

Response ID ANON-DUR2-4Y8W-S

Submitted to Palliative Care Matters for All: strategy consultation
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Section A: Overall strategy

Question 1a Do you agree with the aims for this strategy?

Agree

Please add any comments you have about the strategy aims here.:

The Royal Pharmaceutical Society (RPS) agrees with the strategy aims and our previous and ongoing work aligns with these. For example, Royal Pharmaceutical Society (RPS) and the UK's leading end of life charity Marie Curie hold a partnership which developed and implemented quality improvement standards in end of life care for community pharmacy. This work aligns with the established Royal College of GPs and Marie Curie 'Daffodil Standards for advanced serious illness and end of life care' for GP Practices. The Standards are available for pharmacy teams across the whole of the UK, including Scotland, and provide a free, evidence-based framework to help community pharmacies self-assess and continuously improve their end of life and bereavement care for patients and carers. The RPS supports the phrasing of the aims where the value of other elements of life are given equal weighting to the health elements and therefore prevents the overmedicalisation of care around dying and emphasises the importance of holistic care. Furthermore, we support the aim of equitable access to care and we suggest that this be reflected in each of the outcomes as Scotland has much to do to reduce the variation across the geography of the country.

Question 2a Do you agree with the strategy cornerstones, which form the basis for the strategy and delivery plans?

Agree

Question 2b: Please add any comments you have about the four strategy cornerstones here.:

None

Section B: Strategy outcomes

Question 3a Do you agree with strategy outcome 1 and the proposed actions being developed to deliver this outcome?

Agree

Question 3b: Please add any comments you have about outcome 1 and its actions here.:

Information resources about palliative care are important, for patients, carers and members of the public. These messages may be different and will also require to be published in a format that meets a number of different needs. Pharmacists in any setting – whether that is in community, GP practice or hospital – are a trusted source of credible information for members of the public, and also other healthcare professionals – whether that is general information or more specific palliative care advice on medicines. Community pharmacies can be part of the range of locations where patients can get information including leaflets and other materials.

One aspect discussed later in the strategy is information about Just in Case Medicines. When undertaking our stakeholder engagement for this consultation, a member shared an example of an interaction where a family member asked the question "Just in case what exactly?". We thought this question summed up the gap in understanding which may exist and pharmacists can support understanding through interactions with patients and carers. They may require education to be confident and comfortable to do so and we will discuss this under the relevant outcomes.

In relation to medicines, we have identified that patients and their carers require support to navigate the pathways, including information about access to medicines. At present this can vary across primary and secondary care, including outreach and hospice at home services or in the out of hours period when access to urgent medicines may be required, despite anticipatory prescribing.

Question 4a Do you agree with strategy outcome 2 and the proposed actions being developed to deliver this outcome?

Agree

Question 4b: Please add any comments you have about outcome 2 and its actions here.:

Our member feedback suggested that the wording of Outcome 2 described an action rather than an outcome and that this should be rephrased. With reference to the Managed Care Networks, it must be clear how these will align with established Managed Clinical/Care Networks. These networks must have pharmacy input to ensure leadership in the management of medicines pathways across all sectors for service planning and therefore help address the variation across Scotland.

Question 5a Do you agree with strategy outcome 3 and the proposed actions being developed to deliver this outcome?

Agree

Question 5b: Please add any comments you have about outcome 3 and its actions here.:

The RPS agrees with the approach to data driven care and therefore the need for a minimum data set for palliative care. We suggest that a Once for Scotland approach is taken with respect to data collection and ensure that one single template is used for both NHS, third sector and independent sectors to input. This will allow comparisons and benchmarking for improvement as well as generate the evidence base for interventions and service models. Qualitative data on patient and carer experience will also be important.

Question 6a Do you agree with strategy outcome 4 and the proposed actions being developed to deliver this outcome?

Agree

Question 6b: Please add any comments you have about outcome 4 and its actions here.:

Earlier identification of a palliative care need is important and informed healthcare professionals across all settings in the more generalist environment is required. Pharmacists undertaking medication review in community, primary care or secondary care settings may be the first healthcare professional to identify the palliative care need and will require support through training and materials to support those early conversations and where necessary, signpost or refer to further support. Patients and carers may find it difficult to have a palliative care need identified and healthcare professionals will require the skills to handle these sensitive conversations with compassion.

The Forth Valley poster is a useful example of the value of illustration to share information and educate staff. This particular example could be adapted to be relevant across Scotland and we would value the opportunity to offer specific feedback on its content in relation to the language surrounding medicines, prescribing, supply and administration.

In order to ensure patients can access general and specialist palliative care services, the roles and responsibilities of each profession in each sector must be clearly articulated. This is particularly important when considering medicines pathways and having clear expectations about the prescribing, dispensing and supply of medicines in all settings and in the out of hours period. Enablers to appropriate access, including medicines and pharmaceutical care, is a digital health record that professionals working across all sectors (including community pharmacists) can read and write to.

