

## We need to talk about Palliative Care

### NHS Borders

#### 1. What has been your experience in terms of access to palliative and end of life care?

The key achievements since the publication of Living and Dying Well in 2008 have been in the expansion of the palliative care remit. Those with cancer are still the majority seen but non-malignant disease is gradually an increasing part of our role. Early identification of non malignant disease using such tools as SPICt has been proven to improve quality of life. There is still work to be done, but more people see the role of palliative care as being to support those with a palliative illness, but not just at end of life. There is also a wider perception that (living and) dying is everyone's business both in the local communities and amongst health and social care workers.

Anticipatory prescribing is a concept more accepted, alongside anticipatory care planning, though again this needs to be taken more widely. The correct use of the DNACPR (Do Not Attempt CardioPulmonary Resuscitation) form throughout care provision is improving, but recent guidance from south of the Border has led to further change. There are now the Scottish Palliative Care Guidelines which are universally used and are available on the internet, supporting all care providers to optimise the care of palliative patients. EPCS and EKIS have resulted in improved communication and collaboration across all services but there is still significant work required to ensure 24/7 availability across all care providers.

Locally, the profile has been raised by the successful appeal for a purpose built 8 bedded specialist palliative care unit in 2012. A palliative care needs assessment has recently been completed to help estimate future need, identify current gaps and suggest recommendations. The aim is to deliver equitable and consistent, high quality, person centred care. The recommendations will be available shortly but some will appear throughout this report.

In terms of establishing need, it should be possible to use the causes of death data presented to project how much and what types of palliative care services should be available in the Scottish Borders. However this is not a straightforward exercise (Ingold and Hicks, 2013). Firstly, there is the issue of the increase in the prevalence of multimorbidity which attends an aging population as recently demonstrated by Barnett et al (2012). Secondly, the cause of death may not always be an accurate reflection of diagnosis as there are various factors which affect what is recorded on a death certificate, and certain conditions are particularly under-recorded (Murtagh et al, 2014). However the new way of death certification in Scotland aims to improve the quality of this moving forward. There is also widespread recognition that palliative care needs are determined by much more complex and interacting factors than diagnosis alone<sup>1</sup>. Indeed, there is evidence to suggest that people with different diagnoses experience similarities in how they die (Solano et al, 2006).

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<sup>1</sup> McIlfratrick (2007), and Higginson and Addington-Hall (1999) cited in Murtagh et al (2014, p.56).

Another factor relates to the setting and degree of specialisation of services. The European Association for Palliative Care (Radbruch et al, 2010), for example, cite a widely held view that palliative care and support should be provided in a variety of settings and along a *continuum of specialisation* which includes those services which adopt a *palliative care approach* through *general palliative care* to *specialist palliative care*. However, attempting to estimate the minimum or optimal level of the types of services to meet the palliative care and support needs of a particular community is problematic. In their review of research on this subject Ingold and Hicks (2013) found that the published evidence base on projecting needs for end-of-life care services is contradictory, mostly out of date, and based primarily on models of cancer care.

Fortunately, a recent study by Murtagh et al (2014) has reviewed and compared previous methods for population based estimates of palliative care need, and developed these in the process. They concluded that in high income countries 69%–82% of people who die may benefit from a *palliative approach* to their care; however there are no reliable estimates of the proportions of people who will need *specialist* palliative care. Using the estimated average that 75% of deaths require palliative care, around 920 people each year in the Scottish Borders will require palliative care and support, tailored to their individual needs and preferences. Based on population changes this estimate will rise to almost 960 by 2023. The proportional demand for palliative care is however likely to increase based on a combination of increasing prevalence of cancer, recognition and response to non-cancer conditions requiring a palliative care approach, and the increase in dementia (Calanzani et al, 2013).

While it is not feasible to accurately estimate how many patients in Scottish Borders are currently receiving *generalist* palliative care or primary care involving a palliative care approach, it is possible to estimate how many patients are receiving *specialist* palliative care. Data provided by the Margaret Kerr Unit indicates that 139 patients were discharged<sup>2</sup> in 2013, while data from the Crosscare system<sup>3</sup> indicates that a total of 205 people received specialist palliative care in an outpatient or community setting. While there will be some overlap between these two groups, it can be estimated that between 200 and 350 people (of the estimated total of 920 requiring palliative care approach) received specialist palliative care in Scottish Borders in 2013.

The conclusions drawn from the analysis of service provider and user views gathered for the Scottish Borders palliative care needs assessment are presented below. Further details of the challenges and potential solutions identified by service users and providers can be found in the Stage Two report, available on the Marie Curie website.

