

Anticipatory Care Plans and Advanced Care Plans in Non-Malignant Palliative Care

Background

The Forum aims to facilitate best practice, innovation and encourage learning for those who provide palliative support to patients with a non-malignant diagnosis.

Aim

Gain insight into the understanding, awareness and application of the two terms in clinical practice. For the purposes of the survey advance care planning and anticipatory care planning were defined from the Scottish Governments' Living and Dying Well.

“Advance Care Planning” is the term most commonly referred to in end of life care, although it does incorporate the writing of wills or “Living Wills” now known as advance directives or advance decisions which can be done by the well person early on in life to plan for what may happen at the end of life.

“Anticipatory Care Planning” is more commonly applied to support those living with a long term condition to plan for an expected change in health or social status. It also incorporates health improvement and staying well. Completion of a common document called an anticipatory care plan is suggested for both long term conditions and in palliative care.

Methodology

A 22 question survey was distributed via Survey Monkey. A total number of 359 clinicians completed the questionnaire between June and September 2015.

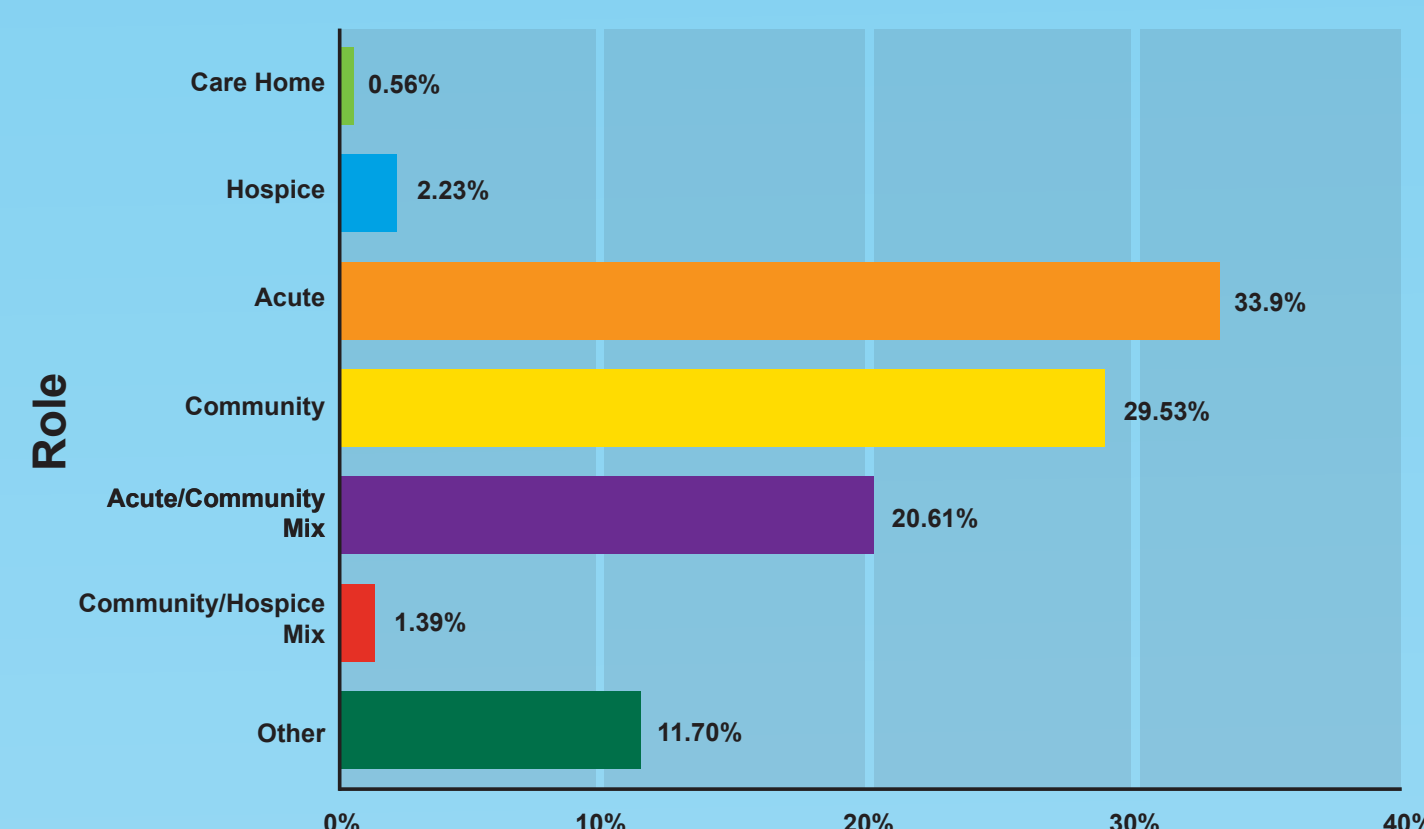


Figure 1: Which setting was your role based in? (n=359)

The majority of respondent worked in the acute (122), community (106) or across the two settings (74). Only 13 respondents worked in a hospice or combined community and hospice setting. Other settings included the voluntary sector, heart failure, rehabilitation and general practice. Almost 50% of respondents were nurses, with the other 50% being made up of GPs, consultants and allied health professionals. All health boards across Scotland with the exception of NHS Shetland, the Ambulance Service and NHS 24 are represented.

Understanding of Advance Care Planning and Anticipatory Care Planning

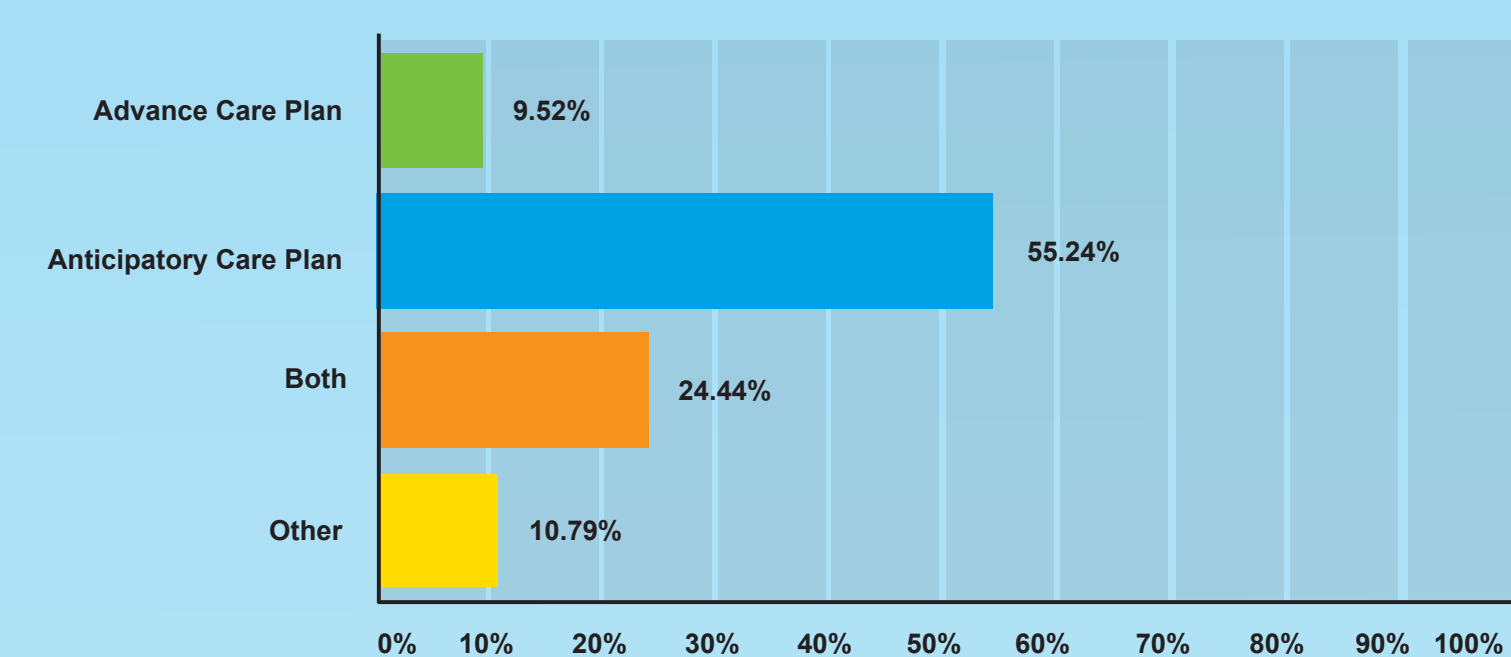


Figure 2: When you hear the term “ACP”, what is your understanding of this acronym? (n=315)

