

Supplementary file 1: Survey questions

Loneliness among people who are terminally ill and their informal carers in Northern Ireland: Perspectives and experiences of health and social care professionals

By completing this survey, you are consenting to participate in this study.

Question	Options
About you	
1. Gender	Female Male Other [open text] Prefer not to say
2. Ethnicity	White Mixed or Multiple ethnic groups Asian or Asian British Black, African, Caribbean or Black British Other ethnic group
3. Age group	18-30 31-40 41-50 51-60 61+ Prefer not to say
4. What is your job role in Marie Curie?	Registered Nurse Healthcare Assistant Patient and family support team Rehab Team
5. Number of years' experience providing palliative care in current or previous role	[Open text] Prefer not to say
Prevalence of loneliness among Marie Curie patients and their informal carers	
<p><i>This study adopts the official definition of loneliness used by the UK Government, i.e.: Loneliness is a subjective, unwelcome feeling of lack or loss of companionship, which happens when there is a mismatch between the quantity and quality of social relationships that we have, and those that we want.</i></p> <p><i>An informal carer is anyone providing unpaid care or support. This could be a spouse, parent, child, other relative, neighbour or friend.</i></p>	
6. To what extent has the COVID-19 pandemic impacted on the prevalence of loneliness among the patients you care for?	No increase in numbers experiencing loneliness Slight increase in numbers experiencing loneliness Moderate increase in numbers Substantial increase in numbers
7. In your opinion/from your perspective, to what extent has	No increase in numbers Slight increase in numbers

the COVID-19 pandemic impacted on the prevalence of loneliness among their informal carers?	Moderate increase in numbers Substantial increase in numbers
<i>While the previous two questions [6 and 7] have focused on loneliness during the pandemic, the following questions focus on loneliness in general (outside of COVID-19)</i>	
8. In your typical pre-pandemic caseload, have you provided care or support for <u>patients</u> who you believe may have been experiencing loneliness?	Yes No [skips to Q11] Don't know [skips to Q11]
9. What caused you to come to this conclusion? Select as many as appropriate.	The patient told me/indicated that they were experiencing loneliness Informal carer told me/indicated that the patient was experiencing loneliness My own observations about the patients' circumstances Other [open text]
10. In your typical pre-pandemic caseload, what proportion of the patients you cared for or supported do you believe may have been experiencing loneliness?	0-25% 26-50% 51-75% 76-100% Don't know
11. In your typical pre-pandemic caseload, have you supported <u>an informal carer</u> who you believe may have been experiencing loneliness?	Yes No [if also selected 'no' to Q8, skips to end of survey; if selected 'yes' to Q8, skips to Q14] Don't know [if also selected 'no' to Q8, skips to Q16; if selected 'yes' to Q8, skips to Q14]
12. What caused you to come to this conclusion? Select as many as appropriate	An informal carer told me/indicated that they were experiencing loneliness A patient or informal carer told me/indicated that the informal carer was experiencing loneliness My own observations about the informal carer's circumstances Other [open text]
13. In your typical pre-pandemic caseload, what proportion of informal carers do you believe may have been experiencing loneliness?	0-25% 26-50% 51-75% 76-100% Don't know
Impact of loneliness on Marie Curie patients and their informal carers	
14. How would you rate the impact of loneliness on the end of life care experiences of the patients you cared for or supported?	<ul style="list-style-type: none"> ▪ Psychological wellbeing <ul style="list-style-type: none"> ➤ Low ➤ Medium ➤ High ▪ Spiritual wellbeing

	<ul style="list-style-type: none"> ➤ Low ➤ Medium ➤ High ▪ Physical wellbeing ➤ Low ➤ Medium ➤ High ▪ Social wellbeing ➤ Low ➤ Medium ➤ High <p>[open text to provide further information, but not mandatory]</p>
15. How would you rate the impact of loneliness on the end of life care experiences of the informal carers you supported?	<ul style="list-style-type: none"> ▪ Psychological wellbeing ➤ Low ➤ Medium ➤ High ▪ Spiritual wellbeing ➤ Low ➤ Medium ➤ High ▪ Physical wellbeing ➤ Low ➤ Medium ➤ High ▪ Social wellbeing ➤ Low ➤ Medium ➤ High <p>[open text to provide further information, but not mandatory]</p>
Possible solutions for reducing loneliness among Marie Curie patients and their informal carers	
16. Is there anything you do in your current practice to address loneliness among a) your patients and; b) their informal carers?	[open text]
17. In your opinion, what are the barriers to reducing loneliness among a) terminally ill patients and; b) their informal carers?	[open text]
18. Is there anything else you would like to tell us about loneliness among terminally ill patients and their informal carers, and how it impacts their care towards end of life?	[open text]

