Item No: 8

Meeting Date: **Wednesday 21st February 2018**

Glasgow City
Integration Joint Board
Performance Scrutiny Committee

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DRAFT PALLIATIVE AND END OF LIFE CARE PLAN

Purpose of Report:	1. To summarise the key issues arising from the consultation exercise. 2. To present an amended plan that reflects the feedback received during consultation.

Background/Engagement:	Published on HSCP website with comment gathered via online responses plus 2 stakeholder events, one for Locality Engagement Forum members and one for care providers.

Recommendations:	The IJB Performance Scrutiny Committee is asked to: a) note the key changes to the Plan, including the proposal to extend the lifespan of the Plan to 5 years; and b) agree that the Plan be implemented via the HSCP's Locality Palliative Care Implementation Groups and key partners.

Relevance to Integration Joint Board Strategic Plan:

Palliative Care is identified in the HSCP's Strategic Plan as a function delegated by Glasgow City Council and NHS Greater Glasgow & Clyde. Effective and accessible palliative care is key to supporting people, their families and their carers. It enables people to remain safely at home, it helps to avoid hospital admissions and minimises delays in hospital.

Implications for Health and Social Care Partnership:

Reference to National Health & Wellbeing Outcome:	Good (Palliative) Care can be reflected in all 9 National Health & Wellbeing Outcomes as experienced by service users, carers and staff.

Personnel:	Glasgow will experience a rising demand for this type of care across the age range of its population as a result of people living longer with long term conditions and the drive to deliver care at home or other community settings. As a consequence, there will be a requirement to consider future workforce requirements and associated funding implications.

Carers:	Carer engagement formed a key part of the consultation process on the draft strategy and ongoing feedback will feature throughout the life of the strategy in order to obtain a measure of our success and to guide ongoing developments.

Provider Organisations:	The HSCP has commissioning responsibility for the 2 Glasgow Hospices (specialist palliative care) as well as its responsibility for commissioning care homes where good generalist (palliative) care should be available to those that require it. The homecare function delivered by Cordia and other providers will also feature prominently in the delivery of generalist (palliative) care.

Equalities:	The plan will be tested against the HSCP's Equalities monitoring process for new policies or strategic documents.

Financial:	The HSCP secured funding from HIS for a 2 year period commencing June 2017 to support an Improvement Advisor post. This person will work with services to address identified areas of improvement. The financial challenges faced by the organisation will apply to our directly provided health and social care supports, to our partner services and also reflected in ALEOs delivering home care. There will be a requirement to further invest in palliative care if the objective of managing more care in community settings is to be realised.

Legal:	There are no legal implications from this paper

Economic Impact:	Good palliative care can reduce the health burden by reducing hospital admissions and reducing lengths of stay in hospital. By using the principles set out in "Realising Realistic Medicine" (http://www.gov.scot/Resource/0051/00514513.pdf), it can also impact on cost by creating co-produced care plans and choice which has potential to reduce unnecessary investigations or minimally effective interventions.

Sustainability:	Sustainability will rely on reliable data collection of outcomes of care that demonstrate demand and the associated financial and workforce adjustments required to meet that demand.

Sustainable Procurement and Article 19:	None

Risk Implications:	An ageing population and the inevitable increase in the number of people with multi-morbidity, frailty and dementia will see a rising requirement for palliative care while advances in treatment options will mean people live with their condition longer than in the past. The financial climate could constrain the organisation's ability to meet this rising need.

Implications for Glasgow City Council:	Requirement to implement the plan

Implications for NHS Greater Glasgow & Clyde:	Requirement to implement the plan

1. Background to the Consultation Process

1.1 Following the IJB meeting 20th September 2017, the HSCP's draft Palliative and End of Life Care Plan was subject to a period of consultation.

1.2 The consultation involved an online survey via the HSCP website (up to 30th November) as well as structured events (late Nov/early Dec), face-to-face feedback at internal meetings and telephone responses.

1.3 The online survey attracted 27 returns in which the majority agreed with the aims but felt that additional content was needed to the actions and priorities sections.

1.4 Structured events were targeted at care providers and representatives of the general public. The event for care providers was held at the Marie Curie Hospice and attracted around 50 participants while the event to gauge feedback from the public, involved bringing the 3 Locality Engagement Forums (LEFs) together. The LEF members numbered around 40 and delivered their feedback via 5 facilitated groups.

