Evaluation of MS Society local groups' role in reducing loneliness for people affected by MS

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1. Project Outline

We have 270 volunteer-led local groups: Providing over 14,000 different local services – bringing the community together, providing information and access to specialist advice, and supporting people to remain active and independent. Together, supporting over 13,000 people every year. Over 130 of our groups provide opportunities to keep physically active – through a range of exercise classes from Tai Chi to Swimming, and Boccia to Pilates.

A key outcome of our Services and Support strategy is to reduce loneliness and social isolation for all those affected by MS, and forging communities that promote health and wellbeing, and provide friendship and support.

People affected by chronic ill health are more likely to be lonely on any given day and chronic loneliness has an adverse physical effect on physiological health in relation to lowered immune function and raised stress hormones.

The purpose of this report is to understand the impact MS Society local groups have in reducing feelings of loneliness and isolation, and use the evidence to promote our local groups (e.g. within our case for support and marketing campaigns).

Objectives

- Evidence if local groups help to reduce loneliness & isolation among people affected by MS.
- Understand how local groups help to reduce loneliness & isolation among people affected by MS.
- Celebrate the role local groups have in reducing loneliness & isolation.
- Develop greater understanding on the extent to which our services meet the needs of different communities.

2. How

Current and previous local group participants were surveyed to understand whether local groups have a role in reducing feelings of loneliness and isolation for people affected by MS.

A literature review scoped the existing field of research into loneliness and isolation, ill health and the role of peer support groups. Telephone interviews were conducted with 8 people affected by MS who were active or previously active in a local group, discussing loneliness, isolation and the role of local groups in reducing both.

From these conversations an online survey was created and sent to 13,000 MS Society members who we believe are active in a local group or had been in the past. 869 respondents completed the survey in July 2018 (7% response rate). The results below are for people with MS, their friends, family or colleagues, carers and partners or spouses.

3. Context

Loneliness is commonly defined as a painful emotion when a person feels they don't have the quality of emotional relationships they need to be happy. It is a mismatch between the relationships a person has and the relationships they want[1]. Social isolation differs from loneliness, it means a person has limited access to a range and frequency of social contact. Loneliness is a subjective measure, a person can still feel lonely within a family or a social setting[2].

A lack of social network and chronic loneliness have been identified as having a direct and detrimental effect of physical health, particularly in relation to raised stress hormones, poorer immune function and reduced cardiovascular health.[3]

A 2018 Office for National Statistics[4] article reports that in 2016 to 2017, there were 5% of adults in England who reported feeling lonely "often" or "always".

There is a strong evidence base that peer support has a positive influence in reducing loneliness. A NESTA/National Voices meta-analysis of evidence from 1,000 studies found that peer support can help people feel more knowledgeable, confident, happy and less alone. What isn't known from a research perspective is if or how different personality types benefit from peer support.

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[1] Perlman & Peplau (1981) Toward A Social Psychology of Loneliness
[2] Campaign To End Loneliness: About Loneliness
[3] Cacioppo J., T., Patrick W (2009) "Loneliness: Human Nature and the Need for Social Connection, (pp336) London WW Norton & Company
[4] "Loneliness: what characteristics and circumstances are associated with feeling lonely". Office for National Statistics April 2018:
https://www.ons.gov.uk/peoplepopulationandcommunity/wellbeing/articles/lonelinesswhatcharacteristicsandcircumstancesareassociatedwithfeelinglonely/2018-04-10
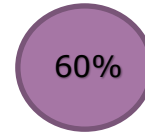
4. Top line results

Have people affected by MS felt isolated and lonely?

As a result of being affected by MS the majority of survey respondents reported having felt isolated or lonely. There is a strong correlation between having felt isolated and also having felt lonely, 42% of respondents had felt both.

58%
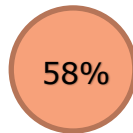
Identify as having felt isolated

60%

Identify as having felt lonely

*"I had to retire due to MS and I missed feeling part of a group."*

Do groups reduce feelings of isolation and loneliness?

Almost 80% of respondents, who had felt isolated or lonely, identified being part of a local group as reducing feelings of isolation and loneliness.

Individuals who are currently active in a local group (77% of respondents) are 30% more likely to agree that local groups reduce isolation and loneliness than individuals who no longer take part in a local group.

