



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

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1. Project Outline

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.

Current and previous local group participants were surveyed to understand whether they had ever felt lonely or isolated and what role, if any local groups have in reducing loneliness and isolation for people affected by MS. The purpose of this report is to illustrate the findings of the survey, celebrate the impact of MS Society local groups, provide evidence to support the MS Society's fundraising and inform the organisational marketing strategy.

1.1.1. Objectives

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

2. Method

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, 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 MSS members who we believe are active in a local group or had been in the past. 869 respondents completed the survey in July 2018.

3. Context

Loneliness is commonly defined as a painful emotion when a person feels they do not 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 want¹. 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 setting².

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

A 2018 Office for National Statistics⁴ article reports that in 2016 to 2017, there were 5% of adults in England who reported feeling lonely "often" or "always". However, living with chronic illness or caring for someone is shown to have a significantly increased impact on loneliness according to studies by Scope⁵ and Carers UK⁶.

There is no one cause of loneliness; it is a complex combination of personal and community factors. However, the loss of a social role and identity recognised as common key triggers to loneliness, particularly when identity is disrupted by an expected or sudden life event⁷. The Campaign To End Loneliness has found a significant stigma attached to loneliness, with 56% of adults saying that admitting to loneliness is difficult⁸.

There is a strong evidence base that peer support has a positive influence in reducing loneliness. A 2015 NESTA/National Voices meta-analysis⁹ of evidence from 1,000 studies found that peer support can help people feel more knowledgeable, confident, happy and less alone. A 2016 Nuffield Trust/Stroke Association study found that peer support enabled people with a way to connect and make new friends after the disruption of a stroke, where participants felt they benefited from the emotional support and practical information provided by people who had lived through similar experiences. What is not known from a research perspective is if, or how, different personality types benefit from peer support.

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>

⁵ "Nearly half of disabled people feel chronically lonely" Scope https://www.scope.org.uk/press-releases/nearly-half-of-disabled-people-chronically-lonely?utm_content=buffer3bece&utm_medium=social&utm_source=twitter&utm_campaign=buffer

⁶ "8 in 10 people caring for loved ones "Have felt lonely or socially isolated". Carers UK August 2017: <https://www.carersuk.org/news-and-campaigns/news/8-in-10-people-caring-for-loved-ones-have-felt-lonely-or-socially-isolated>

⁷ Aiden H, "Isolation and Loneliness An Overview of the Literature", (2016) British Red Cross

⁸ Campaign to End Loneliness: The Loneliness Epidemic: <https://www.campaigntoendloneliness.org/wp-content/uploads/Loneliness-Is-An-Epidemic.pdf>

⁹ Peer Support: What Is It And Does It Work: Summarising Evidence From 1000 Studies; (2015) NESTA & National Voices (p1)

4. Key findings

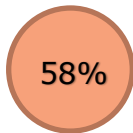
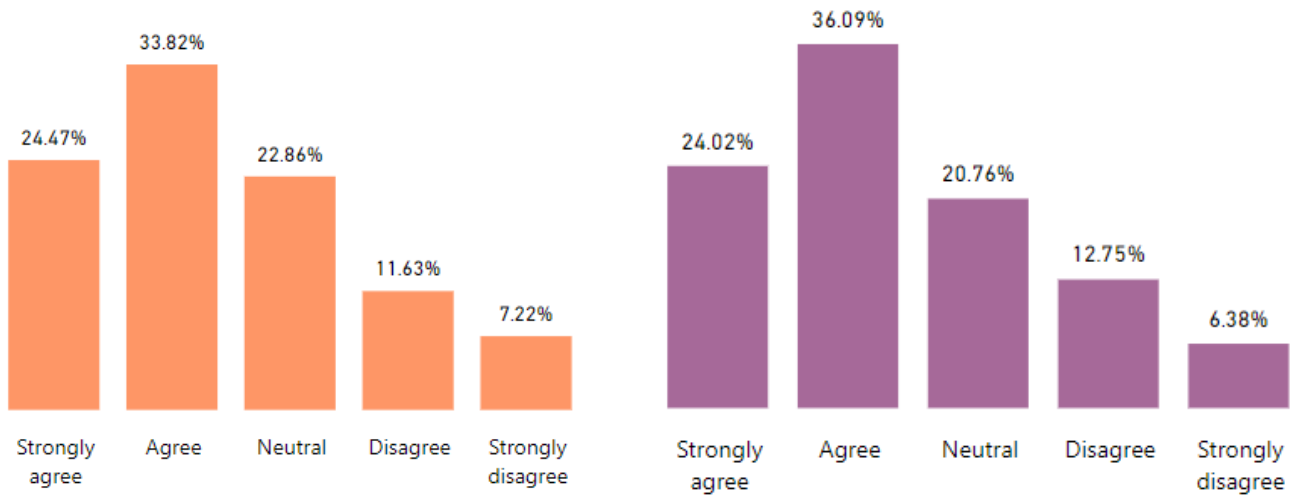
- ▶ **Three in five** people (60%) have felt lonely as a result of being affected by MS.
- ▶ **Three in four** people (78%) who have felt lonely as a result of being affected by MS, identify being part of an MS Society local group as reducing feelings of loneliness.
- ▶ **More than half** of people (58%) have felt isolated as a result of being affected by MS.
- ▶ **Three in four** people (76%) who have felt isolated as a result of being affected by MS, identify being part of an MS Society local group as reducing feelings of isolation.
- ▶ **Four in five** people affected by MS identify 'Meeting other people affected by MS' as the most important aspect of their local group in reducing feelings of loneliness (88% of respondents) and isolation (86% of respondents).
- ▶ **Two in five** people (46%) who had felt lonely as a result of being affected by MS feel there is a stigma associated to feeling lonely.

5. Results

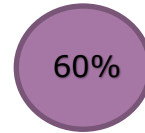
Respondents were asked:
To what extent do you agree with these statements?

"I have felt isolated as a result of being affected by MS."

"I have felt lonely as a result of being affected by MS."



Identify as having felt isolated



Identify as having felt lonely

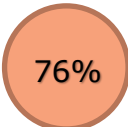
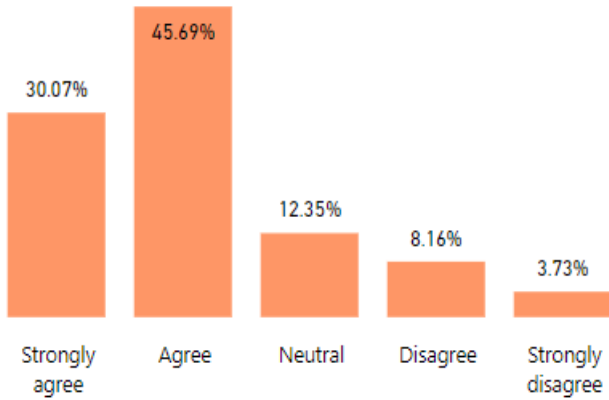
The majority of both current participants and previous participants of local groups have felt lonely or isolated. There is a strong correlation between having felt isolated and also having felt lonely.

Current local group participants (hereafter active respondents) are more likely to identify as having felt lonely, 7% higher than previous participants of local groups (hereafter inactive respondents). However, inactive respondents are more likely to respond 'Strongly agree' to both having felt isolated (9% higher than currently active) and lonely (5% higher than currently active).

