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Macmillan Palliative and End of Life Care Project Carer Survey Report

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Summary from Sandra Campbell FRCN, Macmillan Partnership Nurse Consultant (Palliative & End of Life Care)

On behalf of the Scottish Ambulance Service (SAS) and our partnership with Macmillan, I would like to extend our sincere gratitude to everyone who participated in the recent Carer Survey for the Palliative and End of Life Care Project. Your input is invaluable to our ongoing efforts to improve the quality of end-of-life care in Scotland, and we appreciate your openness in sharing both positive experiences and areas for improvement.

This partnership between SAS and Macmillan was established with a shared vision: to deliver compassionate, responsive, and expert care to individuals nearing the end of life, and to ensure that their carers feel fully supported. The insights gathered from this survey are integral to refining our approach, and we are currently addressing several key areas highlighted in your feedback.

Areas of Focus Based on Feedback:

1. Respect, Compassion, and Person-Centred Care: Many of you emphasized the importance of respect, empathy, and understanding for both patients and carers. We are working to ensure these values remain central in all interactions and that they are reinforced through ongoing staff training.
2. Timely Response: A frequent point raised was the need for quicker ambulance response times, particularly in crisis situations. We acknowledge the importance of timely care and are exploring strategies to minimize response delays where possible.
3. Knowledge of Patient Needs and Background: Several responses mentioned the need for ambulance crews to have a more comprehensive understanding of the patient’s history, including end-of-life care preferences and anticipatory care plans. We are evaluating ways to improve information sharing across care teams while respecting privacy.
4. Effective Communication and Decision-Making: The feedback highlighted the value of clear and compassionate communication, particularly during high-stress moments. SAS is committed to enhancing our communication training to support decision-making that respects the needs and wishes of both patients and carers.
5. Support in Rural and Remote Areas: Challenges faced by those in remote areas were also underscored, such as limited out-of-hours care and connectivity issues. We recognize these unique needs and are coordinating with the relevant teams to develop tailored support solutions.

The survey responses have also provided helpful suggestions regarding symptom control, shared decision-making, and respect for carer perspectives, which align with the principles of Realistic Medicine. These insights reinforce our commitment to delivering dignified, compassionate, and individualized care.

We are deeply committed to ensuring this project evolves to meet the needs of all who rely on it. As we move forward, your continued involvement and feedback will be invaluable in shaping a service that reflects the experiences and needs of those it serves. Please feel welcome to share any additional thoughts or suggestions with us as we refine our approach.

Thank you once again for your invaluable contribution to this project, and for your trust in helping us improve the future of palliative and end-of-life care.

Sandra Campbell FRCN

Macmillan Partnership Nurse Consultant (Palliative & End of Life Care)

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Introduction

This brief report provides a summary of the results of a carer experience survey conducted in April this year. The added value of involving carers and hearing their voice in service development is acknowledged in the Carers National Strategy (SG 2022). Carers Strategy (www.gov.scot) The main purpose of the survey was to facilitate carer involvement and inform the final outcome of the Macmillan Palliative and End of Life Care project.

Background

The Scottish Ambulance Service (SAS) three-year partnership project with Macmillan commenced in April 2022. This was in recognition of the major increase in demand for unscheduled care in palliative and end of life care and of the subsequent increasing demand on ambulance services (Lord et al 2019; Mason et al 2020; Buhrmann 2022; Blackmore 2022). It builds on previous work in England and Wales with a pilot being completed in Forth Valley immediately prior to the pandemic. The overall aim of the project is to improve the quality of care that the Scottish Ambulance Service provides to people with Palliative and/or End of Life Care needs by March 2025 by adopting a whole system approach to care delivery.

The two main objectives are:

1. To develop alternative pathways, by collaborative working with other teams in SAS and multiple teams across Scotland in Health and Social Care and Third Sector.
2. To deliver a robust education programme for SAS staff with a focus on communication skills and symptom control.

