

Item No: 7

Meeting Date: Wednesday 12th April 2017

Senior Management Team

Report By: Paul Adams, Head of Older People & Primary Care Services

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PALLIATIVE & END OF LIFE CARE

Purpose of Report:	To summarise Glasgow HSCP's position relative to current provision of palliative care (to adults) and to the aims, objectives and outcomes expressed in the Scottish Government's "Strategic Framework for Action on Palliative & End of Life Care" Appendix 1. Full extract at
	http://www.gov.scot/Resource/0049/00491389.pdf

Recommendations: The Senior Management Team are asked to: a) Note the work completed to date to establish current position for Adults; b) Note the need to review arrangements for children and young people; c) Note the need to engage further with carers and carer organisations; d) Note the support offered by HIS in funding an Improvement Advisor post on a part-time basis for the next 2 years and the potential this has to enhance the HSCP's approach to service improvement; and e) Support recommendations on key areas that require development over the next 2 years.

Relevance to Integration Joint Board Strategic Plan:

Palliative Care is identified in the Strategic Plan as a function and service delegated by Glasgow City Council and NHS Greater Glasgow & Clyde





Implications for Health and Social Care Partnership:

Reference to National Health & Wellbeing Outcome:	The delivery of good (Palliative) Care can be reflected in all 9 national outcomes as experienced by service users, carers and staff.
Personnel:	Healthcare Improvement Scotland (HIS) Palliative Care Associate Improvement Advisor to support mainstream HSCP services for 2 years from 2017/18.
Carers:	Carers and carer organisations were not part of the initial work but further engagement planned
Provider Organisations:	
Equalities:	
Financial:	HIS funding for 2 years (Improvement Advisor). Expect services in the immediate term to be delivered within current resource but recognise the increasing shift toward community supports and the need to monitor capacity & demand
Legal:	N/A
Economic Impact:	Avoiding the cost of unnecessary admissions to care
Sustainability:	
Sustainable Procurement and Article 19:	
Risk Implications:	Ageing population, rising demand and challenging financial climate.
Implications for Glasgow City Council:	
Implications for NHS Greater Glasgow & Clyde:	

1. Introduction

- 1.1 There are a range of definitions of palliative care, however the WHO version has been adopted within the Government's Strategic Framework and describes Palliative Care as "an approach the improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other symptoms, whether physical, psychosocial or spiritual". "It should be provided through person-centred and integrated health services that pay special attention to the specific needs and preferences of individuals".
- 1.2 The National Institute for Clinical Excellence (NICE) also provide descriptions of "Supportive Care" and "Palliative Care", indicating that everyone facing life-threatening illness will need some degree of supportive care in addition to treatment for their condition. This helps the person cope with their condition and live as well as possible with the effects of the disease. Supportive care encompasses
 - Self help & support
 - User involvement
 - Information giving
 - Psychological support
 - Symptom control
 - Social support
 - Rehabilitation
 - Complementary therapies
 - Spiritual support
 - End of life and bereavement care

Palliative Care is part of supportive care and aims to -

- Affirm life and regard dying as a normal process
- Provide relief from pain and other distressing symptoms
- Integrate the psychological and spiritual aspects of patient care
- Offer a support system to help patients live as actively as possible until death
- Offer a support system to help the family cope during the patient's illness and in their own bereavement

The General Medical Council (GMC) defines end of life as within the last year of life.

The Glasgow working group also considered the statement that Palliative and End of Life Care is simply good care and support delivered to (and with) people who recognize that their death now matters.

2. Background

- 2.1 The Strategic Framework for Action (SFA) was launched in December 2015. In June 2016, the Unscheduled Care Group agreed that the HSCP Lead Officer for Palliative Care would begin work to evaluate Glasgow's provision of palliative care and that, in future, would report to the Primary Care Strategy Group as well as providing updates to the SMT and the Unscheduled Care Group.
- 2.2 A small working group was established (appendix 2) and a number of areas of work considered, including
 - Mapping current service provision
 - Surveying staff/organisations providing palliative care
 - Reviewing existing structures for discussing palliative care in Localities and the connection with wider NHSGGC structures
 - Reviewing the extent to which Palliative and End of Life Care is captured within HSCP strategic documents & priorities
- 2.3 In addition to the activity addressed by the working group, there has also been consideration to
 - Connecting to Anticipatory Care Planning
 - Connecting to the NES work on the development of a National Educational Framework
 - Linking with the 2 Glasgow Hospices (Marie Cure & Prince & Princess of Wales)
 - Linking with the Improving Cancer Journey Team (ICJ)
 - Linking with MacMillan Cancer Care in relation to their "Double Diamond" problem solving approach
 - Existing commissioned services delivered by Marie Curie (Managed Care & Fast Track)
 - Changes to the Health Board Managed Clinical Network arrangements
 - The impact on Carers and the need to explore this area in more detail

3. Evaluation Process

- 3.1 The mapping process (appendix 3) and survey (appendix 4) was supported by Healthcare Improvement Scotland (HIS) who subsequently agreed to provide 2 years funding for a part-time Palliative Care Improvement Advisor on the basis that the learning from Glasgow's work could have a positive, wider contribution.
- 3.2 The review of strategic documentation was carried out by HSCP Planning Managers (appendix 5).

3.3 The review of existing Palliative Care arrangements in Glasgow was supported by the Locality group chairs.

4. Observations

- 4.1 The service map follows the journey through community, specialist and hospital services and provides a snapshot of existing service provision.
- 4.2 The survey attracted just under 200 responses across a range of care providers including Nurses, Social Workers, Home care providers, Doctors, AHPs, Hospice staff, Care home staff and Housing staff.
- 4.3 The return rate was lower than anticipated and might have been affected by the fact that the national survey on Palliative Care Education was run at the same time, possibly creating a sense among respondents that a survey return had been completed.
- 4.4 The survey was not intended to be statistically significant but to serve as a collection of current views across care providers in different settings. The information gathered can be manipulated to provide area or service specific data and provides a basis for discussion and testing of results with a wider cohort in due course. This further testing is important given the uncertainty about what the terms palliative and end of life care actually mean.

5. Outcomes

5.1 There was significant variation in people's understanding of the terms Palliative & End of Life Care

Words associated with Palliative Care



Words associated with End of Life Care



5.2 The survey suggested that -

- There could be more consideration to the impact of illness on family & carers.
 Only around 30% of respondents mentioned support for the family and/or carers of the people being cared for.
- 50-60% believed they were involved in identification of those that would benefit
- Defined roles and systems to share information are needed to deliver good palliative care
- Barriers included public awareness, lack of joined up working, service capacity
 & demand, duplication, knowledge of available services
- People needed to be given a choice of preferred place of death with coordinated care, specialist input as required and fast access to increased care packages as condition deteriorates
- Over 80% of respondents believed that they were aware of local supports for people with palliative and end of life care needs
- Only 35% said they used Anticipatory Care Planning with another 16% "partly" using it.
- 60% said they had access to training on palliative/end life care. A significant number of respondents in social care and housing stated that they had no access to training.
- Of the training available, most reported Macmillan Nurse Facilitators, Hospices, ICJ, Alzheimer's Scotland, online palliative care portal and NES

5.3 The review of strategic documents considered the following –

- HSCP Strategic Plan
- Reshaping Care for Older People
- HSCP Locality Plans
- Carers Strategy

- Winter Plan 16/17
- 5.4 Issues of note included the omissions of references to palliative care in all but one locality plan and the absence of a carer's strategy (awaiting SG guidance). The review also suggested that consideration should be given to the implications of the SFA in the HSCP's developing plans and strategies for Childrens services, Adult MH services, OPMH services, Carers Strategy, Physical Disability Strategy, the HSCP commissioning plan for Unscheduled Care and the HSCP's Primary Care Strategy.
- 5.5 The review of existing Palliative Care Arrangements in Glasgow concluded that the active NE group could be used as a model for the other 2 localities. It was proposed that a single Glasgow HSCP Palliative Care group be created by expanding the NE group. This was rejected by NE members on the basis that a locality focus provided solutions to local issues and there were concerns this would be lost in a larger forum.
- 5.6 It was agreed that NW and South Localities would establish Palliative Care groups that will be live by around Spring 2017. Each group will produce a workplan based on local priorities and this will be shared with the other locality groups in Glasgow in order that common issues are addressed in a similar way that acknowledges up to date approaches.

6. Conclusions

- 6.1 It is clear that Glasgow is already delivering palliative care via a variety of public, private, 3rd sector and voluntary organisations and that connections exist between the city and the wider palliative care community across partnership areas, acute services and indeed nationally.
- 6.2 Palliative & End of Life Care Aims There is evidence that the aims expressed in the SFA are being achieved. The services depicted in the service map are available to anyone who can benefit regardless of age, gender, diagnosis, social group or location. Information from hospice liaison meetings suggest there are "harder to reach" minority ethnic groups in parts of the city who are not accessing services. The recent emphasis on Glasgow's model of anticipatory care is beginning to realise a greater number of conversations in relation to planning ahead. There is a general awareness about the importance of good care whilst there remains some confusion about the terms palliative and end of life.
- 6.3 Palliative & End of Life Care Outcomes as described in the SFA are partially met in terms of access to service and future care planning; however there is a gap in terms

of people's knowledge about available supports and the links between community supports and formal services.

6.4 Palliative & End of Life Care Objectives are partially met but almost all areas can benefit from development and improvement with particular reference to identification, staff training, recognition of wider community supports and an emphasis within strategic plans, research and improvement programmes on enhanced access to palliative and end of life care.