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

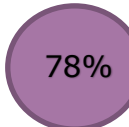
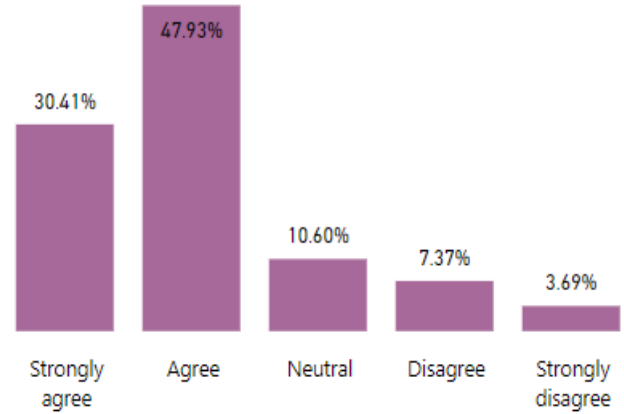
Respondents who identified as having felt isolated or lonely were asked the follow up question:

Does being part of a local group reduce that sense of isolation?



Identify being part of a local group reduced their sense of isolation

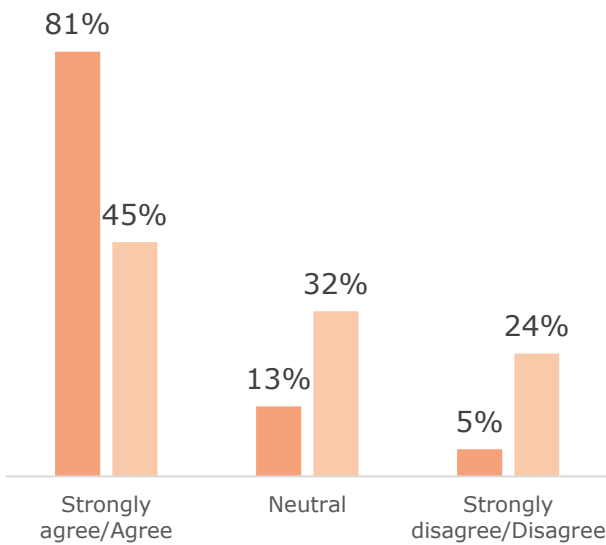
Does being part of a local group reduce that sense of loneliness?



Identify being part of a local group reduced their sense of loneliness

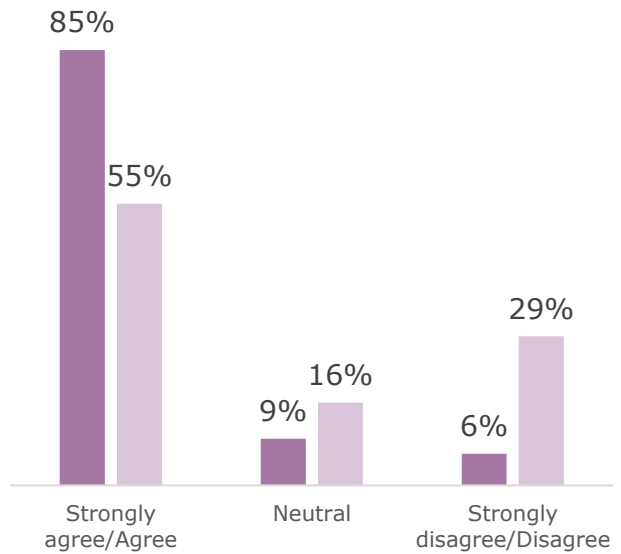
Being involved with a local group helps reduce their sense of isolation.

Active Inactive



Being involved with a local group helps reduce their sense of loneliness

Active Inactive



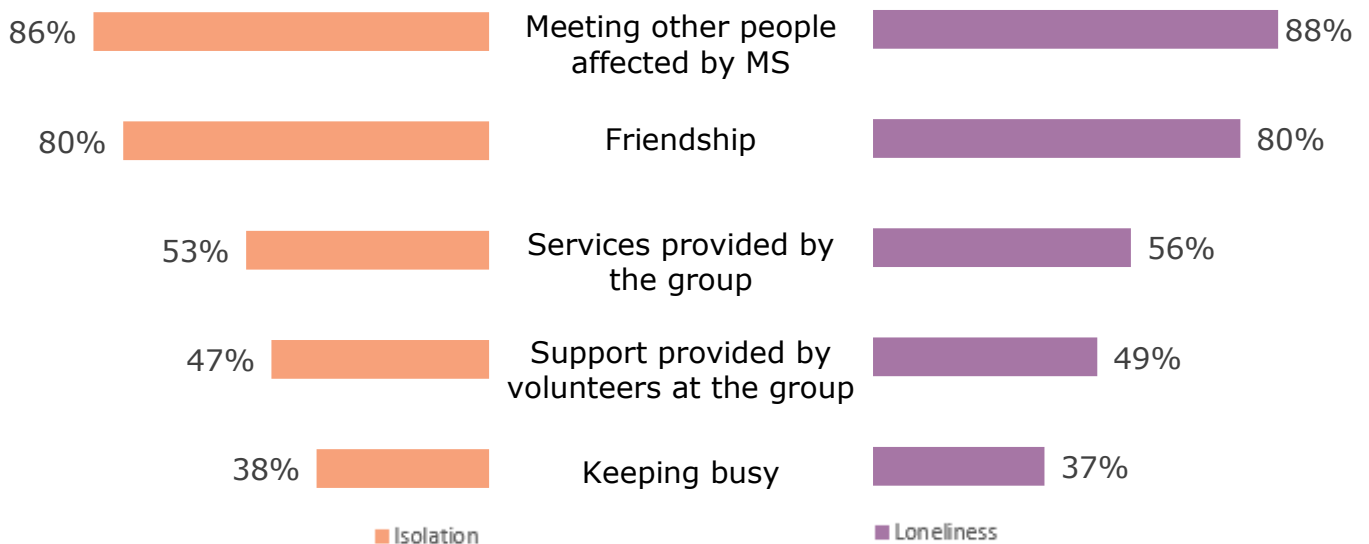
Active respondents have a much stronger positive response identifying local groups as reducing isolation and loneliness in comparison to inactive respondents.

Respondents who have felt isolated or lonely, strongly identify that being part of a local group reduces those feelings. There is a strong positive correlation between respondents who identify local groups as reducing isolation also identifying that they reduce loneliness.

"Knowing that I can talk to a diverse group of people there who understand the same issues as I experience is unbelievably reassuring. I can pick up the phone between meetings and chat to the friends I have made in the group, as well as supporting them."

6. What do respondents value about local groups

Respondents who identified that being part of a local group reduced their sense of isolation or loneliness were asked the follow up multiple check box question: "How has being involved in a local group reduced feelings of isolation or loneliness?"