The team delivering the project consists of:

- Programme Lead (Full time national role)
- Nurse Consultant (Part -time national role)
- 3 Clinical Effectiveness Leads (Full time regional roles)

Method

A subgroup of the Project Steering Group was formed with expert representation from Carers Scotland and Carers NI, Health Improvement Scotland (HIS) and SAS.

The decision to send a questionnaire via Microsoft Forms was taken after exploring the possibility of linking with existing patient and public groups in the different areas developing alternative pathways as part of the project. A questionnaire was then devised seeking two main views: one from those who had experienced palliative care support from a paramedic and one from those who were caring for someone who may require calling for someone with palliative care needs. An equalities monitoring form

was included. Despite the questionnaire being sent to 2500 carers known to Carers Scotland and also via social media, with 200-250 responses expected, the response rate was quite low with only 86 responses received. However, there has been a trend of low responses this year, for which, the reason is unknown.

Results

The questions and a summary of the responses are shown below in Figure 1 and in PowerPoint format in Appendix 1.

Figure 1 Survey results

Question	Response %	Response
1. Have you experienced an ambulance crew visiting for a family member or friend who has or had a life shortening condition, terminal illness or approaching end of life?	83% said yes	
2. What is your relationship to the person the ambulance was arranged for?	90% were a relative	66 relatives, 4 friend, 1 neighbour, 3 Informal carer 0 other
3. How would you rate the care provided?	90% reported it as excellent (72%) or good (18%)	51 excellent, 13 good,6 fair, 2 poor
4. How was the ambulance arranged?	48% of calls were made by the carer	42 people called 999, 11 HCP called 999,13 HCP booked,5 unsure
5. What did the ambulance crew do for your relative, friend?	65% were conveyed 12% remained at home 15% had symptom relief 10% contacted other services	56 Conveyed ,11 remained at home, 13 symptom relief, 9 contacted other services 8 other
6. Did the ambulance crew explain to you and the patient what was happening/what they were doing?	89% reported always (73%) or mostly (16%)	52 Always, 12 mostly, 6 not so much , 2 not at all
7. Did the ambulance crew involve you in making decisions for the patient?	82% reported Always (61%) or mostly (21%)	43 Always, 15mostly, 7 not so much, 7 not at all
8. If you require the services from Scottish Ambulance Service in the future, please tell us what you would expect from the crew for the person you are caring for?	Wordcloud	
9. If you are caring for someone with a life shortening condition, terminal illness or someone approaching the end of life and have never had to call for an ambulance but may have to in the future, what would you expect from the crew for the person you are caring for?	Wordcloud	

An Equalities Monitoring Questionnaire was also completed showing that the majority of carers who responded were females (79%); 60% were over the age of 45; 78 (90%) identified as white (Scottish, British or Irish) and 86% identified as heterosexual. Full results are shown in Figure 2.

Figure 2 Equalities Monitoring Results: 86 Responded

Question	Response
What is your sex?	68 (79%) Female 16 (19%) Male 2 Prefer not to say
Do you consider yourself to be a trans person or have a trans history?	82 (95%) No 4 Prefer not to say
Which age group do you belong to?	Under 16 0 16-25 3 26-35 8 36-45 18 46-55 14 56-65 24 66 and over 14 Prefer not to say 4
Do you consider yourself to be disabled?	23 Yes 59 No 3 Prefer not to say
Which of the following best describes your sexual orientation?	Heterosexual/ Straight 73 (86%) Prefer not to say 5 Gay/ Lesbian 4 Bi/Bisexual 3
How would you describe your religion, religious denomination or belief?	None 37 Christian (COS) 22 Christian Catholic 3 Christian (Other) 6 Prefer not to say 7 Pagan 1 Muslim 1 Buddhist 1
What is your ethnicity?	White Scottish 56 White British 21 Other 3 Prefer not to say 2 White Irish 1 Pakistani 1 Mixed/ multiple ethnic group 1

The survey results and comments will be used to contribute to the evaluation of the project and to inform how the pathways and a model of excellence in palliative care will develop. Overall, the responses were very positive with the following key themes identified:

- ✓ The importance of respect, compassion and care.
- ✓ The importance of the carers voice being heard.
- ✓ The importance of ambulances arriving quickly.
- ✓ The importance of staff being knowledgeable in symptom control.
- ✓ The importance of staff having knowledge of the person.

