HEALTH AND SPORT COMMITTEE
WHAT SHOULD PRIMARY CARE LOOK LIKE FOR THE NEXT GENERATION?
SUBMISSION FROM Scottish Partnership for Palliative Care

About the Scottish Partnership for Palliative Care (SPPC)
SPPC exists to improve people’s experiences of declining health, dying and bereavement. Founded 29 years ago SPPC has grown to be a collaboration of over 100 organisations involved in providing care towards the end of life. SPPC’s membership includes all the territorial NHS Boards, all IJBs, all the hospices, a range of professional associations, many national charities, local authorities, social care providers and universities.

About this response
Around 57,000 people die annually in Scotland. Of these it is estimated that as many as 47,000 people will have needs arising from living with deteriorating health for years, months or weeks before they die.

Current projections suggest that Scotland’s population will rise to 5.78 million by 2037, and that the number of people aged 65 and over will increase by 59%, from 0.93 million to 1.47 million. A likely corollary of this shift is a growth in the proportion of people with multiple long-term conditions and increasingly complex care needs. The demand for palliative and end of life care is projected to change and grow in the coming years. Extrapolating from a recent study of English and Welsh populations it is reasonable to conclude that in Scotland the annual number of deaths will rise by 25% by 2040. Further, the number of those requiring palliative care will increase by between 25 - 40 % by 2040 (the demand for palliative care is likely to grow faster than the number of annual deaths because people may have palliative care needs for longer than a year).

Palliative care is not synonymous with death – it is about life, about the care of someone who is alive, someone who still has hours, days, months, or years remaining in their life, and about optimising wellbeing in those circumstances.

This response is framed specifically in relation to palliative care, but we recognise that many of the issues raised apply more broadly. As wider context we recognise the financial pressures in the health and social care system, failure to effect significant change in the proportion of spend in primary and community services, and recruitment and retention issues.

1. Considering the Health and Sport Committee’s report on the public panels, what changes are needed to ensure that the primary care is delivered in a way that focuses on the health and public health priorities of local communities.

The role of primary care in palliative and end of life care
Palliative care is recognised both nationally and internationally as core business for primary care teams. Primary care teams should play the lead role as “primary case holders”. This involves the early identification of people with palliative care needs, anticipatory care planning, service co-ordination and often the delivery of palliative and end of life care. Most of the rest of this submission explores what primary care teams need to deliver this challenging but rewarding role.
Relationship between primary care, general practice, specialist palliative care (and other medical specialties).

In carrying out this lead role primary care teams need adequate time, and adequate access to specialist advice and support. GPs and community District Nurses are both key to the provision of high-quality palliative and end of life care. However, the relationship between GPs as expert medical generalists and other specialties will vary according to complexity. In non-complex cases towards the end of life there may be little need for medical or other clinical intervention. People may be supported with good nursing care and support from families or carers. However, there should be access to GPs when people have multiple conditions, unclear prognosis, need difficult judgements about the utility of interventions/investigations, polypharmacy and cognitive issues.

Access to specialist palliative care

Primary Care professionals require 24/7 access to specialist palliative care advice and input, alongside other specialties. Often specialist advice and support are ‘hospice’ or ‘hospital’ based. It would be helpful if appropriate specialist services could be based within communities, working more closely with Primary Care teams than is currently the case in many parts of the country.

Time

The need to listen, to explore and to support shared decision-making in complex situations is at a premium in primary care towards the end of life. This takes time and will often require longer than a 10-minute GP appointment. Community nursing staff also require more time to spend with people as they approach the end of life, and to move away from a task-driven workload.

Service Organisation

There is a need for improved communication between and integration with hospital, hospice, independent social care and third sector services. Primary care teams should have better access to hospital at home and hospice at home services. There is potential to exploit to a greater extent the potential for working with 3\textsuperscript{rd} sector organisations. Complex health and social problems should not be seen and managed as medical problems only, and 3\textsuperscript{rd} sector organisations are well placed to offer support relating to non-clinical issues.

There is a need for adequate resourcing of specialist palliative care such that 24/7 advice and support to primary care becomes available across the country.

Multi-disciplinary team meetings are of key importance for people with complex health and palliative care needs. Adequate priority and time must be dedicated to allow staff to attend these meetings, so that effective discussion and planning of care can take place.

Care homes provide important care to people with complex advanced and progressive medical conditions. They need more consistent support from primary care teams, who should be resourced and structured to deliver this. The potential to provide some of this support through advanced nurse practitioners, pharmacists and other members of the Primary Care team should be explored.
There are specific issues relating to the palliative and end of life care of babies, children and young people in the community. Most Community Children’s Nursing services are resourced to work on an office hours schedule, without the contractual flexibility to work out of hours to provide end of life care overnight and at the weekends. There is also a need to address 24/7 specialist medical support to primary care in relation to the paediatric and young adult population.

