End of Life Care:
A General Practice Patient Perspective
December 2023

A joint project between
Ivy Medical Group's
Patient Participation Group and
Nottinghamshire Hospice

"I just wish the practice had more senior GPs and the right NHS environment that would have enabled us to do better on key areas.
This report will help us to seek the right support so we can build a better service for our patients"

Dr Panesar, Principal Partner, Ivy Medical Group

Table of Contents

End of Life Care: A General Practice Patient Perspective

Final Report

1. Document Reference

Title:	End of Life Care: A General Practice Patient Perspective
Date of Report:	December 2023
Area:	General Practice
Leads and Designation:	Lindsay Hall, Patient Participation Group (PPG) Representative, Ivy Medical Group (IMG) Kate Martin, Palliative Care Practice Lead, Nottinghamshire Hospice
Sponsor and Designation:	Tracy Madge, PPG Secretary Strategy Advisor, Ivy Medical Group
Audit Type:	Electronic and paper questionnaire
Link to the original survey	https://forms.office.com/e/Ms0pX2jPP4
Distribution	Arrow Primary Care Network. End of Life Care Board members, part of the Integrated Care Board of NHS Nottingham and Nottinghamshire, NHS England

2. Acknowledgements

Firstly, we would like to thank the patients families, carers and loved ones who took the time to complete the survey. We realise that this may not have been easy to do and we have signposted where ongoing support can be found at the end of this report (Appendix 3).

Secondly we would like to thank the team at Ivy Medical Group (IMG) for their support with this project and their willingness to take a deeper look at people's end of life care experiences from a GP perspective. This was in order to understand where things have gone well and where there may be room for improvements.

3. Executive Summary

Supported by their GP Principal at IMG the Patient Participation Group (PPG) have agreed that end of life care (EOLC) at home is a priority for highlighting and wanted to understand what support the PPG could bring to patients.

A patient from IMG donated funding to Nottinghamshire Hospice to go to improving EOLC at home. This has been used to develop a survey with PPG members, which we understand is the first survey of General Practice that looks exclusively at the provision of EOLC at home.

We have learnt a lot from the results as well as from the process and design of the survey and will we share this across Primary Care Networks. A key finding to acknowledge is that when reading the experience of relatives and carers we must take into account the role played by the NHS team, and the full care delivered, as this may not be captured fully in their replies and comments.

We have made six key recommendations from the analysis of the quantitative and qualitative data and have proposed an action plan from which we can monitor improvements.

This is part one of a two part report and is taken from the results of the EOLC Survey which was carried out at IMG between July and August 2023. Part two of the report will follow in the coming months and will look at the knowledge and skills of GPs, District Nurses and other community partners working with end-of-life patients and their families, specifically in relation to staff confidence and staff support.

4. Context

The survey was initiated by the PPG with the aim of supporting patients and their carers/family with the best quality of care at end of life. The PPG members intend to deliver support that is driven by current experiences.
The survey was co-designed to look at the provision of EOLC in the General Practice setting, specifically in relation to the experience of people registered with the IMG.

5. Key recommendations from the survey:

1) Improve access to information for providers on local EOLC and bereavement services.
2) GPs are still seen as the main point of contact and when patients/carers do not have contact from the surgery their experience of the management of death is seen negatively and of poor quality.
3) Rapid and early signposting for new EOLC patients and families so they have their wishes known as soon as possible.
4) Develop care coordination to monitor and guide patients and families to rapid access for support and information.
5) Share communication in a simple accessible guide.
6) Develop in-depth understanding of EOL in primary care to learn and continually develop high quality care at home.

6. Summary of the Key findings:

Please note that any discrepancies in numbers are due to non-response or not applicable.
Appendix 1 provides the detailed responses.

26 out of 55 people died at home. 13 of these were seen by IMG staff, 11 of which were GPs. 6 were seen by District Nurses. We should celebrate and support GPs and primary care-based staff as they are the key to community end of life care.

5 out of 13 patients were involved as much as they wanted to be and only one person would have like to have been more involved. The remaining people were too ill or died suddenly.

45 out of 55 people felt their loved one had died in the right place and as such, this suggests that hospital deaths should not be seen as a failure.

Symptoms were reasonably well managed, but it was hard to differentiate between hospital and community deaths. GPs could be better supported by signposting to the Palliative Medicine Symptom Advice Line.

It was reported by those completing the survey that 17 out of 55 people had a ReSPECT form or Advance Care Plan in place but this figure is not supported by practice records, which have a higher number. The PPG will work on supporting early conversations and signposting to support in Advance Care Planning.