7. Recommendations

- 7.1 The Senior Management Team are asked to:
 - a) Note the work completed to date to establish current position for Adults;
 - b) Note the need to review arrangements for children and young people;
 - c) Note the need to engage further with carers and carer organisations;
 - d) Note the support offered by HIS in funding an Improvement Advisor post on a part-time basis for the next 2 years and the potential this has to enhance the HSCP's approach to service improvement; and
 - e) Agree to prioritising the following key areas that require development over the next 2 years:
 - Update strategic documents to reflect the HSCP's intentions in relation to Palliative and End of Life Care
 - Develop access to education and awareness sessions, particularly to those groups that identified this as an issue in the survey. The pending educational framework being developed by NES will provide guidance on delivering training in a consistent manner.
 - Reinstate locality Palliative Care Groups and develop work plans that reflect both locality priorities and city-wide themes. Ensure the membership of locality groups, as well as comprising HSCP health and social care representation, is also inclusive of hospice representation, ICJ representation and other relevant local providers
 - Link Glasgow Palliative and End of Life Care approaches and priorities with the work being carried out across HSCPs and Acute services via the Palliative Care Network
 - The information gathered to date is used to focus work that explores end of life care pathways in more detail. This process will bring together public representatives and frontline teams from different sectors (possibly a workshop for each locality) to explore the issues with care pathways in their area and design changes to be tested
 - HSCP services continue to work with people who can benefit from palliative and end of life care to determine where improvements might be realised.

- This work needs to examine how we are inclusive of harder to reach minority groups.
- HSCP services will work with unpaid carers and carer organisations that support people with palliative and end life care needs and use this engagement to shape future services.
- Develop the HSCP's working relationship with the 2 Glasgow hospices and explore opportunities to build on existing services and identify alternative approaches to care delivery.
- Embed Anticipatory Care approaches into mainstream services; ensuring that HSCP staff and partners are equipped to facilitate conversations about death, dying and bereavement and are able to assist people (and their carers) to develop personal care plans that describe existing supports and future preferences.



Strategic Framework for Action on Palliative and End of Life Care - Executive Summary

Vision

By 2021, everyone in Scotland who needs palliative care will have access to it.

Palliative and End of Life Care Aims

- Access to palliative and end of life care is available to all who can benefit from
 it, regardless of age, gender, diagnosis, social group or location.
- People, their families and carers have timely and focussed conversations with appropriately skilled professionals to plan their care and support towards the end of life, and to ensure this accords with their needs and preferences.
- Communities, groups and organisations of many kinds understand the importance of good palliative and end of life care to the well-being of society.

Palliative and End of Life Care Outcomes

- People receive health and social care that supports their wellbeing, irrespective of their diagnosis, age, socio-economic background, care setting or proximity to death.
- People have opportunities to discuss and plan for future possible decline in health, preferably before a crisis occurs, and are supported to retain independence for as long as possible.
- People know how to help and support each other at times of increased health need and in bereavement, recognising the importance of families and communities working alongside formal services.
- People access cultures, resources, systems and processes within health and social care services that empower staff to exercise their skills and provide high quality person-centred care.

Palliative and End of Life Care Objectives

We will achieve this by:

- Improved identification of people who may benefit from palliative and end of life care
- An enhanced contribution of a wider range of health and care staff in providing palliative care.
- A sense among staff of feeling adequately trained and supported to provide the palliative and end of life care that is needed, including a better understanding of how people's health literacy needs can be addressed.
- A greater openness about death, dying and bereavement in Scotland
- Recognition of the wider sources of support within communities that enable people to live and die well.
- Greater emphasis in strategic plans, research activities and improvement support programmes on enhanced access to and quality of palliative and end of life care.

Appendix 2

Glasgow HSCP Palliative & End Life Care Group (Sub-group of Primary Care Strategy Group)

Terms of Reference (October 2016)

Remit of Group

The group will -

- Agree a self-assessment process that examines the HSCP's current provision of Palliative & End of Life Care (PELC) to the Adult population of Glasgow (The outcome of this work will be shared with heads of Children's services for consideration).
- Provide and analysis of the self assessment process in terms of compliance with the Aims, Outcomes and Objectives expressed in the Scottish Government's "Framework for Action on Palliative and End of Life Care 2016-2021.
- Work with key stakeholders in community, hospital and hospice services to determine service gaps, identify solutions and promote service development.
- Determine how best to collaborate with learning and education colleagues and communication departments to raise awareness of palliative and end life care and identify learning needs for those delivering care and support.
- Advise how to reflect the HSCP's approach to Palliative & End Life Care within its Strategy.
- · Agree current and future Pathways of Care
- Ensure that Glasgow HSCP draws on recognised sources of palliative care expertise throughout the NHSGGC geography (e.g. MCN membership).

Membership

Membership will comprise -

- HSCP Head of OPPC paul.adams2@ggc.scot.nhs.uk
- HSCP Clinical Director kerri.neylon@nhs.net
- General Practitioner euan.paterson@ntlworld.com
- Senior Nurse (Adult Services) Wilma.Cowie@ggc.scot.nhs.uk
- Professional Nurse Advisor Ellice.Morrison@ggc.scot.nhs.uk
- Sen.Officer, Commissioning Team James.Thomson@glasgow.gov.uk
- Hospice Representation <u>Miriam.Watts@mariecurie.org.uk</u>
- Acute Representation laura.kelly@ppwh.org.uk
- MCN representation euan.paterson@ntlworld.com
- Health Improvement Scotland (HIS) nathan.devereux@nhs.net
- Old Age Psychiatry Kimberly.Boyle@ggc.scot.nhs.uk

Frequency of Meetings

The group will convene every 2 months, beginning August 2016 and meetings will last approximately 90 minutes

Reporting Structure

The meeting will report to the Primary Care Strategy Group and also share information with the HSCP Unscheduled Care Group.

V3 Oct 2016

Glasgow City Health and Social Care System for palliative care Appendix 3

Created by Healthcare Improvement Scotland and Glasgow City Health and Social Care Partnership Processes/Guidelines ACP Cancer journey team Training •Palliative care IT systems guidelines Just in case Welfare rights orescribing service Direct support to live at home Other Health & Social Care referral In hospital partnerships **District Nursing** Fast Track **General Practice** primary care (Glasgow City) palliative care Palliative care Support for self **Acute Hospital** discharge service team North St Margaret's of Cordia **General Practice** Marie Curie **Scotland** Royal, Stobhill) Home **Urgent Ambulatory** General Practice Day services Community Care Prince & Princess Palliative care Mainstream Specialist connectors Social care direct NHS24 of Wales team South Housing community Self Directed Deep End link (Queen **Acute Assessment** nurses Support Social care workers Care home Elizabeth) Counselling Scottish Unit St Margaret's of respite for carers (residential) **Ambulance** Scotland NHS GG&C Marie Curie Palliative care Alzheimer's Service patient Rehabilitation Day services Scotland team **Emergency** Care home information team n-patient hospice Specialist West/BEATSON Department (Nursing) Out of Hours centres community Dementia link utwith Glasgow City (Gartnavel, District Nursing Community OT nurses workers Royal) Supported Community Confident Accord living pharmacy Palliative care Ardgowan Volunteer caring Community **Hospital Social Work** palliative care team Inverclyde Aryshire hospice Sheltered Counselling groups **Physio** network Lanarkshire housing Volunteer Palliative care Older People Community basea MacMillan helper service team Royal Community AHPs MHLT healthcare Strathcarron •24/7 advice Alexandria Acute Bed St Andrew's Intermediate Caring together Chronic Community St Vincent's **P&P Wales** care programme conditions team psychiatric Winter Beds Day services nurses Learning (Seasonal) Respiratory Specialist Befriender Indirect support Disability team nurse specialists community service Community to live at home nurses chaplaincy Speech & Inpatient hospice Heart failure Learning Bereavement anguage therapy care (P&P Wales and MacMillan Nurse nurse support Disability team Carers support service **Facilitators** Marie Curie) group Care home Counselling services Maggie's centre MacMillan **Ardgowan ACCESS Continuing Care Money Matters** St Vincent's day services Accord day services Fast Track palliative Confident caring care discharge Macmillan pharmacy service service

Appendix 4

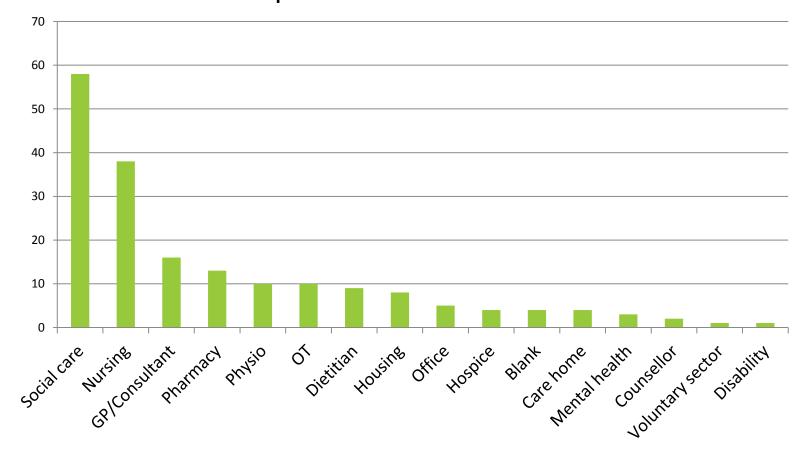


Glasgow City Palliative and End of Life Care questionnaire - Analysis

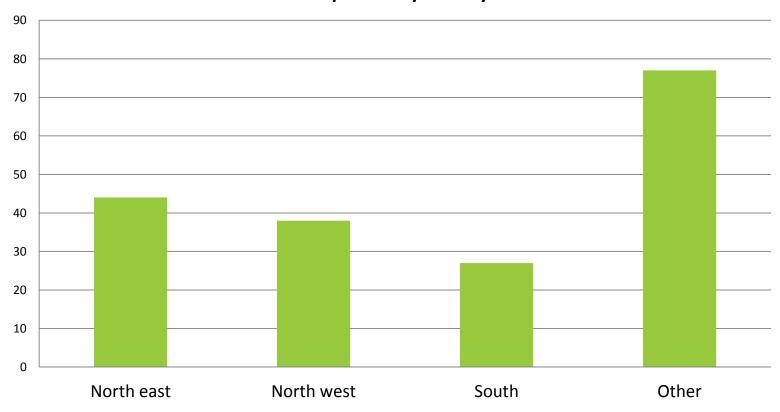




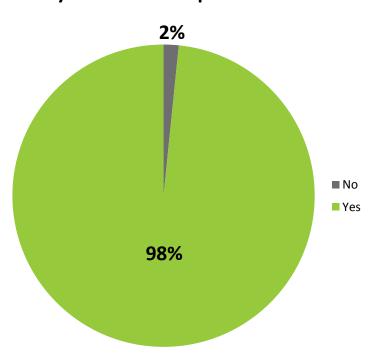
Responses to self assessment - Total 186

