



Mediating engagement in a social network intervention for people living with a long-term condition: a qualitative study of the role of facilitation

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Abstract:

Background: Successful facilitation of patient centred interventions for self-management support has traditionally focussed on individual behaviour change. A social network approach to self-management support implicates the need for facilitation that includes an orientation to connecting to and mobilizing support and resources from other people and the local environment.

Objective: To identify the facilitation processes through which engagement with a social network approach to self-management is achieved.

Method: Thematic analysis was used to analyse data from a longitudinal study design using quasi-ethnographic methods comprising non-participant observation, video and qualitative interviews involving 30 participants living with a long-term condition recruited from a marginalised community.

Results: Findings centred on three themes about the social network approach facilitation processes: Reversing the focus on the self by bringing others into view; Visualisation and reflection as a mediator of positive disruption and linking to new connections; Personalised matching of valued activities as a means of realising preference elicitation.

Discussion and conclusions: Engagement processes with a social network approach illuminated the relevance of cognisance of an individual's immediate social context and forefronting social participation with others as the bases of self-management support of a long-term condition. This differs from traditional guided facilitation of health behaviour interventions that frame health as a matter of personal choice and individual responsibility.

KEYWORDS

Patient facilitation, self-management support, social network intervention, social context, social participation

Background

The onset and trajectory of a long-term condition (LTC) often results in a retreat from activities and interactions taking place in the public sphere.¹ People with LTCs identify loss of social contact, the ability to reciprocate and contribute to society and receipt of resources from the community and locality.² The latter has contributed to the burden of illness and preventing living life as fully as possible.^{3,4} A social network approach (SNA) to self-

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3 management provides a means of mobilising, mediating and accessing support.⁵ It enables
4 people to access and incorporate the resources and connections that provide support for
5 living everyday life and requires attention to be placed on the local environments as a means
6 of engaging individuals in self-management support (SMS) activities.⁵ Whilst guided
7 facilitation is recognised as a necessary component of implementing patient-centred
8 interventions and means of engaging with patients in introducing strategies and practices of
9 SMS^{6,7,8}, little attention has been given to how to effectively bring into view and facilitate
10 elements of social context relevant to a social networked and broader orientation to SMS.
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18 In theory, the delivery of self-management interventions and shared decision-making
19 acknowledge the role of social context.^{9,10,11} In practice, the social and emotional aspects
20 tend to be side-lined whilst SMS trainers' primary orientation is towards prioritising pre-
21 determined health behaviour change and individuals' capacity and responsibility to initiate
22 and sustain strategies for self-management.^{12,13,14,15} Research suggests a risk of creating a
23 sense of disempowerment from a traditional, guided facilitation approach (e.g. Behavioural
24 activation) stemming from the need for individuals to acknowledge that they are unable to
25 cope alone without professionals' support. This in turn risks compounding feelings of
26 worthlessness, low mood and loss of a valued identity.¹⁶
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33 By contrast, the design of facilitation in a SNA needs to reflect as a central tenet the social
34 context and possibilities for social participation relevant to people's lives, particularly of those
35 living in disadvantaged circumstances.^{17,18} Thus, the elements and process of the successful
36 facilitation of socially orientated and networked interventions are likely to differ in terms of
37 processes as well as content. **Building rapport and good communication skills are important
38 pre-requisites for facilitating any SMS intervention. However, a SNA differs in its facilitation
39 processes in orientation towards the idea of connections and linkages based on what is
40 familiar to people in their everyday, domestic lives. There is a need to explore and better
41 understand the nuances of these processes and the potential for achieving engagement by
42 focusing on what is external to the person rather than the focus being internal as part of a
43 personalised, therapeutic process.**
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53 **A social networked intervention (SNI) and facilitation of SMS**

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55 Facilitation of a SNI centres on connecting people to and engaging them in relationships,
56 valued activities and resources through participating in local activities.¹⁹ This is informed by a
57 capabilities approach, which suggests that opportunities individuals have to undertake
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3 valued activities are shaped by interactions between individuals, their environment and in
4 particular their social relationships and expressions of values and preferences.^{20,21}
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9 **The social networked intervention**

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11 An online tool (GENIE—Generating Engagement in Network Involvement) maps social
12 networks, helping people to select their preferences and engage with local support
13 resources. The components of GENIE are described in Table 1:
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17 Table 1 Components of GENIE
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20 21 The role of facilitation

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24 **a) Personal network mapping:** A modified, hierarchical mapping technique using three
25 concentric circles to create visual representations of personal communities.^{22,23}
26 Constructing the network involves the person and facilitator in seeking to understand
27 the actual and potential environment that has relevance for leveraging what is
28 beneficial to living daily life with a LTC.²⁴ This requires the **facilitator to place the**
29 **emphasis on the participant at the centre of the circle and encourage** them to think
30 about why and how some people and resources might be more or less important to
31 them.²⁵
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38 **b) Preference elicitation and linking to resources:** Reflecting on availability and
39 connection to localized support and resources based on personal preferences and
40 acceptability that provide opportunities and encouragement to engage with
41 sustainable health choices.
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46 **Previous research suggested that GENIE worked best as a facilitated process (Kennedy,**
47 **2016), rather than being completed by an individual alone, but questions remain about the**
48 **content and mechanisms of facilitation when using a SNA in a community setting. We were**
49 **interested in exploring the facilitator role when taken up by lay health workers living and**
50 **working in the same community setting as participants, as they were likely to be familiar with**
51 **the culture and values of that locality.**
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58 Research aims

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3 To explore the role of facilitation of a SNI delivered by lay health workers in a community
4 setting.

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6 To identify the facilitation processes through which engagement with a SNA to SMS is
7 achieved.
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10 Methods

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13 A longitudinal, case study design using ethnographic methods comprising non-participant
14 observation, video recording and qualitative interviews. **Participants (n=30)** living with a LTC
15 were recruited from a marginalised community. Data collected (T1) comprised visually
16 recordings of intervention delivery, observational notes and audio recordings of post-
17 intervention interviews. **The use of videos allowed members of the research team to observe**
18 **each intervention taking place, rather than a single researcher, and enabled a more**
19 **accurate, nuanced and collective analysis of the facilitation process.**
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26 **Follow up data were collected at 3 months (T2, face-to-face semi-structured interviews) and**
27 **6 months (T3, telephone interviews) to capture change over time. The circle diagram**
28 **captured changes over time in the position of network members on the map (Vassilev,**
29 **2018). The mapping exercise was also a heuristic device which could indicate relational**
30 **shifts in people's lives over time and enabled the facilitator to elicit people's underlying**
31 **rationales for these. Data collected at different time points reflected how things changed**
32 **subtly, including small changes in relationships and changes in meanings of relationships.**
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39 **Audio recordings were transcribed verbatim. Thematic analysis informed by framework**
40 **analysis included a priori codes /categories relating to the role of facilitation and facilitation**
41 **processes, alongside an inductive approach whereby coding and theme generation were**
42 **directed by the content of the data. Initial coding and collating were undertaken by**
43 **researcher (EJ) to identify broad patterns of meaning prior to the viability of potential themes**
44 **being discussed and agreed within the team. In addition, parts of the dataset were coded**
45 **independently (AR/AK/IV/JE) to ensure inter-rater reliability and coding consistency. Themes**
46 **were refined and defined, including a detailed analysis of each theme to draw out key**
47 **findings.**
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54 **Most salient to this study was engagement in the network mapping, as an initial exercise.**
55 **However, we were also interested in how people reflected over time. Engagement means**
56 **participation in the mapping exercise and what it represents for people in terms of their own**
57 **micro-social world. Engagement is when people's attention is on things outside of**
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3 themselves, e.g. thinking about the people around them and what these people do. On the
4 participant's part, engagement also manifests in raised awareness and reflection over time
5 of the benefits of adopting a SNA to SMS.
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11 Sample and recruitment

