

Scottish Acute Palliative Care Network Event

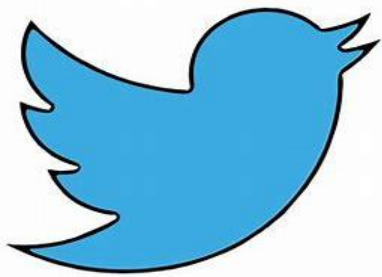
Thursday 16 January 2020



**Building
on the best**



**WE ARE
MACMILLAN.
CANCER SUPPORT**



#sapcn

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Development of the Scottish Acute Palliative Care Clinical Nurse Specialist Forum (SAPCF)

BACKGROUND

The acute hospital palliative care team collaborates with other healthcare professionals in an advisory, supportive and educative capacity to improve the care delivered to palliative patients and their families. Hospital palliative care teams are also involved in improving service delivery of palliative care through research and audit.

Over the past few decades hospital palliative care teams in the UK have developed inconsistently from different backgrounds and vary in their titles, numbers and structure of healthcare professionals involved. The first hospital palliative care team in the UK was founded in 1981 at St Thomas, London and the first in Scotland in 1996 at the Western General, Edinburgh.

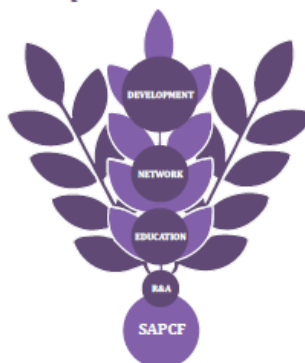
Most hospital palliative care teams consist of clinical nurse specialists as the core backbone of the team with varying levels of support from Palliative Medicine Consultants, Speciality Doctors and other allied healthcare professionals. With increasing clinical workloads the demands on other key dimensions of the service such as education, audit/research, service and quality improvement. In some Scottish hospitals the nurse specialist role can often be very isolated as the service is provided by a lone practitioner, and even in larger teams there can be feelings of isolation due to lack of leadership, direction, strategy and support. It was with this in mind that the founder of the group, an experienced palliative care nurse specialist wanted to highlight the work that hospital based palliative care nurses do and provide a professional forum for networking, providing support, sharing information and collaboration on joint initiatives for practice and service development. The Scottish Acute Palliative Care Nurse Specialist Forum (SAPCF) was developed.

It is well documented that hospital palliative care teams improve the psychological needs, symptom control and insight into the disease of cancer patients (1). Furthermore, it is well evidenced that clinical nurse specialists make a positive impact on patient outcomes and are a pivotal part of service delivery and design (2,3). The work of the SAPCF will continue to build upon what is already known about these teams and work collaboratively to provide a cohesive approach on recommendations for the future delivery of hospital palliative care services in Scotland, including education, research, audit, quality assurance and equity.

AIMS OF THE SAPCF

To promote a unified approach, providing equity of service and best practice approaches for specialist palliative care patients across all hospitals in Scotland irrespective of locality or diagnosis.

To provide a networking infrastructure for all hospital palliative care clinical nurse specialists to allow for peer support, discussion of new and innovative ways of working, dissemination of research and audit, and provide strategic direction for future palliative care services in Scotland.



OBJECTIVES TO FULFILL THE AIMS

The group will fulfil the aims by:

- Leading best practice approaches to the delivery of specialist palliative care in acute Scottish hospitals.
- Publicising and promoting the work of the SAPCF to external stakeholders.
- Establishing sub committees and other work groups as required to fulfill the work-plan of the group.
- Contribute, comment and provide recommendations on the future strategic direction of palliative care in Scotland.
- Partnership working and collaboration to provide peer support.
- Providing educational opportunities for staff working in the acute setting.
- Securing funding without favour or prejudice to support educational events such as study days.
- Acting as a source of information for staff working in the acute setting.
- Undertaking and dissemination of research and audit in palliative care practices across Scotland.

MEMBERSHIP

Any clinical nurse specialist working in a hospital based specialist palliative care team in Scotland will be eligible to join the group. The group is made up of a core management committee and a steering group comprising all the other members. There are currently 30 members with representation from 10 of the 14 health boards across Scotland.

WORKPLAN 2016-2017

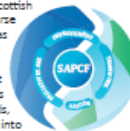
- Raising the profile of the SAPCF including website, poster presentation at conferences, meetings with external stakeholders including SPPC, Scottish Government and Macmillan Cancer Support.
- Development of national database (in line with minimum data set for palliative care).
- Review of current working practices, services offered, referral criteria and referral form, levels of intervention.