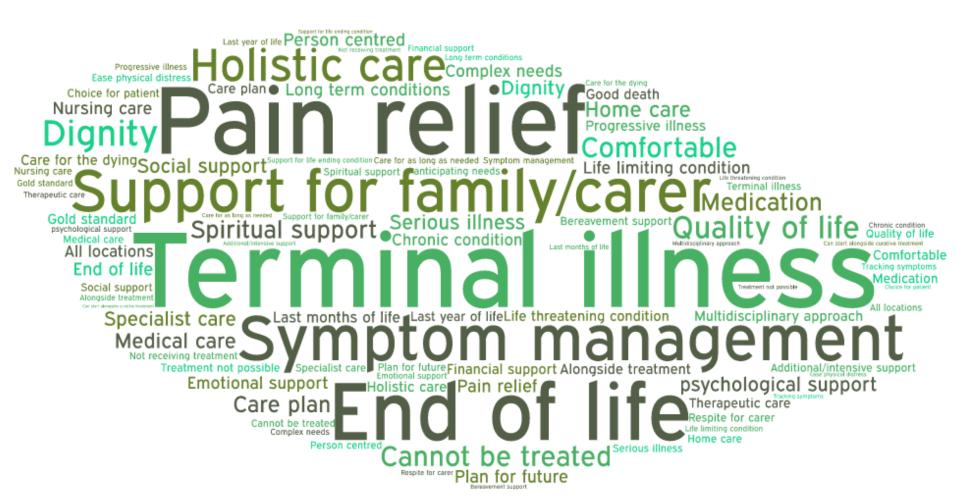


Responses by locality



Do you know what palliative care is?





Most commonly used phrases to describe palliative care:

"Palliative care is the provision of care for people who have a terminal illness which cannot be treated (49%) and/or are at end of life (20%). The holistic care (18%) is focussed on symptom management (29%) and pain relief (25%).

Palliative care aims to improve the quality of life (18%) for the patient, but also provide support to the family and/or carer (27%). Palliative care should also include psychological (17%) and spiritual (13%) support."

Examples from submissions

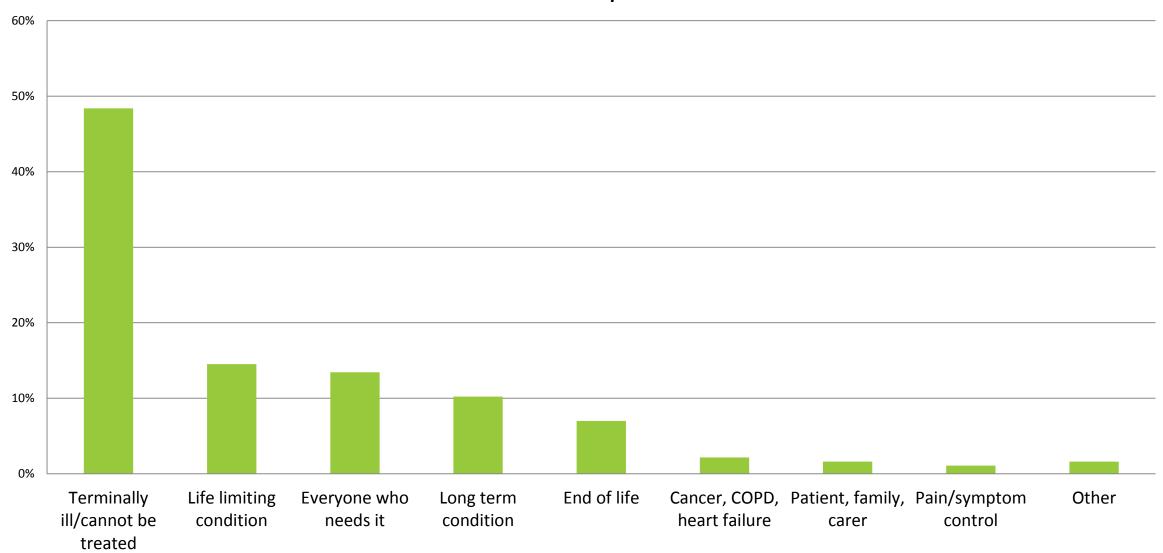
"Palliative care aims to treat or manage pain and other physical symptoms. It will also help with any psychological, social or spiritual needs. Palliative care includes caring for people who are nearing the end of life. This is called end of life care".

"It is end of life care as well as respite for patients with terminal illness I think".

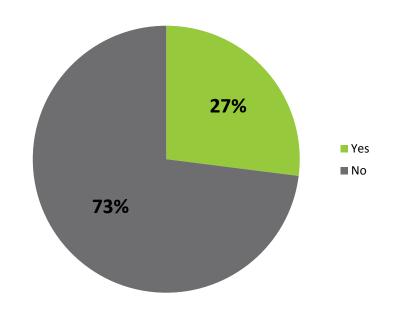
"Palliative care means caring for patients (and supporting their carers) suffering from life threatening conditions through holistic assessment and treatment of their complex physical, psychological and social needs".

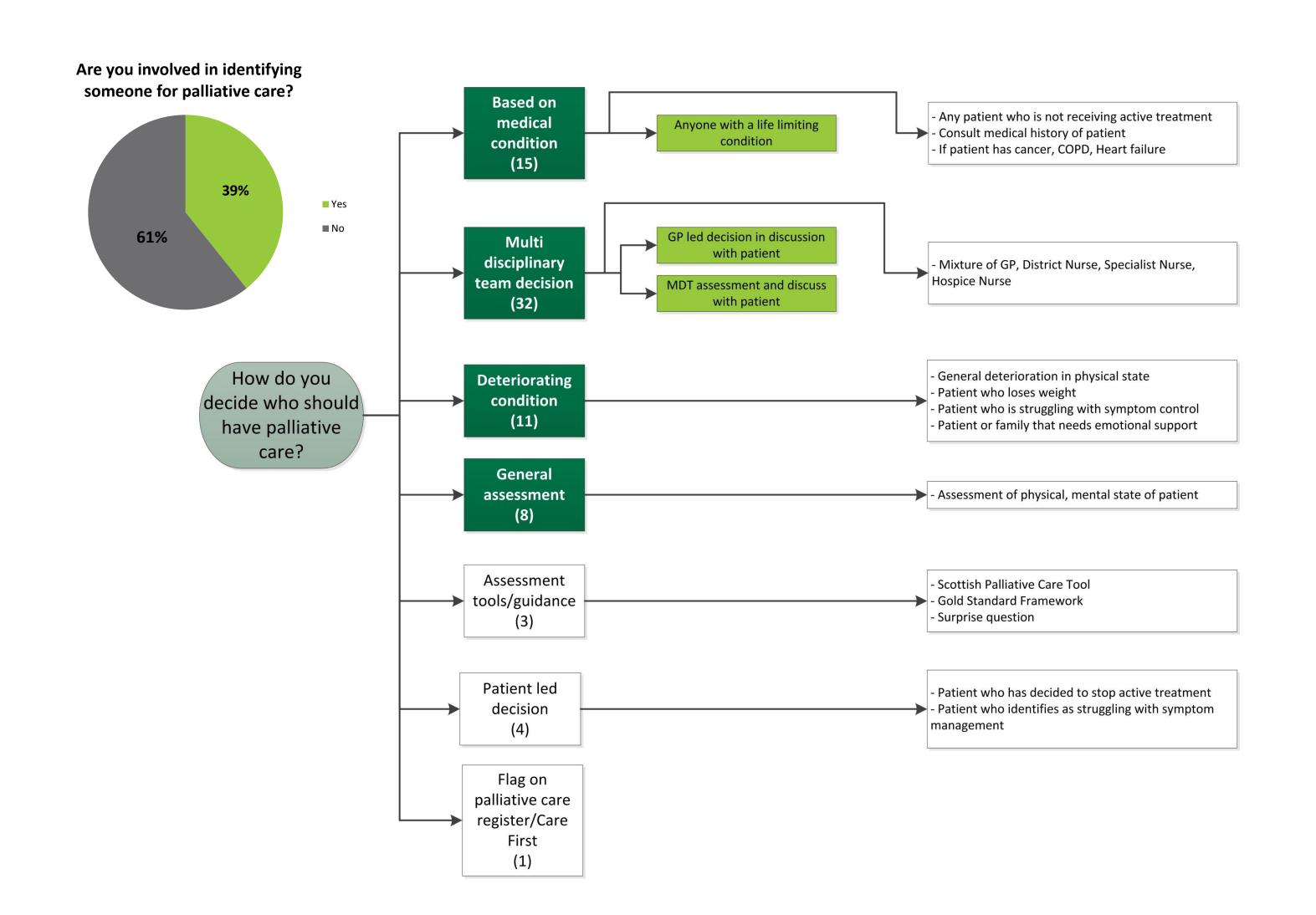
"Providing care and symptomatic relief to patients at end of life or no cure for condition"

Who should receive palliative care?

