vassilev Chronic Illness). We found that most of the illness related work of people with chronic illness was done not by professionals but by network members and that a diverse set of relationships is likely to be needed for best support (Vassilev PLOS paper). We also found that access to weak ties (Rogers Implementation Science paper) some of those mediated through pets (Brooks Chronic illness paper) was very important although often invisible and not acknowledged.

In a more recent paper where we looked at change in networks over time we also found that the work done by network members reduces the cost (through reduced service use) on

the health service (Reeves PLOS paper). In this study we also found social involvement with a wider variety of people and groups supports personal self-management and physical and mental well-being and support work undertaken by personal networks expands in accordance with health needs helping people to cope with their condition.

In another paper we found that access to strong ties (such as family and friends) is more likely to be utilised by people with higher socio-economic status, while linking to community and voluntary organisations was more likely to be beneficial for people with lower socio-economic status.

1. Rogers A, Vassilev I, Sanders C, Kirk S, Chew-Graham C, Kennedy A *et al.*: Social networks, work and network-based resources for the management of long-term conditions: a framework and study protocol for developing self-care support. *Implementation Science* 2011, 6.
2. Vassilev I, Rogers A, Sanders C, Kennedy A, Blickem C, Protheroe J *et al.*: Social networks, social capital and chronic illness self-management: a realist review. *Chronic Illness* 2011, 7.
3. Vassilev, I., Rogers, A., Blickem, C., Brooks, H., Kapadia, D., Kennedy, A., Sanders, C., Kirk, S., & Reeves, D. 2013. Social Networks, the 'Work' and Work Force of Chronic Illness Self-Management: A Survey Analysis of Personal Communities. *PLoS ONE*, 8, (4) e59723
4. Vassilev I, Rogers A, Kennedy A, Koetsenruijter J (2014) The influence of social networks in self-management support: metasynthesis. *BMC Public Health*, 14: 719.
5. Reeves D, Blickem C, Vassilev I, Brooks H, Kennedy A, Richardson G, Rogers A (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): 398340.
6. Vassilev I, Rogers A, Sanders C, Cheraghi-Sohi S, Blickem C, Brooks H, Kapadia D, Reeves D, Doran T, Kennedy A. (2014) Social status and living with a chronic illness: An exploration of assessment and meaning attributed to work and employment. *Chronic Illness*, doi:10.1177/1742395314521641
7. Rogers, A., Brooks, H., Vassilev, I., Kennedy, A., Blickem, C., & Reeves, D. 2014. Why less may be more? : a mixed methods study of the work and relatedness of 'weak' ties in supporting long term condition self- management. *Implementation Science*
8. Brooks HL, Rogers A, Kapadia D, Pilgrim J, Reeves D, Vassilev I: Creature comforts: personal communities, pets and the work of managing a long-term condition. *Chronic Illness* 2013, 9: 87-102.
9. Vassilev, I., Rogers, A., Kennedy, A., Wensing, M., Koetsenruijter, J., Orlando, R., Portillo, M., Culliford, D. (2016) Social network type and long-term condition management support: a cross-sectional study in six European countries, *PlosOne*, 11(8), e0161027
10. Allen, C., Vassilev, I., Kennedy, A., Rogers, A. (2016) Reaching the parts offline support can't: Long-term condition illness work in online communities. A meta-synthesis of qualitative studies, *Journal of Medical Internet Research*, 18(3), e61.
11. Koetsenruijter, J., van Eikelenboom, N., van Lieshout, J., Vassilev, I., Lionis, C., Todorova, E., ... & Angelaki, A. (2016). Social support and self-management

capabilities in diabetes patients: an international observational study. *Patient education and counseling*, 99(4), 638-643.

