Draft
Grampian Palliative and End of Life Care Strategic Framework

FOR CONSULTATION
23rd July to 23rd September 2019
Welcome to the ‘consultation’ on the Grampian Strategic Framework for Palliative and End of Life Care. The aim of this pack is to support wide engagement of the public, staff and partners on the draft Framework which aims to seek views on the proposed vision and requirements for future delivery of sustainable care to meet palliative and end of life care needs of individuals (and their carers and families), regardless of their age, their condition or where they live in Grampian.

The draft Framework has been informed through feedback from individuals who have experienced services, along with a range of engagement initiatives with public representatives, third sector colleagues and clinical/non-clinical staff who have a role in supporting the delivery of Palliative and End of Life Care across the health and care system.

Teams across a number of agencies have a good track record of delivering good outcomes and experience for individuals and families with palliative and end of life needs. However, services have been coming under increasing strain due to a range of challenges. We are also aware from feedback from individuals, families and carers that their experiences can be variable. A process (see next page) has been put in place to develop and implement a robust plan to ensure care appropriately responds to population needs and is sustainable in both the short and longer term.

The pack provides you with a summary of the draft Framework for consultation, along with a set of questions to help sense check and further shape the final Framework to be agreed in November 2019. We would like to hear your views on this – please see the last page for details of how you can do this.

The draft Framework is out for consultation until the 23rd September 2019 - we would really appreciate hearing your thoughts.
High Level Process for Developing the Framework

Preparatory work with teams to understand:
- Needs of people across Grampian
- Demand on current services
- Horizon scanning – what will change in the future
- Pathways and how care is currently delivered
- Experiences and feedback from individuals, families and carers
- Complaints & compliments
- Risks and opportunities
- Benchmarking
- What staff feel works well and what could be improved
- Who needs to be represented at the workshops

Pre-Workshop Engagement & Preparation Work To Support Process (6-8 weeks prior to workshop 1)

WORKSHOP 1 – 14th May 2019
Focus: Clarify current position, issues/challenges, opportunities & discuss vision, future model, key areas for change & markers for success

WORKSHOP 2 – 11th June 2019
Focus: Sense-check proposed vision, principles and model. Clarify key strategic and practical actions across pathway for short, medium & long term

WORKSHOP 3 – 2nd July 2019
Focus: Prioritise actions in terms of impact/value & confirm timescales/leads. Confirm these address key issues & deliver agreed future model of care

Draft Plan out for Consultation (During July – Mid September 2019)

Plan Revised & Finalised Based on Feedback (End of October 2019)

Plan Approved by Integrated Joint Boards (End November 2019)

Grampian Palliative & End of Life Care Strategic Advisory Group Approve Strategic Plan

Current Stage
Palliative and End of Life Care

This Framework covers the journey from identification of palliative care needs through to end of life and care after death.

True quality person-centred palliative and end of life care can only be achieved through an integrated and coordinated approach by the various health and social care agencies/teams, third sector and independent sector working alongside the individual, their carers and families.

Purpose of Framework

The draft Strategic Commissioning Framework aims to set out the direction and focus for the improvement of palliative and end of life care in Grampian. This framework sets out:

• Our shared vision for the future;
• Our shared values and principles for delivering optimum care;
• Standards we are aiming for; and
• Indicators which will tell us we are delivering person-led and equitable care.

In addition to the above, the Framework will set out the key areas for improvement over the next three years.

Scope

This Framework aims to respond to all individuals, carers and families who have palliative and end of life care needs (physical, psychological, emotional, cultural and spiritual), regardless of diagnosis, age or where they reside.

Why do we need a Strategic Framework?

The health and social care system is coming under increasing pressure due to increasing demands, workforce/staffing challenges, increasing expectations and limited budgets and resources. These are also impacting on how we deliver sustainable and quality palliative and end of life care across Grampian.

In order to continue to improve care, we require to be clear what ‘good’ looks like to individuals, carers, families and the teams supporting and delivering care and what will make the biggest difference to them. To do this we need to recognise and build upon the good work already happening, whilst understanding the gaps in care and the factors which will influence this.

In short, the Framework aims to set out a clear direction, along with the key areas of focus for improvement over the next three years.