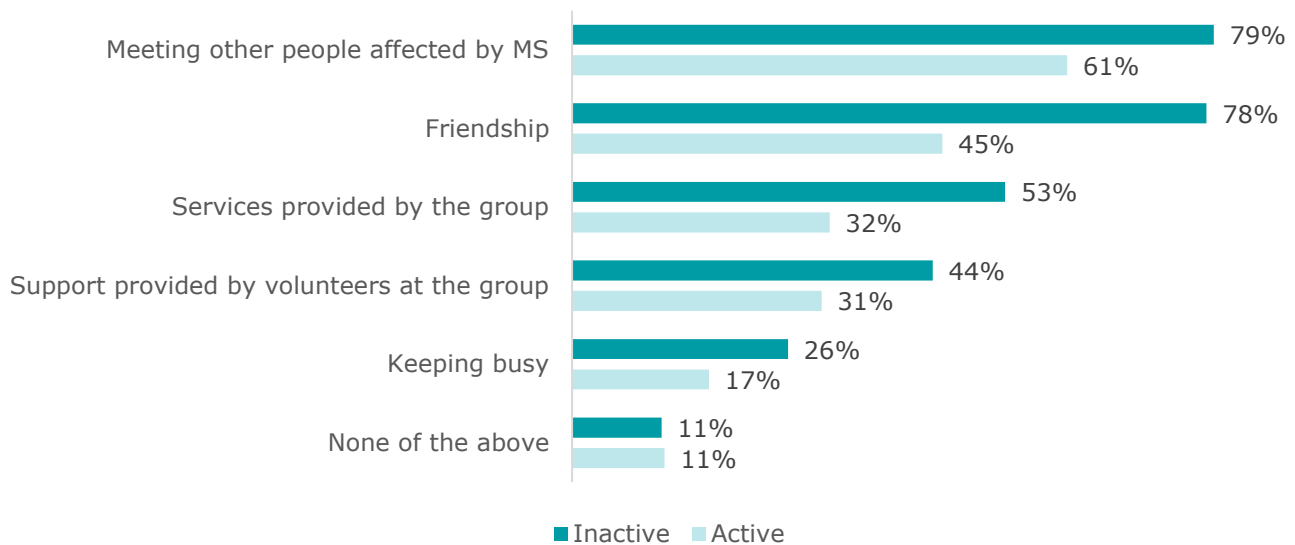
'Meeting other people affected by MS' and 'Friendship' are the most commonly identified factors in reducing feelings of isolation and loneliness, followed by 'Services provided by the group' and 'Support provided by volunteers at the group'.

"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."

Respondents were also asked what aspects they valued generally about their local group, not specifically in relation to isolation or loneliness. They valued the same aspects with the same frequency as the factors which respondents identify as key to reducing loneliness and isolation; 'Meeting other people affected by MS' most often chosen to 'Keeping busy' least often chosen.

"The friendship and support that I have found through joining the group has been invaluable to the state of my MS journey."

"What do you value about your local group?" What respondents value generally, not specifically in relation to isolation or loneliness.



Active respondents value more aspects of local groups than inactive respondents. Potentially, inactive respondents are those that no longer need and value what local groups offer and may subsequently leave.

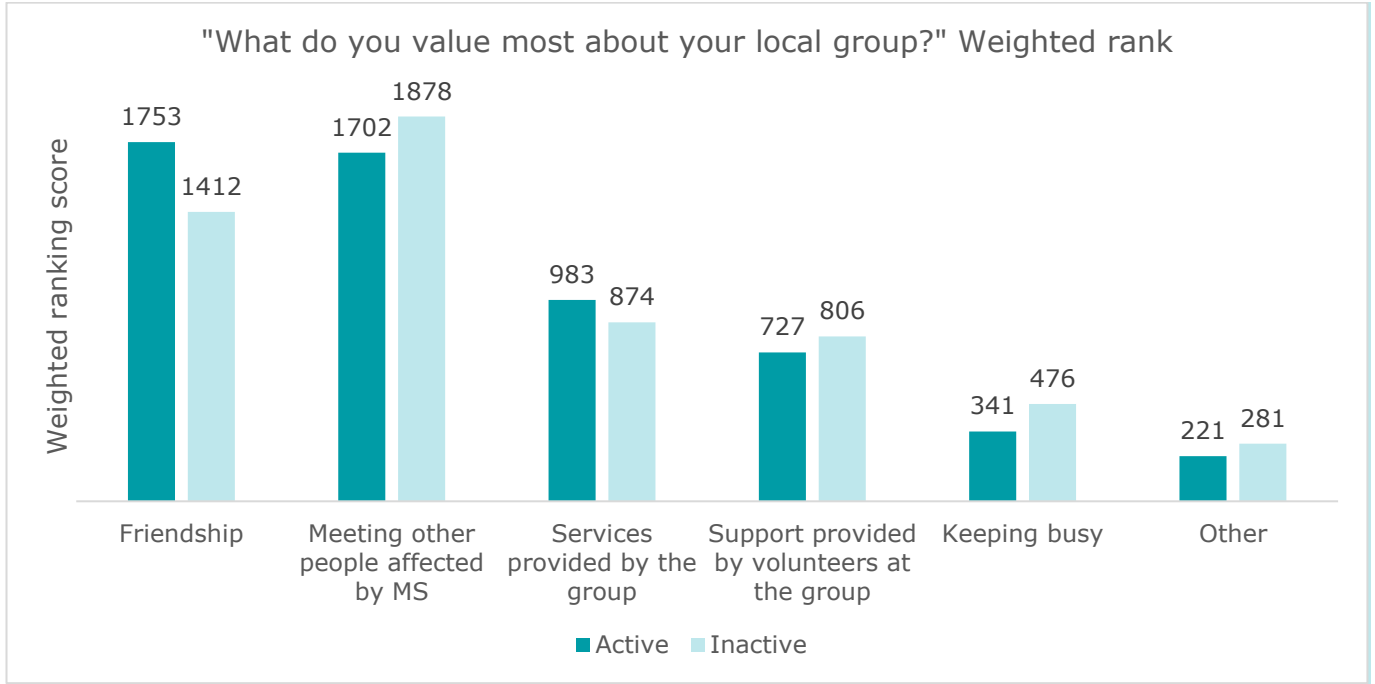
Inactive respondents are particularly less likely to value 'Friendship', 33% lower than active participants. It may be the case that individuals who do not develop strong friendships within the local groups are more likely to leave.

8% of inactive respondents identified an unwelcoming social environment or cliques as an issue at their local group, in comparison <1% of active respondents identified this as an issue.

Inactive respondent:

"[I] did not like my group it was very cliquey and left me feeling more isolated."

Respondents were asked "What do you value most about your local group?" This was to identify general aspects of their local group that they valued and not specifically about loneliness or isolation. However, as the question was asked within a 'Loneliness and isolation survey' they may not have disassociated their response to this question fully. They ranked in order of importance the aspects they had identified as valued from the previous question.



Active respondents identified 'Friendship' as the most important aspect of local groups whereas inactive respondents valued 'Meeting other people affected by MS' as most important.

"[I] have made some fantastic friends all with MS so understand potential problems and offer welcome advice as and when necessary."

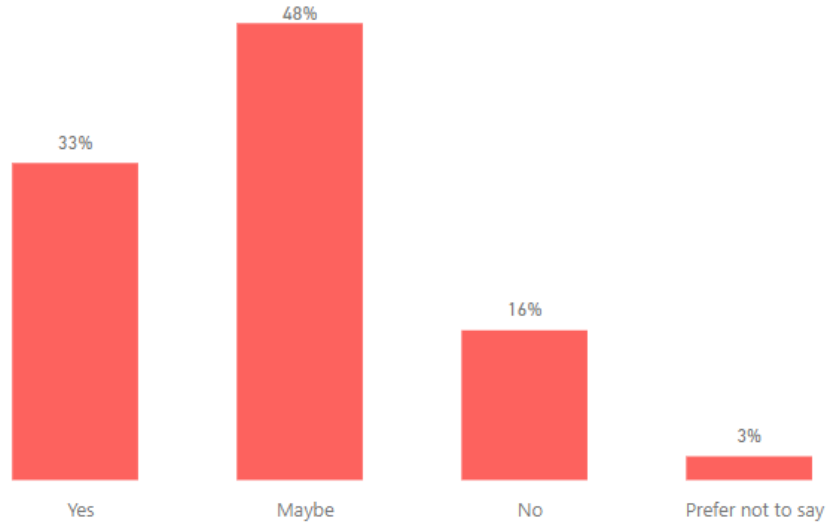
Interestingly 'Services provided by the group' and 'Support provided by volunteers at the group' are the 3rd and 4th most important aspects of local groups, despite the fact that we promote our groups around these services rather than as an opportunity to meet other people affected by MS or to create friendships. Respondents particularly valued sharing of experiences when meeting other people affected by MS:

"[Sharing] information on symptoms and how to overcome them or what helps. What we are entitled to as in help from other organisations."