12 The sample was drawn from a marginalised community, the Isle of Wight. Separated from
13 the mainland, social, economic and political barriers contribute to the marginalisation of the
14 Island, as does an aging, vulnerable population (27% aged 65+ years, 1 in 6 of whom live
15 alone). The full sample took part in observations and interviews (3 participants withdrew).
16 Table 2 shows participants' age, gender, LTC and where the intervention took place.
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22 Participants were recruited via two routes. Firstly, lay health workers identified clients who
23 matched the inclusion criteria, introduced them to the study and invited them to participate.
24 Secondly, the researcher and PPI representative visited support groups (e.g. Diabetes
25 Support Group, Heart Care Club) for recruitment purposes. The facilitator met with the
26 participant on one occasion to deliver GENIE. The researcher was responsible for all the
27 follow-up data collection. Services employing lay health workers were approached to discuss
28 involvement in the research, including training, identifying participants and intervention
29 delivery. Facilitators comprised Health Trainers (n=4), Care Navigators (n=3), Community
30 Navigators (n=1) and Local Area Co-ordinators (n=1). A PPI representative and researchers
31 (n=3) were also trained.
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42 Figure 1 Co-production of network map: participant reflections
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46 Results

47 Observational data provided a visual record of facilitation style, how participants related to
48 facilitators and how comfortable they appeared physically. Notes taken on body language
49 and gestures (e.g. leaning towards laptop screen, pointing to network map, positive
50 response to visual cues) indicated that most participants felt at ease with the facilitator and
51 engaged in the network mapping. Observations revealed that a natural balance of eye
52 contact between participant, laptop and paperwork on the part of the facilitator helped to
53 maintain engagement and co-production.
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59 Text box 1
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Facilitation is viewed as something that is initially co-produced but orientated towards individual ownership of the network map and links to favoured activities. Three themes illuminated the social network mapping and preference linking processes:

1. *Reversing the focus on the self and bringing others into view*
2. *Visualisation and reflection as a mediator of positive disruption and linking to new connections*
3. *Personalised matching of valued activities a means of realising preference elicitation*

1. *Reversing the focus on the self and bringing others into view*

An exclusive focus on individuals' capacity and responsibility to initiate and sustain strategies for self-management can leave those living with a LTC feeling stigmatised and labelled as unable to cope with daily activities. In contrast, co-creation and engagement in network mapping provided a shared activity of both 'doing' and 'interacting' in which respondents began to reverse the focus on the 'self' and bring others into view as attention shifted towards relationships with the people around them. Refocusing away from self, towards other external, relevant sources of support (emotional, practical, physical, spiritual), helped to reduce the risk of acopia whilst increasing feelings of self-worth.

This respondent shifted focus towards support derived from her daughter and pets, when recently widowed:

"If it hadn't been for my daughter and the dog and cat I wouldn't have coped..... I would probably have just crumbled into a little ball.....(the dog) gets me out, gets me going for walks and is very loving. She shows me a lot of love.....it's those stupid little sounding things that keep me going" (HF14)

Face-to-face facilitation provided opportunities for respondents to cognitively re-frame responsibility for LTC management from 'individual' to 'shared'. Facilitators used name generating prompts to elicit successive recall of types of network members (e.g. friends, family, groups, pets), encouraging respondents to expand and diversify their networks:

"If you are looking at it on a computer you think 'Right, ok, what support have I got?' and you wrack your brain trying to think but actually doing it face to face with somebody you can get prompted to think 'Yes, there are more people'. So, then it's actually drawing on those resources, friends, relatives, GPs, pharmacist, whoever, to actually help you get what you need and the support you need" (EU09)

Facilitator prompts were assistive aspects of co-creating the network map:

"I personally think it's better facilitated because there can be the odd prompt, 'Where do you think it sits better there or there?' And then underneath that, why? Because if you are sitting on your own you won't ask yourself those questions, you don't do you, unless you are particularly self-aware? Some people will go through that mental checklist but most people won't" (HF07)

"...but I wouldn't have had all those names down on my own, I certainly wouldn't. I would have looked at it and said who is important? 'Oh [stepdaughter 1] is' and then I would be looking at.. yes, the doctor is but I wouldn't have been, some of these round the outer ones, I wouldn't even dream that they were anything to do with it. So, it was.... you need a bit of a prompt.....my outlook has changed" (EU11)

Conversations embedded in the network mapping activity enabled respondents to move from network member identification to reflect on social and emotional aspects of their relationships, environments and preferences. Facilitated conversation helped to 'unpack' thoughts and beliefs, highlighting the value of social relationships and practices as respondents considered the nature of support associated with particular individuals and groups:

"Each one has a life of its own, it's not just a name or just a club. If I go back to one in particular, the Heart Care Club, there's 15 people there, each one of them I know. I've been going for six years now and I know about them all, I know about their families, I know about their problems, they know about my problems and that sharing of information is very powerful in terms of dealing with things and the inclination to keep it to yourself diminishes because we all, maybe it's a masculine thing," (HF07)

"Well it makes me think about things more if you know what I mean? You take a lot of things for granted and think well that's happening but unless you have them [facilitator]come along, I'd just have been accepting all these things but not putting them in any sort of position in my life. It's made me think more about what does [name] do for me?.. or what does another person do for me?" (EU11)

Relying on others and negotiating support was not always easy:

"Well, it makes you think of different ways that you could do things and I suppose it makes you look at yourself as well..... it makes you evaluate what people will do and what they won't do. I suppose because I've always been independent and rely on

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3 *myself and not other people it's harder to rely on other people or ask them to help, to*
4 *be quite honest” (HF15)*
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7 Facilitated conversations around the network mapping exercise helped respondents let
8 go of expectations from ‘strong’ ties (family) and value social connections with friends
9 and acquaintances (weak ties). Expressing a perceived lack of family support (son had
10 no time to help in the garden; limited contact with sisters), one respondent was able to
11 re-focus on the value of regular visits, shared time and activities with ‘more reliable’,
12 longstanding friendships. Similarly, this respondent was able to acknowledge the
13 importance of ‘weak ties’/acquaintances in his everyday life:
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19 *R: I get an awful lot of support from people that most of.... a lot of people take for*
20 *granted. I don't take the ladies in Morrison's for granted..... or the staff in the Co-*
21 *op..... or bus drivers. I'm aware, but.... a lot of people aren't that aware of that”*
22 *(HF.02)*
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26 Facilitation helped people reflect on the value of shared activities, replacing individual
27 pursuits with joint activities. This respondent took up walking, which became a shared
28 activity with her partner:
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31 *“It may have been that the session that we did maybe made me more mindful of the*
32 *fact that I needed to do more walking and stuff....I've done some walks, quite a few*
33 *walks actuallyand then we [partner and respondent] joined English Heritage and*
34 *National Trust, so it went from there really. It was a gentle walking programme at*
35 *work.....I was keen to do the walking and found that that was really enjoyable, so I've*
36 *stuck with the walking.....” (HF04).*
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43 **2. Visualisation and reflection as a mediator of positive disruption and linking to** 44 **new connections.** 45