Palliative and End of Life Care

<table>
<thead>
<tr>
<th>Palliative care is a person-centred approach that maximises the quality of life of individuals and their families by responding to the individual's needs through every stage of a life-limiting illness. It relieves suffering through the early identification, timely assessment and management of symptoms and other issues, whether these are physical, psychological, emotional, cultural or spiritual.</th>
</tr>
</thead>
<tbody>
<tr>
<td>End of Life Care is the recognition that an individual is entering the dying phase. This can vary between weeks, days or hours, and can be unpredictable as changes can occur suddenly and unexpectedly. It aims to address the needs of individuals' and their families with the focus on supporting a comfortable, peaceful and dignified death.</td>
</tr>
</tbody>
</table>

Bereavement is understood as the entire experience of family members and friends in the anticipation, death, and subsequent adjustment to living following the death of a loved one. (Parkes, C. and R. Weiss, Recovery from bereavement)
Engagement in Developing the Draft Framework

Who has been involved in developing the draft Framework?
The focus of the Framework is whole population, whole pathway and multi-agency. Involvement has included professionals (clinical, non-clinical and management) from Aberdeenshire, Aberdeen City and Moray Health and Social Care Partnerships, community services, acute sector, third sector, care homes, specialist services and independent sector. In addition, we have ensured the voice of the public is heard by including public representatives, advocates via the third sector and inclusion of feedback and experiences received from those who have experienced palliative and end of life care over recent years.

Engagement is continuous. The consultation of this Framework aims to seek wider views from all key stakeholders. We would really welcome your views – please see the end of this document for details on how to do this.

Key Messages from Those Who Have Experienced Palliative and End of Life Care in Grampian

The key messages received from individuals are summarised below. We are continuing to gather experiences from across the system and this will further inform the agreed Framework.

• Where appropriate care and treatment should be provided at home, or as close to home as possible (if this is the preferred option of the individual).
• Plans should be developed and regularly reviewed with the involvement of the individual and their carers/families and should be needs focussed and flexible.
• Caring, empathetic and compassionate staff/teams who respect the individual’s wishes.
• Comfortable surroundings.
• Optimal symptom control.
• Honest, regular and timely communication which supports informed decisions.
• Comfortable, peaceful and dignified death with loved ones present.
• No one should die alone (unless they wish to do so).
• Bereavement support to carers/families when they require it.

“It doesn’t seem fair to ask someone in their last stages of life to travel so far every day for treatment which should surely be available in a hospital with such a large catchment area and ageing population.”

“All those involved in Mum and our family’s care showed a true understanding and practising of ‘nursing’ and will never know the difference that their ‘holistic’ approach made to us.”

“He made the decision to refuse the treatment offered as to him, it did not outweigh the burden. He was now on what he would refer to as the path. Doctors stayed solution focussed, not listening. Still the doctors continued to ‘try to persuade’ him into an avenue of treatment he said no to. To continue this, fixating on your judgements, stops you listening to what really matters to the patient.”

“Right up to my wife’s final hours, the level of loving care and attention was second to none. I have nothing but admiration for this team.”

“We have had very little information about what is happening over the coming weeks and we have repeatedly asked for information.”

“Thank you so much for making what was an extremely difficult time for us all somewhat better knowing my sister was cared for like every patient should be.”
Building on Current Good Practice Across Grampian

Whilst developing this Framework, it is evident that we have dedicated and caring individuals/teams across Grampian. It is also clear that there is a significant amount of good and innovative practice across services in Grampian. Some of these are outlined below.

• **Collaborative/Integrated Working**
  - Integrated approach by nursing, GPs, allied health professionals, care home staff, social work staff and the third sector to provide care at home as per individual’s wishes.
  - Third sector colleagues involved in a number of multi-disciplinary teams across Grampian.
  - Virtual Community Wards in Aberdeenshire practices and Maryhill Practice in Moray where the care of individuals (palliative / end of life) is discussed daily.

• **Creation of Dedicated Facilities**
  - Community Hospitals in Aberdeenshire and Moray have dedicated beds for palliative and end of life care.
  - Palliative Care Suite in Turriff.
  - Huntly Garden Room.