It would be useful to test the marketing of local groups using the most valued aspects, 'Meeting other people affected by MS' and generating 'Friendship', and then measuring any change in engagement.

7. Is there a stigma attached to feeling lonely?

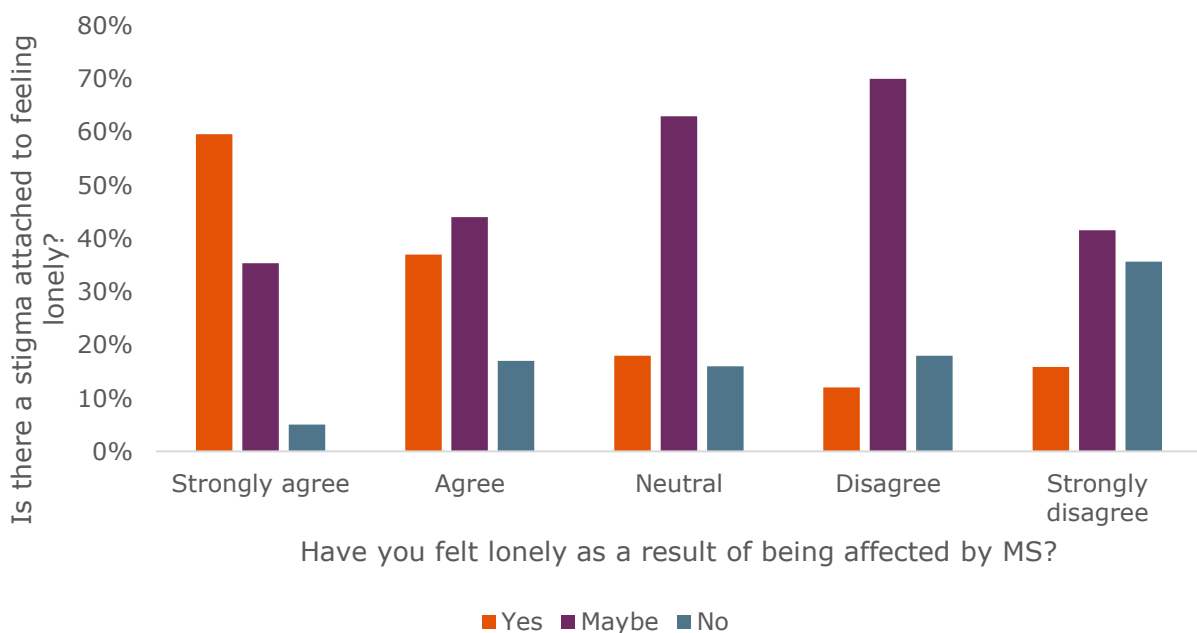
Respondents were asked: "Is there a stigma attached to feeling lonely?"



The majority of respondents, 48%, were unsure whether there is a stigma attached to feeling lonely, though respondents were twice as likely to agree that there is a stigma associated to feeling lonely, 33%, those who did not, 16%.

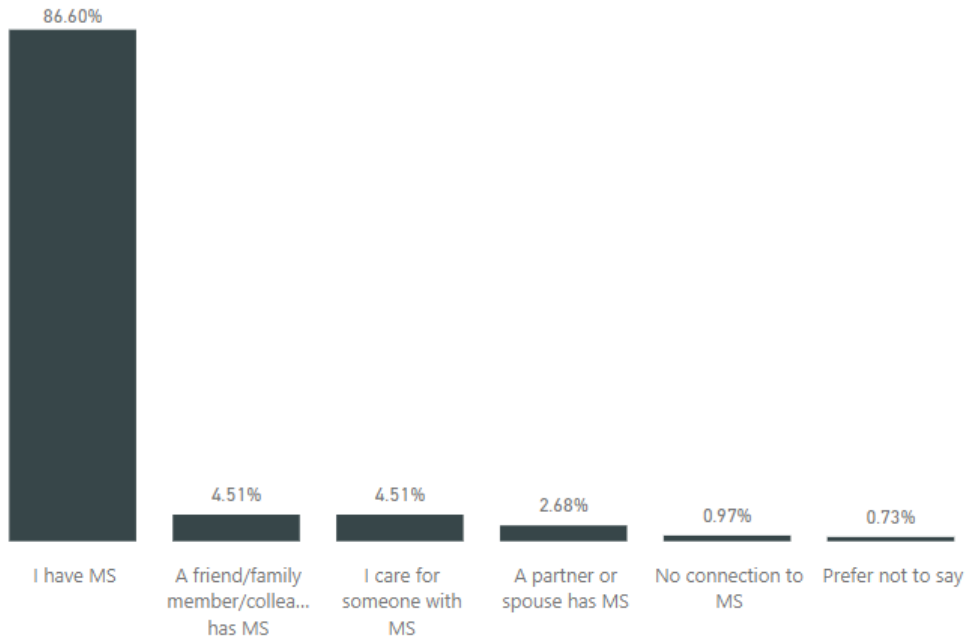
There is a positive correlation between the strength to which respondents identified as having felt lonely and whether they felt there was a stigma attached to feeling lonely. Those who had felt lonely were much more likely to agree that there is a stigma associated to feeling lonely.

"Have you felt lonely as a result of being affected by MS?" by "Is there a stigma attached to feeling lonely?"



8. What is your connection to MS?

Respondents were asked: "What is your connection to MS?"



The majority of respondents were people with MS, 87%. People affected by MS made up 13% of respondents.

Carers

37 respondents identified as Carers, this is a small data set and as such the results are less reliable. Carers identified having felt isolated or lonely with a similar frequency to people with MS. Also a similar frequency of carer respondents identified local groups as reducing those feelings of isolation or loneliness.

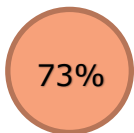


Identify as having felt isolated

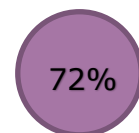


Identify as having felt lonely

Of respondents who identified as having felt isolation or loneliness:



Identify being part of a local group reduced their sense of isolation



Identify being part of a local group reduced their sense of loneliness

Carers who identified local groups as reducing feelings of isolation or loneliness identified similar aspects of the local groups, which reduce those feelings, as people with MS.

In relation to whether local groups reduce feelings of loneliness:

"If we were not part of the group I would certainly feel lonely as others do not understand what my life is like, they do [local group members] and you do not feel so alone then."

'Meeting other people affected by MS' and 'Friendship' were most frequently identified aspects of a local group which reduce feelings of loneliness and isolation, followed by 'Services provided by the group' and 'Support provided by volunteers at the group'.