The responses highlighted the need for crews having knowledge of the person, reflecting the value of future care planning as advocated by Scottish Government. [Future Care Planning Toolkit | Health and social care improvement in Scotland - Future Care Planning toolkit (ihub.scot)]

There were also a number of comments relating to the importance of shared decision making and respecting the carers view in accordance with Realistic Medicine. Realistic conversations: shared decision making in practice | NH (scot.nhs.uk)
These comments also align with the supportive and proactive approach to living with chronic, life limiting conditions suggested by Gawande (2014) and more recently by Winemaker and Sowe (2023) www.waitingroomrevolution.com

Examples of some of the comments are shown in Figure 3.

Figure 3: Examples of comments from questions 8 and 9 (See Appendix 2)

Positive comments	*"We have had (too many) wonderful experiences from the ambulance service and we could not ask for better."* *. "I have always found your service amazing and have never had problems when I phone and I appreciate there are times when there are people who abuse the system. But wonder if it was recorded somewhere on your system that the person has a life limiting condition if it would help you to maybe shorted the time the carer/relative had to spend on the phone explaining all the health problems."* *"Nothing to suggest because, they are the best"* *"Utter respect for ambulance. ….. has since died and the ambulance service were the only support who gave time and compassion - there was no other support, "quote - what do you expect it's a rural area/there's no palliative staff available"* . "*Used ambulance services several times over the yrs. The level of compassion and care has always been exemplary. So would expect same if and when we do need to call them."*
Negative comments	*"It seems that every time … becomes seriously unwell I get asked the same things over and over again. I wondered if there is any way that the ambulance service if they are called for someone who is seriously unwell and who suffers from a life limiting condition could certainly pieces of information like this be logged on your computer system."* "*I would expect them to acknowledge me as my husband's carer and next of kin, to respect the fact I have full PoA for him even though it is not necessarily activated at the time. In the past I have had to argue these points with ambulance staff."* "*When she was being transported from the house to the ambulance, they had first to cross past several houses as my mum's house has no road directly outside her property. there was no blanket over her knees on a cold day, and she had only a thin knee length nightie. a blanket over her knees for modesty and warmth would have been expected. i walked beside her and tried to cover her myself with a blanket while they were on the move, unsuccessfully."*
Other helpful comments from question 9	*"Help and explain things in simple terms."* *"Empathy and the care of the individual looking out for their best Interests."* *"Care and compassion."* *"Just be quick in getting here."* *"Person centred care."* *"To come as quickly as possible and be compassionate."*

All the comments are shown in Appendix 2.

Additional information from carers

People were also asked if they would like to participate in a focus group but only two provided emails. One person responded with very helpful information regarding the challenges in the remote and rural areas. A subsequent telephone conversation with the key messages pertinent to the challenges in remote and rural areas being summarised as:

- Limited access to support and care OOH
- Issues with WIFI contributing to communication problems
- Workforce issues due to geography including staff availability and using external workers from outwith the island not understanding the services or the area

All of these add another layer of complexity in managing the palliative care needs of people living in these areas.

With the persons permission, her contact has been shared with the lead for specific work to address the wider issues within the Remote and Rural areas in line with the Scottish Government agenda.