• **Support**
  - Teams within Roxburghe House and The Oaks provide timely specialist palliative care advice to community and hospital teams.
  - Redesign and development of care at home services, including rapid response services.
  - Delivery of a programme to support people to think ahead, make informed decisions and prepare for end of life.
  - Across Grampian, a number of practices have a designated palliative care GP/clinician for individuals/carers/families which helps ensure continuity and informed decision making.
  - Availability of psychological skills training in significant conversations.
  - The Grampian Palliative and Supportive Care Plan.
  - Grampian Guidance
Overview - Grampian Population

In Grampian around 5,400 people die each year from all causes, around two thirds are aged over 70. People are generally living longer with increased complex co-morbidities.

Cause of Death in Grampian - 2016

<table>
<thead>
<tr>
<th>Main Cause - ICD10 Chapters</th>
<th>Aberdeen City</th>
<th>Aberdeenshire</th>
<th>Moray</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diseases of the Circulatory System</td>
<td>566</td>
<td>748</td>
<td>283</td>
<td>1594</td>
</tr>
<tr>
<td>Neoplasms (Cancer)</td>
<td>598</td>
<td>665</td>
<td>281</td>
<td>1544</td>
</tr>
<tr>
<td>Diseases of the Respiratory System</td>
<td>255</td>
<td>260</td>
<td>130</td>
<td>645</td>
</tr>
<tr>
<td>Mental and Behavioural Disorders</td>
<td>169</td>
<td>180</td>
<td>65</td>
<td>414</td>
</tr>
<tr>
<td>Diseases of the Nervous System</td>
<td>122</td>
<td>123</td>
<td>48</td>
<td>293</td>
</tr>
<tr>
<td>External Causes of Morbidity and Mortality</td>
<td>125</td>
<td>112</td>
<td>48</td>
<td>286</td>
</tr>
<tr>
<td>Diseases of the Digestive System</td>
<td>121</td>
<td>107</td>
<td>43</td>
<td>271</td>
</tr>
<tr>
<td>Other Causes</td>
<td>80</td>
<td>76</td>
<td>43</td>
<td>199</td>
</tr>
<tr>
<td>Endocrine, Nutritional and Metabolic Diseases</td>
<td>57</td>
<td>43</td>
<td>19</td>
<td>119</td>
</tr>
<tr>
<td>Diseases of the Genitourinary System</td>
<td>32</td>
<td>50</td>
<td>19</td>
<td>101</td>
</tr>
<tr>
<td>Total</td>
<td>2126</td>
<td>2361</td>
<td>979</td>
<td>5466</td>
</tr>
</tbody>
</table>

Location of Death - 2016

How will the needs change in the future?

- Over the next 20 years the population aged 65-85 will rise by 39% and those over 85 by 123%
- More people will be living alone - by 2035, 114,000 are expected to be living on their own which represents 37% of all households.

(Data sourced from Grampian Clinical Strategy 2016-2021)

Last 6 months of life

Of the Grampian residents who died in 2016/17, 89.4% of their last 6 months of life was spent at home or in the community.

This data is further split by Health & Social Care Partnerships as follows

- Aberdeen City 89%
- Aberdeenshire 90%
- Moray 90%.

(Data sourced from ISD Scotland)
Key Challenges, Issues and Opportunities

Challenges and Issues

• Respite care locally is limited
• Limited palliative care beds available in community hospitals
• Ability to meet individuals and families expectations of support at end of life
• Referrals to services can be too late to allow us to appropriately respond. Some referrals lack appropriate information
• Access to the right information
• Inconsistency of care across a number of areas and services
• Unable to always meet the demands for equipment
• Teams do not always use the Palliative Performance Scale
• Different assumptions of when someone is palliative or at the end of their life – this is complex and not always easy
• Ensuring timely communication with individual/family and also between professionals
• Delays in getting patients home once agreement has been made this is the right thing to do
• Lack of resources/staffing to provide the wide range of choices/support people would like
• High level of reliance on families to support patient at home but this is not always with the right support to do so
• Admissions/access to care homes can take too long
• Resources are stretched and/or limited
• Being able to deliver equitable care for rural and remote and ageing populations
• Carer support not always available
• Increased service demand
• GP volume of work
• Workforce demographics/challenges
• Loss of experienced/trained staff
• Lack of comprehensive out of hours provision
• Third sector and community assets could be further utilised