46 Visualisation and reflection on the completed network map enabled sense to be made of a
47 novel means of support and how it could be accessed. Reflection on existing network
48 membership opened up possibilities for evaluating the present and anticipating, rehearsing
49 and reconstructing self-management differently for the future.
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52 This respondent acknowledged the value of visualisation through reflecting on the meaning
53 and value that new options for the future might bring in terms of socialising with others:
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3 R: *...a support network tends to go with going out socialising, because if you are not*
4 *going out socialising as much then the support network is not necessarily there, do*
5 *you know what I mean? So, I haven't been going out as much the last year because*
6 *of my illness, so I don't tend to socialise much with people. So, I have been reflecting*
7 *on that....., it did help me, just the visual....cos I'm a very visual learner, so a very*
8 *visual thing has helped” (HF04)*
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13 Rather than SMS being associated solely with the inner motivational life of an individual in
14 relation to behaviour change, reflection on network support through visualisation enabled
15 normalisation of SMS in everyday life and all it involves in terms of social environment,
16 relationships and activities. The following respondent's terminology reflects this, referring to
17 the collective 'we' and 'getting on with our lives', i.e. not 'I', getting on with 'my' life:
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22 *.....it made me focus at a conscious level on the support infrastructure that I have*
23 *available. And that made me feel good, because we're trying to get on with getting on, we're*
24 *getting on with our lives and at an intellectual level you don't rationalise what's going on*
25 *around you. You don't think about it, you sort of take it for granted. And I found the process*
26 *enlightening, because it reminded me of how well supported I am. Which I have to say is*
27 *very, very powerful. it reminded me of what resources I have....it was a useful reminder*
28 *of how many people there are out there that I can access if I need to (HF07)*
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33 Co-creating a visual image of a person's support network seemed to enhance the process of
34 identifying and triggering network members:
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37 *“When you first start off, you start thinking, yes I've got my wife, I speak to my mum, I*
38 *had Diabetes UK.... but then everything else it's like opening up the flood gate! You*
39 *don't realise....Oh yes, I have got things that I can do. I have got people that are*
40 *around me'.... it's actually knowing the amount of people that you've actually got*
41 *around you that you can call on I've got my healthcare trainer, I've got*
42 *neighbours, podiatrist that I see every six weeks, it opens up a lot more.....and yes*
43 *I've got the next circle, yes I go out, I go to Church, I go to bowls, I can speak to my*
44 *pharmacist and if I don't want to go down to the doctors I'll go down and see the*
45 *pharmacist.....so it opens up like a can of worms.then the can is getting opened*
46 *up more and more and then everything spills out and you find out you have got a lot*
47 *more people around you that you can actually rely on” (EU09)*
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55 This respondent commented on the visual design of the three concentric circles acting as an
56 enabler for prioritising individual network members:
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“When you actually think about, if you write it down on a list, you can’t make sense of it Doing it on there [network map], you’re in the centre and everything works out from around you and when you think about it, like these are the people who are most important..... You start thinking about it, pets, support groups, family all those things there. You can actually see it better if it’s actually like a ripple going out. You see where the ones that are most important to you are in the centre near you and rippling out to who you can actuallyso it is actually better having as a circle than just as a list because..... It’s actually prioritising who is most important to you and that circle gives the best way of doing it” (EU09)

As respondents typically viewed self-management as something they had to do on their own, many were surprised to see more network members in their completed diagram than they had anticipated:

“With your health conditions you’ve got to look after number one and make sure that you are aware of what is going on..... I do that on my own..... It (circle diagram) was making sense. I just hadn’t thought that.....I hadn’t thought about who was supporting me or who is supporting me.....I’m surprised that..... there are some people in the circle!” HF01

3. Personalised matching of valued activities as a means of realising preference elicitation.

Facilitators guided respondents through an online preference questionnaire embedded within the intervention. Questions focused on what people valued doing or used to enjoy doing in the past. Rather than imposing a needs-led framework, guiding people to identify what they enjoyed ensured activities were meaningful and relevant, increasing engagement in accessing community resources. **Participants were guided by their own preference and identified 3 activities that most interested them. Most participants (n=25) contacted/tried a new community resource, 2 participants did not take up activities and 3 participants withdrew (Kennedy, 2016; Vassilev, 2018). Follow up data indicated that participants enjoyed their chosen activities, suggesting a cognitive shift from thinking to doing.**

Perceived lack of status difference between respondent and facilitator further increased engagement and proactivity on the part of the respondent. **The lack of status difference was perceived intuitively from the observational data, as participants seemed at ease and open to working together with the facilitator.**

Facilitated conversations represented a safe space for respondents to reflect on and express inner hopes and future wishes, enabling them to re-connect with the things that could bring enjoyment in everyday life. The following example indicates how a respondent living with mobility impairment shared his dream about experiencing an aqua-lung in a swimming pool:

R: *“I haven’t swum for a long, long time and when I did swim I did get some support and I did have somebody with me the whole time in the water.....*

F: *Is that something you’d think about again if there was support?*

R: *..... what I did dream of doing was having an aqua-lung on my back, going underwater and just sitting on the bottom of the pooljust going into a pool or into a large fish tank, sit on the bottom of the tank and look at the fish going round and then stay there for about 5 minutes and then you come back up and that would have given me a lot of pleasure! You know, an achievement. Well, that’s what I would like to do. I’d still like to do something like that – though I would take medical advice even now on that - but that’s one thing I would love to be able to do” (EU02)*

Aligning people’s preferences and activity choices with their social connections, relationships and environment, increased accessibility to activities and sustained engagement. However, findings also revealed social situations and environments that posed challenges. The following respondent was unable to remain in full-time employment due to a LTC, but had identified a voluntary work opportunity which offered her purpose, social contact and fulfilment. Guided facilitation that took into account social and emotional aspects of everyday life enabled reflection on barriers to pursuing valued activities and future possibilities:

“Yes, I love it (voluntary work) But now I can’t go on Fridays because I’m at (partner’s) mum’s and I can’t get there. I find it hard because I need somebody who will take me in the wheelchair.But everything is on (partner’s) time. It’s when he wants to do it, when he’s ready. ... and I have to fit in. It’s hard, so hard. It’s my lifeline really. .. That’s why I feel trapped at times. Not every day, not all the time but a lot of the time..... I feel trapped because I can’t..... it’s not like I can just get on the bus. I’m so dependent on (partner)” (HF06)

The choice of focusing on lay health workers coalesced with the finding from a previous study that a lack of status difference between facilitator and participant was instrumental in allowing a stronger interpersonal element and reciprocity in the discussion to develop (Kennedy et al 2016). In this community-based study lay health workers met people in a

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3 **place of their choice, usually at home.** This participant comments on who is best placed to
4 deliver the intervention and where this should take place:
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7 *“Where’s the best venue?.....I think we’d have to go back to the home but with the*
8 *caveat that they must have somebody with whom they feel comfortable.....people do*
9 *feel threatened, it’s weird, isn’t it? Why? I don’t know... because that’s people. It’s got*
10 *to be non-threatening and in the conflicts context it was always a neutral ground, you*
11 *went to the pub.....but I’m just saying that was what you did. GPs represent*
12 *authority, like it or not it’s true, what I’ve been trained to believe” (EU12)*
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19 Discussion