The majority of respondents agreed with the definitions of advanced care planning (91.75%) and anticipatory care planning (95.24%). However the definition and use of the acronym “ACP” was less clear which could lead to confusion and ambiguity.

Use of Advanced Care Planning/Plans

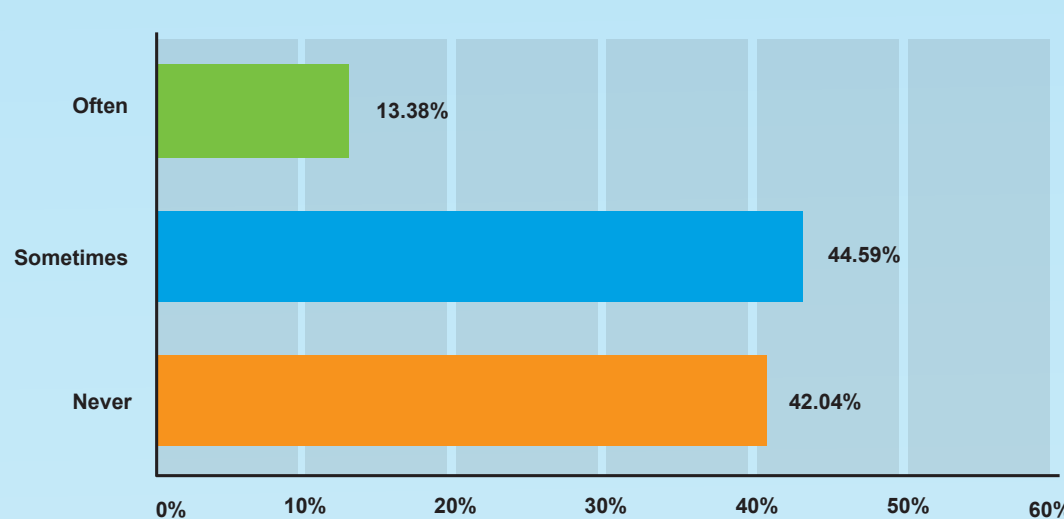


Figure 3a: Do you use advanced care planning/plans as defined? (n=314)

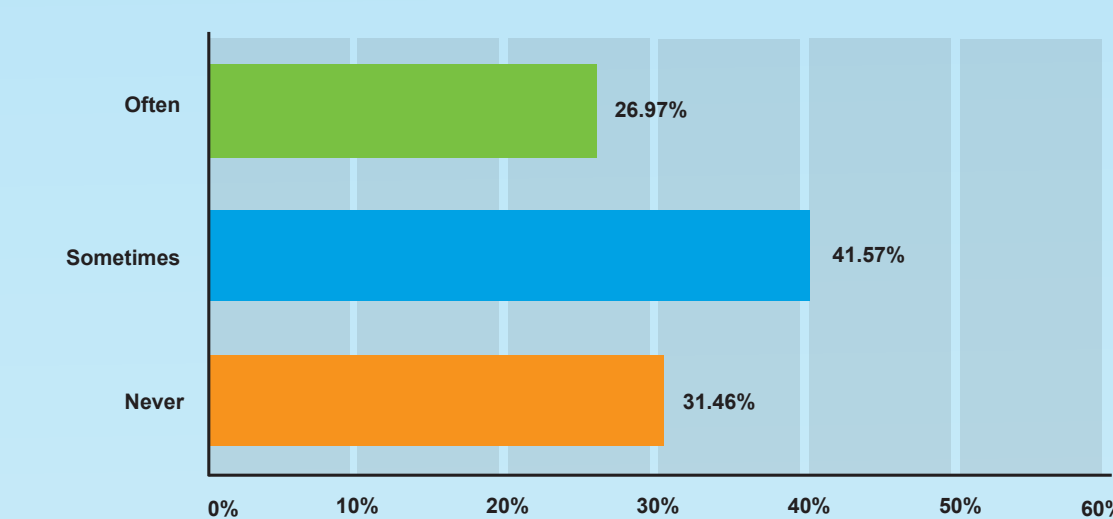


Figure 3b: Do you use anticipatory care planning/plans as defined above? (n=267)

