Jersey Hospice Care

your care, your choice, your time

Health and Social Security Scrutiny Panel review of the Jersey Care Model

Dear Panel Members,

Thank you for inviting the charity to contribute to your understanding and findings in respect of the new Jersey Care Model (the 'Model'). The charity has engaged with the Health and Community Services Department at length in the development phase of the Model which draws widely on the knowledge and services of our local community as well as learning from elsewhere. We believe the Model recognises the value contributed to the health and social care economy by a wide range of providers. It offers an opportunity for the strength of that wider community to be harnessed in the achievement of an ambitious and quality led model of care for our community[1].

Set out below are some general observations followed by a specific response to the terms of reference set by Scrutiny.

Current health and social care system

- Jersey's health and social care system is fragmented and built upon historic relationships that over time evolved to include many siloed forms of service provision by Government and other organisations with a propensity to be poor at working together, evident in an unwillingness to share information, resources and aligned objectives.

- In recognition of these issues and increasing pressure on the finite resources of Health and Community Services and those of providers across the whole system, a number of iterative efforts and proposals to change the manner in which health and social care is delivered in Jersey have been put forward.

- The Jersey Care Model builds on the foundations of this work, recognising the on-going extant problems and the moral and practical imperative to address them. The fundamental proposal is for Health and Community Services to divest itself of its role as sole provider of many of these existing services and to create a healthcare market where services are delivered by a range of organisations working collaboratively to an aligned vision. Critically this vision is for an integrated healthcare model, one that addresses the medical and behavioural factors that form the determinants of good health and wellbeing.

[1] See the Appendix for details of the existing relationship with Jersey Hospice Care

The views of Jersey Hospice Care and the wider Third Sector

- The Model is predicated on an ambition to deliver person centred care wrapped around the individual user. Jersey Hospice Care is wholly supportive of this. The guiding philosophy of Jersey Hospice Care is that every person matters and every person's needs are different and the needs of each person should be assessed holistically.

- Jersey Hospice Care has a real appetite to see the Model delivered and to play a role in that process. The organisation is a sophisticated provider of health care services in Jersey and values the opportunities that working with Government and other providers offer; opportunities which enhance the services we provide our patients.

- We believe this view is shared by many other organisations in the Third Sector. The island has an almost uniquely diverse and vibrant Third Sector. It delivers outstanding support across a whole range of care areas and with the introduction of service level agreements and greater statutory regulation has grown in confidence and maturity.

- Members of the Third Sector have made significant efforts to work more closely together in recent years adopting a variety of innovative practices and working in clusters, not unlike those created in Primary Care.

- The Third Sector maintains strong links with service users[2] and the closeness of that relationship enables it to be an excellent advocate for the priorities and needs of our community. We know:
  - Service users now place much greater emphasis on the importance of having a greater say in the decisions affecting them
  - There is a keen desire amongst service users to reduce institutionalised care and bring services "closer to home"
  - There is also much greater recognition that what matters is what works, irrespective of who is the provider is.
  - Similarly there is little distinction made by services users between what type of professional they see, so long as that individual is competent to provide the care they seek

- This knowledge demonstrates that there is already a willingness amongst service users to adopt and support change; however any large structural change to service delivery,

[2] The term service user is used throughout this document to capture the wide range of people who access and benefit from services, some of whom will be 'patients' but not all.

especially one of this magnitude will require significant investment in “cultural/behavioural change” to secure wider adoption by the whole community.

Comment on the Jersey Care Model and action necessary to deliver it

- Most of the financial, workforce and leadership challenges present in the current Jersey healthcare system are common to other jurisdictions and much can be widely read about, along with mitigation measures. The manner in which funding flows through the system in Jersey is an exception to that. The funding mechanism for primary care must be a key priority for change. Patient access to GPs in Jersey is exemplary but the high cost of access (borne predominantly by the service user) creates inappropriate reliance on other access points across the healthcare system.

- In binary terms we have a choice. We can as a community do nothing while the demands on our healthcare system continue to increase and the proportionate available resources decline. This would risk the quality and safety of current services and inevitably place our most vulnerable at greatest risk. Alternatively, the island can support the introduction of an ambitious plan to change how care is delivered in the island so that we can have the best healthcare system – anywhere.

- Jersey Hospice Care believes that over time Government should be ambitious seek to increase the boundaries of personal and community control, recognising that the foundations of good health extend far beyond healthcare policy. We believe this is achievable in our small island.