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21 Findings from the current study suggest that reversing the focus on self and bringing others
22 into view enables a broader approach to SMS contrasting with traditional, narrower
23 approaches that focus on individualised accountability and responsibility. This broader
24 approach allows co-production work initiated by the facilitator to move towards shared
25 ownership, creating a space in which steer alternates between facilitator and respondent. As
26 attention shifts from self (internal) to others (external), the fluid and flexible nature of this
27 engagement opens up new possibilities for living and managing well that incorporate social
28 relationships and societal participation. **People living with a LTC are often forced to rely on**
29 **their own resources. The SNI helped people to make a cognitive shift from individualised,**
30 **self-management accountability to being ready and receptive to the possibilities of collective**
31 **effort.** This finding resonates with existing research on the purpose of SMS. Morgan et al⁸
32 posited that the purpose of support in narrower approaches to SMS centred on
33 individualized behavioural targets such as lifestyle, self-monitoring and medication taking
34 oriented to biomedical goals. Similarly, facilitation focuses on internal motivation of an
35 individual rather than including those around them. A wider view and scope of facilitation
36 explored here in a SNI highlights the need for a broader vision that incorporates other
37 people, things and activities that are relevant to people’s social contexts, life circumstances
38 and lived experiences.
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51 Findings demonstrate that facilitating visualisation and reflection and expediting engagement
52 with the network mapping exercise, act to assist with positive disruption of established self-
53 management practices. Coherence and shift in perception of SMS from a process that
54 focuses exclusively on the individual to one that incorporates a focus on collective elements
55 and processes occur partly through the co-creation of a visual image of a person’s support
56 network. All respondents entered into the shared network mapping activity with the facilitator
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3 and were able to reflect on its purpose in terms of sense making of how those around them
4 operated as a, or potential, source of support or access to resources that would help with
5 self- management. This suggests that when the complexities of person's life world are
6 presented in a visual format (concentric circles diagram), the information and its implications
7 in terms of personal possibilities and challenges become more accessible, breaking down
8 barriers to health inequality and improving health literacy. In relation to accessibility and
9 sense making, Antonucci²² reported a similar finding when he first introduced the concentric
10 circles hierarchical mapping technique to examine social support networks, commenting that
11 the technique seemed to 'transcend culture, age, life situation and crisis'. However, where
12 the current study adds to this proven technique is by using the image of an existing support
13 network to link into new social connections, imagine future possibilities and increase social
14 participation. Moreover, recognition of people's life worlds and habitus as part of a broader
15 entry into therapeutic landscapes has been highlighted as a means of living life well with a
16 LTC.²⁶

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18 Empowerment and engagement were seemingly attained through the act of facilitation in
19 which meaningful, enjoyable activities were identifiable and alignment could be made of
20 valued preferences with people's social connections, relationships and environment in order
21 to incorporate these into everyday life.

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34 Text box2: Working example

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36 This process suggests that when people identify and are linked to valued activities that
37 match what they enjoy doing, social participation is likely to increase in turn supporting
38 people to manage better in everyday life. Reflecting on what people used to do in the past
39 but no longer do is a powerful means of reintroducing the familiar and for people to
40 reconnect with valued activities from the past.³ It also acts as a counter to traditional
41 approaches to SMS which identify with a predominant focus on education and advice-giving
42 where attention to psycho-emotional issues patients face take a back seat¹⁴ highlighting the
43 need for facilitation to take into account the complexities of social circumstances and
44 emotional responses of people. Implications for future training of healthcare professionals in
45 self-management point to the need for a basis of trust, questioning and flexibility¹⁴. The
46 current study points to how a SNA can incorporate the social, emotional and environmental
47 needs required for creating a meaningful life in chronic illness management. In addition to
48 relational aspects of facilitation, other aspects, such as awareness of locality, a sensitivity to
49 and understanding of the bases of the value attributed to relationships and people's personal
50 networks, collective community and social activities taking place locally are relevant. Thus, a
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3 core element of future facilitation is the requirement of the development of a facilitator's
4 empathy for the life worlds of individuals, in order that mutual empathy can lead to rapport
5 and co-appreciation of the preferences and choices being elicited and the links forged to
6 others in a personal network. The latter is perhaps a salient quality to add to the facilitator-
7 patient relationship and addition to the lexicon of person-centred interventions taking place
8 in primary care and community settings.
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15 Limitations

16 Data for this study comprised observations of the intervention delivery and qualitative, post-
17 intervention interviews with participants. Data collected directly from facilitators was limited
18 to group feedback from lay health workers who took on the GENIE facilitator role for
19 research purposes. Future research would benefit from conducting qualitative interviews with
20 facilitators.
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28 Conclusions

29 **Our findings indicate that facilitating a SNI that includes a network mapping exercise as the**
30 **key object of engagement requires an orientation towards the idea of connections and**
31 **linkages and skills of enabling the exploration of relationships and interactions within**
32 **people's everyday social world** and requires an appreciation of the social environment and
33 sense of place in order that the two people involved can work together authentically.
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3 Abstract:

4
5 **Background:** Successful facilitation of patient centred interventions for self-
6 management support has traditionally focussed on individual behaviour change. A
7 social network approach to self-management support implicates the need for
8 facilitation that includes an orientation to connecting to and mobilizing support and
9 resources from other people and the local environment.

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14 **Objective:** To identify the facilitation processes through which engagement with a
15 social network approach to self-management is achieved.

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18 **Method:** Thematic analysis was used to analyse data from a longitudinal study
19 design using quasi-ethnographic methods comprising non-participant observation,
20 video and qualitative interviews involving 30 participants living with a long-term
21 condition recruited from a marginalised community.

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25 **Results:** Findings centred on three themes about the social network approach
26 facilitation processes: Reversing the focus on the self by bringing others into view;
27 Visualisation and reflection as a mediator of positive disruption and linking to new
28 connections; Personalised matching of valued activities as a means of realising
29 preference elicitation.

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34 **Discussion and conclusions:** Engagement processes with a social network
35 approach illuminated the relevance of cognisance of an individual's immediate social
36 context and forefronting social participation with others as the bases of self-
37 management support of a long-term condition. This differs from traditional guided
38 facilitation of health behaviour interventions that frame health as a matter of personal
39 choice and individual responsibility.

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43 KEYWORDS

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46 Patient facilitation, self-management support, social network intervention, social
47 context, social participation
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49 50 51 Background

52
53 The onset and trajectory of a long-term condition (LTC) often results in a retreat from
54 activities and interactions taking place in the public sphere.¹ People with LTCs identify loss of
55 social contact, the ability to reciprocate and contribute to society and receipt of resources
56 from the community and locality.² The latter has contributed to the burden of illness and
57 preventing living life as fully as possible.^{3,4} A social network approach (SNA) to self-

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3 management provides a means of mobilising, mediating and accessing support.⁵ It enables
4 people to access and incorporate the resources and connections that provide support for
5 living everyday life and requires attention to be placed on the local environments as a means
6 of engaging individuals in self-management support (SMS) activities.⁵ Whilst guided
7 facilitation is recognised as a necessary component of implementing patient-centred
8 interventions and means of engaging with patients in introducing strategies and practices of
9 SMS^{6,7,8}, little attention has been given to how to effectively bring into view and facilitate
10 elements of social context relevant to a social networked and broader orientation to SMS.
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18 In theory, the delivery of self-management interventions and shared decision-making
19 acknowledge the role of social context.^{9,10,11} In practice, the social and emotional aspects
20 tend to be side-lined whilst SMS trainers' primary orientation is towards prioritising pre-
21 determined health behaviour change and individuals' capacity and responsibility to initiate
22 and sustain strategies for self-management.^{12,13,14,15} Research suggests a risk of creating a
23 sense of disempowerment from a traditional, guided facilitation approach (e.g. Behavioural
24 activation) stemming from the need for individuals to acknowledge that they are unable to
25 cope alone without professionals' support. This in turn risks compounding feelings of
26 worthlessness, low mood and loss of a valued identity.¹⁶
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33 By contrast, the design of facilitation in a SNA needs to reflect as a central tenet the social
34 context and possibilities for social participation relevant to people's lives, particularly of those
35 living in disadvantaged circumstances.^{17,18} Thus, the elements and process of the successful
36 facilitation of socially orientated and networked interventions are likely to differ in terms of
37 processes as well as content. Building rapport and good communication skills are important
38 pre-requisites for facilitating any SMS intervention. However, a SNA differs in its facilitation
39 processes in orientation towards the idea of connections and linkages based on what is
40 familiar to people in their everyday, domestic lives. There is a need to explore and better
41 understand the nuances of these processes and the potential for achieving engagement by
42 focusing on what is external to the person rather than the focus being internal as part of a
43 personalised, therapeutic process.
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53 **A social networked intervention (SNI) and facilitation of SMS**