Building on Strengths and Opportunities

• Clear evidence of the majority of cases where good quality, person centred care was received
• Strong partnerships and collaborative working already in place
• Co-located multi-disciplinary teams
• Dedicated and caring individuals and teams with a wide breadth of knowledge and experience
• Wide range of third sector organisations with clear roles in supporting anticipatory care planning and the provision of nursing and support services as part of the wider team
• Good links with Roxburghe House and The Oaks
• Broad range of assets available in the community
• Sharing information of support available to unpaid carers
• Community Hospitals in Aberdeenshire and Moray
• Virtual wards in Aberdeenshire
• Shared vision and values for improvement of care
• Community spirit
• Range of various education resources and programmes for professionals and unpaid carers
• Single point of contact for specialist palliative care advice
• Link workers within the community
• eKIS
• A Local Information System of Scotland (ALISS)
• Anticipatory Care Plans
• Good examples of building compassionate communities
• Ability to flex and respond
Vision, Principles and Outcomes

Vision and Principles

"Our vision is to create an environment where each and every person with palliative and end of life care needs are seen and treated as a unique individual. Within this environment, where needs can change, we will support the person, family and carers at all times."

- Person-led, holistic and flexible care regardless of age, condition or disease
- Timely and effective communication which supports shared decision making and active inclusion of individuals and their carers/families
- Equitable and responsive care regardless of where individuals live
- Collaborative working by all teams/agencies to maximise collective knowledge and available resources which promotes:
  - proactive and responsive assessment, management and review involving the right individuals supported by personalised dynamic anticipatory care planning
  - delivery of coordinated care in the most appropriate setting which responds to needs and wishes whilst managing realistic expectations with honesty, respect, compassion and trust
  - timely sharing of knowledge and information between professionals to optimise care/experiences
  - respect and understanding of the role and responsibilities of all individuals involved in the delivery of person-led, holistic care
- Commitment to ongoing learning, development and support of professionals across the system.

Outcomes

1. Everyone has access to high quality, tailored palliative and end of life care and support which enhances quality of life and ensures their wishes are met for a comfortable and dignified death.

2. Professionals from all agencies have a role in supporting the delivery of palliative and end of life care and have access to support, contacts, training and development which empowers them to deliver the right care, in the right place and at the right time.

3. Compassionate communities actively support individuals, carers and families in the various phases of palliative care, end of life and bereavement and ensures that no one dies alone unless they choose to do so.
Desired Model of Care

“A Model of Care broadly defines the way services should be delivered.”

Palliative and end of life care in Grampian is composed of a wide range of professionals and teams working collaboratively across the health and care system encompassing community, primary care, third sector, independent sector and a network of hospitals including specialist services. They come together to plan and deliver high quality person-led care focussing on safe and equitable care close to home which meets the individual and family needs ensuring optimal wellbeing, support when required and when the time comes a comfortable, peaceful and dignified death.

The model spans the journey from identification of the palliative stage through to end of life and care after death.

Key Features

- Equitable access to person-led care regardless of age, condition/disease or where they live
- Individual’s anticipatory care plan is regularly reviewed and updated based on their needs and preferences, their carer/family needs, along with MDT holistic assessments (physical, psychological, emotional, cultural or spiritual)
- Individuals are empowered to undertake honest and difficult conversations at the earliest appropriate opportunity
- Coordinated and integrated effective working focussed on delivering the best possible palliative and end of life care based on the needs of individuals, their carers and families
- Professionals are adequately supported to care for individuals, families and each other
- Culture of continuous improvement to achieve the best possible outcomes through the effective and efficient use of resources
- Palliative and end of life care is supported as a whole system, rather than a collection of individual services or teams
- Professionals rate the care provided as ‘good enough for their own’
- Leads the way on the delivery of innovative care and leads/contributes to research and best practice
Indicators for Success

How will we know if we have improved care?