Conditions and Triggers to Use

Which conditions or diagnoses are likely to prompt you to use an anticipatory or advance care plan?

Over half the respondents using advance care plans and anticipatory care plans are prompted to do so with all life-limiting conditions. The remaining respondents do so in response to a number of particular life-limiting conditions, the rationale for which is decided locally dependent on resources and service availability.

What is your main trigger for introducing an advanced care plan or an anticipatory care plan?

Deteriorating health is the predominate trigger including general decline, symptomatic patients on maximum tolerated therapy or a clinical episode such as admission. Unlike advance care plans, poor prognosis and repeated hospital admission were popular triggers for introducing anticipatory care plans.

Although circumstances often dictate when, where and how an advanced care plan or anticipatory care plan is discussed, who initiates the discussion?

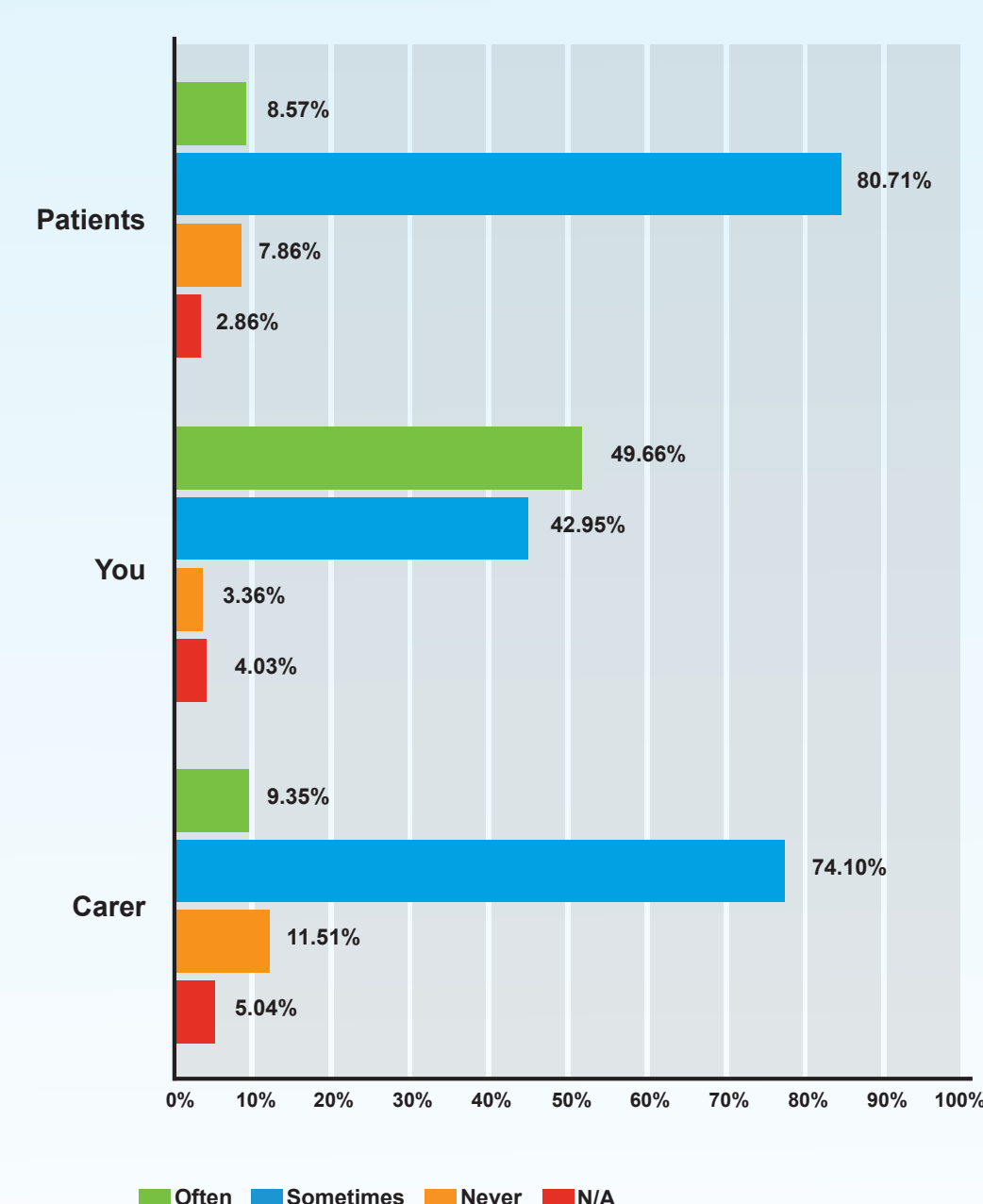


Figure 4a: Who initiates advanced care planning discussions? (n=150)