- Government will have to share resources to promote the change and accept that for a period there will be additional costs, whether borne out of double running, transition or innovation in service design. The immediate aim should be progress not perfection.

- Jersey has an outstanding digital network that offers the opportunity to provide first class access to healthcare data, owned by the individual service user.

- With the right support technology could be used to bring advances across the whole system, working with partners in the island and afar. Government could incentivise both on island organisations and those from afar to share their knowledge and expertise and to be part of this ambitious vision.

- The Model’s success will in part be predicated on the ability to assure the public that the care offered is at very least consistent in quality with that which is delivered today. We

believe that regulation and specifically governance that provides a quality and safety assurance will be critical in demonstrating the Model and the new ways of accessing care, are deserving of the public's trust and confidence.

- An island wide workforce strategy will be necessary to assure the development of sufficient capacity to deliver this Model. Providers can identify where there are gaps and strategies to manage pooled resources in order to ensure a supply chain. We believe there are opportunities for existing services to work together.

- Different models of funding will need to be developed. Government funding will play a large part, but there is also scope for social investment, co-funding models, shared budgets for networked service suppliers etc. and for policy makers to look at creating tax incentives for those that invest in or make donations to charitable service providers.

- We believe at this early stage the roadmap needs to address what is needed where; what is priority to ensure the success of the Model; and importantly what is for Government to achieve and what should form the basis of an organisational partnership. Much of this detail is (not unexpectedly) absent from the current Model documentation.

- To achieve this health planners need to assess what available resources exist from all sources, including a joined up estates register. We think there needs to a complete review as to how all of these resources might be utilised.

- In summary the key work-streams relate to vision clarity and service co-ordination, connectivity, funding, workforce capacity, regulation, governance and prioritisation. Critically system leadership of this Model is essential. If achieved the Model has the potential to significantly improve the experience of patients and the outcomes achieved for them.

Terms of Reference:

To determine whether the Jersey Care Model is appropriate for the Island

1. The Jersey Care Model is an integrated care model that seeks to create a system of care around the user, integrating behavioural health with medical care, within (not exclusively) a primary care setting. The idea being that if the system integrates these elements it can take care of people more seamlessly. We believe an excellent exemplar of this, is the care

already offered by Jersey Hospice Care for palliative patients, following the appointment by Government in 2014 of the system wide leadership role[3].

2. If we look to other examples of collaborative healthcare delivery (which range from decentralisation to delegated through to devolution as in the NHS in Scotland) there is strong evidence that to deliver "good health" you need to connect it to wider public services with a similar focus on the social determinants of health, for example housing, education, sport etc.[4] For the purposes of this response, it is perhaps sufficient to say that the ambition of the Model to give greater power to community providers, those closest to service users is a positive step on a longer term journey to building a healthier island.

3. Specific questions have been raised about the fairness of placing additional service burdens on other providers. Challenges have been raised about the apparent assumption that community providers would be able to meet the requirements of the Model citing a lack of infrastructure, workforce capacity, and clarity on funding streams. Similarly, it has been observed that responsibility for public services, and the boundaries between public and charitable services are not clear cut. Jersey Hospice Care thinks that these are valid challenges, but not a basis on which to lose the opportunity for a more collaborative service delivery provision. Instead it is suggested that these sorts of considerations should be regarded as issues that should be evaluated along with other risks, appetites and mitigation factors. The much more important question at this stage is whether the movement from an institutional based model of care to a community based model is right in principle for Jersey.

4. This is not the first time Government has sought to decentralise service provision. Government has commissioned significant health and social care services from community providers already. In the 1990s Government decided to bring together different nursing services in the island and to formally constitute a community organisation that would have responsibility and accountability for the community nursing services. This led to the constitution of Family Nursing and Home Care. The organisation was commissioned on a block grant funding basis, which over time became a contract for services with a service

[3] See the Appendix
[4] Andy Burnham the Mayor of Greater Manchester which has 'devolved control' of health and care spending, has stated – you can only have good health with good housing, good education, good work, social, digital and transport connections, clean air, safe neighbourhoods and opportunities to be physical active.

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specification and outcome measurements much like other organisations more recently commissioned that are accountable to Government.