- Positive feedback/experience from individuals, families and carers
- Reduction in number of complaints
- Staff satisfied with provision. Good enough for our own
- Optimal symptom control
- Individuals palliative care needs are identified at the earliest opportunity
- Care is in the right setting/service for individual and their needs
- Staff are knowledgeable, skilled and supported to deliver palliative and end of life care
- Access to dedicated palliative care beds when people require these
- Access to formal carer provision when people require this
- Services are responsive to individual needs
- Responsive out of hours provision when required
- Staff can access the right information as and when they require this
- Active creation, use and sharing of Anticipatory Care Plans

Health Improvement Scotland:

Indicators for palliative and end of life care:

1. Increase in the number of people with palliative and end of life care needs who are identified.
2. Increase in the number of people with palliative and end of life care needs who are assessed and have a care plan.
3. Increase in the number of electronic palliative care summaries accessed.
Proposed Key Standards for Palliative and End of Life Care

Identification of Palliative Care Needs
- Proactive identification and transition between chronic disease management to palliative care
- SPICT used in all cases to identify deterioration in health and dying

Assessment of Needs Individual & Family
- Standardised single holistic assessment tool used by MDT to identify individual’s and carer/family needs
- Every individual, where possible is involved in the development of a tailored plan which responds to their needs, choice and control
- Every individual has a named key worker who is responsible for co-ordinating care and regularly reviewing this with individual/family (includes alternative contact if key worker is unavailable)
- Every individual has their resuscitation status discussed with a medical professional and recorded
- Palliative Performance Scale used for ongoing assessment of needs

Maintaining Optimal Wellbeing
- Every individual’s management plan is accessible to all teams with clear anticipatory/escalation plans
- Every individual’s management plan is regularly reviewed and available via eKIS
- Access to critical equipment available 24 hours
- 24/7 access to medicines, advice and support

End of Life Care & Family Support
- Early identification and communication of the dying phase
- Individuals die in the location of their choice (where possible)
- Individuals and families know what support is available and how to access it when they require it
- Access to critical equipment available 24 hours
- 24/7 access to medicines, advice and support

Care After Death & Bereavement Support
- Every family/carer is contacted by a member of the MDT within one week of the death and additional contact thereafter as required
- Every family/carer is aware of local bereavement support and how to access
- Post death debrief for staff is held and learning is shared with local team and wider as appropriate
- All professionals are aware of how to access support

Professionals are able to access specialist palliative and end of life advice 24/7
Every individual (family/carer/staff) can access information and support pre and post bereavement
All professionals providing palliative/end of life care are trained in anticipatory grief & bereavement support

Every individual’s anticipatory care plan is regularly reviewed and updated based on their needs and preferences, their carer/family needs, along with MDT holistic assessments (physical, psychological, emotional, cultural or spiritual)
Timely and effective communication between professionals (and with individuals, their carers and families)
All professionals have an awareness of the NHS Grampian Palliative and Supportive Care Plan

Optimal Model
- Best possible experience for individual, carers & family
- Integrated working
- Equitable access
- Delivery of standards
- Positive staff experience
- Efficient & effective use of resources
Five key priorities for improvement have been identified which will lead to delivery of the shared vision and outcomes. These are outlined below.

1. Care is Tailored to Individual Need and Informed Choice

2. Maximising Comfort and Quality of Life

3. Coordinated Approach

4. People are Effectively Supported to Care for Individuals, Families and Each Other

5. Access to the Right Information and Resources when these are Required

Overleaf, summarises the proposed high level actions identified within Aberdeen City, Aberdeenshire, Moray and as appropriate those services who deliver care across Grampian. These support the delivery of the vision and model of care and critically address the challenges identified by stakeholders in both the short and longer term. These have been developed through multiple engagement opportunities with those accessing services, along with a wide range of professionals from across health and social care services, third and independent sector. We would welcome your views on these.
### Proposed Actions Supporting Delivery of the Priority

#### Aberdeen City

**Major Projects**
- ACP planning – regularly reviewed and updated
- Ensure MDT is key part of the process with information going back to the individual
- Focus on learning about effective communication for all staff
- Enhance social care resource availabilities

**Quick Wins**
- Improved use and review of ACPs
- MDT approach and communication to include individual, carers and family
- Good, clear, accurate and timely hospital discharge to community teams
- Identify key lead worker
- Enable appropriate sharing of information

#### Aberdeenshire

**Major Projects**
- Engagement with communities regarding expectation and culture
- Use of technology to link into meetings virtually
- Maximise opportunities for roll-out of virtual wards across Aberdeenshire
- ACP of individual’s priorities, clear goals and limitations
- Adopting a cultural change in terms of language and attitude
- Importance of flexibility, adaptability, building on relationships, ongoing review & monitoring
- Up to date directory of what is available

**Quick Wins**
- At least 1% of population will have an ACP which is regularly reviewed
- Timely identification of individual’s entering the dying phase
- Inclusion of learning disability palliative care pathway within the strategy
- Develop directory of services and resources
- Reactive ACP planning, agreement of how often a plan will be checked and reviewed
- Clear and frank discussion about expectations
- Point of contact for the individual is agreed
- Joint access of information

#### Moray

**Major Projects**
- Available workforce to support care at home
- Coordinated approach with all agencies involved

**Quick Wins**
- Access to dedicated palliative care beds when people require these.
- Access to formal carer provision when people require this.
- Services are responsive to individual needs.
- Responsive out of hours provision when required.
- Staff can access the right information as and when they require this.