Aspects of local groups that carers value ranked in order of importance for reducing feelings of isolation, feelings of loneliness and what they value overall.		
Isolation – 15 respondents	Loneliness – 15 respondents	Overall. Not related to isolation or loneliness – 37 respondents
1. Meeting other people affected by MS	1. Friendship	1. Friendship
2. Friendship	2. Meeting other people affected by MS	2. Meeting other people affected by MS
3. Services provided by the group	3. Support provided by volunteers at the group	3. Support provided by volunteers at the group
4. Support provided by volunteers at the group	4. Services provided by the group	4. Services provided by the group
5. Keeping busy	5. Keeping busy	5. Keeping busy

In relation to whether local groups reduce feelings of isolation:

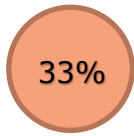
"Being part of a local group has helped me personally and that of my husband who has MS. We have both made friends through the group and increased opportunities to meet others affected by MS."

Stigma

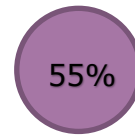
Carers are 8% more likely to agree that there is a stigma attached to feeling lonely than people with MS.

Friend/family member/colleague of someone who has MS

37 respondents identified as friend, family member or colleague of someone who has MS, this is a small data set and as such the results are less reliable. This category of respondents identified having felt lonely with a similar frequency to people with MS. However the proportion who had felt isolated was 25% lower than respondents who had MS. A similar frequency of these respondents also identified local groups as reducing feelings of isolation or loneliness in comparison to people with MS.

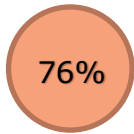


Identify as having felt isolated

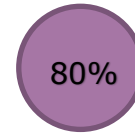


Identify as having felt lonely

Of respondents who identified as having felt isolation or loneliness:



Identify being part of a local group reduced their sense of isolation



Identify being part of a local group reduced their sense of loneliness

Friends, family members and colleagues who identified local groups as reducing feelings of isolation or loneliness identified similar aspects of local groups, which reduce those feelings, as people with MS.

'Meeting other people affected by MS' and 'Friendship' were most frequently identified, followed by 'Services provided by the group' and 'Support provided by volunteers at the group'.

However, when asked what they valued overall (not relating to isolation or loneliness) 'Support provided by volunteers at the group' and 'Services provided by the group' were more frequently identified, 'Meeting other people affected by MS' was less frequently identified.

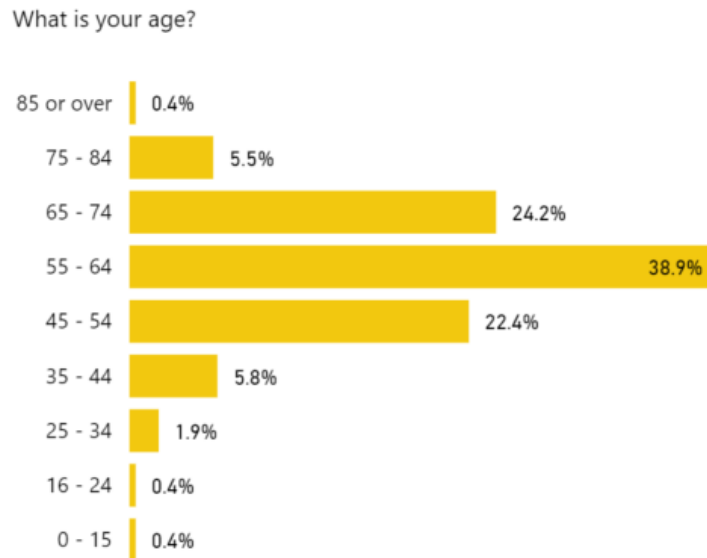
Aspects of local groups that friends, family or colleagues value ranked in order of importance for reducing feelings of isolation, feelings of loneliness and what they value overall.		
Isolation – 16 respondents	Loneliness – 16 respondents	Overall. Not related to isolation or loneliness – 37 respondents
6. Friendship	6. Friendship	6. Friendship
7. Meeting other people affected by MS	7. Meeting other people affected by MS	7. Support provided by volunteers at the group
8. Support provided by volunteers at the group	8. Services provided by the group	8. Services provided by the group
9. Services provided by the group	9. Support provided by volunteers at the group	9. Meeting other people affected by MS
10. Keeping busy	10. Keeping busy	10. Keeping busy

"My daughter has MS and I initially joined to support her; however, I have found the friendship and support from others involved in the group is tremendous."

Stigma

This group are 13% more likely to say there is no stigma attached to feeling lonely than people with MS.

9. Age



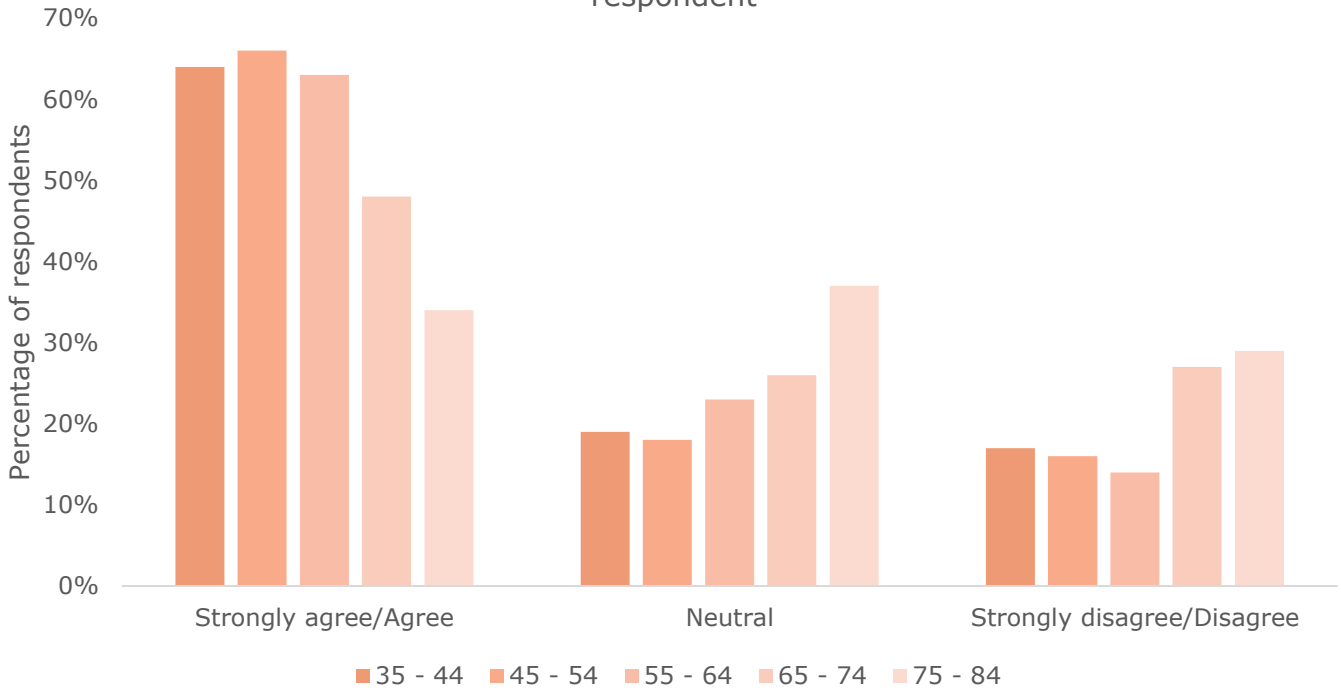
The spread of the respondents' ages matches what we know of our local group population.

Results show there is a negative correlation between increasing age and levels of loneliness or isolation; older respondents report having felt less isolated and lonely. This raises a further question of what is our offer to younger people affected by MS? Younger members are underrepresented in local groups and from the data below they are particularly vulnerable to feelings of isolation and loneliness.