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55 Facilitation of a SNI centres on connecting people to and engaging them in relationships,
56 valued activities and resources through participating in local activities.¹⁹ This is informed by a
57 capabilities approach, which suggests that opportunities individuals have to undertake
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3 valued activities are shaped by interactions between individuals, their environment and in
4 particular their social relationships and expressions of values and preferences.^{20,21}
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9 **The social networked intervention**

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11 An online tool (GENIE—Generating Engagement in Network Involvement) maps social
12 networks, helping people to select their preferences and engage with local support
13 resources. The components of GENIE are described in Table 1:
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16
17 Table 1 Components of GENIE
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20 21 The role of facilitation 22

- 23
24 **a) Personal network mapping:** A modified, hierarchical mapping technique using three
25 concentric circles to create visual representations of personal communities.^{22,23}
26 Constructing the network involves the person and facilitator in seeking to understand
27 the actual and potential environment that has relevance for leveraging what is
28 beneficial to living daily life with a LTC.²⁴ This requires the facilitator to place the
29 emphasis on the participant at the centre of the circle and encourage them to think
30 about why and how some people and resources might be more or less important to
31 them.²⁵
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38 **b) Preference elicitation and linking to resources:** Reflecting on availability and
39 connection to localized support and resources based on personal preferences and
40 acceptability that provide opportunities and encouragement to engage with
41 sustainable health choices.
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46 Previous research suggested that GENIE worked best as a facilitated process (Kennedy,
47 2016), rather than being completed by an individual alone, but questions remain about the
48 content and mechanisms of facilitation when using a SNA in a community setting. We were
49 interested in exploring the facilitator role when taken up by lay health workers living and
50 working in the same community setting as participants, as they were likely to be familiar with
51 the culture and values of that locality.
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55 56 57 58 Research aims 59 60

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3 To explore the role of facilitation of a SNI delivered by lay health workers in a community
4 setting.

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6 To identify the facilitation processes through which engagement with a SNA to SMS is
7 achieved.
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10 Methods

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13 A longitudinal, case study design using ethnographic methods comprising non-participant
14 observation, video recording and qualitative interviews. Participants (n=30) living with a LTC
15 were recruited from a marginalised community. Data collected (T1) comprised visually
16 recordings of intervention delivery, observational notes and audio recordings of post-
17 intervention interviews. The use of videos allowed members of the research team to observe
18 each intervention taking place, rather than a single researcher, and enabled a more
19 accurate, nuanced and collective analysis of the facilitation process.
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26 Follow up data were collected at 3 months (T2, face-to-face semi-structured interviews) and
27 6 months (T3, telephone interviews) to capture change over time. The circle diagram
28 captured changes over time in the position of network members on the map (Vassilev,
29 2018). The mapping exercise was also a heuristic device which could indicate relational
30 shifts in people's lives over time and enabled the facilitator to elicit people's underlying
31 rationales for these. Data collected at different time points reflected how things changed
32 subtly, including small changes in relationships and changes in meanings of relationships.
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39 Audio recordings were transcribed verbatim. Thematic analysis informed by framework
40 analysis included a priori codes /categories relating to the role of facilitation and facilitation
41 processes, alongside an inductive approach whereby coding and theme generation were
42 directed by the content of the data. Initial coding and collating were undertaken by
43 researcher (EJ) to identify broad patterns of meaning prior to the viability of potential themes
44 being discussed and agreed within the team. In addition, parts of the dataset were coded
45 independently (AR/AK/IV/JE) to ensure inter-rater reliability and coding consistency. Themes
46 were refined and defined, including a detailed analysis of each theme to draw out key
47 findings.
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54 Most salient to this study was engagement in the network mapping, as an initial exercise.
55 However, we were also interested in how people reflected over time. Engagement means
56 participation in the mapping exercise and what it represents for people in terms of their own
57 micro-social world. Engagement is when people's attention is on things outside of
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3 themselves, e.g. thinking about the people around them and what these people do. On the
4 participant's part, engagement also manifests in raised awareness and reflection over time
5 of the benefits of adopting a SNA to SMS.
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10 11 Sample and recruitment

12 The sample was drawn from a marginalised community, the Isle of Wight. Separated from
13 the mainland, social, economic and political barriers contribute to the marginalisation of the
14 Island, as does an aging, vulnerable population (27% aged 65+ years, 1 in 6 of whom live
15 alone). The full sample took part in observations and interviews (3 participants withdrew).
16 Table 2 shows participants' age, gender, LTC and where the intervention took place.
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22 Participants were recruited via two routes. Firstly, lay health workers identified clients who
23 matched the inclusion criteria, introduced them to the study and invited them to participate.
24 Secondly, the researcher and PPI representative visited support groups (e.g. Diabetes
25 Support Group, Heart Care Club) for recruitment purposes. The facilitator met with the
26 participant on one occasion to deliver GENIE. The researcher was responsible for all the
27 follow-up data collection. Services employing lay health workers were approached to discuss
28 involvement in the research, including training, identifying participants and intervention
29 delivery. Facilitators comprised Health Trainers (n=4), Care Navigators (n=3), Community
30 Navigators (n=1) and Local Area Co-ordinators (n=1). A PPI representative and researchers
31 (n=3) were also trained.
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42 Figure 1 Co-production of network map: participant reflections
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46 Results

47 Observational data provided a visual record of facilitation style, how participants related to
48 facilitators and how comfortable they appeared physically. Notes taken on body language
49 and gestures (e.g. leaning towards laptop screen, pointing to network map, positive
50 response to visual cues) indicated that most participants felt at ease with the facilitator and
51 engaged in the network mapping. Observations revealed that a natural balance of eye
52 contact between participant, laptop and paperwork on the part of the facilitator helped to
53 maintain engagement and co-production.
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59 Text box 1
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Facilitation is viewed as something that is initially co-produced but orientated towards individual ownership of the network map and links to favoured activities. Three themes illuminated the social network mapping and preference linking processes:

1. *Reversing the focus on the self and bringing others into view*
2. *Visualisation and reflection as a mediator of positive disruption and linking to new connections*
3. *Personalised matching of valued activities a means of realising preference elicitation*

1. *Reversing the focus on the self and bringing others into view*

An exclusive focus on individuals' capacity and responsibility to initiate and sustain strategies for self-management can leave those living with a LTC feeling stigmatised and labelled as unable to cope with daily activities. In contrast, co-creation and engagement in network mapping provided a shared activity of both 'doing' and 'interacting' in which respondents began to reverse the focus on the 'self' and bring others into view as attention shifted towards relationships with the people around them. Refocusing away from self, towards other external, relevant sources of support (emotional, practical, physical, spiritual), helped to reduce the risk of acopia whilst increasing feelings of self-worth.

