**Palliative Care Practice Development Steering Group**



**Minutes of Meeting held on**

**Tuesday 28th August 2018**

**10.00 am – 12.00 pm**

**Room WS201 Beatson WOS Cancer Centre**

Present: Shirley Byron (SB) (Co-Chair), Patricia O’Gorman (PO’G) (Co-Chair), Kirsteen Cameron (KC), Paul Corrigan (PC), Frances Downer (FD), Susanne Gray (SG), Elayne Harris (EH), Susan Jackson (SJ), Bridget Johnston (BJ), Claire O’Neill (CO’N), Nicola O’Neill (NO’N), Anne-Marie Simpson (AMS), Elaine Stephens (ES), Anne Todd (AT)

Apologies: Margaret Connolly, Margaret Fitzpatrick, Les McQueen, Jennifer Pennycook, Graham Whyte

In Attendance: Emma Bradbury

Minutes:

|  |  |
| --- | --- |
| **1.** | **Welcome and Introductions**  SB welcomed everyone to the meeting and introductions were made around the table. |
| **2.** | **Apologies:** Apologies listed above had been received. |
| **3.** | **Minutes of Previous Meeting**  The action points from the minutes of the previous meeting held on Wednesday 22nd November 2017 were reviewed. |
| **4.** | **Action Points from Previous Meeting**   * **Incorporating the issue of Emergency Marriage for people at end of life into the MTA&MP booklet:** SB is in contact with Russell Jones and this is being looked into. * **Palliative Care Online Information:** SB stated that PC will cover this in more detail under Agenda point 8. * **Glasgow and Clyde Palliative Care Network Group (GCPCNG):** Again, SB stated that this will be covered under Agenda point 11. * **National ACP:** To be discussed under Agenda point 6. * **Verification of Death:** To be discussed under A.O.C.B |