1. There was a considerable degree of overlap between the issues identified by service providers and service users.

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<sup>2</sup> There were a total of 168 discharges in 2013, but this included patients discharged on more than one occasion.

<sup>3</sup> Crosscare is a practice management system designed for use within four main areas - hospice care, private care, primary care and corporate care (see <http://www.advancedcomputersoftware.com/ahc/products/crosscare-practice-management-system.php>)

2. Service user challenges were, understandably, based on their personal experience and pointed to a lack of availability and/or consistency of
  - supply of care;
  - provision of support and guidance for patients and unpaid carers;
  - care planning involving unpaid carers and family; and
  - supply of information.
3. Similarly, service providers also identified problems of
  - inconsistency and accessibility of care and support services for patients;
  - the lack of anticipatory care planning; and
  - a lack of information about available services.

## **2. How could it be ensured that access to palliative and end of life care is equitable and available in all areas and for all types of terminal illnesses?**

Early identification, particularly in non malignant disease is crucial and tools should be more widely used to enhance this. Palliative care and anticipatory care planning earlier in the disease process can help reduce futile treatments, improve the likelihood of their preferred place of care at end of life being achieved, and improve patient and carer satisfaction. End of life care with patients with dementia is also a developing need in view of increasing incidence and a more co-ordinated approach with palliative care is needed. Locally we are developing this model in supporting the dementia services and have a Health Promoting Palliative Care (HPPC) strategy. We are also currently looking into the scope of Information Technology/Technology Enabled Care in service development. The publication of the palliative care needs assessment is another opportunity to raise the profile, along with various events linked to the Good Life, Good Death, Good Grief website.

### **Health promoting palliative care**

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1. Address issues with terminology including the term “palliative” and inform both professionals and the public of the benefits of early identification.
  2. Develop a range of Health Promoting Palliative Care events and resources.
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Stakeholders identified issues with both the taboo nature of death, dying and bereavement, and some of the language and terminology relating to palliative care. They told us there was poor understanding of what palliative meant, and there is a need to address the issue of patients’ discomfort regarding the label “palliative care”. Stakeholders also conveyed that encouraging the general public to be more aware of what palliative care was, and providing relevant resources and support at diagnosis, would empower more patients and carers to access support and care when needed.

Stakeholders suggested more public engagement on the subject of death and dying to encourage public discourse and conversations between families - whether

currently facing the death of a loved one or not. For example, the ideas of public events and a media campaign<sup>4</sup> were suggested to improve public awareness and dialogue regarding death, dying and bereavement.

### Identification

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1. Provide training and support to identify patients with palliative and supportive care needs in primary and secondary care using recognised tools.
  2. Provide training and support for practitioners to have difficult conversations with patients and carers including dealing openly with uncertainty, breaking bad news and managing expectations.
  3. Develop computerised searches/prompts for primary and secondary care which would help improve identification of patients who would benefit from a palliative approach.
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Service providers in the Scottish Borders recognised the need for early identification of patients with terminal illnesses to ensure that all patients, regardless of condition, have equal access to care and support. They suggested adopting an approach throughout primary and secondary care which reliably identifies patients who need palliative care input, and initiates anticipatory care planning involving the relevant professionals – whether generalist or specialist. This would allow the appropriate types of care and support to be put in place from the point of diagnosis. Use of prognostic indicator tools such as the Supportive & Palliative Care Indicators Tool (SPICIT<sup>TM</sup>) was specifically suggested by stakeholders. Palliative care services can help reduce the incidence of futile treatments at the end of life and improve patient satisfaction and symptom control.

GPs suggested yearly training updates for medical and nursing staff; it was also proposed that each medical practice (of which there are currently 26 in the Scottish Borders) could have a “palliative care lead” with a good understanding of guidelines and extra experience gained through training/exposure to palliative care in a hospital setting.

A recent report on how end-of-life care can be improved in the context of health and social care integration identified suggested creating standardised and automated on-screen prompts within GP records systems that would prompt GPs to initiate certain aspects of end-of-life care at an appropriate time. The use of such prompts could also be extended to secondary care clinics.

### Holistic Care and Support

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1. Develop use of IT systems such as email, Skype and telecare, especially in remote areas.
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<sup>4</sup> A Radio Borders campaign was previously conducted throughout Good Life Good Death Good Grief awareness week in May 2014.

Scottish Borders GPs identified that while communicating by telephone can be time consuming and limited to office hours, facilitating more emailing between social and health care professionals would allow more flexibility in the timing and enable a greater number of professionals to be notified about important changes to a person's condition, care and support.