5. Much more recently, at the beginning of the last decade the then Minister for Health Anne Pryke led a review[5] of the future of our health and social care services. That review identified pressing challenges: a rapidly aging population; growing demand for services; spiralling costs; difficulties associated with the recruitment of staff plus buildings and facilities in need of significant financial investment and not least a new hospital within ten years. Government was cognisant of the need to address these challenges urgently. The public consultation demonstrated 86% of the public were in favour of a fundamental redesign of care services. Islanders stated that they wanted services that "wrapped" around the individual delivered in the community - not just at the hospital or in institutions. Islanders stated that Government needed to give people choice and the ability to get the right care, from the right person at the right time. This desire from people to be the driver in the decisions made about their own care has not gone away and yet many of the steps proposed by the Minister remain to be implemented[6]. The Jersey Care Model offers a means to address that.

To assess how the proposed Jersey Care Model will be delivered and by whom.
To consider the implications of the Jersey Care Model on the delivery of health services.

6. The Jersey Care Model is an opportunity for like-minded organisations to step up and be the catalyst for change. Doing nothing is not an option, we must respond to the 'threat' and turn it into an opportunity to design and deliver better healthcare. And if we accept change must happen, we should accept that change created together, positive practical collaboration between people, organisations and places is much more powerful that anything Government or a single organisation can achieve alone. The role for Government will be to determine clearly - the role other providers such as charities can play.

7. We believe that the proposed new Jersey Care Model will succeed if it is based on principles of co-design, that is if it involves a diverse and inclusive range of stakeholders in the rethinking of services. To-date Government has actively sought to collaborate with current healthcare providers and the wider community in the designing of this new model.

[5] The work was undertaken by KPMG and led to the 2011 Green Paper 'Caring for each other, Caring for ourselves'

[6] The service level agreement entered into with Jersey Hospice Care in 2014 was a consequence of this workstream

Representatives from Jersey Hospice Care have been consulted throughout and it is represented on the governance board for Health and Community Services[7]. At each meeting of the Board a service user is invited to present, as 'an expert' of their own experience of the system. Jersey Hospice Care is encouraged by this approach, which demonstrates Government is engaging with service users and recognising the value of their insights into the strengths and weaknesses of the system.

8. Third Sector organisations are often established in response to an unmet need and/or to challenge unfairness. In that sense they support positive change in their own communities and they build social action around an issue with valuable knowledge and expertise that can be harnessed in service design. There is an opportunity for Government to encourage that advocacy role across the Third Sector (and beyond). This means not precluding organisations from speaking up if they receive funding from Government for or in relation to an existing service and taking steps to facilitate greater representation from the Third Sector in leadership roles within Government. A positive step in this direction is the development of the aforementioned Health and Community Services Board in 2019. This offers a more porous governance structure, with the appointment of representatives from a handful of community partner organisations (including both Third Sector and Primary Care) to the board.

9. What is not clear is the degree to which overall responsibility for services will pass from Government to other providers. Will it be collaboration or complete 'devolution' of health care? If the latter will Health and Community Services step aside and led the provider get on with it? Our view is Government should fund provision and with appropriate regulation in place, providers should have autonomy to deliver services.

10. We also recognise that working closer with Government, will for many organisations require resources that they do not currently have. Thought will have to be given to how this capacity is achieved without diverting donated funds and other resources that would or should be directed to service delivery and not spent on long periods of consultation about different approaches to service design or delivery that may or may not be achieved. 'Consultation fatigue' has been evident in the past - borne out of the fact that discussions about bringing change to the healthcare model have been taking place for a long time. There has to be a

[7] A range of stakeholders are invited to sit on the board and will in due course be rotated.

balance between engaging stakeholders in policy development and diverting them from the cause which they have been set up to support. There needs to be a commitment of resources to this work-stream by Government, from ground level up.

11. The Third Sector is not homogenous, and it rejoices in its diversity and differences. Similarly, it is recognised in Jersey that the way in which different departments of Government behave, approach and deal with the sector varies. There are different processes and inevitably personalities that influence and shape the success of different relationships. Tensions can arise, such as unrealistic deadlines, inadequate resourcing, inappropriate levels of funding, time-consuming consultations or insufficient consideration given by civil servants to the need for individual trustee boards to be properly consulted before decisions can be authorised. An effective mechanism for all providers and stakeholders to work together collaboratively will be essential to the success of the Model.

To assess the potential impact of the new care model on patients; in respect of the quality of service provided and any financial implications.