Another person shared their email on the form inviting contact which also resulted in further helpful telephone communication and engagement. This person highlighted the challenges faced for young people with a chronic illness with complex needs and a fluctuating health status resulting in many hospital admissions. Challenges included:

- Having to tell the story to crews repeatedly despite an anticipatory care plan being in place
- Repeatedly being asked about DNACPR status despite one being place and causing unnecessary distress in being asked in times of crisis
- Having to go through the normal process for ordering patient transport and be asked all the routine questions every time an ambulance is required
- Lack of communication to patient transport staff that more than 2 staff are required and when 2 arrive, if for a hospital discharge, the discharge can be delayed

All of the above information was very helpful and the carer was keen to stress she was not complaining but if this information can help inform change and improvement, it will improve other people's quality of lives too. The solution to the issue with repeatedly going through the whole assessment process re access to patient transport is to have a record of her condition digitally available. The solution suggested regarding the communication issue relating to being repeatedly being asked about her condition is that if the crew had access to the clinical background prior to arrival at the house, they could simply ask "What has changed today that you have called an ambulance or require an ambulance?" The information will be shared with the relevant teams.

Another issue related to the variation of acceptance of the patient's fully Therapy Dog, but this has not been an issue with the ambulance service and is being shared with the relevant Board as feedback and not in the form of a complaint.

Additional support

There was also engagement by the lead for SAS and the Nurse Consultant with the lead for Carers in the CHAS (Children's Hospice Association Scotland) resulting in the development of a poster to demystify the potential trauma of children requiring an ambulance. This poster will also show the pathway for all staff if an ambulance is required when a child is in one of the two hospices. It will be informed by the children and their families.

Conclusion and Recommendations

Conducting the survey has been extremely valuable, despite the low response, with the richness of data providing evidence that will inform the project outcomes. Most of the feedback shows that care in a crisis situation near the end of life provided by SAS is excellent or good. The benefit of open and honest, compassionate communication as advocated by Mannix (2017, 2022) was threaded through the comments. The areas identified in the themes as important to people caring for someone who requires an ambulance can be summarised as: carers want their loved ones to be treated with respect and compassion by staff who arrive quickly in a time of crisis and distress, are knowledgeable in symptom control and have an understanding of the persons condition and listen to the carer.

The results of the survey confirm that the education provided to staff to date is appropriate as the themes identified are embedded in the programme with the main topics being delivered in the communication programme and the symptom control sessions which are fully informed by the Scottish Palliative Care Guidelines whilst embracing. The fundamentals of palliative care are also taught. Scottish Palliative Care Guidelines | Right Decisions It is also suggested to staff to consider the patient Dignity Question (PDQ) by Chochinov (2005) *"What do I need to know about you to provide the best care possible?"* as the basis for their assessment. The area of concern for some about reducing the risk of time delays is recognised in the development of the alternative pathways.

The key recommendations from this report are that the information obtained from conducting the survey:

1. Is used to inform future education programmes.
2. Is used to inform further engagement work and policy development regarding shared decision making and consent.
3. Is shared widely in the organisation and with teams across the country who participated in collaborative work to develop alternative pathways.
4. Is shared with the carers network.

Acknowledgement is paid to the members of the subgroup for their valuable contribution to conducting the survey (See Appendix 3). And acknowledgement is also paid to the carers who took the time to complete the survey.

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Appendix1 PowerPoint of Results

Scottish Ambulance Service
University National NHS Board

Carer Experience Survey for those supporting people with Palliative Care needs who required the services of Scottish Ambulance Service

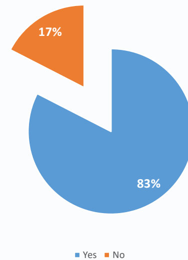
86 responses to survey

Macmillan Palliative and End of Life Care project

MACMILLAN CANCER SUPPORT

Scottish Ambulance Service
University National NHS Board

Have you experienced an ambulance crew visiting for a family member or friend who has or had a life shortening condition, terminal illness or approaching end of life?
71 respondents answered yes
15 respondents answered no



Macmillan Palliative and End of Life Care project

MACMILLAN CANCER SUPPORT

Scottish Ambulance Service
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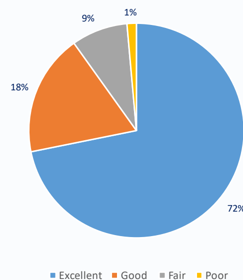
How would you rate the care provided?