CONCLUSION

Although a relatively new forum it is an exciting time for the group, with a view to working in partnership generating ideas and projects with the vision of providing specialist palliative care services that is person centred, safe effective, efficient, equitable and timely to any palliative patient in any acute Scottish hospital. We look forward to contributing and influencing the development, delivery and evaluation of local and national strategies, policies and guidelines.

For any further information or questions about the group please contact:
Shona Dickson, Chairperson and Founder on
shonadickson@nhs.net

REFERENCES
1. Hughes J, and Evans C. 2012. What is the evidence that palliative care teams improve outcomes for cancer patients and their families? Cancer 123(1):423-430.
2. Smith J. 2013. Improving the experience and experience outcomes. Cancer Nursing Practice 22(1):1-4.
3. National Cancer Institute. 2011. Palliative Care: A Guide for Patients and Families. National Cancer Institute. Available from: <http://www.nationalcancer.org/pdq/palliativecare/Patient>. [Accessed 10/10/2015].



Getting to know one another: Mix and Map



Aims and Expectations for the Day



Aim

To improve palliative and end of life care in acute hospitals

Focus in Scotland:-

To improve shared decision-making (SDM) and information-sharing in the acute medical setting for people with deteriorating advanced disease and their families by:

- A structured approach to communication and information-sharing by hospital teams.
- Collaborative work with patients, families and support groups to develop patient information resources to support active participation in care planning conversations.

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Findings from Scoping and Baselineing

1. No systematic identification of people who may benefit from anticipatory care planning
2. Levels of staff expertise and confidence regarding discussing deteriorating health with patients and families vary greatly, but there is enthusiasm for learning and improvement by all ward staff, including experienced consultants.
3. ACP conversations with patients and families are typically conducted by senior staff, with only occasional involvement by junior doctors and nursing staff.
4. The role of nursing and auxiliary staff in SDM through their formal and informal contact with patients and families is largely overlooked.
5. Poor patient awareness and readiness to discuss their future treatment and care is a key barrier to effective SDM.
6. As a result of system pressures nurses are rarely able to join medical ward rounds, thus limiting their critical contribution to SDM processes.
7. Conversations and their outcomes are often poorly documented in notes.
8. Discharge letter templates do not encourage inclusion of ACP-related information or prompts for community-based care professionals, leading to such information being omitted.
9. Staff currently do not make good use of existing information resources, e.g. the Scottish national DNACPR leaflet.

What People Did

- Process changes
- Education activities
- Development and testing of conversation guides

One acute area's change actions

- Effective Communication for Healthcare (EC4H) training
- More structured Treatment Escalation Plan
- Improved learning opportunities for junior medical staff
 - e-Learning
 - Role play
 - Test communication guides
- Updating of ward information resources to include PEoLC issues
- Audit on people for whom AMU admission was not in their best interest
- Culture change – purposeful, deliberate attention to SDM

Good conversations about ACP & DNACPR

Dr Kirsty Boyd

Consultant in Palliative Medicine and EC4H Programme
Lead Tutor

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Good conversations about ACP & DNACPR

RED-MAP	
R eady	Can we talk about your health and care? What's changed?
E xpect	What do you know/ want to ask/ expect?
D iagnosis	We know.../ We don't know... Your questions/ worries?
M atters	What's important to you now and in future?
A ctions	What can help... Options we have are... This does not work... / will not help you because...
P lan	Let's plan ahead for when/ if....

Good conversations about ACP & DNACPR

NHS
SCOTLAND

Information for patients and families about treatment and care planning in hospital

what matters to you?

ask what matters • listen to what matters • do what matters

www.whatmattersyou.scot

EC4H **NHS**
SCOTLAND

Anticipatory Care Planning

*Identify the right people.
Find out what matters.
Talk about what we can do;
and things that will not help.
Plan care together.*

Scottish Partnership for Palliative Care

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SPICt **THE UNIVERSITY of EDINBURGH** **NHS**
SCOTLAND

Identify: people with deteriorating health

Unplanned hospital admissions

Performance status is poor or deteriorating: spends more than half the day in bed or chair.

Depends on others for most care needs due to physical and/or mental health problems.

Progressive **weight loss**; remains underweight; loss of muscle mass.