The care and support given by the practice team to the person who died was considered outstanding, excellent or good by 24 out of 55 people and fair or poor by 23 out of 55 people. 8 people were not sure.

The care and support given by the practice team to the carer or loved one was considered outstanding, excellent or good by 15 out of 55 and fair or poor by 25 out of 55 people. 15 people were not sure.

The action plan focuses on five key recommendations for quality improvements for end-of-life care at the IMG.

Free text comments indicated a need for signposting to bereavement services.

7. Themes

Appendix one includes the full transcript from the free text. Combining this with the quantitative analysis above provides a number of emerging themes are shown in Table 1 below:

Table 1: Themes

Theme	Comments
GP contact	Need for regular, personal, face to face and telephone contact from the GP This needs to be a practice contact as patients/carers see failure of this as GP issue even when care has transferred to the community team
Co-ordination of care	A service that can signpost patients and carers to the right person to meet their EOLC needs.
Gratitude	When EOLC is done well it is seen to be excellent care
After death support	If EOLC has not been co-ordinated carers/families feel like they have failed Follow up via care co-ordination is essential via a compassionate conversation with someone who knows the patient/carer and can signpost to other support services

8. Action Plan for 2024

Themes	What	Whom (strategic)	Whom (local)	When	Quarterly Progress Or measures
1. Improve access to information for providers.					
Care co-ordination	Make information about local EOLC and bereavement services i.e. palliative medicine symptom advice line, Nottinghamshire Hospice and other end of life care providers, more accessible to GPs and include national directives e.g. One Chance to Get it Right -	ICB EOL strategic group.	GPs and community teams supported by PPGs	March 2024	

Themes	What	Whom (strategic)	Whom (local)	When	Quarterly Progress Or measures
	Priorities of Care for the Dying Person and the Ambitions documents				
2. GPs as the main point of contact					
GP Contact	Patients and carers need to have regular contact with a named clinician from the practice, by phone and face to face	GP providers	Community teams	March 2024	
3. Share communication in a simple accessible guide.					
GP contact	Improve communication for patients/families by producing a guide containing local providers of social care, hospice care, clinical and spiritual care. Host quarterly events in each of the local communities of Burton Joyce, Lambley, Stoke Bardolph and Lowdham.	ICB EOL strategic group.	GPs and community teams supported by PPGs	March 2024	
4. Rapid and early signposting for new EOL patients and families so they have their wishes known as soon as possible.					
Care Co-ordination	Support patients/families with Advance Care Planning conversations so that patients wishes and preferences about care at end of life are known, documented and	Providers of care	GPs and community teams supported by PPGs	January 2024	

Themes	What	Whom (strategic)	Whom (local)	When	Quarterly Progress Or measures
	shared with other health professionals				
5. Develop care coordination to monitor and guide patients and families to rapid access for support and information.					
GP Contact	Consider the role of care coordinators in the support of all patients identified in the last year of life	ICB EOL strategic group.	GPs	March 2024	
6.	**7. Develop in-depth understanding of EOL in primary care to learn and continually develop high quality care at home.**				
Care Co-ordination	Share the survey with PCNs and repeat annually to assess progress and learning against the actions	ICB EOL strategic group. Supported locally by providers and championed by PPGs	GPs and PCNs	March 2024	

9. Aims and Objectives of the survey

To seek the experiences and opinions of the families, carers and friends of those that had died at home under the care of their GP and to provide IMG and PPG with a baseline from which to identify gaps in service.

10. Criterion and Standards

Discussion meetings with the Leads and Sponsor, alongside guidance from National Association for Care at End of Life (NACEL), helped formulate the questionnaire.

11. Methodology

The questionnaire was developed by the working group, named above as Leads and Sponsor and an electronic version of the questionnaire was created using Microsoft Forms.

The link to the electronic version was sent to all who are registered with the IMG, either at Lambley Lane Surgery or Appletree Medical Practice. The link was sent to a total of 5244 people aged over 18 and a text message to signpost the survey and ask for their input. The paper version of the questionnaire was left at the reception desks at practices and a poster advertised on surgery notice boards. The poster was shared widely via the website, on note boards at local venues and on social media channels.

The questionnaires were completed anonymously and consent was implied by the fact that participation was entirely voluntary and no incentives were used to encourage completion of the questionnaire.

The questionnaire consisted of 26 questions with an Equality, Diversity and Inclusion addendum to gain information such as age, gender, sexual orientation and ethnicity of the person who died. Please note the survey captures experiences of white people only.