Stakeholders also identified the need to improve access to care for people living in remote areas, and suggested that the ability to communicate through alternative media such as email and Skype could give better access to information and care.

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2. Ensure availability of clear and up-to-date electronic information about services and support available nationally & locally.
  3. Ensure provision of clear, sensitive and appropriate information explaining what caring for someone may entail and relevant information as to what happens at the end-of-life.
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Scottish Borders GPs told us that with the increased pressure to keep to appointment times it was essential to have easy access to relevant information which could be printed off at the time of the consultation - ensuring patients and carers were kept well informed about sources of further information and services available.

Similarly, carers felt ill informed as to what services were available and how to access these – for example who to approach to organise transport, equipment etc. Carers in the Scottish Borders also identified the need to have clear guidelines as to what was expected of them as a carer; specifically, there was a need identified for information about what to expect at the end of life – i.e. the signs and symptoms of dying.

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4. Increase availability of palliative care and support services outside of normal working hours.
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Home palliative care services have been proven to double the chance of dying at home and improve symptom control<sup>5</sup>. Stakeholders in the Scottish Borders identified the need to address gaps in the provision of 24/7 care and support. Specifically they requested better access to Marie Curie Nursing services (particularly in remote areas) and the piloting of a *Hospice at Home* service to support existing social services, district nurses and carers/families and enable round-the-clock care.

Stakeholders also identified the need for a “rapid response” team, or similar model, for overnight or weekend care to prevent delays in discharge and or avoidable hospital attendances/admissions.

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5. Develop a palliative care respite facilitation and support service providing co-ordinated access to existing respite provision (including Third Sector) in the community.
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<sup>5</sup> Gomes et al (2013)

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6. Develop volunteer support to patients and carers with daily tasks/companionship in all settings.
  7. Address the lack of age appropriate inpatient facilities and free end-of-life care at home for those under 65 years old.
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Carers in the Scottish Borders indicated that respite care should be more readily available in the Scottish Borders – for the benefit of both the person with the terminal illness and their carer/family. While it may be that *more* palliative care respite beds are required, *facilitating access to existing beds* is also an important factor.

Stakeholders also indicated that better use should be made of opportunities to access voluntary organisations and volunteers who can provide additional support to all people with terminal illnesses and their carer/families, whether housebound, living alone or in hospital. This could include volunteer visitor services which provide social, emotional and practical support to terminally ill people and carers - usually through regular visits to their home.

It was also identified by stakeholders that there was a lack of non-specialist care facilities for younger patients (under 65) who were unable to return home due to incapacity or care needs.

It is the NHS (rather than the Local Authority) that pays for continuing care, however changes that will be coming into force mean that continuing care will only be provided for free in NHS facilities and patients receiving continuing care in non-NHS facilities will be required to pay accommodation costs. Exactly how this will pan out under the new health and social care partnerships is currently unclear, however Scottish Borders Council<sup>6</sup> do not charge for any non-residential care services received by people in receipt of palliative care (where a DS1500 form has been completed by the person's doctor).

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8. Ensure appropriate use of/access to specialist palliative care and community inpatient beds.
  9. Ensure 24/7 access to effective generalist and specialist palliative care advice.
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Stakeholders identified issues with access to specialist palliative care beds in the Margaret Kerr Unit, and local specialist palliative care advice/support - particularly after hours and at weekends.

Specifically, it was identified that delays in discharge due to lack of available alternative places of care or timely provision of social care packages often led to specialist palliative care beds not being so available. GPs also identified difficulties with access to community beds, particularly for those people living in areas without a community hospital.

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<sup>6</sup> Scottish Borders Council (2015)



### 3. Can you identify any areas in terms of access to palliative and end of life care that should be focused on as priorities?

The main priorities and objectives to improve palliative and end of life care focus to a great extent on communications. There needs to be a single shared system accessible to all including patients to ensure information is available to all regarding each patient, which avoids repetition of difficult conversations and the reassurance of the patient and family that we are working together. The role of technology enhanced care (TEC) has also been highlighted locally and nationally as Scotland has various geographical challenges in terms of equity of provision. Communication skills need to be developed across all sectors and the value of time to allow these conversations to occur should not be underestimated. There should be a shared language for all those involved in care including the patient, with demedicalisation of their condition. Patients should be involved in the co-design of

services. There should be a seamless transition from active management to best supportive care at the time which is appropriate to that individual. The role of a lead person in each team such as the dementia champion role or the role of a team huddle to ensure continuity may be worth considering. Health promoting palliative care (HPPC) should involve the public more, and we should engage with the media to encourage a more positive reporting of end of life care. Other staff should also be encouraged to support the HPPC principles.