Grading of care	Total
Excellent	51
Good	13
Fair	6
Poor	1

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How was the ambulance arranged?

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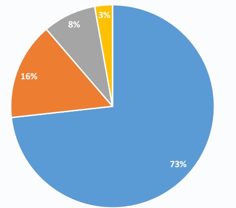
Did the ambulance crew explain to you and the patient what was happening/what they were doing?

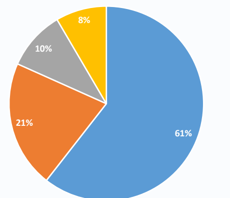


Rating	Total
Always	52
Mostly	11
Not so much	6
No not at all	2

■ Always ■ Mostly ■ Not so much ■ No not at all

Macmillan Palliative and End of Life Care project

Did the ambulance crew involve you in making decisions for the patient



Rating	Total
Always	43
Mostly	15
Not so much	7
No not at all	6

■ Always ■ Mostly ■ Not so much ■ No not at all

Macmillan Palliative and End of Life Care project

Appendix1 PowerPoint of Results (contd.)

If you are caring for someone with a life shortening condition, terminal illness or someone approaching the end of life and have never had to call for an ambulance but may have to in the future, what would you expect from the crew for the person you are caring for?

Macmillan Palliative and End of Life Care project

If you require the services from Scottish Ambulance Service in the future, please tell us what you would expect from the crew for the person you are caring for?