|  |  |
| --- | --- |
| **5.** | **Future Direction of PCPDSG** (All)  SB explained that since the demise of the MCN, there is currently no real reporting structure for the PCPDSG. SB informed the table that group members had been emailed by the co-chairs requesting feedback on whether the PCPDSG should continue in its present format or for the group to be disbanded. Feedback received by email was very positive about the continuance of the PCPDSG and the general consensus of those in attendance at the meeting today was that it is an important and helpful group.  CO’N expressed that she feels the PCPDSG is important as the group is inclusive and well represented by all areas and that it is a way for relevant information to be fed back to the different care settings. CO’N also emphasised about the importance of the PCPDSG agendas being relevant to each area represented.  SJ expressed the view that from a hospice point of view the group is very helpful, as it encourages communication between different areas.  BJ believed that it’s important to know what’s happening across the different areas and expressed the view that the group provides good access to information.  PC mentioned that the group is helpful from a website point of view, to get advice/feedback on what to put on the website.  SG mentioned that for those who work in small teams it is a very helpful way to have contact/communication with peers.  CO’N suggested contacting the Directors of Nurses to see if they can suggest who the group should report to. Bridget then discussed the NMAP Nursing, Midwifery, Allied Professionals (NMAP) group which she attends and offered to raise this at the next meeting as a possible reporting structure for the PCPDSG. SB stated that this would be very helpful as it is important for the group to have measurable outcomes to demonstrate what it’s achieving.  ***ACTION:*** *SB and PO’G are to review the Terms of Reference and feed back at the next meeting.*  SB reminded those present to think about relevant Agenda topics to discuss at PCPDSG meetings and to let her/PO’G know in advance, so that these can be added to future agendas.  BJ to discuss PCPDSG reporting back to NMAP group. |
| **6.** | **National ACP** (Shirley Byron/Patricia O’Gorman)  SB explained that health care staff are being encouraged to use the National ACP document within the HSCPs in Primary Care, but that this is variable. Social care are also encouraging the use of this document in Care Homes and it has been introduced by Carers as part of a test of change using SPAR in Riverside Social Care home when residents show signs of declining health. Care home staff are being asked by their managers to initially fill in the last 5 pages of the document (My Summary) and then gradually complete the rest of the booklet when opportunities to discuss future wishes around care arise with residents and their families.  KC informed the table that there are still some ACP documents in stock, but once they run out it will be possible to get a link to request more. This will be an electronic file where it will be possible to add a logo and then be required to print it out (as these would not be colour printed or bound into booklets, it’s not ideal).  CO’N and SJ said they rarely see patients/residents with an ACP in place. CO’N acknowledged that there are important conversations taking place quite often, but these are not getting recorded onto an ACP. It was agreed that the ACP National document was not well publicised in June last year.  AMS mentioned that use of the ACP document in care homes was very varied.  KC brought up the Respect form (a copy was passed around the table) and mentioned that this is a resource that is often overlooked/dismissed, but feels that it’s very useful as a visual information tool. KC acknowledged that it is the sharing of electronic files that appears to be challenging.  SB stated that the Respect document is very useful in the Red Bag (a social care initiative for patients awaiting discharge which consists of a bag containing items such as a change of clothing, continence supplies, medication, information about DNACPR, etc.)  CO’N informed the table that the Respect form is being piloted in the Forth Valley.  EH mentioned that the Resus Council have a person whose role now is to focus just on RESPECT and that this document may eventually replace DNACPR. |
| **7.** | **DNACPR Update** (Shirley Byron)  It was confirmed that the person who was the Resuscitation Lead has now left, PC is waiting to hear back who is now taking this role on.  ***ACTION:*** *PC to feed back to the group once he has been told.*  The Resus website does not have the updated National guidelines and currently nothing on StaffNet.  CO’N informed the group that following the 2016 Review the Guidelines for GGC were developed, but these do not appear to have been cascaded down.  ***ACTION:*** *SB to contact Craig Masson to find out about this (following feedback from PC – action point above).* |
| **8.** | **Palliative Care Online Information update** (Paul Corrigan)  PC projected the draft webpage to show the group the hospice information. PC is planning to send out an email to the 6 hospices to find out if they are happy with the hospice information contained on the website.  SJ stated she will let the hospice education staff know and feed back.  ***ACTION****: SJ to feed back responses of hospices to PC*  PC informed the table that there will be further updates and that it’s not possible to put all the hospice training on the website’s Education Calendar as there isn’t enough space.  SB mentioned that the Agenda and Minutes of the PCPDSG are put on the website after they have been approved. SB asked the table to let PC know if there is any other information that they feel should be added to the website. |
| **9.** | **Bereavement update** (Bridget Johnston/Anne Todd)  BJ detailed the function of the Bereavement group. They meet quarterly and are trying to represent all groups. Every NHS board in Scotland has a contract with CRUSE. From statistics they have it doesn’t appear that they receive many referrals from Acute. There are also bereavement services at the Beatson (however funding is an issue) and at the Royal Hospital for Sick Children. BJ explained that the biggest bereavement complaint was that loved ones’ possessions were returned to the family in a carrier bag with a label. In response to this the Hessian Bag was implemented for acute patients. This bag increases the dignity shown towards the bereaved and has had very good feedback. It has been agreed at board level that it will be taken on board in future budgeting.  BJ also stressed that Bereavement Support is not just about caring for relatives who are bereaved but also for supporting staff who have had a difficult bereavement either personally or professionally.  ***ACTION****: BJ to send PC what she has for CRUSE to put on the website*  AT gave an update on the new Bereavement service which has recently been established, consisting of herself as manager and 2 other staff members who are based at GRI. It has been funded by Macmillan for 3 years. It has been designed using the guidance from The Shaping Bereavement Care. There was bereavement support previously, but there was no coordinated structure. This new team is trying to address that. She is happy to share what they have produced thus far (copies of 3 documents for each attendee). AT stressed that it is very much early days and she would welcome any input on the handouts.  From the service commencing in July 2018 there has been 130 referrals which also include staff referrals. There have also been some complex referrals that Anne has had to deal with for e.g. organ donation, repatriation and funeral poverty.  Anne stated that the team are monitoring Financial Inclusion support requests and are trying to get patients referred to the service at the start of their journey to ensure patients and families get access to all the benefits they are entitled to as early as possible. They have also completed an Engagement action plan document, which has been very well received so far.  PO’G queried about the Death Certificate, AT explained that the staff seem to want to continue to give that out in the wards. It was suggested that there exists some need for extra training and support to ensure that it is being done properly.  AT also mentioned that they have designed a flowchart showing the process to follow regarding MCCD and a cultural/religious procedures quick reference tool that has proved very useful for ward staff and is happy to share it with the group.  ***ACTION:*** *AT to email copy of this flowchart to the group.*  CO’N brought up the issue of funeral poverty and informed the table that the Scottish Government has launched a consultation on draft guidance on funeral costs. The consultation will close on 8th November, see link below:  <https://consult.gov.scot/social-security/statutory-guidance-on-funeral-costs> |
| **10.** | **Hospice update** (Susan Jackson)  The role previously held by Jane Miller is now held by Liz Smith. The 6 hospices are not currently having regular meetings but they are trying to implement that now and have a more structured approach.  SJ stated that the plan is that in future one person representing the 6 hospices will attend the PCPDSG meetings. |
| **11.** | **Glasgow and Clyde Palliative Care Network Group** (All)  CO’N updated the table regarding this network group. They have had 2 meetings to date. The main focus is the communication web, it should allow the transfer of information for those involved in Palliative Care. There is representation from a wide area, however there is no reporting structure. They are due to meet on 29th August 2018. The decision will hopefully be made if it should just be made into a virtual group.  PC brought up the webpage of Glasgow and Clyde Palliative Care Network group to show the list of contacts, link below:  <http://www.palliativecareggc.org.uk/?page_id=3650> |
| **12.** | **A.O.C.B.**   * VoED   BJ brought up that it appears there will be changes in the future with regard to VoED – that it will be replaced by Confirmation of Death. Others present mentioned how they had been directed to continue using VoED until officially told otherwise.  There have been no new guidelines on this distributed as yet, likely because this still needs to be agreed at senior level.  ***ACTION****: This should be added onto the next Agenda to see what updates there have been.*   * Enhanced Palliative Care Course for Generalists   CO’N informed the table that this course is still in the early stages, however it has a tight turnaround, it is hoped that there will be a draft manual next spring. It is Neil Pryde, Lead Cancer GP in Fife, who is setting it up. Macmillan has provided some money to set it up and it will consist of a manual and 2 education training days. It is targeted towards GPs, hospital doctors, nurses, AHPs, etc. The course won’t be free, the costings are still under discussion but it will hopefully be kept as low as possible. The manuals will be costly to produce. This course will be aligned with NES Education Framework. There will hopefully be further details on this course in the near future. |
| **13.** | **Date of Next Meeting**  The next meeting will be held on Wednesday 21st November 2018 at 10.00 am - 12.00 pm in room WS201 in The Beatson West of Scotland Cancer Centre. |