Access to palliative care includes access to medicines, both in and out of hours. There is variation across Health Boards with regard to locally negotiated Community Pharmacy Palliative Care Networks. These are not mentioned within the strategy and provide an important infrastructure to support timely access to care in communities, for the growing population of palliative care patients who choose to die at home, in their care home or hospice setting. Community pharmacies opt in to the palliative care network and agree to stock a core list of medicines and provide information for patients and local healthcare professionals during working hours. A further option is for pharmacies to opt in to an out of hours supply arrangement. The existence of these networks should be included in the strategy with a commitment to exploring a national approach to the provision of these community pharmacy services. NHS Inform allows patients and the public to identify pharmacies that are part of the palliative care network through their Service Directory and it would be beneficial to reference this in the strategy.

Question 7a Do you agree with strategy outcome 5 and the proposed actions being developed to deliver this outcome?

Agree

Question 7b: Please add any comments you have about outcome 5 and its actions here.:

We strongly support the use of a digital platform for the sharing of appropriate, timely, accurate patient records which ensures optimal care for patients. We are pleased to see a commitment that the national electronic urgent and emergency care plan for health and social care will be accessible to all staff in health and extending to social care, care homes and independent hospices. Community pharmacies must be included in the first phase of this work. Some professional groups (including pharmacists) may need additional training and support around accessing records, how to find the information and how to use information effectively and appropriately in the delivery of care.

We are concerned that current Scottish Government commitments to the digital integrated health and social care record and to the digital prescribing and dispensing pathway have not yet been delivered and have been delayed. This suggests that aspirations within this strategy for a national electronic urgent and emergency care plan for health and social care may face barriers. From our work in exploring community pharmacist access to the Emergency Care Summary, we know that there is variation across Scotland in access to the Emergency Care Summary. In some health board areas, community pharmacists have access to Clinical Portal and additional information such as the Key Information Summary. Innovations may need to augment and spread current initiatives e.g. clinical portal access to prevent delays in implementation.

Question 8a Do you agree with strategy outcome 6 and the proposed actions being developed to deliver this outcome?

Agree

Question 8b: Please add any comments you have about outcome 6 and its actions here.:

The RPS is in agreement that collaboration across the health and social care landscape is required to improve the experience of patients and their families in timely, equitable access to medicines. As described in other answers, we agree that patients and their families need more information about the medicines used to manage symptoms when patients approach the end of their life. We received feedback on the terminology used, comparing "Anticipatory Care Medicines" with "Just in Case medicines". One example is that the latter phrase provokes the question – just in case what exactly? Whereas the former, suggests a more planned approach to that of a reactive response to developing symptoms.

One theme was clear from our member engagement, that healthcare professionals, including pharmacists and members of the pharmacy team, need to have the skills to handle these conversations with patients and families with the necessary detail and specifics, avoiding vague language that can be open to interpretation. Being able to inform patients and their families about the medicines, the symptoms they are prescribed for, how and when they are administered, how they are monitored for effectiveness and what the potential side effects might be. We received feedback from members that support for carers to administer subcutaneous medicines, where appropriate, was missing from the strategy.

The role of pharmacists goes beyond the supply of the medicine. Pharmacists can be seen as leaders in the conversations with patients, families and with healthcare professionals. Pharmacists in any setting, as part of their delivery of pharmaceutical care to patients, may be the first professional that identifies a palliative care need for a patient. As part of the multidisciplinary team – whether that is in general practice or in specialist settings, pharmacists play a role in supporting other healthcare professionals in their palliative practice with a particular focus on the safe and effective use of

medicines.

The Royal Pharmaceutical Society (RPS) has developed a comprehensive approach to assessment and credentialing for advancing pharmacist roles through its Post-registration, Core Advanced and Consultant Curricula. These curricula are designed to ensure pharmacists have the necessary capabilities to practice at each level of their career and assures the public and other professionals of the pharmacist's level of practice. There is already an established network of specialist palliative care pharmacists who have formed the Scottish Palliative Care Pharmacist Association. We believe it is of paramount importance that advanced and consultant level palliative care specialist pharmacists, who are wholly or partly hospice based, continue to be developed and these roles deployed across Scotland. These advanced pharmacists would utilise their skills to benefit wider availability of quality medicines advice and care across pharmacy settings, the health and social care workforce and patients; and deliver effective leadership on the safe and effective use of medicines in palliative care and care around dying for the benefit of the wider health and care system.

Question 9a Do you agree with strategy outcome 7 and the proposed actions being developed to deliver this outcome?