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### Assessment, care planning and review

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1. Develop and support (through training and education) anticipatory care planning throughout primary and secondary care for all people with terminal illnesses.
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Stakeholders identified that there is variation in the application and quality of anticipatory care planning in both primary and secondary care, and that patients and family/carers should be actively involved in formulating and maintaining care plans.

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2. Carer awareness training for professionals
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Stakeholders told us that embedding anticipatory care planning into practice will also require training for patients and families/carers, and an understanding by health and social care professionals of the role that patients and families/carers play in coordinating care. Carers in particular identified there was very little recognition of their role in contributing to the development and review of care plans.

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3. Ensure continuity /accessibility of IT systems (e.g. KIS) between Primary and secondary care, provide training and support to practitioners in their use and benefits, and promote awareness and involvement of patients and carers in this.
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Stakeholders also told us that there is inadequate communication between professionals, including an overreliance on IT systems for care planning which are not joined up or accessible to all relevant staff, and suggested the need for *communication systems and IT infrastructure that is cross boundary between services*. In particular, GPs suggested that the Key Information Summary (KIS) should be made available throughout secondary care; currently there is limited access and it is not always a real-time assessment.

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4. Ensure holistic assessment of palliative care and support needs on any attendance (including admission) to acute hospital including Polypharmacy review, Anticipatory Care Planning and alert back to GP that patient has been referred to specialist palliative care team.
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5. Ensure re-assessment on preparation for discharge with identification of changing needs and timely notification to community teams for appropriate follow up action.
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Stakeholders identified communication problems between secondary and primary care, for example in relation to identifying in discharge letters or any clinic letters that the patient's condition has reached the palliative stage. Where patients *are* identified as being palliative within secondary care, however, GPs indicated that there is a secondary issue with delays in communication (discharge letters can take 3 weeks to come through) and a lack of consistency, for example, in terms of information on whether DNACPR status had been discussed. GPs felt this delay could be reduced by notifying the relevant community teams while discharge is being planned<sup>7</sup>. There are developments in the pipeline to add on anticipatory planning information to the immediate discharge letter, which is now electronic and is currently being rolled out to all wards. Tools to aid this identification are being developed for inpatient care.

Carers identified that the lack of pre-discharge assessment and care planning can delay the organisation of packages of care leading to delays in discharge and/or the risk of readmission to hospital. Stakeholders also suggested that clear referral pathways and signposting of services by all staff would prevent inappropriate referral to specialist palliative care rather than social work for assessment.

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6. Ensure comprehensive and on-going assessment of carers' needs and recognition their assets and contribution within all settings, through statutory carer assessment/support plan.
  7. Support for carers should be available to all, for as long as required.
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Stakeholders told us that there was a need for clear care and support plans for carers, as well as patients, to help empower them to access the various types of support that are available – for example in relation to the financial burden faced by carers. Specifically, it was suggested that services such as Borders Carers Centre should continue to be available to all who need them - after death and for as long as was deemed necessary.

#### **4. When is the right time to begin discussing options for Palliative Care, who should be party to that discussion, who should initiate it and where should it take place?**

Discussions around a more palliative approach should be held by the most appropriate person for that individual, which may be GP, hospital consultant known to the patient or in acute situations the referring GP/admitting consultant. Good anticipatory planning will reduce the need for the latter. Discussions should be done in a timely, non-acute phase of their disease and identifying them through chronic

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<sup>7</sup> NHS Borders is currently developing electronic immediate discharge letters for both inpatients and outpatients.

deterioration. It should take place according to the individual but in a supportive environment where interruptions are unlikely.

We are currently developing tools to aid the hospital teams to identify chronically deteriorating patients and ask for this discussion to be had with the patient by the most appropriate clinician involved.

#### **5. What works well in discussing palliative and end of life care and how is good practise communicated? Where do the challenges remain?**

The numerous letters of commendation and ongoing support of our team through fundraising is testament to the excellent care patients do receive. Where we get suggestions for improvement these are currently being included in our current review of the service. The needs assessment was to focus on areas of improvement rather than what we do well.

#### **Continuous improvement**

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1. Ensure effective communication between all involved parties when death occurs, and feedback on areas for improvement.
  2. Develop ongoing Satisfaction surveys to support service improvement.
  3. Improve awareness of feedback (including complaints) processes and ensure responses to complaints are transparent and sensitive.
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Stakeholders identified the need for routine and ongoing ways of identifying and sharing areas of good practice and learning lessons when things don't go to plan.