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Appendix 2

Comments: questions 8 and 9

Comment	Positive	Negative	Neutral /Informative
Question 8 If you require the services from Scottish Ambulance Service in the future, please tell us what you would expect from the crew for the person you are caring for?	**1**.I would expect any member of SAS, to talk and listen to me or a member of my family, which they always do, any time I have had to call for my elderly mother or daughter, they have always shown tremendous empathy and understanding, our youngest daughter who was born at 24 weeks weighing 1lb now has Brittle Asthma and Adrenal Insufficiency, but does not let it hold her back, and she is now in her final year of study at Glasgow Caledonian University studying BSc Paramedic Science, and is out on placement in the Ambulance as I type this, it's been her dream since the age of 10 to become a member of The SAS, she is especially proud of them as we are of her. **2.** Probably the same as above. It's so hard when you're caring for someone with a life limiting condition and trying to keep track of all the health problems attached to this. It's almost like if there was anyway of recording this on your system so the families don't have to go through the same things over and over again. I have always found your service amazing and have never had problems when I phone, and I appreciate there are times when there are people who abuse the system. But wonder if it was recorded somewhere on your system that the person has a life limiting condition if it would help you to maybe shorted the time the carer/relative had to spend on the phone explaining all the health problems. I hope this makes sense if it doesn't, please don't hesitate to contact me at … **3.** excellent they are **4.** Understanding (he has Alzheimer's) and patience, clear explanation of what they are doing and why. **5** Nothing to suggest because, they are the best **6** A service that actually follows the NHS values Advocate, support and administration of pain relief. Showed upmost professionalism and compassion and actually listened to family and attempted to get …. opinion unlike random nurse who called them and condescending GP who they dealt with disbelief. Utter respect for ambulance. ….. has since died and the ambulance service were the only support who gave time and compassion - there was no other support, "quote - what do you expect it's a rural area/there's no palliative staff available/ we'll arrange ARCH - emergency responders- one 15 minute visit in 5 days!/ we don't " do" hospital at home here...As my Health and social care partnership Aberdeenshire is proposing cutting funding to Marie Currie nurses	**1**This is possibly just a personal issue, or possibly not. I guess most people who have someone with a life limiting condition will have several things in place like us such as a DNR and possibly POA too. It seems that every time … becomes seriously unwell I get asked the same things over and over again. I wondered if there is any way that the ambulance service if they are called for someone who is seriously unwell and who suffers from a life limiting condition could certain pieces of information like this be logged on your computer system. **2**.To arrive quicker **3.** I would expect them to acknowledge me as my husband's carer and next of kin, to respect the fact I have full PoA for him even though it is not necessarily activated at the time. In the past I have had to argue these points with ambulance staff. **4**. symptom control if indicated. good communication between the ambulance personnel and the patient AND carer. taking the patient held records to the ward - or at least the Just In Case sheets - my mum didn't take these with her as the paramedic said only the DNA CPr was needed. As a result it was difficult for the ward medical staff to know how much Morphine she had had in the previous 24 hours , as she had had to call out the District nurse 3 times and then the GP , who all gave SC morphine, prior to the paramedic giving IV Morphine before the journey to the ward. When she was being transported from the house to the ambulance, they had first to cross past several houses as my mums house has no road directly outside her property. there was no blanket over her knees on a cold day, and she had only a thin knee length nightie. a blanket over her knees for modesty and warmth would have been expected. i walked beside her and tried to cover her myself with a blanket while they were on the move, unsuccessfully. **5.** Compassion knowing it is stressful. Not asking unnecessary questions (which can be upsetting)	**1** Understanding (he has Alzheimer's) and patience, clear explanation of what they are doing and why. **2** Complex needs **3**.Compassionate and professional response and full information **4.** Friendly, calm, speaking to older people with respect, sense of humour, **5** To be empathetic to the reason for the call , but also that they should have access to recent interactions with the NHS e.g. DNA CPR and request for "place of death" **6.** understanding of life limiting illness advanced Alzheimer's **7.** I would expect them to assess the needs of the patient and carer and provide care that would reduce the need for admittance to hospital **8** Kindness, Compassion, Strength, Support, Honesty, Integrity, Friendly Manner, Respect and Good Communication. **9.** Emergency care . Kindness and first aid as required. Transfer to hospital if required. **10.**Emergency care . Kindness and first aid as required. Transfer to hospital if required **11.** I never had to use them I had district nurses and gp together **12** Care, kindness and patience **13** Being there when needed as fast as possible, being respected by the team as unpaid carer! Unpaid carers should not be underestimated, after many years 24/7 caring carers gained a lot of knowledge, about the patient's health conditions. **14** Quick access to information on medical and nursing care records Skills to assess and ameliorate symptoms Excellent communication skills Authorisation and skills to medicate as appropriate, training to assess patient need and the practical skills to administer medications appropriately e.g. syringe drivers Compassion and respect for patient and those people present who are important to them. No pressure regarding the time required for the visit and hospital **15** Respect, patience, kindness - I assume that efficiency and technical skills are taken for granted **16** Compassion at all times **17** Tell person i.e. carer how serious it is **18** I would expect them to be treated with professionalism, dignity and respect. **19**. Treated with care, compassion, kindness. Consideration for unique circumstances, situation. **20** Prompt response and caring attitude. **21**Assess the patient and offer best scenario. Ambulance staff recommended stay at home but were told by hospital to take him in. This a 2.5 hour wait on ambulance, seen & sent home 5 hours later with wrongly written prescription. Not ideal. Ambulance staff were overruled **22** Kindness, calm and reassuring manner, a wee touch of humour or a friendly remark, and no judgment - these are so appreciated as sometimes everyone is in a tizzy and worried about doing/having done the right thing **23** An understanding that the parent/carer knows the needs of the child/adult best especially when they have