The questionnaire consisted of simple opinion responses i.e. Yes/no, strongly agree/disagree, multiple choice questions and free text comment boxes.

We received 54 responses via Microsoft Forms and one paper version over a two-month period. A paper response was then added to provide complete insight electronically.

Analysis of the data was completed in part automatically by MS Forms and by the Palliative Care Practice Lead at Nottinghamshire Hospice with the intention of sharing the results across the ICS.

12. Population v sample size

55 responses in total v 5244 people registered across the two practices.

13. Limitations of the study:

Although the survey's primary aim was to capture the experience of care at home, the differentiation of questions and survey layout enabled both hospital and community death experience to be documented.

The survey did not specify the month and year of death of the patient and as such we had responses from several people where the death occurred a number of years ago. This was evident in the "other comments" section which has been included at the end.

Because we had not specified the date of death, it is difficult to know the percentage of people who responded in relation to the number of people registered at the practice.

On review of the patients medical notes some of the experiences reported do not include the full care delivery that the patients received. Future surveys may have to include a cross reference so the full experience of EOLC can be reviewed.

14. Results

Please note that discrepancies in numbers are due to people feeling the questions were not applicable or were not sure of the answer.

As stated in the limitations of the study, due to the design of the survey, the results after question 6 are difficult to distinguish between hospital deaths and deaths in the community.

There is some rich data around the care and support provided by the practice in Appendix 2. The initial results are grouped into 6 sub-sections below.

14.1 Knowing your relative is dying

For patients the phase of dying was sudden or unexpected (60.2%), for the remainder of patients a discussion about facing dying did occur (23%) and was communicated sensitively most of the time but for 21.7% family felt there could have been improved communication and sensitivity.

Only 7.6% of respondents felt that the patient could have been told they were dying but was not.

For those close to the patient (carer/relative) being told death was expected happened for the majority, however 16.3% were not prepared for the expected death.

14.2 Choice – being part of decision making

When death was expected patient were being part of the decision making. 7.6% of respondents felt their relative would have liked to have been more involved.

31% of people completing the survey believed that the patient had an Advanced Care Plan (ACP) or ReSPECT form in place however this figure is not supported by practice records.

This data remains useful as a baseline for IMG practitioners to explore opportunities for documentation of ceiling of treatment and care decisions.

Alongside this, 48.5% agreed or strongly agreed that staff made plans for the person's care that took account of their individual requirements and wishes.

14.3 Symptom management and place of care at end of life

Family/carer perception in 61% of respondents was that the patient received sufficient relief of pain and other symptoms
77.6% felt that the person died in the right place, this included both hospital and home/care home.

14.4 Confidence in staff

62% agreed or strongly agreed that staff had the skills to care for someone at the end of their life. This will be further explored in part two of this project.

14.5 Emotional support and care after death

51% did not feel they were given enough emotional support. The free text comments reflect some of the distress felt by carers and how this then impacts of bereavement and adjustment. Demonstration of compassion on the day of death is an area that can be improved.

14.6 Care after death

27% felt the care and support they received on the day the person died was either outstanding, excellent or good. 32% felt the care and support they received from the practice on the day the person died was poor.

15. Appendix One: Quantitative Results

The original survey can be found by clicking the link below:
https://forms.office.com/e/Ms0pX2jPP4

Table 2 Questions and responses

Q. No	Question	No of replies	%
Q1	What was your relationship to the person who died?	No.	%
	Husband/wife	25	45%
	Son/daughter	11	20%
	Son in law/daughter in law	1	1.8%
	Brother/sister	3	5%
	Parent	9	16%
	Friend	1	1.8%
	Other	5	9%
Q2	Where were they cared for in the last few days of their life?	No.	%
	Home	24	44%
	Relative's home in area	2	3.6%
	Relative's home out of area	0	
	Nursing or residential home	7	13%
	In hospital	21	38%
	Combined	1	2%
Q3	Did a member of staff from Ivy Medical Group see them in the days before they died?	No.	%
	Yes	13	23%
	No	42	77%
Q3a	If Yes Which health care professional were they seen by (you can choose more than 1 if applicable)	No.	%
	Doctor	11	84%
	Practice Nurse	2	15%
	District Nurse	6	46%
	Advanced Clinical Practitioner	1	7.6%
	Other	0	
Q4	Did staff explain to the person that they were likely to die in the next few days?	No.	%
	Yes	3	23%
	No, could have been told	1	7.6%
	No, died suddenly/unexpectedly	2	15%
	No, too unwell/unconscious	4	30%
	No, the person did not want to know	1	7.6%
	No, other	1	7.6%
	Don't know	1	7.6%
Q5	Did staff involve the person in decisions about care and treatment as much as they would have wanted in the last two to three days of life?	No.	%
	They were involved as much as they wanted to be	5	38%
	They would have liked to be more involved	1	7.6%
	They would have liked to be less involved	0	
	They were not able to be involved	6	46%