76%
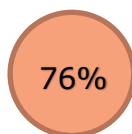
Identify being part of a local group reduced their sense of isolation
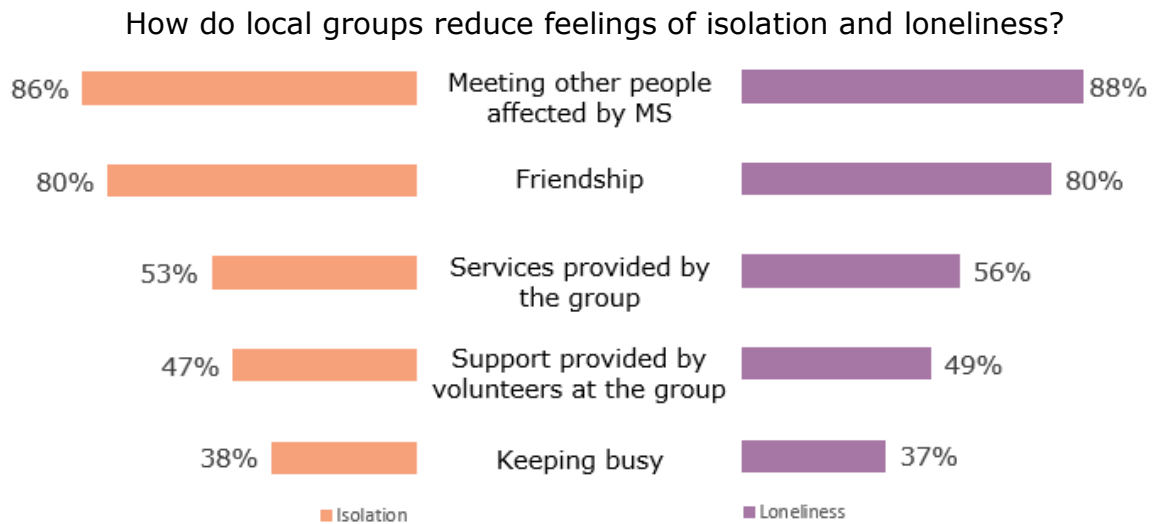
78%
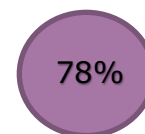
Identify being part of a local group reduced their sense of loneliness

"Knowing that I can talk to a diverse group of people there who understand the same issues as I experience is unbelievably reassuring."

How do groups reduce feelings of isolation and loneliness?

The most valued aspects of local groups and the most important factors in reducing feelings of isolation and loneliness are 'Meeting other people affected by MS', 86% of respondents, and 'Friendship', 80% of respondents.

How do local groups reduce feelings of isolation and loneliness?

	Isolation	Loneliness
Meeting other people affected by MS	86%	88%
Friendship	80%	80%
Services provided by the group	53%	56%
Support provided by volunteers at the group	47%	49%
Keeping busy	38%	37%

"The first time I met other people with MS I felt a sense of relief and could talk about things I'd never even spoken to other people about."

4

Is there a stigma associated to feeling lonely?

The majority of respondents were unsure if there was a stigma associated to feeling lonely (48%). Twice as many respondents said there was a stigma associated to feeling lonely (33%) as respondents who felt there wasn't (15%).

Respondents who had felt lonely were much more likely to agree that there is a stigma associated to feeling lonely:

Is there a stigma associated to feeling lonely?