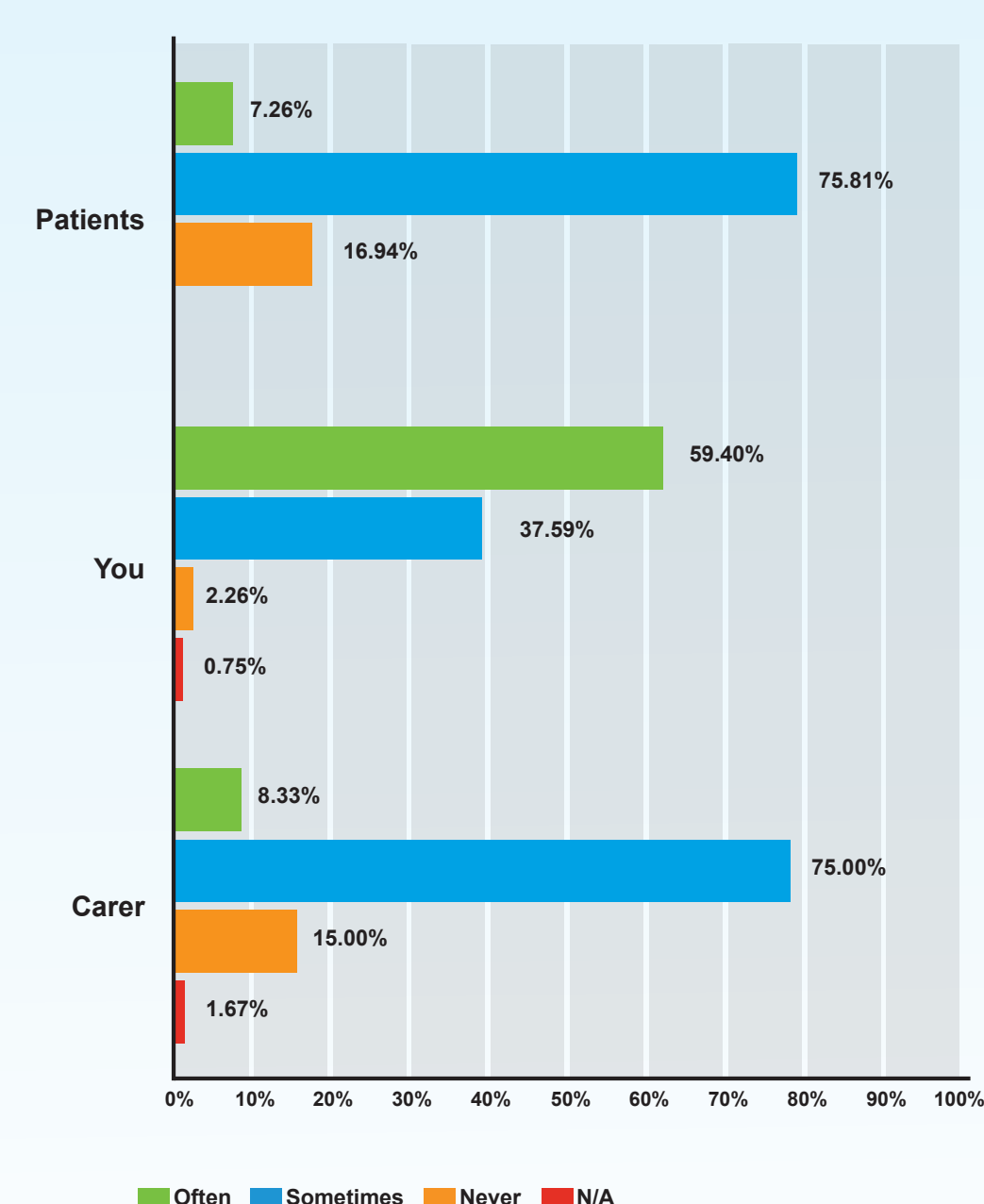


Figure 4b: Who initiates anticipatory care planning discussions? (n=150)

It is clear that individual patient circumstance will dictate who, where and when the discussion will commence, however the clinician was most likely to initiate the discussion.

In your opinion, what are the positives of using an advanced care plan and anticipatory care plan?

This question was asked as a free text answer with responses reviewed and grouped into themes. The top 10 responses for both advance and anticipatory care planning are shown below.

Advance Care Planning (n=136)	Anticipatory Care Planning (n=128)
Respects Patient Choice	Respects Patient Choice
Staff Co-ordination	Staff Co-ordination
Eases Medical Planning	Eases Medical Planning
Encourages Acknowledgement/Discussion of End of Life	Prevents Unnecessary Intervention
Allows Patient Planning	Same as Using an Advanced Care Plan
Reduces Family or Carer Stress	Allows Patient Planning
Reduces Patient Stress	Encourages Acknowledgement/Discussion of End of Life
Prevents Unnecessary Intervention	Reduces Hospital Admission
Avoid Problem of Cognitive Decline and Patients Inability to Decide	Involves Carers and Families
Reduces Hospital Admission	Better Care

Table 1: Top 10 positives of using advanced and anticipatory care planning