Symptoms; persist despite optimal treatments of underlying conditions.

Person (and family) focusing on **quality of life**, less interventions, palliative care.

www.spict.org.uk

Talking about Anticipatory Care Planning (RED-MAP) **NHS**
SCOTLAND

Ready Can we talk about your health and care? What's changed?

Expect What do you **know** / want to ask / **expect**?

Diagnosis We **know**... / we don't know... **Questions or worries?**

Matters What is **important** to you now and in future?

Actions What can help... **Options** we have are...

Plan This does not work... / will not help you because...
Let's plan ahead for when / if...

Anticipatory Care Planning (CPR-Talk) **NHS**
SCOTLAND

Do Talk about CPR or DNACPR as part of ACP.
Find out what people know and expect.

ACP Discuss what is happening & thinking ahead.

Check What matters to you now and in future?

Prepare What we can do is.../CPR does not work when...

Record Discussion and agreed plans for ACP & CPR

Evaluation

“Each hospital has come up with a different approach to improvement, and for us here that has fostered a sense of ownership related to the changes we’re making. That’s a really important approach to take.”

The nurses didn’t used to be involved in this, and as a result some information would be missed, or picked up wrongly by other members of the team. Now everyone is involved in the conversations, so everyone is working from the same page.

“We’re working at over 100% capacity just now, our winter beds crisis is still impacting on us. So in terms of getting other things done, without additional resources it’s really difficult.

“BotB has impacted on us as staff, because we talk about the concept of optimal care now, and we didn’t before.”

Key Learning 1

- Evidencing activity and impact is a big challenge
- Timescales are long
- Competing priorities (and crises)
- Many ward staff are very interested and engaged
- The programme has been a catalyst for change
- Evidence of positive impact for people and their families

Key Learning 2

- Channel more resources to ward level
- Extra resources needed to measure change and evidence impact.
- Value and measure cultural change as well as process and activity change.
- Availability of local resources should be conditional on clearly identified local leadership and plan
- Increase input and feedback from the public, patients and families.
- Sustain activity for a longer period

Building on the Best Phase 2

- Overarching aim:
 - To improve palliative and end of life care on hospital wards in Scotland and by doing so, improve the experiences and outcomes of patients and their families.
- 3 Workstreams to achieve this aim:
 - Establish a multidisciplinary network for leaders of care towards the end of life in hospitals.
 - Support and fund local QI projects.
 - Undertake a strand of public engagement activities in collaboration with Good Life, Good Death, Good Grief and other stakeholders.

Resources and references

- Building on the Best
<https://www.palliativecarescotland.org.uk/content/building-on-the-best/>
- Effective Communication for Healthcare
<http://www.ec4h.org.uk/>
- NES Realistic Medicine
<https://learn.nes.nhs.scot/18350/realistic-medicine>
- 4 videos for professionals about using the RED-MAP communication guide.
<https://www.spict.org.uk/other-resources/>
- Hospital doctors' experiences of caring for dying patients
https://www.rcpe.ac.uk/sites/default/files/jrcpe_48_4_gray.pdf

Short Stories Showcasing work undertaken from across Scotland

- Evelyn Paterson, NHS Forth Valley
- Marianne MacLeod, NHS Fife
- Paul Graham, NHS Lanarkshire

'Quick Wins'

- Anticipatory/End of Life Electronic Prescribing Protocol
- 'Whole team' collaborative approach to improving end of life care

PROTOCOL - Inpatient Treatment Protocol for ALBERT EINSTEIN (500000005)

Height 173 cm Weight 69.000 kg BSA 1.82 sq m Age 70 yrs

PHM JAC

ANTICIPATORY END OF LIFE CARE PROTOCOL

Drug Description: Route:

Dose & Description: is equivalent to Alternative Dose & Description:

Frequency: STAT: ☐ Administer Now: ☐

PRN: ☐ Notes:

Start Medication on: Time: Stop Medication after: Dev's: ☐ Dose(s):