#### Acute/Specialist Services

**Grampian-wide**
- Management of individual’s, carers & families expectations – understand how the system supports them
- Review of ‘Care and support when you are diagnosed with a life-limiting condition in Grampian’ leaflet
- Introduce Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) documents as standard

### How will we know if we have made a difference?

- Positive feedback/experience from individuals, families and carers
- Reduction in number of complaints. Staff satisfied with provision. Good enough for our own.
- Optimal symptom control.
- Individual’s palliative care needs are identified at the earliest opportunity.
- Care is in the right setting/service for individual and their needs.
- Staff are knowledgeable, skilled and supported to deliver palliative and end of life care.
- Access to dedicated palliative care beds when people require these.
## Proposed Actions Supporting Delivery of the Priority

### Aberdeen City

**Quick Wins**
- Rapid response/crisis team – increase resources in community

**Major Projects**
- Identify systemic problems and a collective view on gaps, barriers and good practice
- Identifying an individual coordinator for each individual’s palliative care journey

### Aberdeenshire

**Quick Wins**
- MDT approach and communication to include individual, carers and families
- Weekend access to equipment
- Regular reviews/feedback of condition/symptoms
- Escalation pathways
- Improve access to medicines via PEOlC pharmacies – fast access to less common specialist medication
- Enable appropriate sharing of information

**Major Projects**
- Engagement with communities regarding expectation and culture
- Use of technology to link into meetings virtually (e.g. ECHO)
- Maximise opportunities by roll-out of virtual wards across Aberdeenshire
- ACP of individual’s priorities, clear goals & limitations
- Adopting a cultural change in terms of language and attitude – be willing to ‘let go’ of pre-conceived ideas (need training)
- Up to date directory of what is available
- OOH support/debrief and access/broader resource to support

### Moray

**Quick Wins**
- Establish what comfort means to individual in support plan
- Recognition of individuals comfort where they have communication difficulties or behavioural issues
- Person-centred assessment – dependant on needs
- Rapid access to equipment as required
- Coordination of resources in facilitating wishes
- Timely access to ‘just in case’ medications
- 24 hour access to medication/support and information

**Major Projects**
- Skilled/trained workforce – ensure high quality and ongoing education/support is available to all teams

### Acute/Specialist Services

- Increased symptom management clinics in Grampian
- Practice education remotely replicating Specialist Training

### Other Grampian-wide

- Last Aid Courses
- Importance of flexibility, adaptability, building on relationships, ongoing review & monitoring
- Management of patient & family expectations – understand how the system supports them
- Review of ‘Care and support when you are diagnosed with a life-limiting condition in Grampian’ leaflet
- Using technology such as ECHO to deliver education across Grampian

### How will we know if we have made a difference?

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- Services are responsive to individual needs.
- Responsive out of hours provision when required.
- Staff can access the right information as and when they require this.
- Active creation, use and sharing of Anticipatory Care Plans.
## Priority 3 - Coordinated Approach

### Proposed Actions Supporting Delivery of the Priority

#### Aberdeen City

**Quick Wins**
- Named contact nurse or GP
- Support palliative care leads
- Create palliative care forum - all services/system
- Evolve third/independent sector (ALISS/SSD)
- Ensure future delivery links to commissioning strategy in practice
- KIS should be updated regularly and accessible to all professionals
- Improve and regularly update ACPs with all agencies having access
- Advertise Palliative Care Liaison Service
- Practitioner Network
- Collaborative documentation of existing services that are available in particular areas

**Major Projects**
- Joined up working relationships – link to OOH, Social care and GMEDS
- Unblock GDPR misconceptions
- IT solutions to enable sharing of information
- Link Person - allocated named lead professional
- One assessment referral form that can evolve with changing needs