Q. No	Question	No of replies	%
	Not sure	1	7.6%
Q6	Did the person have an advance care plan/ReSPECT form in place before they died? An advance care plan/ReSPECT form might describe future treatment plans, the place they would prefer to be cared in, the use of life saving treatments, their values and beliefs and end of life care wishes and goals.	No.	%
	Yes No Don't know	17 30 8	31% 54.5% 14.5%
Q7	Did you have to call emergency services e.g. an ambulance or Out of Hours 111 or attend hospital i.e.. Emergency Department in the last few weeks of their life?	No.	%
	Yes No	27 28	49% 51%
Q8	Did you have to call emergency services e.g. and ambulance or Out of Hours 111 or attend hospital i.e.. Emergency Department in the last few days of their life?	No.	%
	Yes No	19 36	35% 65%
Q9	I felt that staff looking after the person communicated sensitively with them	No.	%
	Disagree Neither agree nor disagree Strongly disagree Strongly agree Agree N/A	8 6 4 16 17 4	14.5% 10.9% 7.2% 29% 30.9% 7.2%
Q10	I was confident that staff looking after the person had the skills to care for someone at the end of their life	No.	%
	Disagree Neither agree nor disagree Strongly disagree Strongly agree Agree N/A	5 8 5 18 17 2	9% 14.5% 9% 32% 30% 3.6%
Q11	I felt that there was good coordination between different members of staff	No.	%
	Disagree Neither agree nor disagree Strongly disagree Strongly agree Agree N/A	8 11 3 6 23 4	14.5% 20% 5.4% 10.9% 41% 7.2%
Q12	I felt the person was given sufficient pain relief	No.	%
	Disagree Neither agree nor disagree Strongly disagree Strongly agree Agree	6 7 1 9 25	10.9% 12.7% 1.8% 16.3% 45%

Q. No	Question	No of replies	%
	N/A	7	12.7%
Q13	I felt the person had sufficient relief of symptoms other than pain (such as nausea, breathlessness or restlessness)	No.	%
	Disagree	8	14.5%
	Neither agree nor disagree	8	14.5%
	Strongly disagree	1	1.8%
	Strongly agree	11	20%
	Agree	22	40%
	N/A	5	9%
Q14	I felt that staff made a plan for the person's care which took account of their individual requirements and wishes	No.	%
	Disagree	6	12.7%
	Neither agree nor disagree	9	16.3%
	Strongly disagree	5	9%
	Strongly agree	8	14.5%
	Agree	19	34%
	N/A	8	14.5%
Q15	In the circumstances, I felt that they died in the right	No.	%
	Disagree	5	9%
	Neither agree nor disagree	2	3.6%
	Strongly disagree	3	5.4%
	Strongly agree	24	43.6%
	Agree	19	34%
	N/A	2	3.6%
Q16	Did a member of staff explain to you that the person was likely to die in the next few days?	No.	%
	Yes, clearly	20	36%
	Yes, but not clearly	5	9%
	Yes, but only when asked	1	1.8%
	No, but could have been told	9	16.3%
	No, died unexpectedly	17	30%
	Not sure	3	5.4%
Q17	Did staff involve you in decisions about their care and treatment as much as you wanted in the last two to three days of life?	No.	%
	I was involved as much as I wanted to be	31	56%
	I would have liked to be more involved	12	21.8%
	I would have liked to be less involved	0	
	I was not able to be involved	7	12.7%
	Not sure	5	9%
Q18	I was communicated to by staff in a sensitive way	No.	%
	Disagree	4	7.2%
	Neither agree nor disagree	4	7.2%
	Strongly disagree	4	7.2%
	Strongly agree	22	40%
	Agree	17	30%
	N/A	4	7.2%
Q19	I was asked about my needs	No.	%
	Disagree	17	30.9%