Most thought the benefits of advanced and anticipatory care planning were similar. However, a small number of respondents expressed concern that advance care plans were an inappropriate and overly-formal way of dealing with end-of-life care.

In your opinion, what are the barriers that prevent advanced and anticipatory care planning being initiated?

This question was a free text answer and the top ten responses provided below.

Advance Care Planning (n=135)	Anticipatory Care Planning (n=128)
Staff Difficulties Initiating Discussion	Staff Difficulties Initiating Discussion
Uncomfortable Topic	Patient Denial
Patient Denial	Time
Carer/Family Denial	Lack of Understanding of Anticipatory Care Planning
Time	Same as Using an Advanced Care Plan
Lack of Understanding of Advance Care Planning	Staff Co-ordination
Patient Refusal to Discuss	Patient Refusal to Discuss
Patient Concern that Treatment will be Withdrawn	Uncomfortable Topic
Uncertain Prognosis	Lack of Communication
Family/Carer Concern that Treatment will be Withdrawn	IT Systems

Table 2: Top 10 positives of initiating advanced and anticipatory care planning

The main barriers to implementing advanced and anticipatory care plans were, staff difficulties initiating discussion, general difficulties with discussing sensitive issues which required acceptance and careful communication from medical staff, patients, relatives and carers. Respondents also often considered advance and anticipatory care planning a time consuming process that ought not to be rushed.