12. Marqués-Sánchez, P., Muñoz-Doyague, M., Martínez, Y., Everett, M., Serrano-Fuentes, N., Van Bogaert, P., Vassilev, I. and Reeves, D. (2018) The importance of external contacts in job performance: a study in healthcare organizations using social network analysis. *International journal of environmental research and public health*, 15(7), p.1345.
13. Ellis, J., Vassilev, I., Kennedy, A., Moore, M., & Rogers, A. (2019). Help seeking for antibiotics; is the influence of a personal social network relevant? *BMC Family Practice*, 20, [63]. DOI: 10.1186/s12875-019-0955-2
14. **Band, R., James, E., Culliford, D., Dimitrov, B., Kennedy, A., Rogers, A., & Vassilev, I. (2019). Development of a measure of collective efficacy within personal networks: A complement to self-efficacy in self-management support? *Patient Education and Counseling*. DOI: 10.1016/j.pec.2019.02.026**
15. **Reidy, C., Foster, C., & Rogers, A. (2019). A novel exploration of the support needs of people initiating insulin pump therapy using a social-network approach: a longitudinal mixed-methods study. *Diabetic Medicine*, [DME-2019-00314]. DOI: 10.1111/dme.14155**
16. Serrano Fuentes, N., Rogers, A., & Portillo, M. C. (2019). Social network influences and the adoption of obesity-related behaviours in adults: a critical interpretative synthesis review. *BMC Public Health*, 19, [1178]. DOI: 10.1186/s12889-019-7467-9
17. Allen, C., Vassilev, I., Lin, S. X., Culliford, D., & Rogers, A. (2019). The contribution of internet use in personal networks of support for long-term condition self-management. *Chronic Illness*, 15(3), 220-235. DOI: 10.1177/1742395318759588
18. Allen, C., Vassilev, I., Kennedy, A., & Rogers, A. (2019). The work and relatedness of ties mediated online in supporting long-term condition self-management. *Sociology of Health & Illness*. DOI: 10.1111/1467-9566.13042

Linking to voluntary and community organisations

One element of GENIE is the facility to link people with local voluntary and community organisations (VCOs) they are interested in. We reviewed the effectiveness of social interventions to link people attending health services to community support, most interventions are facilitator led. We have studied how VCOs influence self-management, people often join VCOs in response to a health-related event. We have also explored how VCOs construe the type of support they offer to people with long-term conditions. We have explored the wider role of engagement with local and community groups in supporting self-management through a focus on asset-based community development approaches.

1. **Mossabir, R., Morris, R., Kennedy, A., Blickem, C., & Rogers, A. 2014. A scoping review to understand the effectiveness of linking schemes from healthcare providers to community resources to improve the health and well-being of people with long-term conditions. *Health and Social Care in the Community*, doi: 10.1111/hsc.12176,**
2. **Jeffries, M., Mathieson, A., Kennedy, A., Kirk, S., Morris, R., Blickem, C., Vassilev, I. and Rogers, A. (2014) Participation in voluntary and community organisations in the United Kingdom and the influences on the self-management of long-term conditions. *Health & Social Care in the Community*, doi: 10.1111/hsc.12138**

3. Morris, R., Kirk, S., Kennedy, A., Vassilev, I., Jeffries, M., Blickem, C., Brooks, H., Sanders, C., & Rogers, A. 2014. Connecting local support: a qualitative study exploring the role of voluntary organisations in long-term condition management. *Chronic Illness*, DOI: 10.1177/1742395314551098
4. **Harrison, R., Blickem, C., Lamb, J., Kirk, S., & Vassilev, I. (2019). Asset-based community development: narratives, practice, and conditions of possibility - a qualitative study with community practitioners. *SAGE Open*, 9(1), 1-11. DOI: 10.1177/2158244018823081**
5. Blickem, C., Dawson, S., Kirk, S., Vassilev, I., Mathieson, A., Harrison, R., Bower, P. and Lamb, J. (2018) What is asset-based community development and how might it improve the health of people with long-term conditions? A realist synthesis. *SAGE Open*, 8(3), p.2158244018787223.
6. Bossy, D., Foss, C., Knutsen, I., & Rogers, A. Institutional logic in self-management support: coexistence and diversity. *Health & Social Care in the Community*, 1-25.
7. **Rogers, A., Vassilev, I., Pumar, M. J. J., Todorova, E., Portillo, M. C., Foss, C., ... Lionis, C. (2015). Meso level influences on long term condition self-management: stakeholder accounts of commonalities and differences across six European countries. *BMC Public Health*, 15(622), 1-11. DOI: 10.1186/s12889-015-1957-1**

Implementation and evaluation

Genie has been implemented in a range of contexts supporting different populations including people with long-term conditions, people who are lonely or isolated.

An earlier version of the GENIE intervention (without the network diagram) was called PLANS (Blickem papers). This part of the intervention includes questions developed to elucidate people's preferences for activities or resources related to well-being, health and support. These were used as part of a RCT telephone support intervention for people with chronic kidney disease which had positive outcomes (for blood pressure and quality of life) (Blakeman PLOS paper).

In the current version of GENIE the intervention includes network mapping and existing network members are linked to activities and local resources valued by the participant. The analysis has demonstrated impact on a range of health and well being outcomes for different populations. In two RCTs we have also demonstrated savings of £175 and £220 per user of Genie.