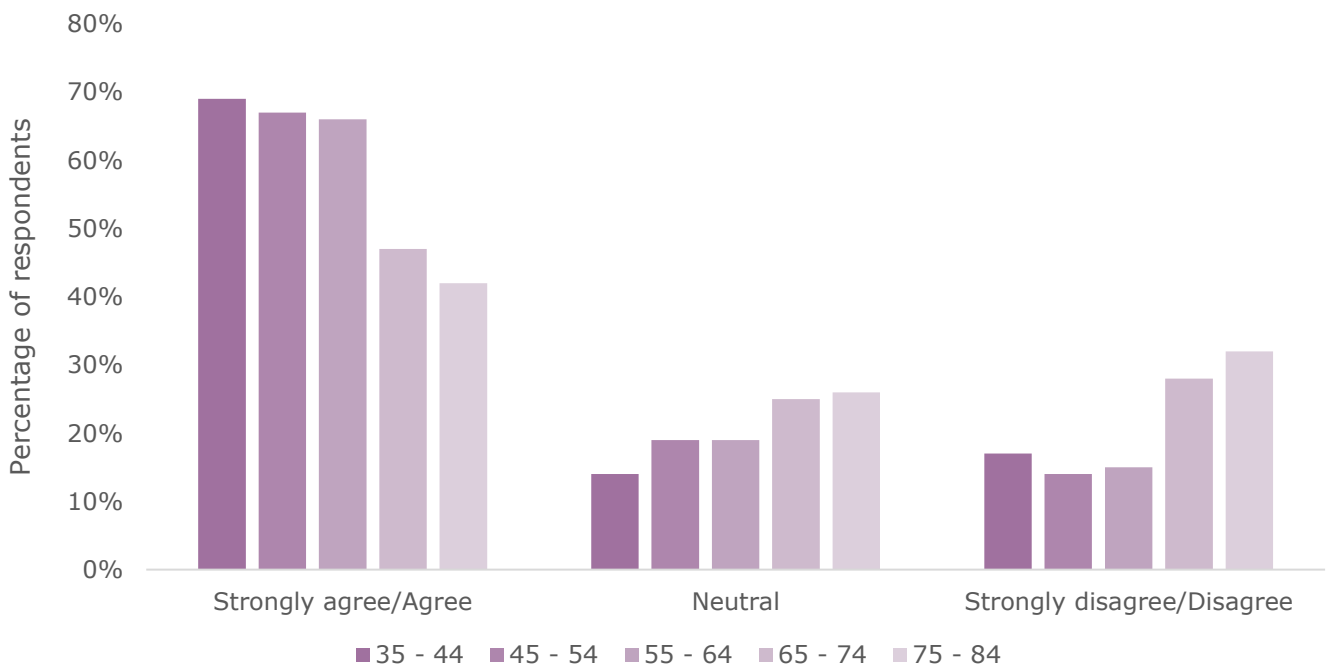
"Meeting others at the local group has been a real life-line. I really wish more young people with MS attended."

Respondents in the age categories of 0 – 14, 15 – 24, 25 – 34, and 85 or over, have been removed from the two charts below as there were too few respondents. The charts below show the negative correlation between age and isolation or loneliness.

"I have felt isolated as a result of being affected by MS" by age of respondent



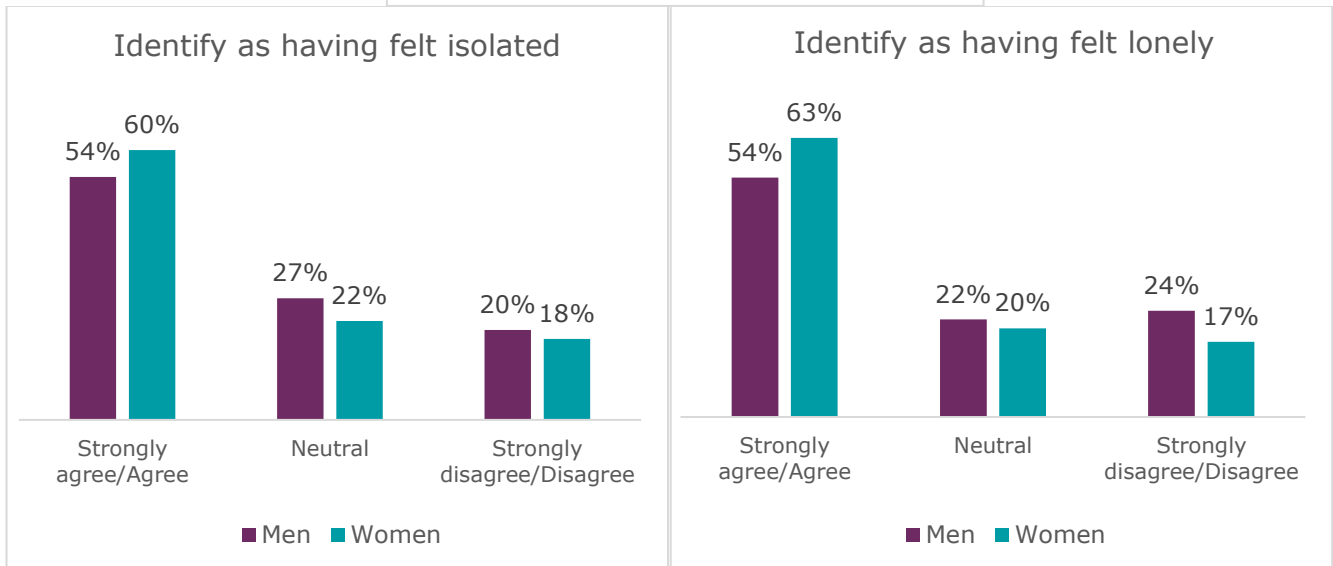
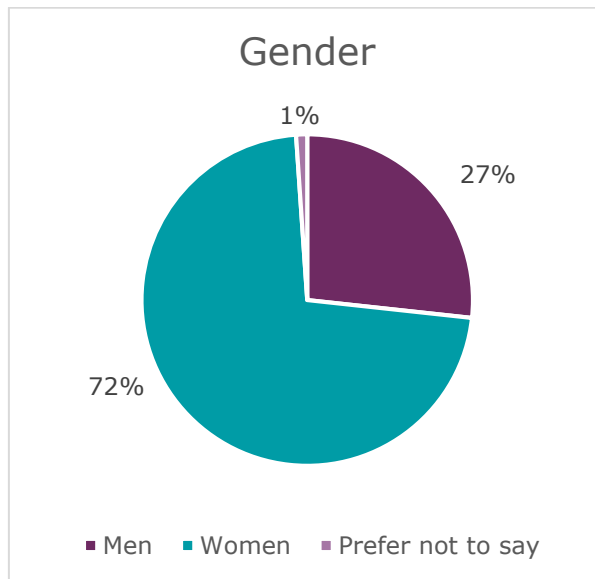
"I have felt lonely as a result of being affected by MS" by age of respondent



Gender

72% of all respondents were female and 27% were male. In the UK people with MS are 68% female and 32% male. Of respondents who have MS, 76% identified as female and 23% as male. This suggests that women with MS are more likely to be part of an MS Society local group than men with MS.

2% of respondents identified as trans (an umbrella term to describe people whose gender is not the same as, or does not sit comfortably with, the sex they were assigned at birth), it is estimated ~1% of the UK population identify as trans¹⁰. The number of trans respondents was too small to do correlation analysis to isolation or loneliness data.



Male respondents identify as having felt isolated 6% less frequently and having felt lonely 9% less frequently than women. This corresponds with a UK wide trend identified in the Community Life Survey¹¹.