2. The **<u>key messages</u>** arising from the consultation are as follows –

- The HSCP should consider a 5 year plan rather than the 3 year timeframe suggested in the draft document. Plan now reflects this timescale.
- The timescales set for the Priorities are unrealistic and need to reflect the time required to implement changes that involve multi-agency delivery.
- The Plan should make reference to the Scottish Government's Health & Social Care Delivery Plan and the commitment to Palliative Care services. It should align to the provisions of legislation (e.g. Children & Young Peoples Act 2014) and be mindful of approaches such as "Getting it Right for every Child" (GIRFEC) (*see key aim 4.3*).

- Carers, Families & Communities where people live, need to feature more prominently and there needs to be reference to the community supports that can be accessed and the information available (*see actions 13, 15, 16, 27*).
- The plan needs to be clearer about the way services are delivered, not just the planning structures (*see Appendix 1*).
- Need to be clear about the measures that will be used to show the plan is working (*see actions 13 & 23*).
- Equipment and Technology need to feature in the plan as they have a significant contribution to supporting people at home (*See actions 25 & 26*)
- Importance of Bereavement and Counselling services should feature (*see action 28*).
- There are misconceptions regarding Palliative Care and the plan needs to include a definition to provide some clarity (*see page 1 & 2 of the plan*).
- Greater differentiation is needed between the needs of children (at various ages, including babies) and adults and there needs to be greater clarity around transitions (age related and "place of care" related) (*see action 5*).
- The impact of an ageing population on both workforce and finance will challenge the Partnership's ability to deliver the stated aims. This needs to be reflected in the organisation's workforce and budget plans (*see actions 22 & 24*).
- The language used in the plan needs to be understandable for professionals and members of the public alike.
- Anticipatory Care Plans should strive to enhance communication between care providers and effort needs to be made to raise awareness of the tools available and the skill of introducing people to ACP (*see key aim 4.1 & action 10*).
- There should be more emphasis on how to increase the number of people with Key Information Summaries (KIS) (*see action 11*).
- The plan does not make reference to the delivery of care in Prisons or to those people with a Learning Disability (other than reference to harder to reach populations) (*see action 16*).

3. Financial Implications

3.1 The previous paper set out the HSCP's current spend on palliative care, including –

- Responsibility for commissioning services from Glasgow Hospices (£4M+)
- Purchase of Managed Care and Fast Track nursing services (£1/2M+)
- Purchase of equipment (from Equipu joint store) approx £370K
- Mainstream nursing provision approx £1.5M

3.2 The above does not include spend on residential and nursing home accommodation that is required when care provision within the "family home" is no longer an option due to various circumstances including multi-morbidity, frailty and dementia.

3.3 The inevitable increase in the number of people requiring palliative care will have implications for further investment. Alternatives to the "family home" will require spend in a range of community based accommodation settings to prevent people being admitted to hospital and there will be a subsequent increase in demand and the cost of equipment provision. There will be a requirement to grow the number of care practitioners at both generalist and specialist level which will be part a pending workforce projection exercise.

4. Recommendations

4.1 The IJB Performance Scrutiny Committee is asked to:

a) note the key changes to the Plan, including the proposal to extend the lifespan of the Plan to 5 years; and

b) agree that the HSCP Implements the Plan via its Locality Palliative Care Implementation Groups and key Partners.

Palliative & End of Life Care Plan (final draft)

2018-2023

Contents

1. The Scottish Government adopted the World Health Organisation (WHO) Definition of Palliative Care in its Strategic Framework for action.

"Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

WHO Definition of Palliative Care for Children

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders (WHO; 1998a):

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes.

2. Our Vision

2.1 The HSCP's strategic vision reflects the intentions of the Scottish Government's Strategic Framework for Action and the Scottish Partnership for Palliative Care. That is that by 2021, everyone in Glasgow who needs palliative care will have access to it regardless of age, diagnosis or circumstance and that the care provided will be safe, effective and person-centred.

2.2 Staff delivering care will be supported via learning and education opportunities to understand how best to make a significant difference to a person's wellbeing, even in the last months, weeks, days and hours of that person's life.

2.3 Glasgow will be a place where people die well, are supported throughout Bereavement. Communities and individuals are able to help each other through declining health, death, dying and bereavement.