1. James, E., Kennedy, A., Vassilev, I., Ellis, J., & Rogers, A. (2020). Mediating engagement in a social network intervention for people living with a long-term condition: a qualitative study of the role of facilitation. *Health Expectations*. DOI: 10.1111/hex.13048
2. **Bloom, I., Welch, L., Vassilev, I., Rogers, A., Jameson, K., Cooper, C., ... Baird, J. (2020). Findings from an exploration of a social network intervention to promote diet quality and health behaviours in adults with COPD: a feasibility study. *Pilot and Feasibility Studies*, 6, [15]. DOI: 10.1186/s40814-020-0553-z**
3. **Vassilev, I., Rogers, A., Kennedy, A., Oatley, C. and James, E., 2019. Identifying the processes of change and engagement from using a social network intervention for**

- people with long-term conditions. A qualitative study. *Health Expectations*, 22(2), pp.173-182.**
4. Reidy, C., Bracher, M., Foster, C., Vassilev, I., & Rogers, A. (2018). The process of incorporating insulin pumps into the everyday lives of people with Type 1 diabetes: a critical interpretive synthesis. *Health Expectations*, 21(4), 714-729.
DOI: 10.1111/hex.12666
 5. Walker, S., Kennedy, A., Vassilev, I., & Rogers, A. (2018). How do people with long-term mental health problems negotiate relationships with network members at times of crisis?. *Health Expectations*, 21(1), 336-346.
 6. **Kennedy, A., Vassilev, I., James, E., & Rogers, A. (2016). Implementing a social network intervention designed to enhance and diversify support for people with long-term conditions. A qualitative study. *Implementation Science*, 11(27), 1-15.
DOI: 10.1186/s13012-016-0384-8**
 7. Vassilev, I., Rowsell, A., Pope, C., Kennedy, A., O’Cathain, A., Salisbury, C., & Rogers, A. (2015). Assessing the implementability of telehealth interventions for self-management support: a realist review. *Implementation Science*, 10(1), 1-25.
DOI: 10.1186/s13012-015-0238-9
 8. **Blakeman, T., Blickem, C., Kennedy, A. P., Reeves, D., Bower, P., Gaffney, H., ... Rogers, A. (2014). Effect of information and telephone-guided access to community support for people with chronic kidney disease: randomised controlled trial. *PLoS ONE*.
DOI: 10.1371/journal.pone.0109135**
 9. **Blickem C, Kennedy A, Vassilev I, Morris R, Jariwala P, Blakeman T et al.: Linking people with long-term health conditions to healthy community activities: development of Patient-Led Assessment for Network Support (PLANS). *Health Expectations* 2013, Sep;16(3):e48-59. doi: 10.1111/hex.12088. Epub 2013 Jun 3**
 10. **Blickem C, Kennedy A, Jariwala P, Morris R, Bowen R, Vassilev I et al.: Aligning everyday life priorities with people's self-management support networks: an exploration of the work and implementation of a needs-led telephone support system. *BMC Health Services Research* 2014, 14: 262.**

Developing theory

We have been working towards developing a theory of social network support based on the emerging empirical evidence. Social networks influence self-management support through three mechanisms: navigation, negotiation and collective efficacy. The dynamics and nature of support within networks suggests four types of network: generative, proxy, avoidant and struggling.

1. Vassilev, I., Rogers, A., Sanders, C. Kennedy, A. Blickem, C. Protheroe, J., Bower, P. Kirk, S., Chew-Graham C. & Morris, R (2010) Social networks, social capital and chronic illness self-management: a realist review, *Chronic Illness*, 7(1): 60-86.
2. Vassilev, I., Rogers, A., Kennedy, A., & Koetsenruijter, J. 2014. The influence of social networks on self-management support: a metasynthesis. *Bmc Public Health*, 14, (1) 719
3. Kennedy, A., Rogers, A., Vassilev, I., Todorova, E., Roukova, P., Foss, C., Knutsen, I., Portillo, M.C., Mujika, A., Serrano-Gil, M., Lionis, C., Angelaki, A., Ratsika, N., Koetsenruijter, J., & Wensing, M. 2014. Dynamics and nature of support in the

- personal networks of people with type 2 diabetes living in Europe: qualitative analysis of network properties. 2014 *Health Expectations*, doi: 10.1111/hex.12306,
4. Vassilev, I., Rogers, A., Kennedy, A., Todorova, E., Roukova, P. (2017) The articulation of neoliberalism: narratives of experience of chronic illness management in European context, *Sociology of Health and Illness*, 39 (3).
 5. Vassilev, I., Band, R., Kennedy, A., James, E., & Rogers, A. (2019). The role of collective efficacy In long-term condition management: a metasynthesis. *Health and Social Care in the Community*. DOI: 10.1111/hsc.12779