

**PALLIATIVE END OF LIFE CARE-NATIONAL IMPLEMENTATION ADVISORY GROUP
(NIAG)
SCOTTISH GOVERNMENT HEALTH AND SOCIAL CARE INTEGRATION
DIRECTORATE
MINUTE OF MEETING**

Date: 16 August 2017
Time: 14:00 – 17:00 pm
Venue: St Andrews House, Edinburgh

Attendees

- Alison Taylor, SG – Interim Chair
- Jackie Alexander, NES
- Mark Hazelwood, SPPC
- Katherine Ross, Scottish Care
- Maria McGill, CHAS
- Pat Carragher, CHAS
- Scott Murray, St Columba's Hospice
- David Clark, University of Glasgow
- Susan Lowes, Marie Curie
- Michelle Church, HIS
- Paul Leak, Scottish Government
- Tim Warren, Scottish Government
- Jane Johnstone, Scottish Government
- Lesley Whyte, NES
- Janice Turner, NES
- Clare Tucker, NES
- Phillip Gillespie, SSSC
- Helen Stevens, Scottish Government
- Ron Culley, Western Isles NHS, (VC)
- Bridget Johnstone, Glasgow University
- Jackie Stone, St Columba's Hospice
- Jackie Alexander, NES
- Sandra Campbell, NHS Forth Valley
- Paul Baughan, HIS
- Ag Iyayi-Igbinovia, ISD
- Jenny Armstrong, ISD
- Heather Edwards, Care Inspectorate
- Donald Macaskill, Scottish Care
- Amy Dalrymple, Alzheimer Scotland
- Charles Watherston, Scottish Government – minutes

Apologies

- Geoff Huggins, Scottish Government
- Blythe Robertson, Scottish Government
- June Wylie, HIS
- Jeremy Keen, Highland Hospice
- John Nugent, Scottish Government
- Christina Naismith, Scottish Government
- Richard Meade, Marie Curie
- Marjorie Marshall, Scottish Government
- Sally Shaw, Care Inspectorate
- Thomas Monaghan, HIS

1. WELCOME AND APOLOGIES

1. Alison Taylor welcomed everyone to the meeting. She noted Geoff Huggins' apologies and that she would be chairing the meeting in his stead.

2. MINUTES OF PREVIOUS MEETING, MATTERS ARISING

- **Matters arising**

2. There were no matters arising or issues raised with the previous minutes. It was noted that actions from the previous meeting of the group had either been completed or would be discussed under the relevant agenda item.

3. BEREAVEMENT PRESENTATION

3. Dr Janice Turner (Principal Educator: Medical Education) and Dr Clare Tucker (Project Lead Grief and Bereavement) of NES provided a presentation on NES' bereavement work to the group.
4. Clare Turner explained that the bereavement work was a key component of the Scottish Patient Safety Programme and a variety of resources had been produced to support the training of medical professionals in bereavement. It was noted that this was important from not only a person centred perspective but also a resilience perspective.
5. It was noted that there were also videos that had been produced as part of this work and that a link to these would be circulated to the group. (<http://www.sad.scot.nhs.uk/video-wall/>)
6. The group welcomed this work and there was a short discussion where members asked what the next steps were. Pat Carragher reported that work was underway to build bereavement work into the undergraduate curriculum and that this would be very helpful.
7. Janice Turner noted that although this work was aimed at medics, work still had to be done to reach social care staff. The group agreed that this was something that merited further thought. Alison Taylor noted that since linking the palliative care and bereavement work in Scottish Government, this workstream had become more prominent and joined to other SG work. She noted that the palliative care team would share the resources with other policy colleagues to reflect on how this work can be built on when developing related policy.

4. INTEGRATION DATA

8. Alison Taylor noted that Paul Leak would be presenting on this item.
9. Alison Taylor reported that following the integration of health and social care a Ministerial Steering Group had been brought together consisting of Ministers, COSLA and other interested stakeholders to discuss matters relating to integration. Alison noted that data was a focus of the group and that there was a working group dedicated to this.
10. Paul provided a short presentation to the group on the data that was being developed for the Ministerial Steering Group. He noted that the purpose of this data was to get a sense

of how the integration of health and social care services in the broader sense was progressing rather than looking at the detail of each data point specifically. This was particularly important given the complexity of the data.

11. There was a discussion on the use and limitations of the data. It was asked whether the purpose of the data was to help monitor performance, however Alison Taylor noted that it is up to Health and Social Care Partnerships to make changes based on the needs of their local population. As such this data would be used to help inform Partnerships when making planning decisions rather than as a performance monitoring tool. Tim Warren agreed and noted the importance of this data in supporting Partnerships in the commissioning of services.
12. David Clark noted the critical role of data in understanding progress and asked if there were any underlying assumptions attached to the data. Alison clarified that no assumptions had been made as at this early stage that may result in unhelpful judgements.
13. Scott Murray welcomed this and asked whether there was scope to investigate whether an analysis could be done focussing on the use of Key Information Summaries (KIS) to get a sense of progress in this area. Paul agreed to explore this further with the data group.