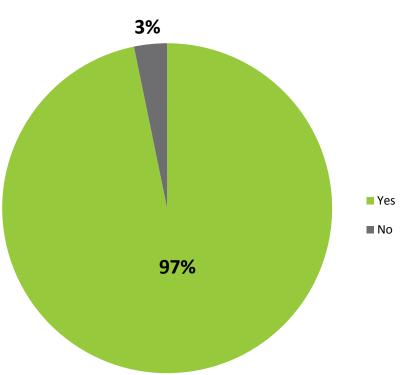


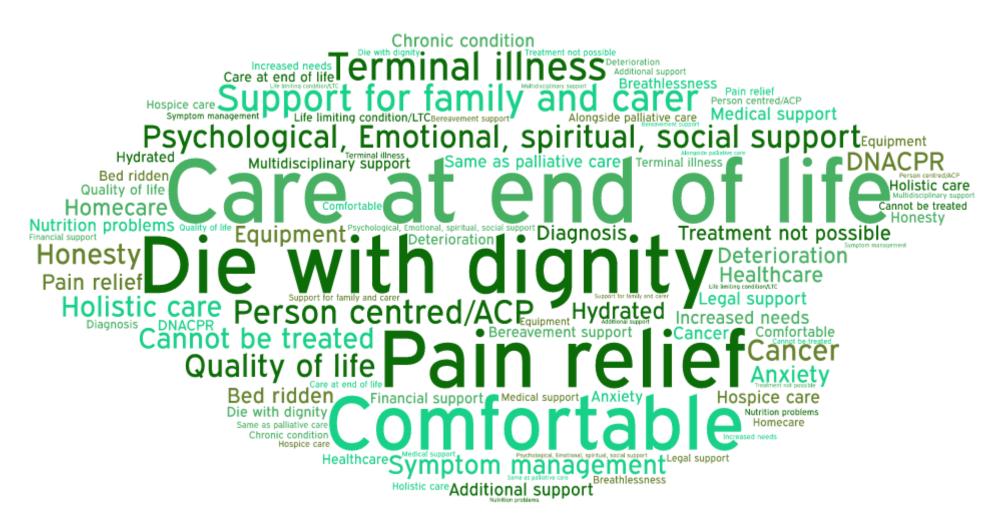
Does palliative care include support for the family and/or carer?





Do you know what end of life care is?





Most commonly used phrases to describe end of life care:

End of life care is the provision of care for someone who has a **terminal illness which cannot be treated** (19%) and their **family or carer** (15%). The care is delivered at the **end of their life** (54%), and can start in the **last year** (11%), **months** (8%), **weeks** (6%), or **days** (13%) of the person's life.

The care focuses on symptom management (11%) and pain relief (18%), to ensure the person is comfortable (15%) and can die with dignity (18%).

It includes support for psychological, emotional and spiritual needs (15%), and often involves some form of care plan (13%).

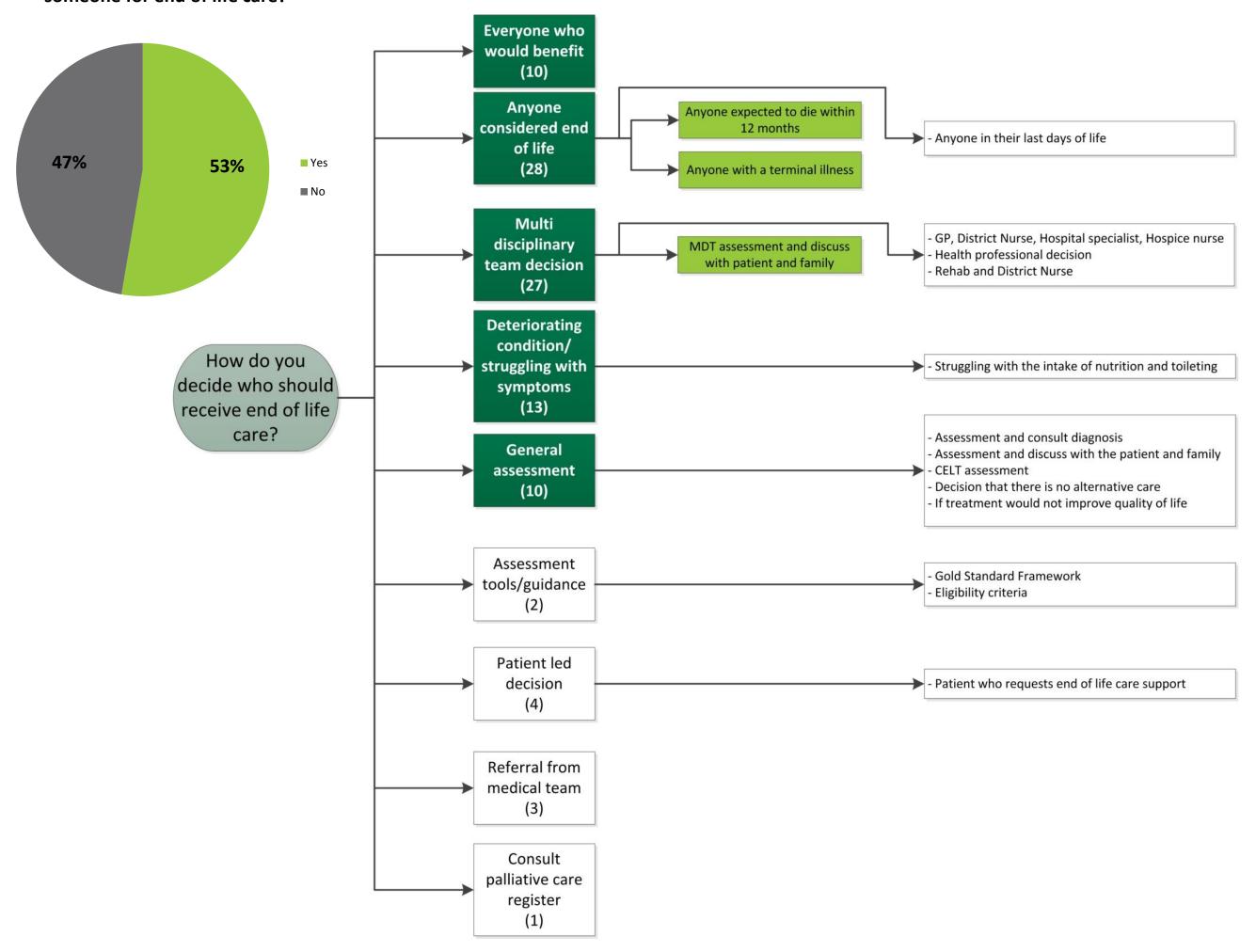
Examples from submissions:

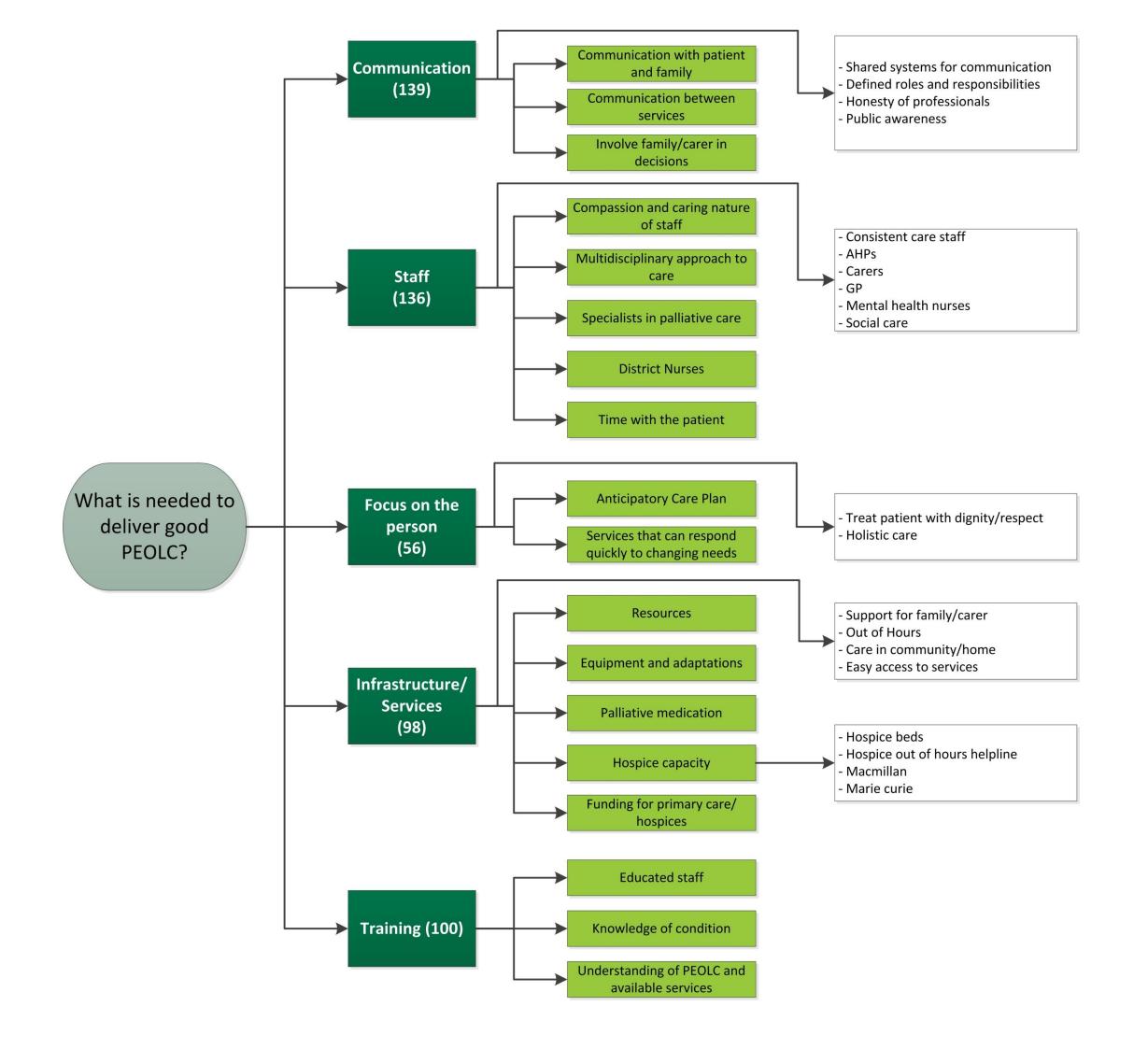
"Provision of care and support to patients who at the end of their life i.e. no cure for their condition e.g. cancer, heart failure, COPD etc"