**Technology**

Primary Care professionals currently work with several different clinical systems which do not ‘talk to one-another’. Effective technology, with shared electronic clinical records is required to support the planning and co-ordination of care. Effective systems are needed to support the documentation and appropriate sharing of care planning across the health and care system. It needs to be possible for people working in different settings to update these plans as well as to access them. The current work on Respect by NHS FV and the National Digital Service is encouraging, but at an early stage. Citizen access to their own data also needs to be supported. Power of attorney and advance directive documents need to be flagged and accessible.

People value continuity of care but manpower issues, the development of MDTs and service provision organised on a cluster basis can make continuity through a single relationship more difficult. Effective sharing of information can go some way to ensuring that each practitioner is aware of preferences, history and previous communications.

Technology has a role in improving access to specialist knowledge and in developing the knowledge and capacity of the primary care team. Highland Hospice pioneered (in Scotland) the ECHO approach and other hospices are now expanding this.

The use of simple technologies such as Skype and email as a means of interacting with people needing care may also help with continuity of care, as well as reflecting the changing ways in which people expect to engage with all sorts of services. *Attend Anywhere* is an example of using VC technology for consultations. Changing working practices is a bigger barrier than technological limitations.

**Workforce**

*Training* - Primary care teams need access to training and development to ensure that they are skilled and confident in providing palliative and end of life care. The NES Education Framework sets out clearly different domains and levels relating to different roles. A training resource based on the content of the Scottish Palliative Care Guidelines is in development, but there is a need for consistent investment to develop and sustain skills, knowledge and confidence. This should include spiritual care. As well as formally structured training other approaches to role development should be available for all members of the primary care team. One example is the First5 project which could be expanded [https://www.rcgp.org.uk/clinical-and-research/resources/bright-ideas/career-start-gp-programme-for-first5-gps.aspx](https://www.rcgp.org.uk/clinical-and-research/resources/bright-ideas/career-start-gp-programme-for-first5-gps.aspx).

*Nursing* - The roles of Advanced Nurse Practitioners and District Nurses are critical but how the roles interrelate needs careful thought and may be different in different geographies.
(and with each clinical case). Without a suitably skilled District Nursing workforce of adequate size primary care cannot deliver palliative and end of life care adequately.

**New/extended roles** - Enhanced roles (could be AHP, nursing, potentially complemented by lay people) within the primary care team with an explicit focus on ACP and eliciting values and preferences would be very valuable. ACPs which are rich in content and covering not only clinical care decisions, but social care aspects too are important.

**The public as partners**

Despite being both universal and profound, the experiences of death, dying and bereavement have some of the characteristics of marginal issues in Scottish society. There are low levels of public (and professional) awareness, knowledge, discourse and engagement relating to these issues. This represents an opportunity. SPPC is developing a scalable public education course *End of Life Aid Skills for Everyone*. Building on the work of others SPPC is also running the *Truacanta* project to explore how community development approaches can build informal community capacity for mutual help and support though death, dying and loss. Such initiatives have the potential to encourage discussion and planning for end of life and to increase the availability of informal support. Professional support for and work with family/informal cares remains critically important.

2. **What are the barriers to delivering a sustainable primary care system in both urban and rural areas?**

Many of the issues raised in response the Q1 apply to both urban and rural areas. However, models of service delivery for remote, sparsely populated rural areas need to reflect local circumstances. Hub-based MDTs which make sense in urban areas is not the right model in rural areas. Local multi-purpose clinicians can maintain continuity, offer proximate access and are popular with communities. Such roles will often be GPs but could, in very remote and sparsely populated areas, also be ANPs working in close collaboration with visiting GPs.

Funding and resources remain a barrier to the delivery of sustainable primary care within both urban and rural areas. The balance of resource between acute hospital-based services and community-based services has been skewed towards hospital over a number of years. If we are to achieve our national priority of caring for people in their own home we must provide adequate funding for community staff, including social care workers.

3. **How can the effectiveness of multi-disciplinary teams and GP cluster working be monitored and evaluated in terms of outcomes, prevention and health inequalities?**

Identifying and measuring outcomes in palliative and end of life care is challenging. SPPC produced a paper on this topic for Sir Harry Burns’ review of indicators and targets and it can be accessed here [here](https://www.palliativecarescotland.org.uk/content/publications/FINAL---SPPC-Submission-to-Review-of-Targets-and-Indicators.pdf)

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