This respondent shifted focus towards support derived from her daughter and pets, when recently widowed:

"If it hadn't been for my daughter and the dog and cat I wouldn't have coped..... I would probably have just crumbled into a little ball.....(the dog) gets me out, gets me going for walks and is very loving. She shows me a lot of love.....it's those stupid little sounding things that keep me going" (HF14)

Face-to-face facilitation provided opportunities for respondents to cognitively re-frame responsibility for LTC management from 'individual' to 'shared'. Facilitators used name generating prompts to elicit successive recall of types of network members (e.g. friends, family, groups, pets), encouraging respondents to expand and diversify their networks:

"If you are looking at it on a computer you think 'Right, ok, what support have I got?' and you wrack your brain trying to think but actually doing it face to face with somebody you can get prompted to think 'Yes, there are more people'. So, then it's actually drawing on those resources, friends, relatives, GPs, pharmacist, whoever, to actually help you get what you need and the support you need" (EU09)

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3 Facilitator prompts were assistive aspects of co-creating the network map:
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6 *"I personally think it's better facilitated because there can be the odd prompt, 'Where*
7 *do you think it sits better there or there?' And then underneath that, why? Because if*
8 *you are sitting on your own you won't ask yourself those questions, you don't do you,*
9 *unless you are particularly self-aware? Some people will go through that mental*
10 *checklist but most people won't"* (HF07)
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14 *"...but I wouldn't have had all those names down on my own, I certainly wouldn't. I*
15 *would have looked at it and said who is important? 'Oh [stepdaughter 1] is' and then I*
16 *would be looking at.. yes, the doctor is but I wouldn't have been, some of these round*
17 *the outer ones, I wouldn't even dream that they were anything to do with it. So, it*
18 *was.... you need a bit of a prompt.....my outlook has changed"* (EU11)
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23 Conversations embedded in the network mapping activity enabled respondents to move
24 from network member identification to reflect on social and emotional aspects of their
25 relationships, environments and preferences. Facilitated conversation helped to 'unpack'
26 thoughts and beliefs, highlighting the value of social relationships and practices as
27 respondents considered the nature of support associated with particular individuals and
28 groups:
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33 *"Each one has a life of its own, it's not just a name or just a club. If I go back to one in*
34 *particular, the Heart Care Club, there's 15 people there, each one of them I know.*
35 *I've been going for six years now and I know about them all, I know about their*
36 *families, I know about their problems, they know about my problems and that sharing*
37 *of information is very powerful in terms of dealing with things and the inclination to*
38 *keep it to yourself diminishes because we all, maybe it's a masculine thing,"* (HF07)
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43 *"Well it makes me think about things more if you know what I mean? You take a lot of*
44 *things for granted and think well that's happening but unless you have them*
45 *[facilitator]come along, I'd just have been accepting all these things but not putting*
46 *them in any sort of position in my life. It's made me think more about what does*
47 *[name] do for me?.. or what does another person do for me?"* (EU11)
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52 Relying on others and negotiating support was not always easy:
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54 *"Well, it makes you think of different ways that you could do things and I suppose it*
55 *makes you look at yourself as well..... it makes you evaluate what people will do and*
56 *what they won't do. I suppose because I've always been independent and rely on*
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3 *myself and not other people it's harder to rely on other people or ask them to help, to*
4 *be quite honest” (HF15)*
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7 Facilitated conversations around the network mapping exercise helped respondents let
8 go of expectations from ‘strong’ ties (family) and value social connections with friends
9 and acquaintances (weak ties). Expressing a perceived lack of family support (son had
10 no time to help in the garden; limited contact with sisters), one respondent was able to
11 re-focus on the value of regular visits, shared time and activities with ‘more reliable’,
12 longstanding friendships. Similarly, this respondent was able to acknowledge the
13 importance of ‘weak ties’/acquaintances in his everyday life:
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18 *R: I get an awful lot of support from people that most of.... a lot of people take for*
19 *granted. I don't take the ladies in Morrison's for granted..... or the staff in the Co-*
20 *op..... or bus drivers. I'm aware, but.... a lot of people aren't that aware of that”*
21 *(HF.02)*
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25 Facilitation helped people reflect on the value of shared activities, replacing individual
26 pursuits with joint activities. This respondent took up walking, which became a shared
27 activity with her partner:
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31 *“It may have been that the session that we did maybe made me more mindful of the*
32 *fact that I needed to do more walking and stuff....I've done some walks, quite a few*
33 *walks actuallyand then we [partner and respondent] joined English Heritage and*
34 *National Trust, so it went from there really. It was a gentle walking programme at*
35 *work.....I was keen to do the walking and found that that was really enjoyable, so I've*
36 *stuck with the walking.....” (HF04).*
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43 **2. Visualisation and reflection as a mediator of positive disruption and linking to** 44 **new connections.** 45

46 Visualisation and reflection on the completed network map enabled sense to be made of a
47 novel means of support and how it could be accessed. Reflection on existing network
48 membership opened up possibilities for evaluating the present and anticipating, rehearsing
49 and reconstructing self-management differently for the future.
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52 This respondent acknowledged the value of visualisation through reflecting on the meaning
53 and value that new options for the future might bring in terms of socialising with others:
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3 R: *...a support network tends to go with going out socialising, because if you are not*
4 *going out socialising as much then the support network is not necessarily there, do*
5 *you know what I mean? So, I haven't been going out as much the last year because*
6 *of my illness, so I don't tend to socialise much with people. So, I have been reflecting*
7 *on that....., it did help me, just the visual....cos I'm a very visual learner, so a very*
8 *visual thing has helped” (HF04)*
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13 Rather than SMS being associated solely with the inner motivational life of an individual in
14 relation to behaviour change, reflection on network support through visualisation enabled
15 normalisation of SMS in everyday life and all it involves in terms of social environment,
16 relationships and activities. The following respondent's terminology reflects this, referring to
17 the collective 'we' and 'getting on with our lives', i.e. not 'I', getting on with 'my' life:
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22 *.....it made me focus at a conscious level on the support infrastructure that I have*
23 *available. And that made me feel good, because we're trying to get on with getting on, we're*
24 *getting on with our lives and at an intellectual level you don't rationalise what's going on*
25 *around you. You don't think about it, you sort of take it for granted. And I found the process*
26 *enlightening, because it reminded me of how well supported I am. Which I have to say is*
27 *very, very powerful. it reminded me of what resources I have....it was a useful reminder*
28 *of how many people there are out there that I can access if I need to (HF07)*
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33 Co-creating a visual image of a person's support network seemed to enhance the process of
34 identifying and triggering network members:
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37 *“When you first start off, you start thinking, yes I've got my wife, I speak to my mum, I*
38 *had Diabetes UK.... but then everything else it's like opening up the flood gate! You*
39 *don't realise....Oh yes, I have got things that I can do. I have got people that are*
40 *around me'.... it's actually knowing the amount of people that you've actually got*
41 *around you that you can call on I've got my healthcare trainer, I've got*
42 *neighbours, podiatrist that I see every six weeks, it opens up a lot more.....and yes*
43 *I've got the next circle, yes I go out, I go to Church, I go to bowls, I can speak to my*
44 *pharmacist and if I don't want to go down to the doctors I'll go down and see the*
45 *pharmacist.....so it opens up like a can of worms.then the can is getting opened*
46 *up more and more and then everything spills out and you find out you have got a lot*
47 *more people around you that you can actually rely on” (EU09)*
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55 This respondent commented on the visual design of the three concentric circles acting as an
56 enabler for prioritising individual network members:
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“When you actually think about, if you write it down on a list, you can’t make sense of it Doing it on there [network map], you’re in the centre and everything works out from around you and when you think about it, like these are the people who are most important..... You start thinking about it, pets, support groups, family all those things there. You can actually see it better if it’s actually like a ripple going out. You see where the ones that are most important to you are in the centre near you and rippling out to who you can actuallyso it is actually better having as a circle than just as a list because..... It’s actually prioritising who is most important to you and that circle gives the best way of doing it” (EU09)