#### Aberdeenshire

**Quick Wins**
- Listen to/Understand/Compassion
- Post death debrief for staff
- Third sector role agreement with each other
- Out of hours support for carers/responders around death
- Lead person for each person identified (person might change at different times)
- Shared understanding of services (patients, families and staff)

**Major Projects**
- Clarity in ECS, EPCS, KIS and ACP
- Formal engagement of care homes role and support for palliation
- Education and Training
- Compassion
- Enabling nursing home support/education/third sector
- Shared learning (ECHO)
- OOH support/debrief/support and access/broader resource to support

#### Moray

**Quick Wins**
- Resource mapping
- Making connections
- Publicising service

**Major Projects**
- 7 day, 24 hour service
- Continuity of service
- IT connectivity

### Acute/Specialist Services

- Expand palliative care nursing team in Aberdeen Royal Infirmary
- Simplifying referral process (removing barriers)
- Practice education remotely replicating Specialist Training
- More specialist consultants in Aberdeen Royal Infirmary for review of patients and to give education/support to staff
- Easier access to specialist palliative care clinics – have more remote clinics

### Grampian-wide

- Education re palliation conversation skills and practical help through a variety of third sector organisations
- Coordinated approach to ACP, ECS, EPCS and KIS – standardising and shared access to key information
- Using technology such as ECHO to deliver education across Grampian
- Tailor the provision of education to all professionals involved in delivering palliative and end of life care

### How will we know if we have made a difference?

- Positive feedback/experience from individuals, families and carers
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- Services are responsive to individual needs.
- Responsive out of hours provision when required.
- Staff can access the right information as and when they require this.
- Active creation, use and sharing of Anticipatory Care Plans.
## Proposed Actions Supporting Delivery of the Priority

### Aberdeen City

**Quick Wins**
- Carers groups/drop in's
- Anticipatory care planning in advance involving wider MDT
- Staff and family support
- Ongoing consideration of educational needs of staff/learning needs analysis
- Patient referrals at the right time

**Major Projects**
- Identify systemic problems and a collective view on gaps, barriers and good practice
- Allocated lead professional named person
- Better planning and listening
- Support for non-malignant diseases
- Education

### Aberdeenshire

**Quick Wins**
- Self support/help guidance for OOHs staff
- Checking in with staff regularly (for instance team meetings, regular feedback, reflective practice)
- Increased opportunities for shared training and support (for patients, carers, families)

**Major Projects**
- Identify systemic problems and a collective view on gaps, barriers and good practice
- Development of compassionate communities ('Inverclyde Model')
- Streamline recruitment processes and prioritise recruitment

### Moray

**Quick Wins**
- Publicising/awareness of service
- Flexibility in service
- Develop compassionate communities

**Major Projects**
- Identify systemic problems and a collective view on gaps, barriers and good practice

### Grampian-wide

- More specialist consultants in ARI for review of patients and to give education/support to hospital staff
- Easier access to specialist palliative care clinics – have more remote clinics

- Using technology such as ECHO to deliver education across Grampian
- Tailor the provision of education to all professionals involved in delivering palliative and end of life care

### How will we know if we have made a difference?

Reduction in number of complaints.

Staff satisfied with provision. Good enough for our own.

Care is in the right setting/service for individual and their needs.

Staff are knowledgeable, skilled and supported to deliver palliative and end of life care.

Access to dedicated palliative care beds when people require these.

Access to formal carer provision when people require this.

Services are responsive to individual needs.

Responsive out of hours provision when required.

Staff can access the right information as and when they require this.

Active creation, use and sharing of Anticipatory Care Plans.
### Priority 5 - Access to the Right Information and Resources when these are Required

**Proposed Actions Supporting Delivery of the Priority**

#### Aberdeen City
- **Quick Wins**
  - Carers groups/drop in’s
  - Improve and regularly update ACPs
  - Mapping of available support resources and making these accessible
  - Dedicated respite
  - Children’s respite and care centre
  - Palliative care specific beds

- **Major Projects**
  - Allocated lead professional named person
  - Review GP palliative meetings and correct ACP usage – truly multi-agency
  - Planning with flexibility

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#### Aberdeenshire
- **Quick Wins**
  - Increase number of people with an ACP and ensure that these are regularly reviewed and available as appropriate

- **Major Projects**
  - Link IT systems so that key information is available to all health and social care professionals to access quickly and easily as required
  - Ensure that community hospitals are appropriately resourced in order to enhance palliative care provision

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#### Moray
- **Quick Wins**
  - Access to care and allocated on a priority basis

- **Major Projects**
  - 24 hour access to equipment
  - Palliative care training – local and at an appropriate level

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#### Acute/Specialist Services
- More specialist consultants in ARI for review of patients and to give education/support to hospital staff
- Easier access to specialist palliative care clinics – have more remote clinics

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#### Grampian-wide

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### How will we know if we have made a difference?