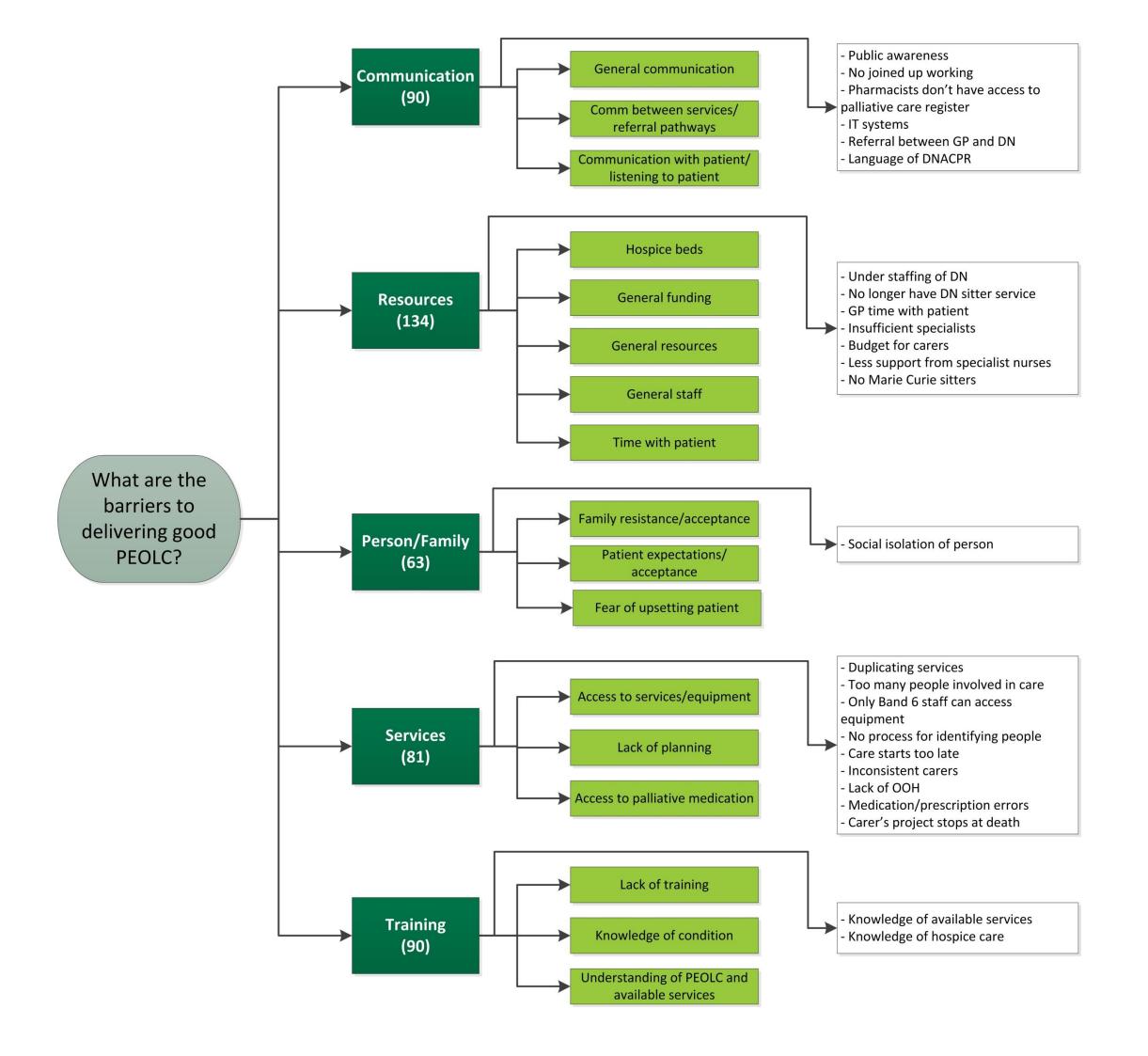
"End of life care is support for people who are in the last months or years of their life. It should help a person to live as well as possible until they die, and to die with dignity. A person's wishes and preferences should be taken into account as care is planned. Support should also be provided to family, carers or other people who are important to that person"

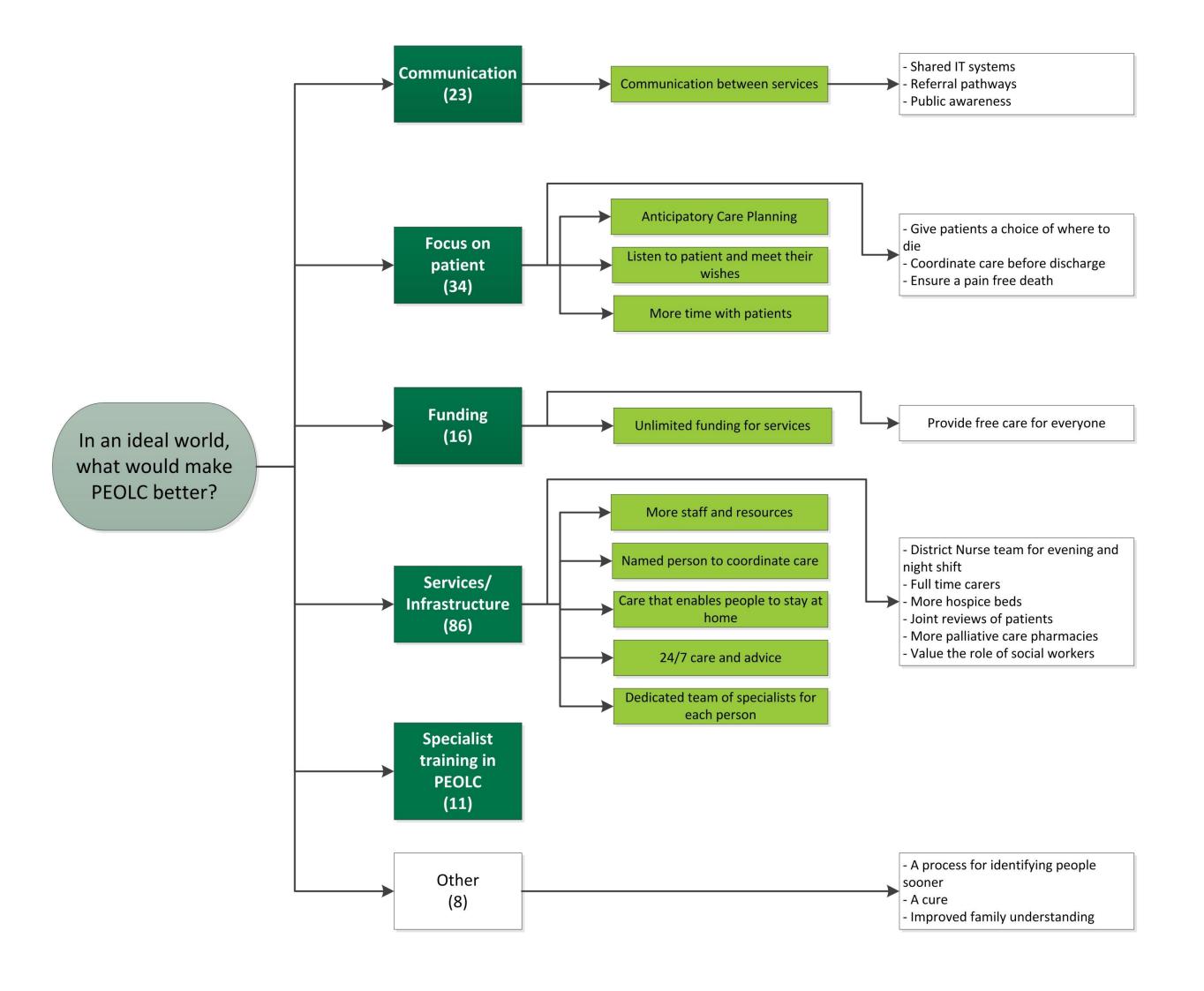
"I think that End of life care, is when a person has reached a stage of the disease/condition process that no further invasive interventions should be carried out. The comfort and wishes of the person should be followed. I tend to think that by this stage a person is mainly being cared for in bed"