Q. No	Question	No of replies	%
	Neither agree nor disagree	6	10.9%
	Strongly disagree	6	19.9%
	Strongly agree	6	10.9%
	Agree	14	25%
	N/A	6	10.9%
Q20	I was given enough emotional help and support by staff	No.	%
	Yes	27	49%
	No	28	51%
Q21	I was given enough practical help and support by staff	No.	%
	Yes	27	49%
	No	28	51%
Q22	Were you spoken to about your spiritual/religious/cultural needs by staff	No.	%
	Yes	6	10.9%
	No	49	89%
Q23	Overall, how would you rate the care and support given by the practice team to the person who died?	No.	%
	Outstanding	4	7.2%
	Excellent	5	9%
	Good	15	27%
	Fair	10	18%
	Poor	13	23%
	Not sure	8	14.5%
Q24	Overall, how would you rate the care and support given by the practice team to YOU and other close relatives or friends during the person's final day?	No.	%
	Outstanding	1	1.8%
	Excellent	5	9%
	Good	9	16.6%
	Fair	7	12.7%
	Poor	18	32%
	Not sure	15	27.2%
Q25	If you have any further comments regarding the care and support given to the person who died or to you and other close relatives or friends, please detail below. Please include any suggestions for improvement to our service e.g. a bereavement café, follow-up call etc.	No.	%
	See appendix for full comments		
Q26	What was the ethnicity of the person who died?	No.	%
	White - British	53	96%
	White - Irish	1	1.8%
	White - Any other White background	1	1.8%
	Mixed - White and Black Caribbean	0	
	Mixed - White and Black African	0	
	Mixed - White and Asian	0	
	Mixed - Any other mixed background	0	
	Asian or Asian British - Indian	0	
	Asian or Asian British - Pakistani	0	
	Asian or Asian British - Bangladeshi	0	
	Asian or Asian British - Any other Asian background	0	

Q. No	Question	No of replies	%
	Black or Black British - Caribbean	0	
	Black or Black British - African	0	
	Black or Black British - Any other Black background	0	
	Other Ethnic Groups - Chinese	0	
	Other Ethnic Groups - Any other ethnic group	0	
	Prefer not to say	0	
		0	
Q27	What was the age of the person who died?	No.	%
	0 – 18	0	
	18 - 40	1	1.8%
	41 – 55	3	5.4%
	56 – 70	9	16.3%
	70+	42	76.3%
Q28	What was the gender of the person who died?	No.	%
	Woman	26	47.2%
	Man	29	52.7%
	Non-binary	0	
	Prefer not to say	0	
Q29	What was the sexual orientation of the person who died?	No.	%
	Heterosexual	52	94.5
	Bisexual	1	1.8%
	Lesbian/gay	0	
	Prefer not to say	2	

16. Appendix Two: Qualitative Results

We received 54 anonymous responses for Question 26 suggesting a real desire for people with lived experience of end-of-life care to share their story. Question 26 asked respondents if they had any further comments regarding the care and support given to the person who died or to you and other close relatives or friends. Table 3, below, captures the themes and examples.

Clinicians involved in the care of end of life patients see EOLC as one of the most rewarding aspects of their work. It is therefore important to acknowledge that when relatives and carers are asked to recall the experience it may not reflect the total care delivered, as detailed in the patient record.

Table 3: Themes and examples from the free text

Respondents comments (anonymised)
Understanding who is the lead contact and who is lead clinician responsible for symptom and crisis management to deliver person centred care e.g. *The care system seemed disjointed and isolating for us as a family, who were trying to do their very best for my father-in-law.*
More follow up calls and contact from lead clinician and GP during and after death e.g. *Would have been nice to talk to someone throughout this period*
Differing experience of care - from brilliant to not being as good as carers/families believed it should be e.g. *The most impressive response from the surgery was that the GP - a young woman whose name I forget - called in unannounced one day and sat with my wife on her bed and spent time simply talking with her. My wife found this personal visit very comforting and demonstrated that the doctor was a truly caring person: I shall never forget what she did.* *I was not made aware of any bereavement services open to me or my family. Although this has not been a problem for me it might be useful to ensure that this information is routinely made available to family members when deaths are reported to the practice.*

17. Appendix Three: Ongoing support

Thank you very much to all the carers, family members and loved ones for taking the time to complete the survey which has helped us to produce this report. We really appreciate it and hope it will lead to improved services in the future.

If reading this report has made you realise you would like extra support or someone to talk to, you could contact your local bereavement counsellor, support group on one of the numbers below.

- **Cruse Bereavement Care Phone: 0808 808 1677**
- **The Samaritans Phone: 116 123**
- **Bereavement Advice Centre Phone: 0800 634 9494**

If you want to raise a concern or complaint with the service provided, in the first instance please contact the practice manager on 0115 9132500 or via the email below:
nnicb-nn.ivymedicalgroup@nhs.net
Alternatively you can call NHS England Patient Experience and Complaints on 0115 883 9570.