As respondents typically viewed self-management as something they had to do on their own, many were surprised to see more network members in their completed diagram than they had anticipated:

“With your health conditions you’ve got to look after number one and make sure that you are aware of what is going on..... I do that on my own..... It (circle diagram) was making sense. I just hadn’t thought that.....I hadn’t thought about who was supporting me or who is supporting me.....I’m surprised that..... there are some people in the circle!” HF01

3. Personalised matching of valued activities as a means of realising preference elicitation.

Facilitators guided respondents through an online preference questionnaire embedded within the intervention. Questions focused on what people valued doing or used to enjoy doing in the past. Rather than imposing a needs-led framework, guiding people to identify what they enjoyed ensured activities were meaningful and relevant, increasing engagement in accessing community resources. Participants were guided by their own preference and identified 3 activities that most interested them. Most participants (n=25) contacted/tried a new community resource, 2 participants did not take up activities and 3 participants withdrew (Kennedy, 2016; Vassilev, 2018). Follow up data indicated that participants enjoyed their chosen activities, suggesting a cognitive shift from thinking to doing.

Perceived lack of status difference between respondent and facilitator further increased engagement and proactivity on the part of the respondent. The lack of status difference was perceived intuitively from the observational data, as participants seemed at ease and open to working together with the facilitator.

Facilitated conversations represented a safe space for respondents to reflect on and express inner hopes and future wishes, enabling them to re-connect with the things that could bring enjoyment in everyday life. The following example indicates how a respondent living with mobility impairment shared his dream about experiencing an aqua-lung in a swimming pool:

R: *"I haven't swum for a long, long time and when I did swim I did get some support and I did have somebody with me the whole time in the water....."*

F: *Is that something you'd think about again if there was support?*

R.: *.... what I did dream of doing was having an aqua-lung on my back, going underwater and just sitting on the bottom of the pooljust going into a pool or into a large fish tank, sit on the bottom of the tank and look at the fish going round and then stay there for about 5 minutes and then you come back up and that would have given me a lot of pleasure! You know, an achievement. Well, that's what I would like to do. I'd still like to do something like that – though I would take medical advice even now on that - but that's one thing I would love to be able to do"* (EU02)

Aligning people's preferences and activity choices with their social connections, relationships and environment, increased accessibility to activities and sustained engagement. However, findings also revealed social situations and environments that posed challenges. The following respondent was unable to remain in full-time employment due to a LTC, but had identified a voluntary work opportunity which offered her purpose, social contact and fulfilment. Guided facilitation that took into account social and emotional aspects of everyday life enabled reflection on barriers to pursuing valued activities and future possibilities:

"Yes, I love it (voluntary work) But now I can't go on Fridays because I'm at (partner's) mum's and I can't get there. I find it hard because I need somebody who will take me in the wheelchair.But everything is on (partner's) time. It's when he wants to do it, when he's ready. ... and I have to fit in. It's hard, so hard. It's my lifeline really. .. That's why I feel trapped at times. Not every day, not all the time but a lot of the time..... I feel trapped because I can't..... it's not like I can just get on the bus. I'm so dependent on (partner)" (HF06)

The choice of focusing on lay health workers coalesced with the finding from a previous study that a lack of status difference between facilitator and participant was instrumental in allowing a stronger interpersonal element and reciprocity in the discussion to develop (Kennedy et al 2016). In this community-based study lay health workers met people in a

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3 place of their choice, usually at home. This participant comments on who is best placed to
4 deliver the intervention and where this should take place:
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7 *“Where’s the best venue?.....I think we’d have to go back to the home but with the*
8 *caveat that they must have somebody with whom they feel comfortable.....people do*
9 *feel threatened, it’s weird, isn’t it? Why? I don’t know... because that’s people. It’s got*
10 *to be non-threatening and in the conflicts context it was always a neutral ground, you*
11 *went to the pub.....but I’m just saying that was what you did. GPs represent*
12 *authority, like it or not it’s true, what I’ve been trained to believe” (EU12)*
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19 Discussion

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21 Findings from the current study suggest that reversing the focus on self and bringing others
22 into view enables a broader approach to SMS contrasting with traditional, narrower
23 approaches that focus on individualised accountability and responsibility. This broader
24 approach allows co-production work initiated by the facilitator to move towards shared
25 ownership, creating a space in which steer alternates between facilitator and respondent. As
26 attention shifts from self (internal) to others (external), the fluid and flexible nature of this
27 engagement opens up new possibilities for living and managing well that incorporate social
28 relationships and societal participation. People living with a LTC are often forced to rely on
29 their own resources. The SNI helped people to make a cognitive shift from individualised,
30 self-management accountability to being ready and receptive to the possibilities of collective
31 effort. This finding resonates with existing research on the purpose of SMS. Morgan et al⁸
32 posited that the purpose of support in narrower approaches to SMS centred on
33 individualized behavioural targets such as lifestyle, self-monitoring and medication taking
34 oriented to biomedical goals. Similarly, facilitation focuses on internal motivation of an
35 individual rather than including those around them. A wider view and scope of facilitation
36 explored here in a SNI highlights the need for a broader vision that incorporates other
37 people, things and activities that are relevant to people’s social contexts, life circumstances
38 and lived experiences.
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51 Findings demonstrate that facilitating visualisation and reflection and expediting engagement
52 with the network mapping exercise, act to assist with positive disruption of established self-
53 management practices. Coherence and shift in perception of SMS from a process that
54 focuses exclusively on the individual to one that incorporates a focus on collective elements
55 and processes occur partly through the co-creation of a visual image of a person’s support
56 network. All respondents entered into the shared network mapping activity with the facilitator
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3 and were able to reflect on its purpose in terms of sense making of how those around them
4 operated as a, or potential, source of support or access to resources that would help with
5 self- management. This suggests that when the complexities of person's life world are
6 presented in a visual format (concentric circles diagram), the information and its implications
7 in terms of personal possibilities and challenges become more accessible, breaking down
8 barriers to health inequality and improving health literacy. In relation to accessibility and
9 sense making, Antonucci²² reported a similar finding when he first introduced the concentric
10 circles hierarchical mapping technique to examine social support networks, commenting that
11 the technique seemed to 'transcend culture, age, life situation and crisis'. However, where
12 the current study adds to this proven technique is by using the image of an existing support
13 network to link into new social connections, imagine future possibilities and increase social
14 participation. Moreover, recognition of people's life worlds and habitus as part of a broader
15 entry into therapeutic landscapes has been highlighted as a means of living life well with a
16 LTC.²⁶

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18 Empowerment and engagement were seemingly attained through the act of facilitation in
19 which meaningful, enjoyable activities were identifiable and alignment could be made of
20 valued preferences with people's social connections, relationships and environment in order
21 to incorporate these into everyday life.