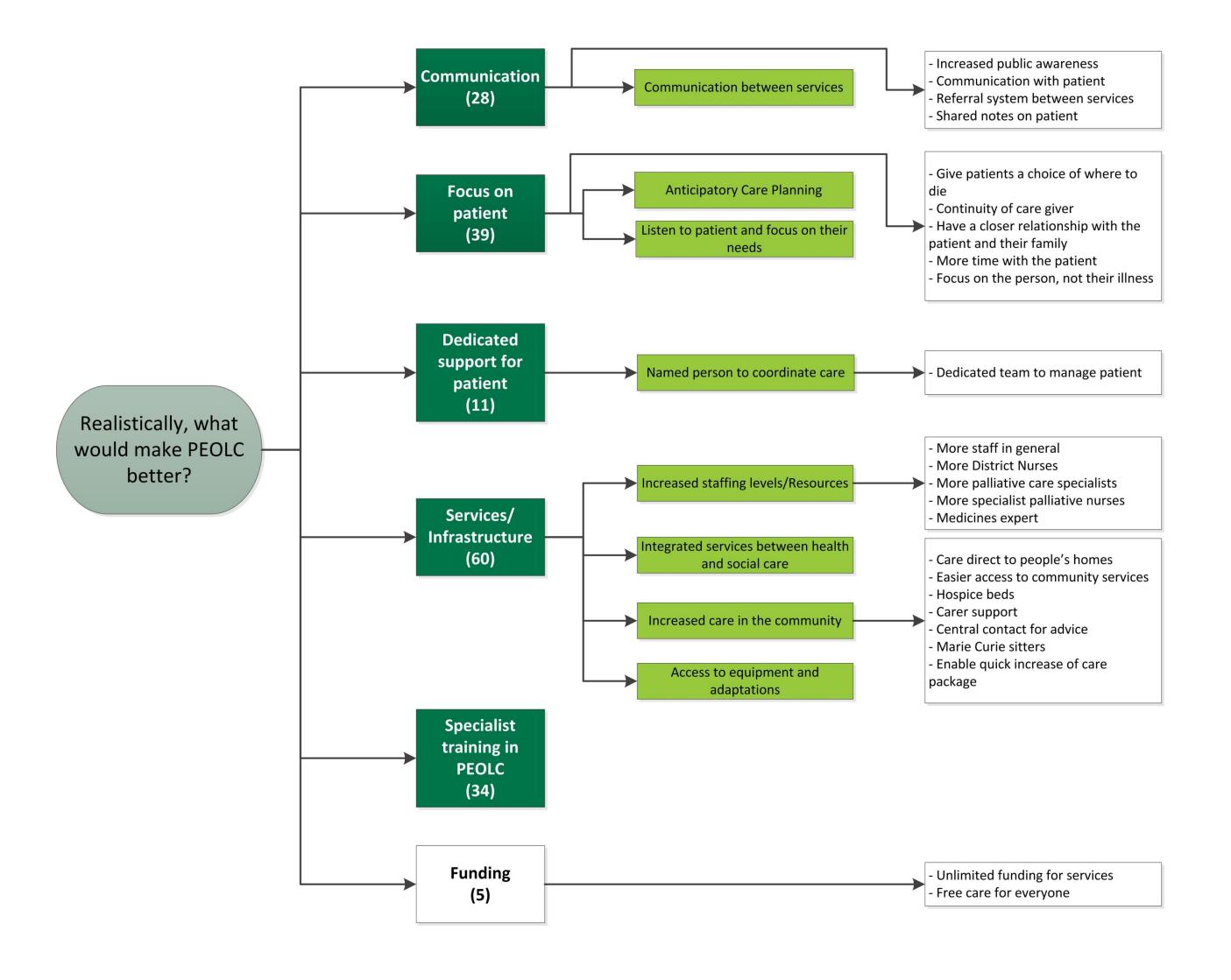
Are you involved in identifying someone for end of life care?