- Access to dedicated palliative care beds when people require these.
- Access to formal carer provision when people require this.
- Staff can access the right information as and when they require this.
## Glossary of Terms

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tbody>
<tr>
<td>ACP</td>
<td>Anticipatory Care Plan</td>
</tr>
<tr>
<td>ALISS</td>
<td>A Local Information System for Scotland</td>
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<tr>
<td>Compassionate Communities</td>
<td>A Compassionate Community provides support to someone who is dying. The community could be family, neighbours, local organisations, a faith group, local businesses or people living in a particular area. People in a Compassionate Community help care for a dying person through small acts of compassion, supporting the dying person during their end of life, often enabling them to die well and, if possible, at home. Palliative care professionals, are also a vital part of a Compassionate Community.</td>
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<tr>
<td>ECHO</td>
<td>Electronic knowledge sharing network</td>
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<tr>
<td>ECS</td>
<td>Emergency Care Summary</td>
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<tr>
<td>eKIS</td>
<td>Electronic Key Information Summary</td>
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<tr>
<td>ePCS</td>
<td>Electronic Palliative Care Summary</td>
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<tr>
<td>GDPR</td>
<td>General Data Protection Regulations</td>
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<tr>
<td>GMEDS</td>
<td>Out of hours service which deals with the non-emergency, urgent health needs of patients. It operates from 6pm to 8am, Monday to Friday; and 24 hours a day, Saturday, Sunday and public holidays. The service is open to all residents and temporary residents in Grampian.</td>
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<tr>
<td>GP’s</td>
<td>General Practitioners</td>
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<tr>
<td>KIS</td>
<td>Key Information Summary</td>
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<tr>
<td>MDT</td>
<td>Multi-Disciplinary Team</td>
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<tr>
<td>OOH</td>
<td>Out Of Hours</td>
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<tr>
<td>PEOeLC</td>
<td>Palliative and End of Life Care</td>
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<tr>
<td>ReSPECT</td>
<td>Recommended Summary Plan for Emergency Care and Treatment</td>
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<tr>
<td>SPECT</td>
<td>Supportive &amp; Palliative Care Indicators Tool</td>
</tr>
<tr>
<td>SSD</td>
<td>Scottish Services Directory</td>
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</table>
It is important that we ensure the Grampian Palliative and End of Life Strategic Framework is deliverable and fit for purpose in achieving good quality and sustainable care in both the short and longer term. We would be grateful if you could provide feedback on the draft Framework and also specifically consider the following questions.

1. Do you feel the proposed vision and principles for palliative and end of life care is right? If not, why not?

2. Do you agree with the proposed key five priorities of focus? If not, why not?

3. Do you feel the proposed actions will support the delivery of quality and sustainable care in your local area now and in the future? If not, why not?

4. Are there any additional actions/priorities which you wish to add?

Please provide your feedback by 5pm on 23rd September 2019 by:

- e-mailing - nhsg.involve@nhs.net
Contacts

If you have any questions or concerns about this consultation or would like to get more involved in the work of NHS Grampian please contact us:

**By email:** nhsg.involve@nhs.net

**By voicemail:** 01224 558098

**By post:** Palliative and End of Life Care Consultation
NHS Grampian
Freepost

If you would like to request a member of the team to attend a specific group or event to talk about these proposals, please let us know.

We would love to hear your views about this framework and would appreciate you taking 5 minutes to fill in this simple survey:  [http://bit.ly/GrampPEoLCRQuestionnaire](http://bit.ly/GrampPEoLCRQuestionnaire)

All consultation materials can be made available in large print and other formats and languages, upon request. Please call NHS Grampian Corporate Communications on 01224 551116 or 01224 552245.