Drug Description	Dose	Frequency	Start Date/Time	PRN	Stop After	Route	PRN Notes	PRN Notes	Usage
▲ MORPHINE SULPHATE 10 mg in 1 mL 2 mg			03-Jan-2020 11:08	<input checked="" type="checkbox"/>		Subcutaneous	Hourly max 6 dose For PAIN / B		
▲ MIDAZOLAM 10 mg in 2mL Injection 2 mg			03-Jan-2020 11:08	<input checked="" type="checkbox"/>		Subcutaneous	Hourly max 6 dose DREATHLES		
LEVOMEPROMAZINE 25 mg in 1 mL inject 2.5 mg			03-Jan-2020 11:08	<input checked="" type="checkbox"/>		Subcutaneous	8-12 hourly for N&V AGITATION		
HYOSCINE BUTYLBROMIDE 20 mg in 1 m 20 mg			03-Jan-2020 11:08	<input checked="" type="checkbox"/>		Subcutaneous	Hourly max 120mg for RESPIRA		

Ok Cancel Protocol Information Help

What Matters at End of Life


FVRH Palliative Care Nurse Specialists - Evelyn Paterson, Lesley Murclano, Helen Upfold and Morven Kelleff

NHS Forth Valley



COMMUNICATE

- Informative, timely and sensitive communication is an essential component of each individual person's care.
- Investing time to provide information, elicit and clarify expectations will improve care experience.
- Conversations about what to expect when someone is dying can improve understanding and expectations.




COLLABORATE & CO-ORDINATE

- Significant decisions about a person's care, including recognizing the possibility of dying are made through MDT discussion.
- Ensure appropriate and realistic decisions about care that will be individualized and goal focused.
- Recommend early discussion with patient and family


USING PRINCIPLES OF END OF LIFE CARE IN CLINICAL PRACTICE.

Ref: Caring for People in the Last Hours and Days of Life. National Statement. Scottish Government 2013.



CARE & COMFORT

- Recognize, anticipate and meet care needs - physical, psychological, social and spiritual.
- Think about actual and potential symptoms and plan ahead to ensure comfort is optimal.
- Consider referral to PCI, spiritual care team, AHPs to ensure individual care needs are addressed in a holistic and responsive way.



COMPASSION

- Relatives and carers need comfort and care too.
- Grief and loss result in many difficult emotions that will necessitate empathy and understanding.
- Spiritual care support may be valuable.
- Ensure general comfort including seating, overnight facilities, Quiet Time signs.
- Always check - "Is there anything else that would help?"
- Do they want to participate in care delivery?

October 2018

“The long game”: Innovation and cultural change

A Quantitative and Qualitative Evaluation of the ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) Process in Forth Valley
Stewart's ReSPECT pilot: A Case for Change
April 2019

ReSPECT Report: NHS Forth Valley, April 2019





Forth Valley Vision

DIGITAL SERVICE
NHS EDUCATION FOR SCOTLAND

Why Carer support in acute hospital?

- Carers (Scotland) Act 2016- came into force April 2018- duty on NHS boards to involve carers prior to discharge
- Patient / family=Unit of care
- By supporting the carer discharge has more chance of success
- Often the patient's main concern
- Carers do not always feel well supported -impacts on health and coping in bereavement
- Setting realistic expectations
- Healthcare savings.
- Recording interventions- direct contacts.

Do we assess carer support needs?

- Challenges of carer assessment in the acute setting
 - Where ? How? Who? What?
 - Is the carer aware they are being assessed?
 - Is it person centred? Is it relevant ?
 - Outcome- where do we document? Governance issues? What happens next?
 - **In Fife:** CSNAT www.csnat.org –Training to obtain licence
 - Use of sticker and hand held record
 - 3 month audit
- 49 assessments offered (8 not returned)
- Main concerns identified -Knowing what to expect in the future/knowning who to contact/Equipment required



Compassionate Inverclyde's Aim:

“ To create Scotland's first Compassionate Community.
A community where everyone recognises that we all
have a role to play in supporting each other in times of
crisis, end of life and loss.

Ordinary people helping ordinary people

No-one Dies Alone

- Project Board
- Pilot
 - 1 Acute Hospital
 - 2 Community Hospitals
- Recruit & Train Volunteers
- Brief Staff about NODA