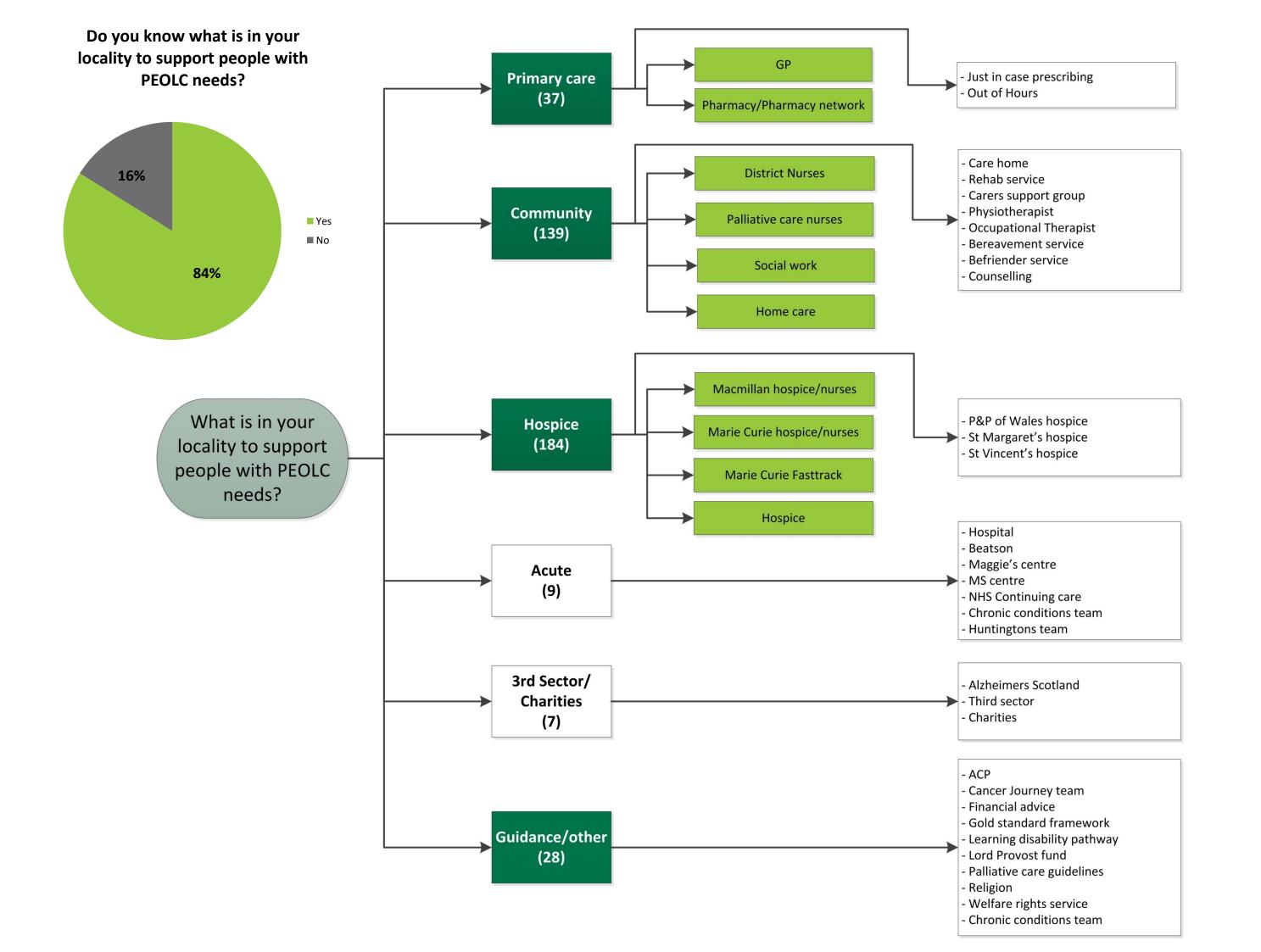


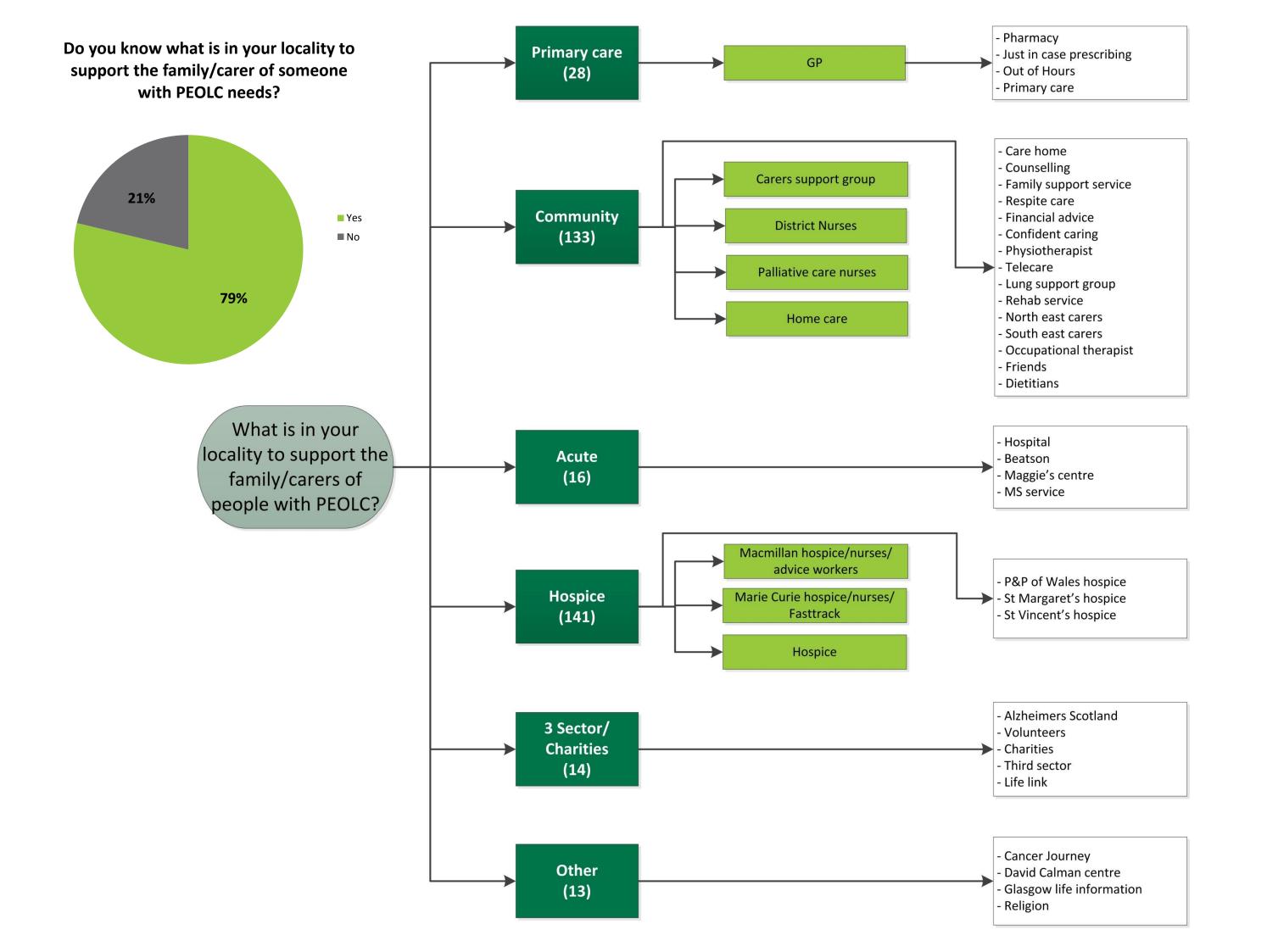


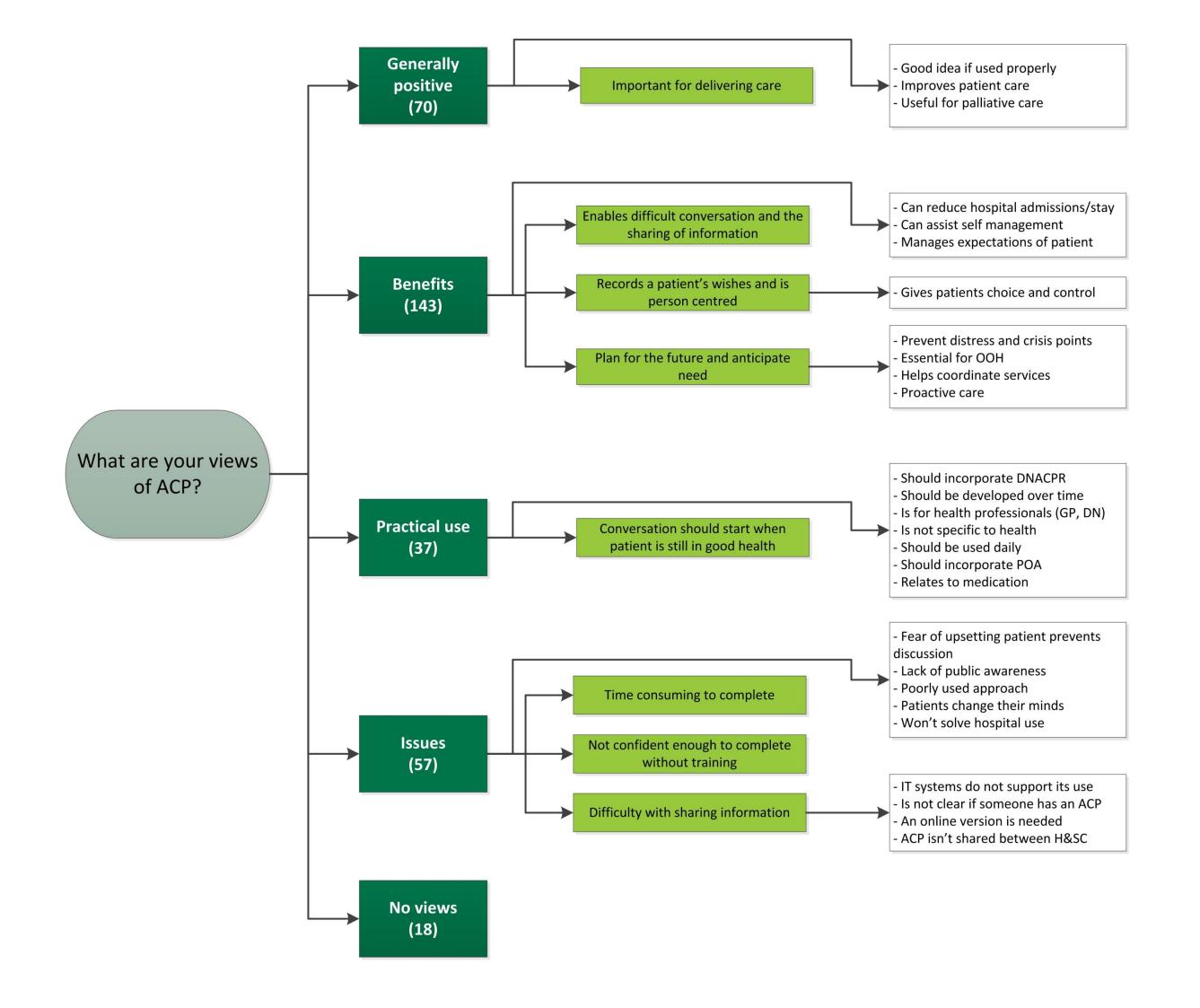




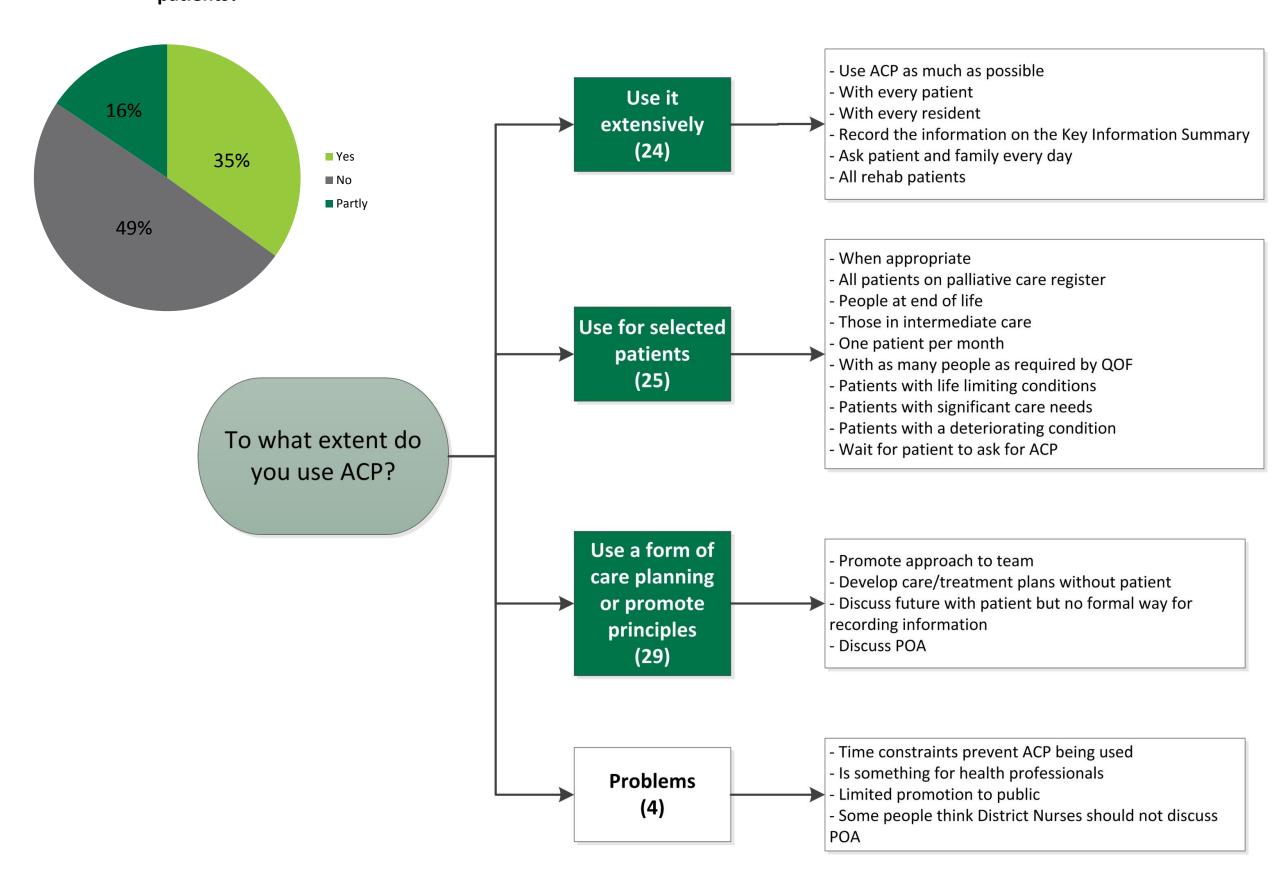




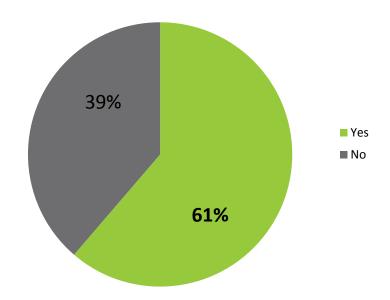




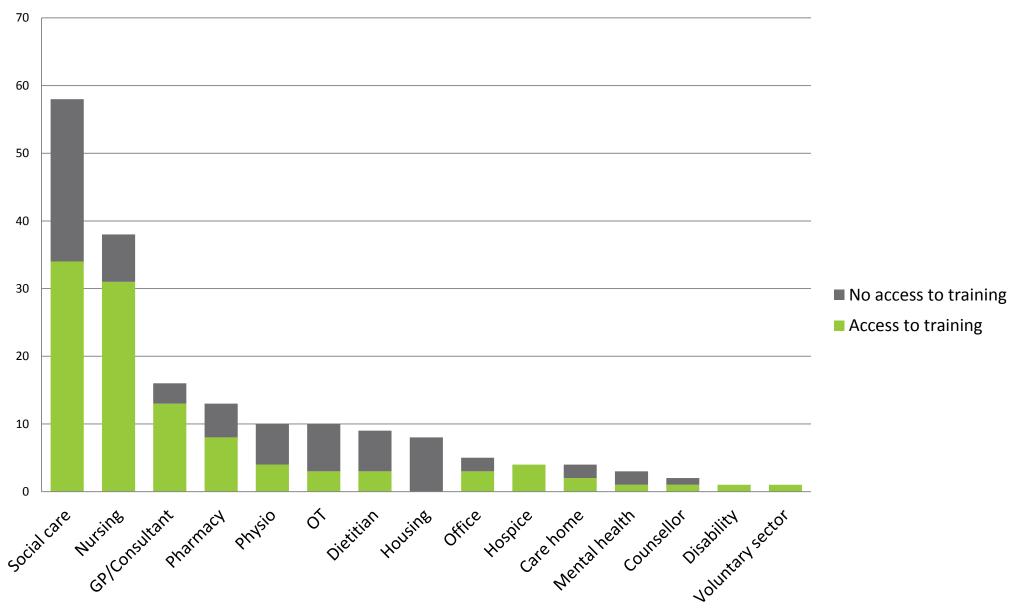
Do you use Anticipatory Care Planning with patients?

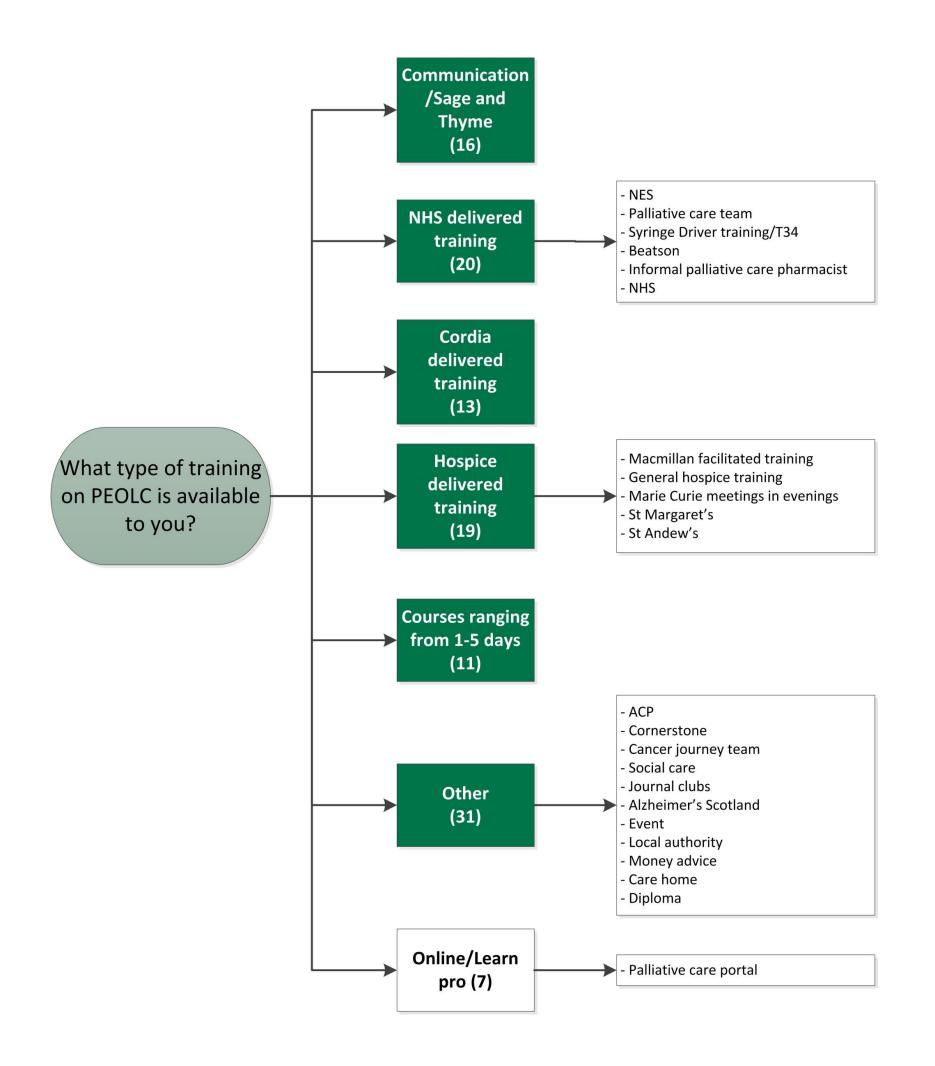


Do you receive training on palliative and/or end of life care?



Number of staff with access to training by profession





APPENDIX 5

GLASGOW CITY HSCP

PALLIATIVE CARE STRATEGIC ASSESSMENT

Introduction

As part of the HSCP's self-evaluation of its current position in relation to the Strategic Framework for Action on Palliative & End of Life Care, this paper scrutinises the HSCP's strategic documents to establish the extent to which Palliative and End of Life Care is identified within our priorities.

This review has looked at the following:

- HSCP Strategic Plan 2016-19;
- Reshaping Care for Older People;
- HSCP Locality Plans;
- Carers strategy; and,
- the winter plan 2016/17

It should be noted that the integration scheme for HSCP includes strategic planning responsibility for hospital based palliative care which will be taken forward as part of the HSCP's strategic commissioning plan for unscheduled care due to be reported to the IJB in March 2017.

HSCP Strategic Plan

The HSCP strategic plan was approved by the IJB in April 2016 and sets out the strategic direction for the Partnership for the three year period 2016-2019. The strategic plan has the following key action in the older people's strategy map:

 encourage greater openess about dying and support older people and families make future plans.

Reshaping Care Strategy

Glasgow's Reshaping Care Strategy was launched in 2013 and revised and updated in 2014. The strategy includes the following reference to palliative care in section 5 on commissioning priorities:

- Palliative care aims to improve the quality of life of patients and their families facing the problem of life-limiting illness. This approach continues to develop in line with the original intentions set out in the 2008 national action plan "Living & Dying Well", Building on Progress 2011 and Reflecting on Progress 2012. In the community setting, Glasgow supports palliative care to patients at end of life via GP practices, community nursing and hospice services. GP systems generate ePCS Electronic Palliative Care Summary, which provides clinical information about palliative care patients to out of hours (OOH) and acute hospital services.
- A longstanding service level agreement is in place with Marie Curie Cancer Care to provide nursing services to people with palliative care needs. This