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34 Text box2: Working example

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36 This process suggests that when people identify and are linked to valued activities that
37 match what they enjoy doing, social participation is likely to increase in turn supporting
38 people to manage better in everyday life. Reflecting on what people used to do in the past
39 but no longer do is a powerful means of reintroducing the familiar and for people to
40 reconnect with valued activities from the past.³ It also acts as a counter to traditional
41 approaches to SMS which identify with a predominant focus on education and advice-giving
42 where attention to psycho-emotional issues patients face take a back seat¹⁴ highlighting the
43 need for facilitation to take into account the complexities of social circumstances and
44 emotional responses of people. Implications for future training of healthcare professionals in
45 self-management point to the need for a basis of trust, questioning and flexibility¹⁴. The
46 current study points to how a SNA can incorporate the social, emotional and environmental
47 needs required for creating a meaningful life in chronic illness management. In addition to
48 relational aspects of facilitation, other aspects, such as awareness of locality, a sensitivity to
49 and understanding of the bases of the value attributed to relationships and people's personal
50 networks, collective community and social activities taking place locally are relevant. Thus, a
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3 core element of future facilitation is the requirement of the development of a facilitator's
4 empathy for the life worlds of individuals, in order that mutual empathy can lead to rapport
5 and co-appreciation of the preferences and choices being elicited and the links forged to
6 others in a personal network. The latter is perhaps a salient quality to add to the facilitator-
7 patient relationship and addition to the lexicon of person-centred interventions taking place
8 in primary care and community settings.
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15 Limitations

16 Data for this study comprised observations of the intervention delivery and qualitative, post-
17 intervention interviews with participants. Data collected directly from facilitators was limited
18 to group feedback from lay health workers who took on the GENIE facilitator role for
19 research purposes. Future research would benefit from conducting qualitative interviews with
20 facilitators.
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28 Conclusions

29 Our findings indicate that facilitating a SNI that includes a network mapping exercise as the
30 key object of engagement requires an orientation towards the idea of connections and
31 linkages and skills of enabling the exploration of relationships and interactions within
32 people's everyday social world and requires an appreciation of the social environment and
33 sense of place in order that the two people involved can work together authentically.
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Table 1 Components of GENIE

Stage	Activity	Purpose
Step 1: Mapping using concentric circles	<p>People, places, pets and objects (social network members) are mapped onto 3 concentric circles. Different circles capture the importance of each network member in supporting long-term condition (LTC) management, together with relationship and frequency of contact</p>	<ul style="list-style-type: none"> • To explore how network members, contribute to SMS in everyday life • To create a visual image of existing support network • To guide a conversation about extending current support and accessing new sources of support • To capture change over time
Step 2: Preference questionnaire	<p>13 online questions covering a range of local community activities and resources within the person's postcode area</p>	<ul style="list-style-type: none"> • To find out what an individual enjoys doing or used to enjoy doing in the past • To link relevant network members to chosen activities • To select 3 most important activities in order to prevent information overload

Step 3: Linking to local activities	Intervention software selects from internal database all relevant local resources that correspond to individual's chosen activities. Information is displayed, including location of activity on Google map	<ul style="list-style-type: none">• To link individuals with prioritised and valued local activities• To discuss opportunities and challenges relating to attending a new activity
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For Peer Review

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Table 2: Demographics/LTC/location

ID	Gender	Age	LTC	Location of observation and T1 interview
01	F	51	Diabetes T2	University
02	M	70	Diabetes T2, Cerebral Palsy	Home
03	F	57	Diabetes T1	Cancer support centre
04	M	54	Diabetes T2	Community library
05	M	70	Diabetes T2	Community library
06	M	68	Diabetes T2	Home
07	F	59	Diabetes T2	Community library
08	F	66	Diabetes T2	Home
09	M	43	Diabetes T2	Medical centre
10	F	66	Diabetes T2	Medical centre
11	M	75	Diabetes T2	Home
12	F	59	Diabetes T2	Community library
13	M	76	Visual impairment, diabetes T2	Home
14	M	73	Diabetes T2	Home
15	M	67	Diabetes T2	Home
16	F	50	Behcet's disease, associated arthritis	Home
17	M	70	Parkinson's, epilepsy, arthritis, depression, intestinal disorder	Home
18	F	83	Heart disease	Home
19	F	48	Multiple sclerosis	Community library
20	M	84	Parkinson's, arthritis	Home
21	F	45	Multiple sclerosis	Home
22	M	69	Heart disease, in recovery from prostate cancer	Home
23	M	67	Heart disease/heart attack, arthritis, nerve damage	Home
24	M	81	Heart disease, arthritis, diabetes T2	Home
25	M	45	Multiple sclerosis	Home

26	M	69	Atrial fibrillation, arthritis	Home
27	M	81	Heart disease, arthritis, prostate cancer	Home
28	F	56	Arthritis, depression	Home
29	F	45	Arthritis, asthma, anxiety/depression, plantar fasciitis	Home
30	F	66	Castleman's disease, diabetes, heart disease, arthritis, depression	Home

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Text box 1: Example

Instances of excessive focus on the laptop and paperwork captured evidence of disengagement, for example participant sitting back, distancing himself from the screen, folding his arms and vaping [HF10].

For Peer Review

Text box 2: Working example

One participant had been recently diagnosed with diabetes T2 when she went through the intervention. One of the key things she wanted to do was to meet other local people with diabetes type 2 who were a similar age to herself (mid 40's). Working through Genie together with the facilitator, they identified a local, peer-to-peer support group for people recently diagnosed with diabetes T2, Sugarbuddies. Here the participant reflects back during her 6-month follow-up interview:

"I'm excited about Sugarbuddies. I feel that I'm getting more involved with it and they are people of my age group and by talking to them I understand what they're going through. I'm not on my own.....it's not the end! There is life, you know, and it's positive compared to this time last year. What is the saying? Knowledge is power? It's opened up new doors for me....a new world – I'm very excited. There are very exciting times ahead!" (EU01)

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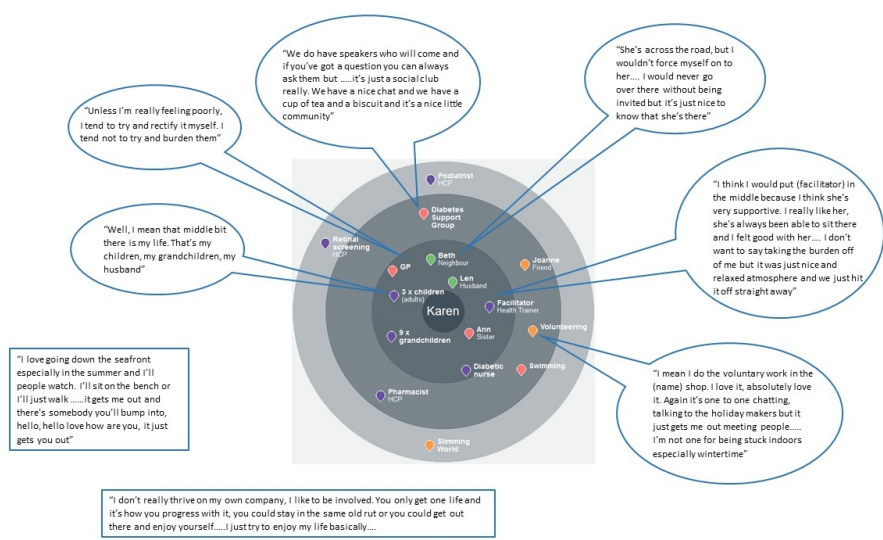


Figure 1

338x190mm (96 x 96 DPI)