3. Key Aims

3.1 People and their families and carers have timely and focussed conversations with appropriately skilled professionals to plan their care and support toward the end of life. The National Anticipatory Care Plan will be used to support this process and capture people's needs and preferences. http://ihub.scot/anticipatory-care-planning-toolkit/

3.2 The HSCP's Palliative Care Plan will not be used in isolation but as part of a suite of material aimed at engaging people in their care and improving quality of life and wellbeing. This includes for example some of the material in the Scottish Government's 3rd Dementia Strategy (http://www.gov.scot/Publications/2017/06/7735/downloads), in Realising Realistic Medicine (http://www.gov.scot/Resource/0051/00514513.pdf), in the Carers Act 2016 (http://www.legislation.gov.uk/asp/2016/9/contents/enacted) and in the HSCP's Carer Strategy.

3.3 The Palliative & End of Life Care Plan will align with the aims set out in the Scottish Government's Health & Social Care Delivery Plan (http://www.gov.scot/Resource/0051/00511950.pdf), in particular the aim that by 2021 "everyone who needs palliative care will get hospice, palliative or end of life care" and that "all who would benefit from a Key Information Summary (KIS) will receive one". That Plan also indicates that people will receive more sensitive end of life support that will aim to support them in the setting that they wish.

4. Actions – "What will we do"

The HSCP will -

1. Work with our staff and with partners to identify learning and education needs and will use the NES National Palliative Care Educational Framework "Enriching & Improving Experience" (http://elearning.scot.nhs.uk:8080/intralibrary/open_virtual_file_path/i2564n4083939t/Palliative%20framework%20interactive_p2.pdf) to achieve a consistent approach.

2. Task Locality Palliative Care groups with implementing the Plan and ensuring that Locality implementation reflects an understanding of specific population needs in relation to palliative and end of life care.

3. Ensure that Locality groups are representative of a full range of partners, including e.g. Improving Cancer Journey (ICJ), Hospices, 3rd & Independent Sector Providers, Health & Social Care staff, Practice Development/Macmillan Facilitators and Carer Services/Organisations.

4. Ensure that the outputs and outcomes from Locality Palliative Care forums inform the HSCP's Palliative Care Steering Group and SMT and are shared with the wider palliative care community via the HSCP's website and the NHSGGC palliative care website.

5. Develop a more detailed understanding of Palliative Care services for Babies, Children and Young People to compliment the work undertaken for Adult services. This will involve work with HSCP Children's Services staff, Children's Hospice representatives, Paediatric/Acute hospital services and 3rd & independent sector providers.

6. Ensure Locality Plans and HSCP strategic documents capture the main palliative care priorities identified by Locality Palliative care groups.

7. Be part of the wider Glasgow & Clyde Palliative Care Network which will provide a platform for shared learning.

8. Outline the pathways between general care and specialist palliative and end of life care and check that these are clearly communicated at a local level and understood by those requiring and those delivering services.

9. On an ongoing basis, develop conversations with groups of health and social care providers, using the information gathered in our palliative care survey 16-17, to establish key areas for improvement and use the Associate Improvement Advisor to support approaches that enhance care delivery.

10. Embed Anticipatory Care approaches, using National ACP documentation where appropriate and ensure that staff are equipped to facilitate conversations about death, dying and bereavement; including the potential benefits or side effects of various care and treatment options.

11. Work with the HSCP's Primary Care Strategy Group, with Locality Primary Care Implementation groups and with Cluster and Practice Quality Leads (CQLs & PQLs) to achieve maximum benefit from their "Expert Medical Generalist" and MDT Leadership skills, to enhance the quality of ACPs and increase the number of people with Key Information Summaries (KIS).

12. Continue to support the Primary Care Palliative Care Team in delivering Palliative and End of Life care training to Health and Social Care staff who work in community settings.

13. Establish, in collaboration with patients, carers and Carer Groups, an ongoing feedback mechanism that informs the HSCP about people's experience and areas where further development might be required. This might include e.g. feedback on the care provided or the impact on family/carer wellbeing. Validated tools will be used where possible.

14. Consider the psychosocial and health impact on staff who work with the very ill, the dying and the bereaved on a daily basis and explore ways of supporting those staff to alleviate stress and possible absence from work.

15. Improve access to information for people requiring palliative care and their carers and families. This will include online and physical resources and will cover medical/clinical issues as well as non-medical issues such as Power of Attorney and Financial Advice.

16. Work within Locality groups to ensure that service provision is equitable and consideration is given to identifying and engaging with "harder to reach" groups, including e.g. ethnic minorities, people with a learning disability and people in prison.