provision is closely linked to mainstream services and maximises delivery through a match-funding agreement. An additional component called "Fast Track" which facilitates early discharge home from hospital with comprehensive support has been positively evaluated under the Change Fund initiative and it is intended that this will further evolve via the Integrated Care Fund.

- Palliative care activity links closely with other initiatives in Glasgow such as
 Anticipatory Care planning (for Palliative Care this is based on the document
 "My Thinking Ahead and Making Plans"), Power of Attorney, Resuscitation
 (DNACPR) and Benefits / Money Advice.
- The challenge for Glasgow is to improve quality of life for people with palliative care needs; reducing the need for them to be admitted to hospital. Collaboration across health, social care and 3rd sector partners can deliver safe, timely and effective care at home.

HSCP Locality Plans

In 2016 the HSCP developed locality plans for 2016/17 for each of the three localities – North East, North West and South. References to palliative care were only found in the North West Locality Plan where one of the main priority areas identified by Older People's services was to improve the quality of life of patients and their families facing the problem of life threatening illness. Progressing the implementation of recommendations and actions arising from a multi-agency palliative care learning event is identified as a key action for 2016/17.

Carers Strategy

The HSCP does not have a carer's strategy as we are awaiting Scottish Government guidance on the new Carers Act. The Act highlights palliative care as a key priority area for carer support though we are waiting on what this mean and what their definition of palliative care. In Glasgow our carer services treat palliative care referrals as priority one which means the case will be allocated immediately or within one day.

Winter Plan 2016/17

The HSCP Winter Plan for 2016/17 includeds the following statement under anticipatory care planning:

"all patients with palliative and end of life care needs will be invited to work with clinicians to develop an advanced care plan which contributes to an electronic palliative care summary being completed within eKIS;"

Conclusion

Actions relating to palliative acre and the framework for action are referenced in key HSCP plans and strategies but there are some notable gaps for example only one locality plan refers to palliative care. Consideration should be given to the implications of the framework for action in the HSCP's developing plans and strategies for:

- children's services;
- adult mental health services;
- older people's mental health services;
- the forthcoming carers strategy;
- the forthcoming physical disabilities strategy;
- the HSCP's commissioning plan for unscheduled care; and,
- the HSCP's primary care strategy.