	unless you're loved one has cancer as an unpaid carer you are absolutely on your own as there is no effective palliative support apart from the area ambulance service 7. empathy, to be able to explain in plain terms what is happening, to involve the person if they are conscious, to be honest I've always found them to be all of those things and more when I've had to call an ambulance or they attended to my relative. **8.**Respect, empathy, skill. All of which I experienced on the several times I needed to call them. **9**. We have had (too many) wonderful experiences from the ambulance service and we could not ask for better. **10**. My son has complex health needs. When we have required an ambulance for him, we have been impressed at how much staff listen to what we say about his needs or support. There is much respect and acknowledging our views and opinions. We feel respected and valued. **11**. My expectations from the crew would be to provide sympathetic patient focused care and not focus so much on guidelines, my relative had experienced chest pain and the GP contacted the ambulance service to take to hospital (GP did not listen to my relatives wish to stay at home), when the ambulance arrived they done their obs ECG etc and the ECG had some concerning features to the crew, rather than just take him to hospital they asked him what he wanted, as he was in the end stages of life his main focus was pain control. The paramedics gave him his wish and got his pain under control and referred into Hospital at Home to follow up care and involve the palliative care team. To summarise just listen to what the patient wants, a trip to the hospital isn't going to prevent them dying but controlling their pain will let them die peacefully **12**. Exactly what I received. They were empathetic to our situation, made attempts for other pathways to keep the patient at home. They respected the patients wishes and included us in the decision making process. **13**. Professional as they always are Patient and understanding Be allowed to get the patient in the hospital quickly and not be stuck in the ambulance with the paramedics for eleven hours like it currently is **14**. Keep doing what they already do **15**. The teams do an amazing job. **16**. To just do what they are so good at doing. **17.** Compassion and empathy. They're always very good to us! **18**. Used ambulance services several times over the yrs. The level of compassion and care has always been exemplary. So would expect same if and when we do need to call them.	Get to the hospital quickly no hanging around **6.** Listen more to the carers as they know the individual best **7.** To come quicker , I know things are severely stretched but the service needs to run more ambulance technician courses as my daughter would thrive in a career like this but can't get in **8.** Give more reassurance to the patient, and communicate more	complex needs and this should be listened to well when making a judgement in their care/medical intervention. **24.** Care, compassion and transparency **25** Explanations **26.** Confident approachable friendly knowledgeable kind sensitive and someone who cares about the family not just the patient **27**. Honesty, engaging with the patient and relatives **28**. Caring person who will look after my family **29.** Try to make comfortable as much as possible to remain at home and understand the conditions and circumstances **30**. Compassion and patience. Understanding of our need and want to keep him at home and avoid hospital if possible. Knowledge of how to manage end of life symptoms. **31**. Don't need for him any longer **32** Emergency medical treatment **33**. Same as before, please discuss options with me, if i stipulate that my loved one would like to pass away at home making me take him to hospital is not feasible. **34.** Speedy response, sympathetic, empathy, knowledgeable, diligent and caring. **35.** Understanding and friendly **36.** Friendly caring willing to listen **37.** To understand the patient as an individual and do what is in the best interests for them **38.** Person centred care **39.** Information throughout and reasoning behind it **40.** To include me, even if the person has capacity it's still me staying to care for them, I know what's best sometimes or if they're not their usual self. **41.** To calm me and my client down make sure we knows everything that's happening **42.** Compassion **43** To be kept updated and part of the decision making at all times. Crew to take into account that as a family member communication is pivotal in gaining trust and respect **44** Help me Keep my Mum comfortable and not take her to A&E **45**. Compassionate and caring towards patient and family at what would be a traumatic time. • **46.** Give more respect to the First responders who were there first who did a wonderful job with my dad the crew were very sharp with the two first responder **47** Compassion, patience, clear communication with an understanding that many aged over 50 have hearing loss. Ongoing explanation as clinical assessment takes place as well as explanation on treatment and next steps.