¹⁰ "The Truth about Trans". Stonewall September 2018: <https://www.stonewall.org.uk/truth-about-trans#trans-people-britain>
¹¹ "Loneliness – What characteristics and circumstances are associated with feeling lonely?". ONS September 2018: <https://www.ons.gov.uk/peoplepopulationandcommunity/wellbeing/articles/lonelinesswhatcharacteristicsandcircumstancesareassociatedwithfeelinglonely/2018-04-10>

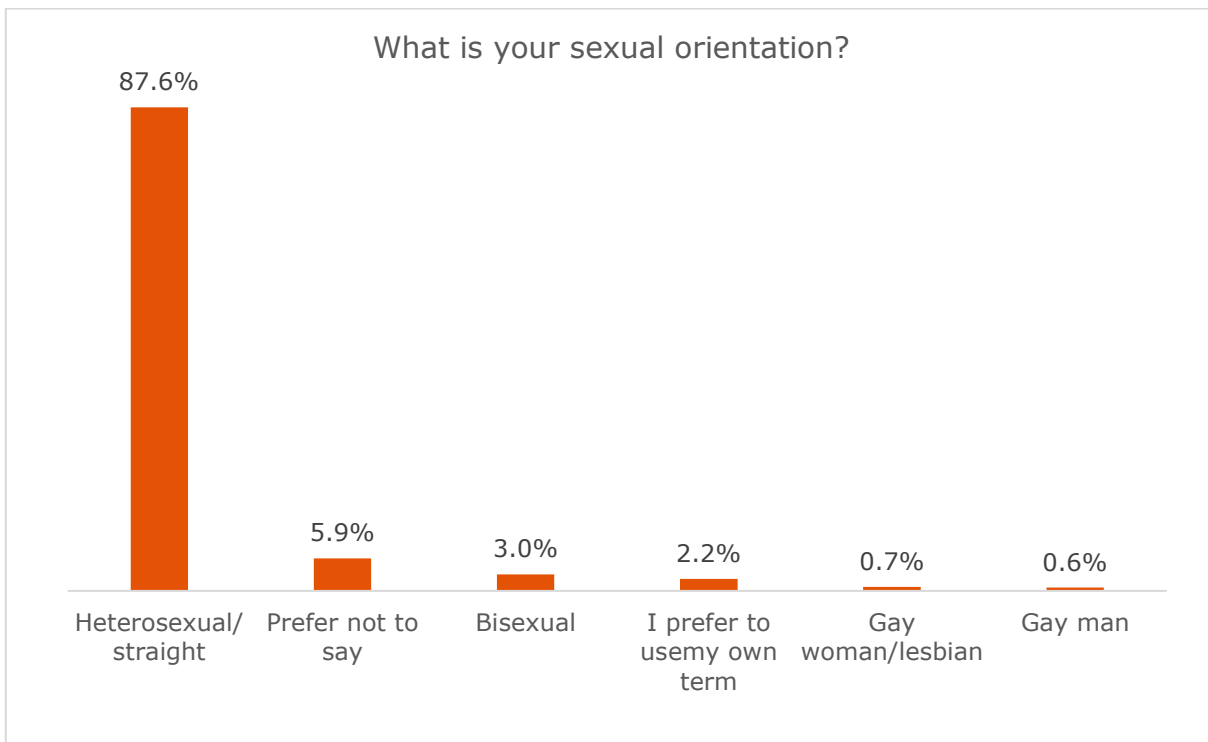
Respondents who identified as 'A partner or spouse of someone who has MS' or 'I care for someone with MS' were predominately male. These two groups have identified as having felt less lonely or isolated than people with MS. This may contribute to the lower levels of isolation and loneliness amongst male respondents. Further research is required to understand the extent of the correlation between gender, connection to MS and feelings of loneliness and isolation.

10. Ethnicity, sexual orientation and religion

Ethnic group	Respondents %
White: British	92.8%
White: Other	2.4%
White: Irish	1.6%
Asian or Asian British: Indian	0.7%
Other ethnic group	0.5%
Mixed: White and Asian	0.5%
Black or Black British: Caribbean	0.4%
Mixed: Other	0.4%
Mixed: White and Black African	0.1%
Black or Black British: African	0.1%
Mixed: and Black Caribbean	0.1%
Asian or Asian British: Chinese	0.1%

The low number of non-White: British respondents has limited what correlations can be made between demographic and loneliness or isolation data. It does appear to highlight the limited diversity of our local groups with regards to ethnicity.

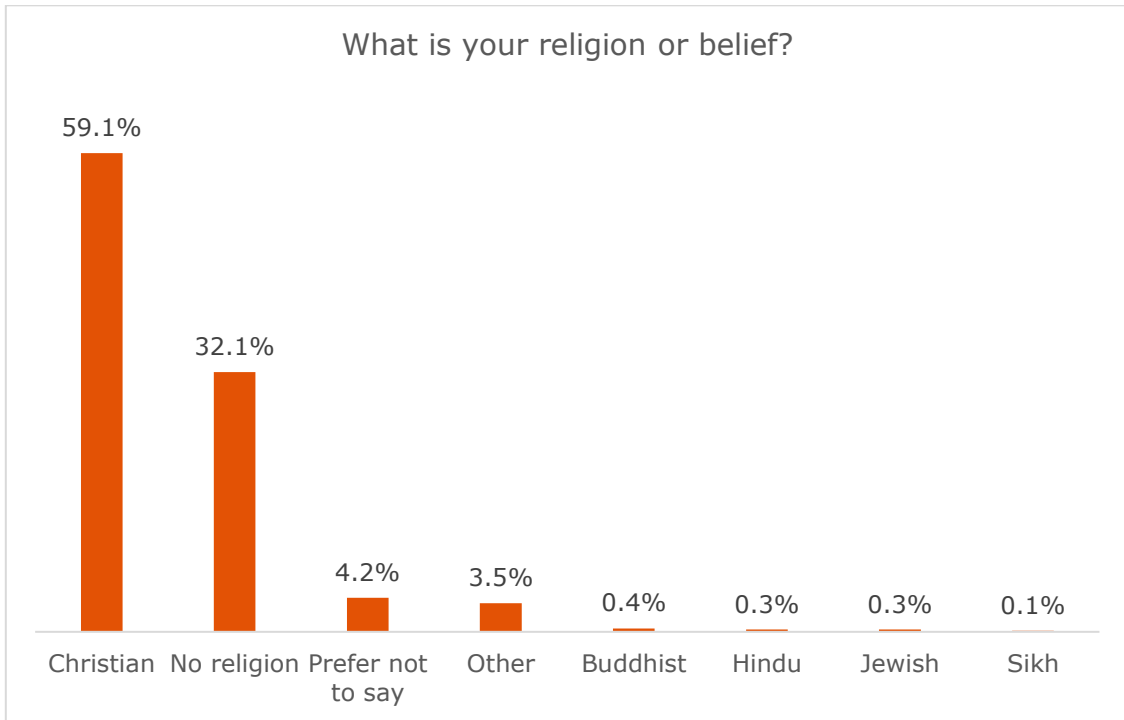
Sexual orientation



4.3% of respondents (31) identified as lesbian, gay or bisexual (LGB), above the UK wide proportion, 2%¹². LGB respondents identified as feeling isolated, 55%, and lonely, 58% on a similar level to heterosexual/straight respondents, the largest respondent group.