Action: Data group to consider how best to measure uptake of KIS.

14. Alison Taylor suggested that it may be helpful at a future meeting to have a HSCP Chief Officer present a session on how the practical uses of this data. The group agreed that this would be helpful.

Action: HSCP Chief Officer to be invited to a future meeting to discuss the use of HSCP data.

5. NIAG WORKPLAN (NIAG 17-09 & 17-10)

15. Helen Stevens reported that there had been some changes to the workplan including:
 - New RAG column added to show progress.
 - Age reference column added.
 - Including a 'last updated/next update' marker on the document.
 - New issues in the issues and risks log.
16. It was noted that good progress had been made on the majority of the commitments in the SFA but that it would be helpful to consider how to link data to this.
17. David Clark suggested that it might be helpful to consider how we measure progress towards the overarching aim of the SFA rather than solely the commitments themselves. The group agreed with this and a variety of information types and sources were suggested as being helpful.
18. Paul Leak agreed to consider the data suggested with the data group to identify any opportunities to demonstrate progress towards the overall aim.

Action: Paul Leak and data group to consider how best to demonstrate progress toward overarching aim.

- **Palliative and End of Life Care Funding**

19. Helen Stevens tabled a paper on the palliative and end of life care funding. This split the 2016/2017 financial year allocations into the various commitments in the SFA. It was noted that some commitments may show a higher or lower spend than expected as to avoid double counting work covering multiple commitments had been recorded under the most relevant commitment.
20. The group welcomed this paper and suggested a similar one be produced for the next financial year.

6. SFA COMMITMENTS – FOR DISCUSSION

- **Commitment 3 – Educational Framework**

21. Lesley Whyte reported that the framework had now been published and work had begun to embed this across health and social care. Donald Henderson noted that there were particular challenges when it came to supporting those who work in care homes but that it was essential these people had the support that they needed to develop. Lesley agreed and noted that her and colleagues would be mindful of this when taking forward this work.

- **Commitment 6 – Public Discussion**

22. Mark Hazelwood reported that a person had recently been appointed to post to help take this work forward. He noted that as was discussed at the previous NIAG, the first action was to upscale and spread existing work and explore opportunities for new work. Mark also reported that subgroups were being formed to help with this work.
23. The group welcomed this work and there was a short conversation about how best to establish if the work is meeting the aim of the commitment. Mark reported that a report was being worked on which would provide a helpful view on activity to date and some suggestions for next steps. He noted that this was likely to be ready in the new year and that it would be presented at the Spring 2018 meeting of the NIAG.

- **Commitment 1 – Identification and Coordination Improvement**

24. Michelle Church provided a short update noting that following the last meeting a sixth test site was now agreed (Dundee City) and that HIS were in talks with the HSCP to establish which local projects should be taken forward. She also noted that each of the test sites were at different stages and as such required different types of support.
25. The group welcomed this progress and asked when reporting on this work would begin. Michelle advised that as this work was still at the 'setup' phase for most HSCPs, it would likely be a few years until it would be reasonable to gather learning. However, it was noted that an early analysis was available from Glasgow which had proved helpful, and HIS were looking to support early analysis across sites when possible to help share learning at an early stage.

26. Alison Taylor suggested that when some messages became available it would be helpful to speak to Ron Culley and understand how HSCPs would best receive learning.

7. SFA COMMITMENTS – FOR INFORMATION

- **Commitment 2 – Strategic Commissioning**

27. Tim Warren reported that the SLWG had completed a draft advice note and that this was now being considered by Ron Culley to provide a HSCP Chief Officer perspective. The group welcomed this work and asked when a final draft would be ready and when would the note be published.
28. Tim advised that further work would be done over the coming months with a view to having a discussion on a final draft at the next NIAG. Following this, the note would be published before the end of the year.

- **Commitment 4 – Support for Children and Young People**

29. Maria McGill and Pat Carragher provided a short update on their work. Maria noted that CHAS were working on an update to the CHiSP study which would be helpful in understanding more about the palliative care needs of children and young people across Scotland and inform future service development. Additionally Napier University had been commissioned to do a piece of work to look at nursing education needs with a view to drafting an educational framework within the next year.
30. Maria also reported that there had been a large increase in referrals to CHAS (c~30%) and she estimated that CHAS was now seeing around 70% of under 5's with palliative care needs.
31. Pat reported that work was being taken forward to establish a 'network' that would support professionals working with children and young people with palliative care needs and drive up the standard of care.
32. He also reported that advice on CYPADM was almost ready and that consideration was being given to developing a neo-natal ACP.

8. ANY OTHER BUSINESS

33. No other business was noted and members were thanked for their time.

NEXT MEETING

34. Date of next meeting will be 13 December 2017 14:00 to 17:00, St Andrews House
[Secretariat note – The venue for this meeting has changed to Victoria Quay due to room issues at St Andrews House.]