Scottish Acute Palliative Care Network Pt 1

Exploring purpose, activities and potential areas of work

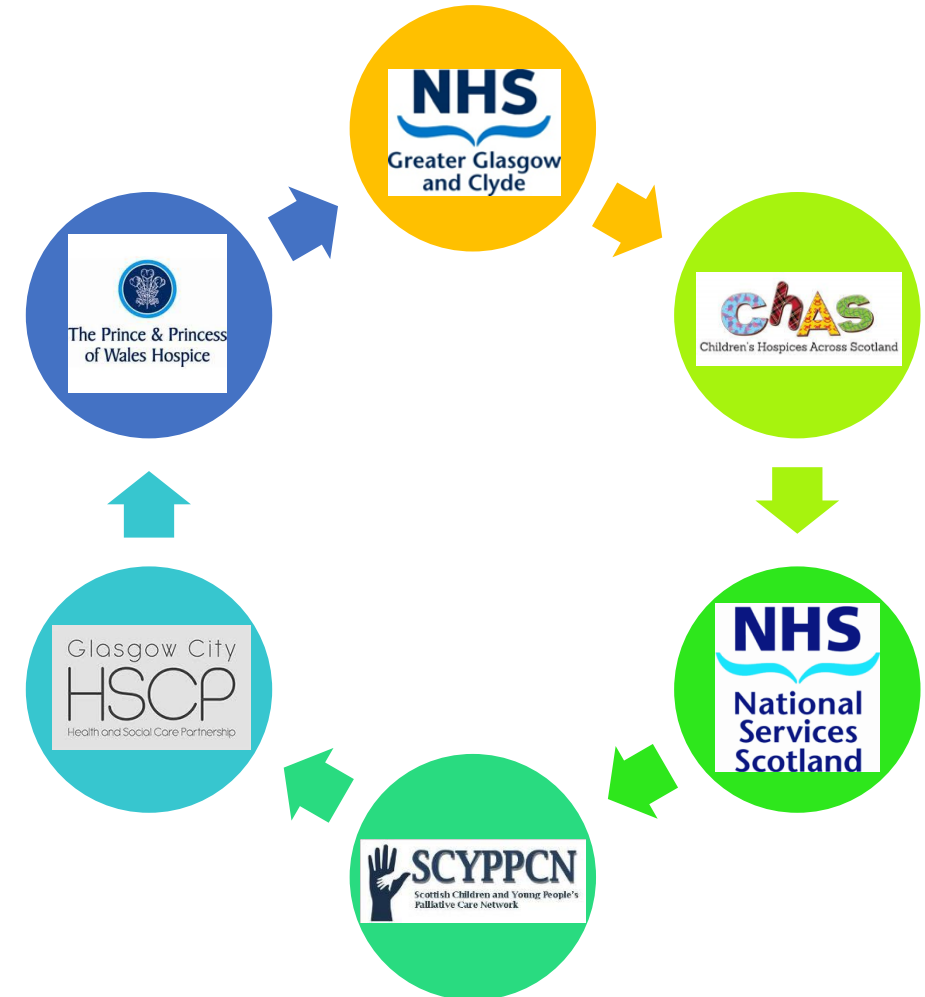
Group Discussion

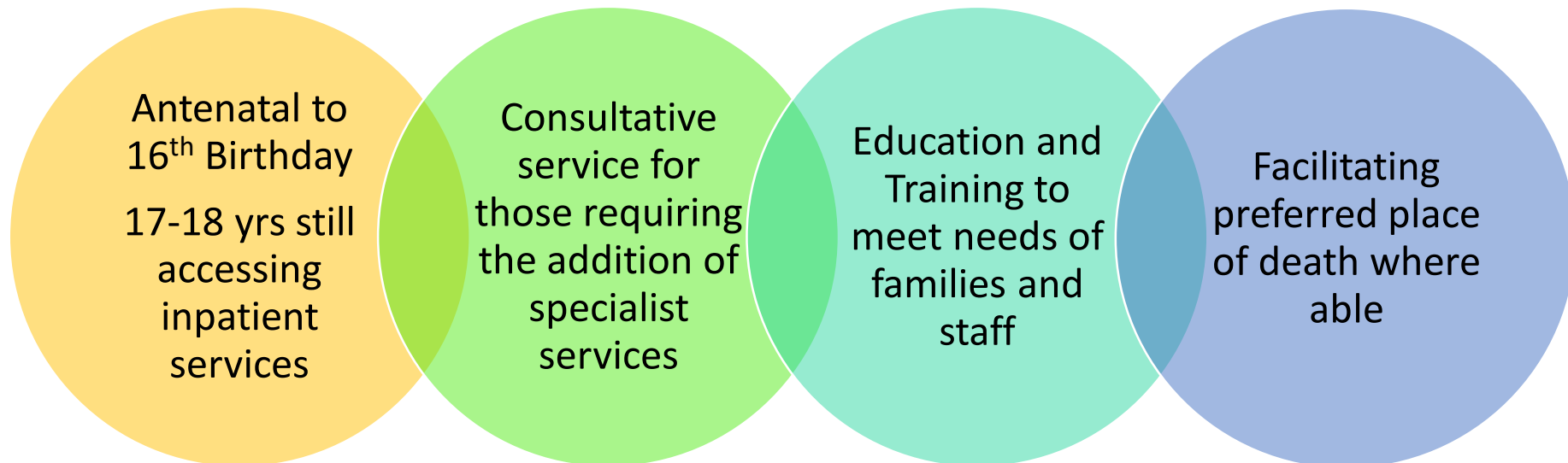
- What do you wish to gain from the SAPCN?
- What could you or your team contribute to the SAPCN ?
- What activities/work/collaboration should the SAPCN undertake?
- What should the top 3 initial priorities be for the SAPCN?