The first of these was a straightforward mechanism for communicating when a death occurs either in hospital or in the community so that all those involved in the care of the person are made aware and have the opportunity to share any learning points, whether positive or negative.

A further suggestion was the use of ongoing satisfaction surveys to support service improvement at both local and national level. Currently in the Scottish Borders (and across Scotland) the population of people receiving palliative and end-of-life care and their carer/families have no route to provide feedback on their experiences outwith the formal complaints, concerns and compliments processes. On a related point, carers expressed a concern that complaints were not always dealt with compassionately and completely to allow 'closure'.

The most significant challenges are linked to resources.

Time is a valuable commodity and essential to have the most effective, supportive and holistic conversations around care.

Staff availability, recruitment and retention, staff welfare and burnout in such a demanding area and education of staff alongside equipment needs of patients and

the demands associated with eHealth and technology enabled care are all resources which are issues.

Clearly there are also financial demands in terms of initial costs and sustainability. Patient related challenges include the management of the patient and family particularly in non malignant disease where there is a certain amount of uncertainty in terms of disease progression. Some patients with multiple comorbidities do not fit under the specialist palliative care label for each individual condition and therefore it is crucial that the patient is assessed as a whole person and that one clinical specialty identifies need for palliative care input.

Locally we are involving staff in service development including core values and ethos/vision.

In terms of how we can support these improvements, integrated IT systems with access for all who need it to allow seamless care are essential. We need to balance confidentiality and perceived concerns with the overriding need to provide safe and effective care. The information about the patient is owned by the patient and development of patient held records could be an option. Holistic assessment of patients with care plans including preferred place of care, DNACPR, ceilings of treatment and levels of intervention should be shared at every opportunity and required in for example immediate discharge letters/clinic letters and all primary care correspondence.

We also need to use current resources more effectively eg expanding the need for HPPC through the SPPC website, alongside a variety of creative measures which include developing compassionate communities to support patient and carers and encouraging self management and creating resilience, improving collaborative working, and valuing and supporting paid and unpaid carers. Clearly the hope is that integration will support this and we need to ensure significant input into integration boards for both palliative and end of life care to maximise resource allocation and scope re capacity. However we also need to be realistic that joint integration will not provide all the answers.

We do need to support staff through this period of change and acknowledge the pressures that change brings. A top down approach will not work and staff should be encouraged to be involved at all stages.

Locally we have been involving staff in service development and have been involved with the integration board regarding projects for service development based on the needs assessment outcomes which have been discussed with the executive team at NHS Borders.

**6. What is the role of anticipatory care plans in supporting Palliative Care discussions and how can their uptake be improved?**

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**7. How should information about Palliative Care be made available to patients and their family during any initial discussions and how easily available is this information?**

Information should ideally be provided for patients and families in a timely manner according to the needs and the clinical picture. Some require all information up front, some in a more piecemeal fashion and the information is currently provided by staff as and when asked for. The use of electronic information systems may enable this, allowing patients and families to access the information at the right time for them.

**8. What training and support is provided Health and Care staff on discussing Palliative Care with patients and families and are there any areas for improvement?**

Carers relayed that equipment was often left in the home for a significant period after death, when the preference was to have it removed. It was suggested that social care staff should have the training to contact bereaved relatives to provide timely uplift of equipment after death or when death occurs in hospital.

Some training is available related to end of life care, around the care of patients with dementia and in house training about any area of care is available if requested. However financial restrictions make it difficult for staff to be released for training and for backfill to be provided.

We are in the process of employing an end of life care facilitator funded by Macmillan, which will be a full time nurse for 2 years to support end of life care throughout NHS Borders. A substantial element of the role will be education.

**9. How do Health and Care organisations ensure that the discussions about palliative and end of life care are taking place at the right time?**

Communication and co-ordination

Use of advancing digital services

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<sup>8</sup> NHS Borders is currently developing electronic immediate discharge letters for both inpatients and outpatients.

**10. What are the challenges in recording and documenting Palliative Care priorities and how well are those priorities communicated between different health and care providers?**

The challenges in recording/documenting palliative care priorities is to apply the same overarching principles yet to allow individual area and patient variations to suit the needs of each area and patient.

We had representation of health and social care providers on our needs assessment and the plan is to involve care providers and users in the development of services and keep them aware of our strategic direction. Opportunities for feedback encourage continued interest and support.

**NHS Borders**