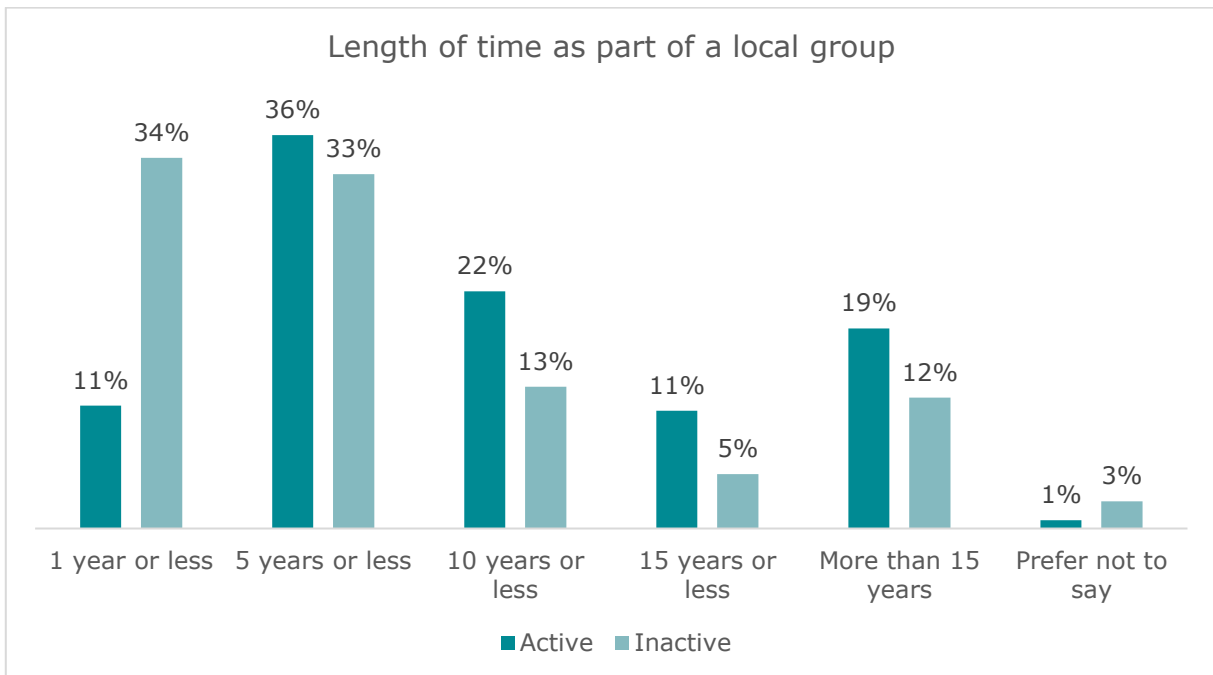
¹² "Sexual identity, UK:2016". Office for National Statistics April 2016: <https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/sexuality/bulletins/sexualidentityuk/2016>

Religion



There were no significant difference between Christian respondents' isolation and loneliness data and those with no religion. The other religion or belief groups sample size was too small to draw significant conclusions.

Length of time as part of a local group



There is a positive correlation between respondent age and length of time as part of a local group, as would be expected.

Similar to age there is a negative correlation between length of time participating in a local group and levels of loneliness, individuals who have been a group for longer have felt less isolation and loneliness. The correlation between feelings of isolation and loneliness to age is slightly stronger than the correlation to length of time in a local group.

"Loneliness is not an issue for me as I have made many friends through the Group over a number of years and remain in contact with them."

Potentially respondents who have been active in groups over a number of years have established friendships which reduce feelings of loneliness.

A lack of diverse demographic data prevents us from doing intersectional analysis and understanding how different characteristics of people affected by MS may influence their feelings of isolation and loneliness or how local groups support them.

"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."

11. Summary

Have people affected by MS felt isolated and lonely?

As a result of being affected by MS the majority of respondents reported having felt isolated, 58%, or lonely, 60%.

Do groups reduce feelings of isolation and loneliness?

Almost 80% of respondents identified being part of a local group as reducing feelings of isolation and loneliness.

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 were 'meeting other people affected by MS' (86% of respondents) and friendships (80% of respondents).

Is there a stigma associated to feeling lonely?

Respondents were largely unsure if there was a stigma associated with feeling lonely, 48%. However, twice as many respondents said there was a stigma associated to feeling lonely, 33%, as respondents who felt there was not, 15%. Respondents who had felt lonely were much more likely to agree that there is a stigma associated to feeling lonely.

What demographic factors affect feelings of isolation and loneliness?

Younger respondents reported having felt more isolated and lonely than older respondents. Correspondingly individuals who had been in a local group for a longer amount of time reported lower levels of isolation and loneliness.

People with MS and carers experienced similar levels of isolation and loneliness, 53%-60% of respondents. Friends, family members and colleagues of someone with MS experienced similar levels of loneliness as people with MS, 55%, but had feelings of isolation much less frequently, 33% of respondents.

Respondents were over 96% white, which reflects the diversity in local groups

12. Further questions and recommendations

The results of the survey have identified several further questions:

- What is the role of online and social media communities
- What factors influence individuals to leave groups?
- Are there other ways in which we can brand and market our groups?
- What is our offer to younger people affected by MS?

What is the role of online and social media communities

The project looked at MS Society local group's model which is predominantly face-to-face peer support and activity groups. The MS Society also has an active online forum (total members 37,369) and social media community.

Online local groups avoid transport and venue issues and can have low support costs. Some respondents identified in open text responses the benefits of online communication:

"I personally found speaking to people better online."

We suggest the survey is extended in the next phase to online communities to establish the role of MS Society's forum and social media in reducing feelings of isolation and loneliness. This survey should to ascertain what, if any, demand there is for online communities to develop into off line, local friendship groups, particularly among the younger age demographic.

Understand what factors influence individuals to leave groups.

The survey did not ask inactive respondents why they had left a local group. However, the results identify that active and inactive respondents value groups differently.

Inactive respondents value all aspects of local groups with less frequency than active respondents. The largest difference is for 'Friendship'. Inactive respondents identify 'Friendship' as a valued aspect 33% less often than active respondents. Is not developing friendships within a local group a key factor in individuals leaving groups?

Additionally 4% of respondents identified transport, travel and the distance to their nearest local group as an issue in open text responses.

"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."

However, do inactive respondents have different needs and could this reflect their reasons to no longer be part of a local group? It may be the case that inactive respondents no longer experience feelings of loneliness or isolation and hence do not need the benefits of being part of a local group. Asking respondents about their current levels of loneliness or isolation may identify whether this is a leaving factor.

From the data, groups have a large impact on reducing feelings of loneliness and isolation. Further research could allow us to understand and reduce the factors which lead to individuals leaving groups.

How do we market our groups to people affected by MS?

Services and the support provided by local groups is one of the key factors we use to attract people to us. The majority of respondents stated that meeting other people affected by MS and friendships were the aspects that they valued most about local groups.

We suggest testing new messaging which emphasises the value of local groups in developing local friendships with people who know what is like to be affected by MS.

What is our offer to younger people with MS?

The survey results show a correlation between increasing age & length of time in a local group and decreasing feelings of loneliness and isolation. The age group of respondents shows that the majority of local group participants are in the 55 – 64 age bracket. If younger people affected by MS are more vulnerable to feelings of isolation and loneliness, how can we ensure our local group services are reaching this community?

"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."

13. 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, 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 as well as identifying further research around loneliness with the charity's online communities.

14. Appendix

Digital materials created by Galatea Mancini available at:

P:\Services and Support\Local Networks Programme\Projects\Reducing loneliness evaluation\Digital workups

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