17. Work with Marie Curie and Prince and Princess of Wales hospices in the provision of care, using their specialist expertise to take forward new and innovative approaches to delivering palliative care in the community and avoiding admissions to hospital as appropriate. We will also work closely with other hospices, particularly St. Margaret's of Scotland (and their associated HSCP, West Dunbartonshire) who care for many Glasgow residents and provide nurse/carer education.

18. Continue to work with Macmillan Cancer support in delivering information, education and testing new developments.

19. Develop our relationship with secondary and tertiary specialist palliative care services to ensure effective and timely transitions between places of care with particular emphasis on the involvement of families and carers in planning care and the provision of appropriate patient information at the point of discharge.

20. Develop our relationship with the 3rd and independent sectors in the planning and delivery of effective and sustainable service provision

21. Continue to work with Scottish Government departments to share practice innovation and to refine reporting and feedback mechanisms to give greater clarity on the impact of good palliative care.

22. Consider the workforce and financial implications of meeting the increasing need for palliative and end of life care in community settings and work with partners to maximise resource ulilisation while identifying future funding opportunities. This will need to link to the HSCP's Workforce Strategy and to the Scottish Government's National Health & Social Care Workforce Plan http://www.gov.scot/Publications/2017/06/1354/downloads.

23. Review data sources and agree a suite of measures that can be used to determine the impact of the strategy over its 5 year lifespan. This will include provision for ongoing monitoring and development of measures.

24. Maximise the totality of financial and personnel resource deployed in the city in order to develop a coherent and connected approach to the provision of good palliative and end of life care. By doing do, reduce the number of people who die in acute hospital settings and reduce the number of days spent in hospital in the last 6 months of life.

25. Work in partnership with Equipu to monitor the provision of equipment to people with palliative care needs. This will include the identification of commonly used equipment, the planning of future provision and the review, on an ongoing basis, of service response, particularly to those who require items urgently.

26. Embrace advances in telecare and telehealth for people with palliative and end of life care needs to enhance monitoring and safety within the community environment.

27. Identify in the 3 Glasgow Localities, the best approach to involving carers, families and communities in the support of people requiring palliative and end of life care.