12. We are at a juncture in healthcare where there are huge challenges when it comes to ensuring the delivery of quality services and it comes down to needing to deliver more services of the same or better standards for less money. The Jersey Care Model is offering a new approach, it promises to sweep away the top down approach to delivery and offers an opportunity to try new approaches led importantly by those closest to the those that need the services. Civil society organisations have argued for this approach for decades. The Model promises to place the resources and the aspirations of service users at the centre of service design. Overarching safeguarding and governance measures are going to be key to ensuring that the community has confidence in this new delivery model and to providing an assurance of care standards. [8]

13. The introduction of the Jersey Care Model does not mean that the financial pressures evident now will disappear, in fact the consequences of demography – people living longer with chronic ill health and frailty is set to make the financial position even harder. But at Jersey Hospice Care we believe the best answer is to work together. We believe that by

[8] Regulation of the charity sector by the newly established Office of the Charity Commissioner will be one such mechanism.

pooling resources, skills and experience, providers of any size have the best chance of delivering successful outcomes across the health and social care system. We support Government's initiative to work with other agencies and in particular its decision to embrace community providers as trusted parties in ongoing service reform.

14. We do recognise the risks that changing the system presents from poorly co-ordinated delivery, duplication of effort and wasted resources. The reality of such risks means those most in need and the most vulnerable will be the most exposed. However, the threat of a decline in services and reducing budgets should inspire us all to come together and overcome the challenges change might present.

15. Together there is an opportunity to think about how we shape new, pooled funding arrangements with a view to co-designed public and charitable services that address priorities in a focused and conscious way. This should also include recognition of the importance of funding innovation and scaling. Jersey is primed to be a sandbox for technological innovation why not in the area of digital healthcare.

16. Perhaps the work already undertaken by Government to unlock dormant bank accounts and trust funds could be applied in this area. There also needs to be recognition that funding of initiative in the sector will probably require more than one model in order to have the most impact.

To examine the possible effects of the proposals on the current and future health sector workforce.

17. The Jersey Care Model recognises that without growth and/or adaptation in the care workforce, the present challenges in recruitment and turnover will persist. The workforce issues exist now, they are not contingent on the introduction of the Model. There needs to be a whole system commitment to addressing these issues. Without this form of commitment, the current workforce issues are likely to persist, and we already have a high vacancy factor in nursing roles in the island and the workforce in the local home care market is very depleted. Innovation and modernisation are factors however that we believe will attract staff to being part of the new care Model.

18. There will be a cost that arises out of working differently especially in the early stages, even for purely voluntary organisations, arising out of increased infrastructure, even it is just training and support to facilitate service change. Many of the organisational changes that have taken place at Jersey Hospice Care in recent years are changes that service provider organisations across the sector will have to go through, if they are to offer strong governance and be organised in a business-like structure. It will have to be a cost borne as part of the implementation of the Model by Government. There also needs to be a commitment by Government that it will not require Third Sector organisations to enter into contracts on such a basis as they are making a loss or that as a consequence of any contracting arrangements with Government the organisation is unable to pay staff a competitive wage.

19. There is an opportunity for Government to provide increased on island training and support resources for the health and social care sector workforce. This could also include training and resources to help Third Sector organisations increase their understanding of contracting with Government and providing commissioned services, along with learning how to scale up best practice that already exists.

20. It is our experience that there is a very vibrant Third Sector community in Jersey that would like to be part of the conversation around shaping the health and social care sector and this includes taking on more of a delivery role. This is not the Third Sector getting involved for the sake of it, but rather seeking to promote choice and improvement in services built around the knowledge and needs of those we work closest with.

21. Government contracts can diversify an organisation's income streams and help ensure that the support provided by the organisation remains sustainable. However, there are associated risks that range from public perception, to the contract being offered on a short-term basis. These issues can make the circumstances of working with Government difficult. Similarly, sometimes payment based on results can be inappropriate and lead to disruptive service delivery. Accordingly, all of these issues need to be carefully thought through to ensure sustainable service and workforce arrangements.

22. The Model is predicated on delivering services differently. It does not follow automatically that the new Model and/or invention of new services will create or add to existing workforce

challenges. It could be that the resources are deployed differently. Much has for example been said about the need to have a 24 hour nursing service, however data from the Emergency Department at the General Hospital suggests there are few admissions overnight requiring nursing care.[9] However, across the whole system of healthcare there is cumulative evidence of a need to have an out of hours provision. There is also evidence that from time to time surges in need arise in relation to different service areas. Potentially therefore we could take the current Rapid Response Model that supports care out of hours until 10.30/11 pm and add to it with a range of professionals, drawing from the other emergency services that are already operating. Making it a multi-professional service where a call into the service from the carer of a palliative patient, needing help because mum has fallen out of bed, results in a professional trained in lifting patients safely being sent to help, instead of a specialist palliative clinical nurse specialist. The professional could be a paramedic or a police officer etc. The team could be physically co-located, or accessible through a virtual hub and physically located with their own organisation.