Co-ordination and Communication of Plans

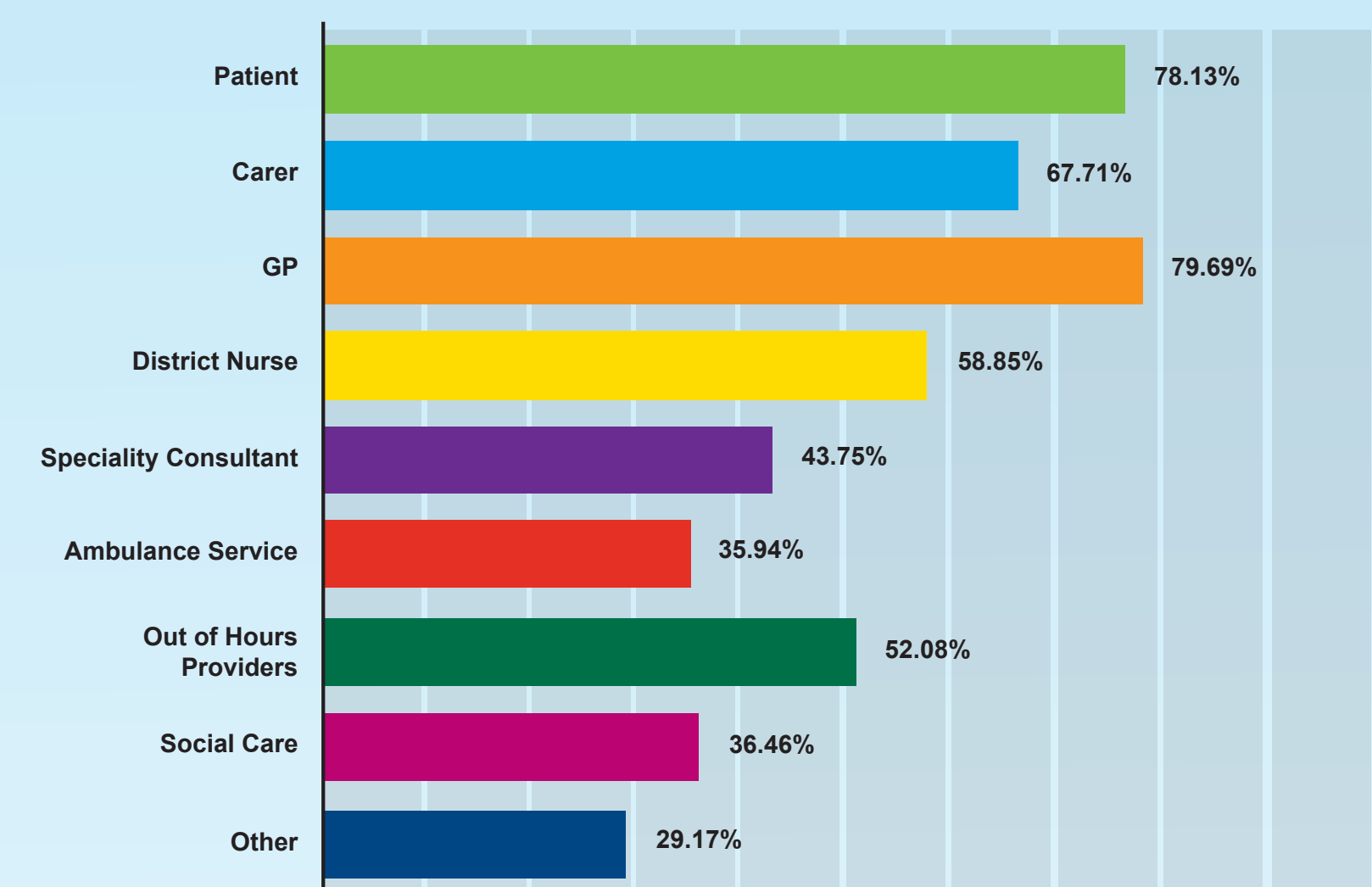


Figure 5: Who is the advanced or anticipatory care plan shared with? (n=192)

Sharing is crucial to ensuring the patient remains appropriately supported with their choices recognised, including out-of-hours episodes. Only 32% of respondents are sure plans are uploaded to KIS. Similarly over 60% of respondents were unaware if they are loaded onto the local clinical portals.

Conclusion

- Confusion remains over the use of the acronym “ACP”
- Both advance and anticipatory care plans are valuable tools
- There is a lack of confidence to initiate conversation in right way
- Sharing and communication of the completed plan including written, verbal and electronic can be challenging for several reasons
 - Lack confidence and therefore use of electronic means (KIS and clinical portal)
 - Lack of compatibility between community and acute systems
 - Limitation in amount of information that can be shared through KIS