Short Stories Showcasing work undertaken from across Scotland 2

- Caroline Porter, Glasgow's Children's Hospital & CHAS
- Jennifer Gray, NHS Tayside
- Claire O'Neill, NHS GG&C

Glasgow Children's Hospital - Paediatric Supportive and Palliative Care Team





My Role as an Acute Palliative Care Pharmacist

Jennifer Gray

Specialist Clinical Pharmacist for Neurosurgery,
Palliative Care and Pain Services

Ninewells Hospital

Dundee

Current Role

- Conduct patient symptom assessment and drug therapy management
- Provision of medication counselling to patients, caregivers, and families
- Discharge Planning/Liaising with primary care
- Medicine Information
- Supply Issues Management
- Attendance at weekly MDT meetings
- Intrathecal Medication
- Qutenza Treatment
- Education and Training

Ambitions for the Future

- Pharmacist led Symptom Control Clinic for outpatients
- Improve medication prescribing process for inpatients



Inspiring Leadership

Leading self, leading with others in a
palliative care setting.



Inspiring Leadership



- 2016 Facilitators identified the challenges Clinical Nurse Specialists raised often similar.
- Jan 2017 Inspiring Leadership 1st Cohort 10 band 6 CNSs
- Jan 2019 2nd cohort band 7 11 CNSs and AHPs now WoS
- Feb 2020 3rd cohort starts band 6 CNSs, AHPs WoS and now open to Pall Med STs.
-2021 Scotland wide cohort....advertise through this network....

Inspiring Leadership



Programme design

- Focus Groups identified key themes of programme, this was linked with **leadership behaviours** set out in the NHS Scotland Leadership Qualities Framework
- 360, Myers Briggs encourage linking to PDP
- Master classes – QI, influencing skills.
- Action learning sets
- Quality Improvement project- embed QI methodology into roles
- Q and A with a leadership panel – raising strategic awareness
- Burdett grant has funded 1st 2 cohorts and evaluation.

National Context

- Richard Mead (Marie Curie)
- Pam Levack (PATCH)

Building
on the best

PATCH

Palliation And The Caring Hospital

OSCR
Scottish Charity Regulator
www.oscr.org.uk

Registered
SCIO
SC044231

Pam Levack Medical Director



Palliation
And
The
Caring
Hospital

Dedicated to supporting
specialist palliative care
for patients & families in
Scottish hospitals.



PATCH

BUSY IN THE BORDERS!

**We work closely with
the Margaret Kerr Unit,
Macmillan and Marie Curie**

So far we have:

**Funded palliative care courses
for 24 nurses across the
Scottish Borders.**





1st PATCH Nurse in Scotland



Scottish Acute Palliative Care Network Pt 2

Group Discussion



Building
on the best

Network Practicalities

Co-chairs:

Deans Buchanan, Palliative Care Consultant, NHS Tayside

Marianne MacLeod, Specialist Occupational Therapist, NHS Fife

Claire O'Neill, Macmillan Lead Nurse and Clinical Service
Manager for Palliative Care, NHS GG&C

Next Steps



Launch of Quality Improvement Project Fund

- All projects should be focused on an area of improvement of palliative care.
- Any acute clinical area can apply
- Projects to last between 6-12months
- 2 sizes of grants:
 - Up to £1,000
 - Up to £10,000

<https://www.palliativecarescotland.org.uk/content/bobscot-grants/>



Photo by [Annie Spratt](#) on [Unsplash](#)