- Respondents who have felt lonely
- Respondents who have not felt lonely
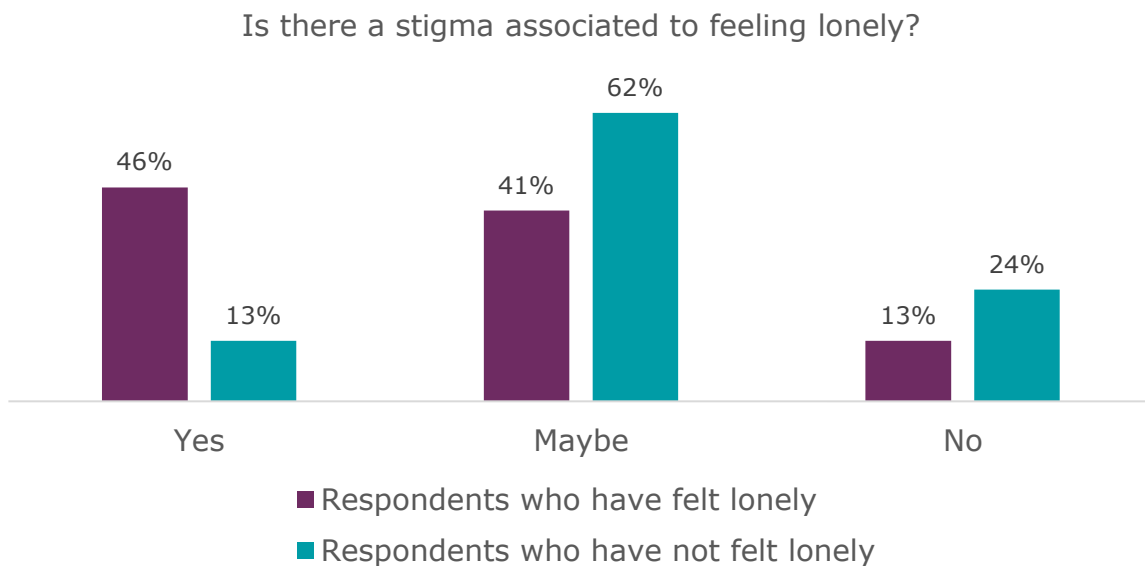
What demographic factors affect feelings of isolation and loneliness?
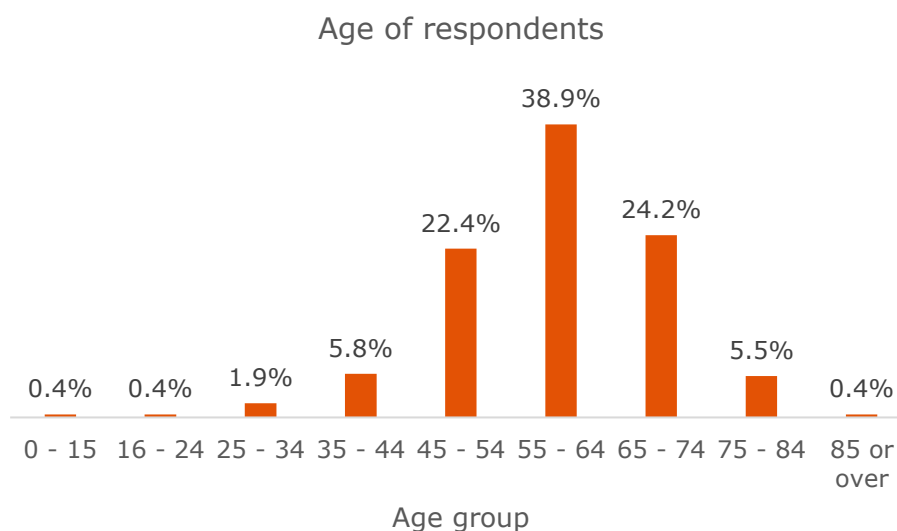
Age of respondents

As respondent's age increased, there was a slight decrease in individuals reporting feelings of loneliness and isolation.

People with MS and carers of people with MS (37 respondents) experienced similar levels of isolation and loneliness. Friends, family members and colleagues of someone with MS (37 respondents) experienced similar levels of loneliness as people with MS (55% of respondents) but had feelings of isolation much less frequently (33% of respondents).

Respondents were over 96% white reflecting the diversity of our local groups. We are working to understand the extent to which our services meet the needs of different communities, and have specific strategies in place to increase reach, relevance and impact in under-served groups.

> *"The MS Society needs to make its position on equality and inclusivity clear to groups and do more to reach certain parts of the community."*

5.   Conclusion

This is the first time services and support have explored the issue of loneliness with participants of local groups. The strength of the response, the evidence of a link between being affected by MS and being lonely or isolated, and the reported value of belonging to a local group, shows the role and impact of MS Society's local group offer.

This data should provide an evidence base for fundraising, angles for communications content and evidence for policy submissions. The survey identifies important questions over the messaging the MS Society should consider using in relation to; the purpose and value of local groups, the need to evaluate our support offer to younger people affected by MS (who experience higher levels of loneliness and isolation) as well as identifying further research around loneliness with the charity's online communities.

6.   Next steps

- We will work to improve the reach of our local groups, forging communities that promote health and wellbeing, and provide friendship and support.

- Identify the impact of online and social media communities.
    - We have 37,369 members of our online forum, to what extent does this community have the same impact as local groups?

      "I personally found speaking to people better online."

- Develop and test marketing messages on the benefits of our local groups identified and evidenced in this report.

- Use validated scales to understand the different types and causes of loneliness for people affected by MS so we can address them.

7. Questions raised

- What factors influence individuals to leave groups?
    - o Ex-members of local groups identified 'Friendship', as an aspect of local groups that they value, 33% less than active local group members.
    - o 4% of respondents identified transport issues as a barrier to attending local groups.

    "My problem is [the local group] is an hour's drive away and so I can only go when I am fit enough to drive that distance."

- What is our offer to younger people affected by MS?
    - o Younger respondents reported higher levels of isolation and loneliness. The majority of our local group attendees are aged 55-64.

    "It was a good group but the people who went were mostly older than me so I felt left out a lot of the time."

- How do local groups reach a more diverse base of people?

We surveyed **people affected by ms** and found out that:

58% have felt isolated

60% have felt lonely

76% said being part of a local group reduced their feeling of **loneliness** or **isolation**