28. Ensure there is local clarity in relation to accessing Bereavement and Counselling services.

5. Table of Priorities (These will be reviewed and updated by the Palliative Care steering Group x 2/year)

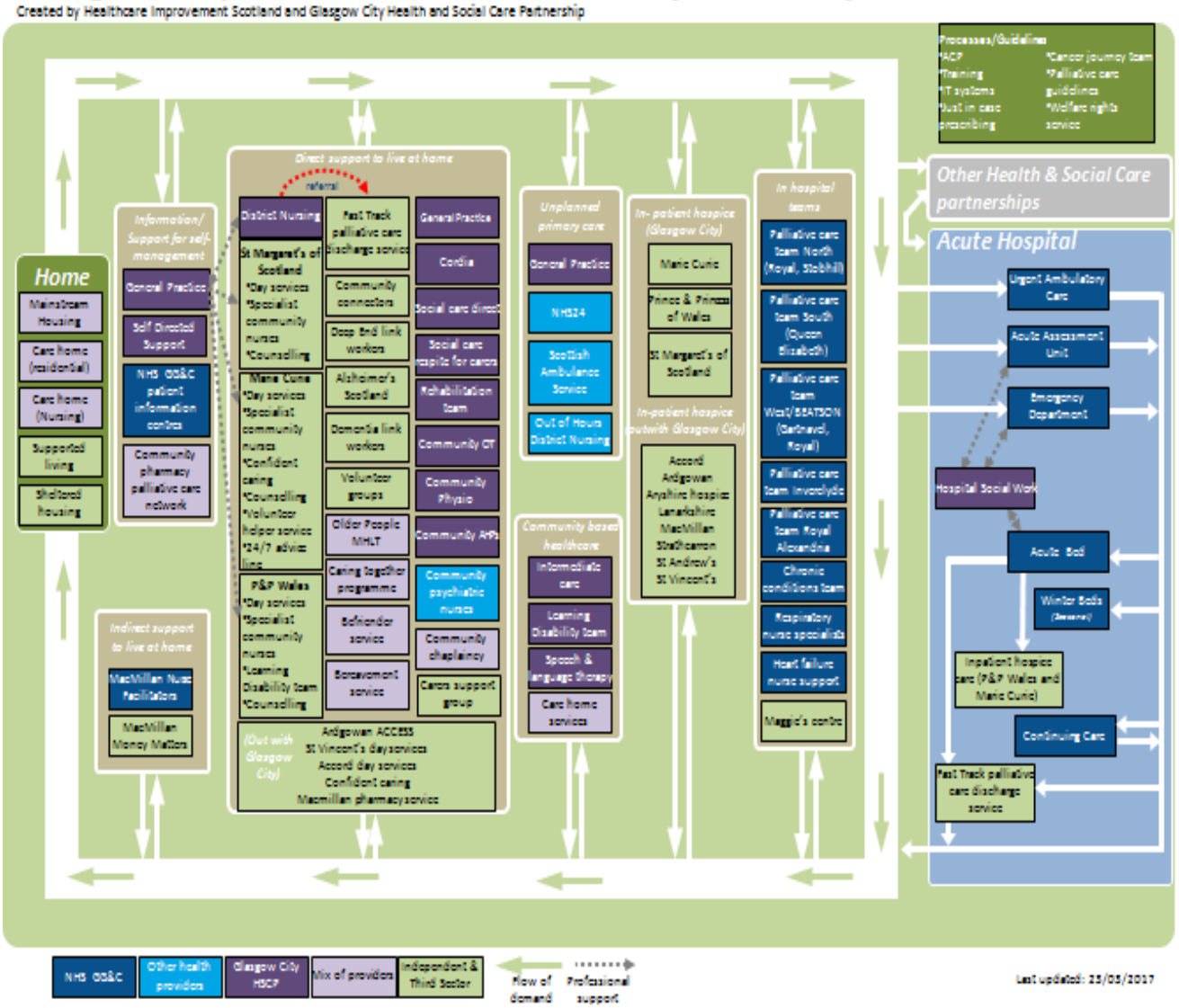
Priority	Timescale
Structure	
1. Establish an HSCP Palliative Care structure. 2. Establish links with wider Palliative Care Network. 3. Establish a web-based mechanism for sharing outputs of Palliative Care forums. 4. Locality Palliative Care Groups to agree a workplan based on the commitments outlined in the Palliative and End of Life Care Plan.	Complete Complete In Progress (report March 2018) April 2018
Policy & Planning	
1. Develop a forecast of workforce implications in collaboration with partners in order to establish commissioning intentions. 2. Review data sources and identify appropriate performance monitoring arrangements and outcome measurement. This will include what we currently collect, what we need to collect and how we can utilise electronic systems to extract data and translate that into informative reports. 3. Link with the Glasgow Hospices to embed their provision into the totality of provision and develop and agree innovative approaches to delivering palliative care when refreshing the Service Level Agreement 2018-23.	In progress (report March 2018) March 2018 March 2018
Education	
1. Introduce and use the NES Palliative Care Education Framework “Enriching	April 2018 – December 2020

& Improving Experience" across our services.	
Communication & Collaboration	
1. Test Palliative Care Strategy with groups of carers in keeping with the Carer Scotland Act 2016. 2. Establish a mechanism for regular engagement with Carers groups and use this feedback to refine service delivery. 3. Establish closer working with acute based palliative care services to address transitions. 4. Develop a clearer understanding of Palliative Care for Children by reviewing current provision in greater depth.	Complete March 2018 Ongoing April 2018
Practice	
1. Transition from using the Glasgow Anticipatory Care Planning documentation to testing the National suite of material and using this as the standard ACP/Personal Plan across the range of HSCP services. 2. Engage with Primary Care Strategy Group & Cluster Quality leads to examine how best to increase the number of people with a Key Information Summary (KIS). 3. Evaluate the extent to which the HSCP's directly provided services (Residential & Day Care Services) utilise identification tools, e.g. "Supportive Palliative Action Register" (SPAR) and aim to achieve a consistent approach across Residential Units. 4. HIS funded Associate Improvement Advisor will develop a workplan based on engagement with care providers and reflective of the HSCPs commitments.	Ongoing April 2018 Ongoing (August 2018 report) February 2018

Appendix 1

Glasgow City Health and Social Care System for palliative care

Created by Healthcare Improvement Scotland and Glasgow City Health and Social Care Partnership



Appendix 2 - Structure (Governance & Reporting Process)

Outline of Glasgow's delivery model and connection to other HSCP structures & wider