Agree

Question 9b: Please add any comments you have about outcome 7 and its actions here.:

In 2020, NHS Forth Valley in partnership with Children's Hospices Across Scotland, set up a Community Pharmacy Paediatric Palliative Care network; extending the already established community pharmacy palliative care network to hold medicines for use in the paediatric population. It would be of benefit if the strategy acknowledged the palliative care community pharmacy networks in Scotland and establish whether there is a need for a national paediatric network.

Question 10a Do you agree with strategy outcome 8 and the proposed actions being developed to deliver this outcome?

Agree

Question 10b: Please add any comments you have about outcome 8 and its actions here.:

Feedback from our members suggested that this outcome could be rephrased as it reads as an action rather than an outcome at present.

To ensure that healthcare professionals have access to the appropriate level of training for their practice, palliative care education needs to be integrated across all stages of practice. We recognise that professionals move between roles and sectors and their learning needs will change and education providers must be agile to support that. In terms of undergraduate education, feedback during our work to develop the Daffodil Standards for community pharmacy with Marie Curie, identified that further work is required to ensure that palliative care education is "uncoupled" from cancer care education and training.

The Palliative Care Education Framework described in the strategy is a good example of a curriculum which can be tailored to meet the needs of the individual. We agree that the Scottish Palliative Care Guidelines continue to be the preferred resource with sustained investment in the evidence base to support the recommendations and best practice within. Any educational material developed nationally must be accessible for the workforce practicing across the integrated landscape of palliative care services including health, social care, third and independent sectors as part of the integrated models of care.

Question 11 Please add any further comments you have about the draft strategy outcomes and actions here

Please add any further comments you have about the draft Strategy outcomes and actions here:

In order for healthcare professionals to optimise their support for patients, an awareness of available services in their local area is important for signposting and onward referral where appropriate. E.g. rapid response teams, Marie Curie support line

Section C: Strategy content

Question 12a Community action and support - Do you think this strategy explains why it is important to encourage people, families and communities to come together, support each other, take action and talk more openly?

Unsure / Don't know

Question 12b: Please add any comments you have about how to do this better in Scotland.:

The explanation is clear, however, engagement with the public around this strategy and in the benefits to earlier identification of palliative care needs will require a widespread and robust public campaign. Engagement across the spectrum of health, social care, third and independent providers will be necessary.

Question 13a Earlier access to palliative care - Do you think this strategy explains why getting palliative care long before someone is dying can help adults, children, their families and carers?

Unsure / Don't know

Question 13b: Please add any comments you have about earlier access to palliative care here.:

See answer to Q12

Question 14a Improving access to palliative care and support - Do you think that the actions in this strategy can improve the experiences of people with different personal characteristics and circumstances?

Yes

Question 14b: Please add any comments you have about impacts of the strategy on these or other groups of people here.:

Yes, utilising better quality data will support the developments required to ensure that people in these groups can experience consistent, equitable and timely access to palliative care.

Question 15a Language and terms used in the strategy - Do you think the strategy explains what is meant by the terms palliative care for adults; palliative care for children; care around dying; and future care planning?

Unsure / Don't know

Question 15b: Please add any further comments you have about any of the terms that are used in the draft strategy.:

We received member feedback on "Future care planning" in the context of palliative care did not include death or dying in the definition. The move away from "end of life care" to "care around dying" appears satisfactory.

Section D: Further Comments

Question 16 Please add any other comments or suggestions you have about the draft Palliative Care Strategy here

Please add any other comments or suggestions about the draft Palliative Care Strategy here:

About you

What is your name?

Name:

Fiona McIntyre

Are you responding as an individual or an organisation?

Organisation

What is your organisation?

Organisation:

Royal Pharmaceutical Society Scotland

Further information about your organisation's response

Please add any additional context:

We are the Royal Pharmaceutical Society, the professional membership body for pharmacists and pharmacy.

Our mission is to put pharmacy at the forefront of healthcare.

Our vision is to become the world leader in the safe and effective use of medicines.

Since RPS was founded in 1841 we have championed the profession, and are internationally renowned as publishers of medicines information.

We promote pharmacy in the media and government, lead the way in medicines information, and support pharmacists in their education and development.

The Scottish Government would like your permission to publish your consultation response. Please indicate your publishing preference:

Publish response with name

Do you consent to Scottish Government contacting you again in relation to this consultation exercise?

Yes

What is your email address?

Email:

Fiona.McIntyre@rpharms.com

I confirm that I have read the privacy policy and consent to the data I provide being used as set out in the policy.

I consent

Evaluation

Please help us improve our consultations by answering the questions below. (Responses to the evaluation will not be published.)

Matrix 1 - How satisfied were you with this consultation?:

Very satisfied

Please enter comments here.:

Matrix 1 - How would you rate your satisfaction with using this platform (Citizen Space) to respond to this consultation?:

Very satisfied

Please enter comments here.:

Asking for additional information