	• **19.** Give more respect to the First responders who were there first who did a wonderful job with my dad the crew were very sharp with the two first responder 20		
Question 9 If you are caring for someone with a life shortening condition, terminal illness or someone approaching the end of life and have never had to call for an ambulance but may have to in the future, what would you expect from the crew for the person you are caring for?	**1.**As I said, I don't ever have to really expect a SAS crew to act in a certain way, they always act with care, understanding and empathy. **2.** Same as above but faster service to hospital. **3.** The same caring approach as given when an ambulance was arranged **4** The challenge is always that our daughter is very complex, but I have always felt the ambulance team were respectful and keen to listen when it was exactly what we needed. **5.** Keep doing what they have done **6.** Same level of service as already received		**1.** let them to die 😉 **2.** understand the incredible work of family carers **3** Support! **4**Falling & being unable to get up is an emergency , not an elective call and should be responded to asap -being "on the floor" is not comfortable. People with life-shortening illnesses should be prioritised closely behind immediately life threatening calls e.g. cardiac arrests & serious RTAs **5.** Appropriate intervention that would reduce the need for admission to hospital **6.** To arrive at my home in a satisfactory time-frame. To have an understanding of what the "person/patient" needs both on arrival and during the journey to hospital/hospice and be professional, kind and considerate. **7.** Respect, Good Communication, Kindness, Compassion and Caring Manner. **8.** Empathy and understanding of the situation. Professional help . Put in place appropriate care . **9.** To arrive quickly **10**. Being there when needed as fast as possible, being respected by the team as unpaid carer! Unpaid carers should not be underestimated, after many years 24/7 caring carers gained a lot of knowledge, about the patient's health conditions - a good cooperation, communication might be essential! **11.** Swift access to information on medical and nursing care records Skills to assess and ameliorate symptoms Excellent communication skills Authorisation to administer medication ,training to assess patient need and the practical skills to administer medications appropriately e.g. syringe drivers . Compassion and respect for the patient and the people present who are important to the patient No pressure regarding the time needed for treatment and hospital transfer if required . **12.** Reassurance for all involved, prompt and thorough assessment and advice. **13.** I would hope that preparation had been done by GP /Hospital Team or Community that a clear plan was in place and that it was ensured for everyone involved that they had a clear understanding of what that meant . **14.** Care, compassion and a dignified, person centred approach. **15**. Good listeners, understanding to situations they may not encounter everyday (complex needs), involve parents/carers in their plans, phone ahead to hospital if being admitted **16** Empathy for the situation that has resulted in the 999 call, treatment to alleviate any pain, care and respect for the patient and keeping both the patient and family informed of any decisions made on their behalf **17** Compassion **18.**Caring and making them comfortable **19.** Compassionate, caring, soft tones

			20. To still speak to them not speak past them like they aren't their or speak about their condition in front of them even if they think they can't hear they may have spells of hearing and it's dignifying **21.** Compassion and patience. Understanding of our need and want to keep him at home and avoid hospital if possible. Knowledge of how to manage end of life symptoms. **22** Compassion and communication **23** Depending on their end of life plan I would only contact the ambulance crew if they required medical treatment unrelated to their diagnosed condition **24.** Help, and explain things in simple terms **25.** Empathy and the care of the individual looking out for their best Interests **26.** Care and compassion **27.** Just be quick in getting here **28**. Person centred care **29.** To come as quickly as possible and be compassionate **30** To include me, even if the person has capacity it's still me staying to care for them, I know what's best sometimes or if they're not their usual self. **31** Not to talk about any of life in front of the patient **32**. Compassion **33** For the crew to be caring and compassionate **34** Compassionate and caring towards patient and family at what would be a traumatic time.
Themes emerging	Appreciation of areas identified as excellent /good practice overall: Compassion, empathy, respect, kindness	Areas for improvement Reduce time delays Need for information about the person Good communication	Helpful suggestions re what is important to the care and the person: COMPASSION KINDNESS EMPATHY PERSON CENTREDNESS TIME – NEED FOR URGENCY CARER VOICE TO BE HEARD

Appendix 3

Subgroup membership

Sharon Bleakley — Strategic Engagement Lead Health Improvement Scotland

Sandra Campbell — Macmillan Nurse Consultant (SAS)

Keri Fickling — Macmillan Clinical Effectiveness Lead (SAS)

Scott Mackinnon — Macmillan Programme Lead (SAS)

Richard Meade — Director Carers Scotland

Carmen Morrison — Engagement Advisor Health Improvement Scotland

Chris Purnell — Engagement Lead (SAS)