To understand the proposed Jersey Care Model in the context of the future hospital and other health facilities on the Island.

23. The Jersey Care Model is the system by which health and social care will be delivered, the future hospital will be part of the infrastructure from which acute care will be delivered.

24. Hospitals are often perceived as the ‘anchor’ in a health care system, even where a mature community health provision exists. The debate surrounding the location of the future hospital in Jersey is clear evidence of the community’s emotional attachment to the location of the building. The new hospital will be an important ‘place’ in the minds of people and it will give our health care system a physical identity. All of these considerations have a significant importance outside of strict clinical considerations.

25. Quality community care is a means of reducing pressure on institution based care (such as from the future hospital). With heavy investment in community care through the Jersey Care Model, it should be possible to assess and triage significantly more patients in

[9] There is much greater evidence of a need for a sitting service.

community settings, alleviating unnecessary or inappropriate referrals into hospital. Jersey Hospice Care has acted like a hub for palliative care patients, offering a single point of access to a very wide range of services. More provision in the island in hub based form or through using the already valuable parish resources, could alleviate pressure upon the Hospital. More importantly for patients investment in community care could and should mean receiving the right care in the right place, which because of inadequate current provision in Jersey isn't always possible now.

26. The proposed Model does offer the new hospital (when built) a clear role for acute care and aligned to that a function in the wider healthcare economy as both a place of employment and resource. The hospital may also have an important role in educating people on ways to prevent illness and promote health and well-being and treat patients.

27. Outside of Jersey some hospitals are reviewing their offering through implementing the popular Buurtzorg community nurse led model from the Netherlands. This is a model of care which offers a combination of medical and support services. It has received international acclaim across the world and it could work well in Jersey. It could be a new cost effective way of working that would offer a solution to the current challenges posed by the local home care market. It is another example of teams working together where the emphasis is on providing the service and not the organisation or professional tasked with delivery.

28. Other acute hospitals are investing in non-traditional partnerships to promote the wider health agenda. Jersey Hospice Care has already invested in a partnership relationship with the current hospital in respect of nursing development. We would value a wider partnership, such an initiative could offer leadership, management, knowledge and skills benefits and opportunities for both organisations.

Emelita Robbins
Chief Executive
Jersey Hospice Care
30 January 2020

Appendix

Jersey Hospice Care

Jersey Hospice Care is one of the largest providers of charitable healthcare services in the island, supporting some 2% of the adult population through a range of palliative care and supportive services accessible to patients with any life limiting illness and their families and islanders living with bereavement. The charity's greatest strength is its connection to the islanders it serves and without whose support the charity would not exist.

The charity was started in 1981 by a group of healthcare professionals who believed that there should be some provision in place for patients at the end of their lives and for whom medical 'curative treatment' was no longer on offer. Fundraising led to the appointment of one home care sister offering care to patients with a terminal cancer or motor neurone diagnosis at the end of life.

The charity has gone on to pioneer a fully-fledged specialist palliative care service for islanders with any life limiting or life threatening condition and is recognised as one of the leading British hospices now[10].

Palliative care is a service that improves the quality of life of patients and their families by effectively relieving, managing and preventing the most complex and acute symptoms throughout the course of a patient's illness and in due course at the end of life.

The charity acts as an advocate on a range of healthcare issues, critically the importance of palliative care education and strong governance in healthcare, as well as on specific matters such as the introduction of personal care records and advance care directives.

Our workforce is made up of some 500+ people; four fifths of whom are volunteers, who work across the whole of the organisation to support the specialist paid professionals who deliver the clinical and supportive services. We are full of gratitude that together we are changing the lives of everyone we care for.

The charity works at all times in close collaboration with Government and a wide range of other healthcare providers from primary and secondary care. From being entirely funded by charitable donations, since 2014 Government has met some 8% of the charity's expenditure and more recently committed to extending that support to reflect the widening remit of the charity. We pride ourselves on putting patients first and existing to meet the changing needs of the community we serve.

Jersey Hospice Care's partnership with Government

The Jersey Care Model builds on the foundations of the work carried out under the Health and Social Services 2012 White Paper "Caring for each other, caring for ourselves" and the subsequent proposition to the States of Jersey "A new way forward for Health and Social Care" (P82/2012). The

[10] Jonathan Ellis, Director of Policy and Advocacy, Hospice UK,

ambition was to ensure that "the right care is provided, in the right place, by the right person, at the right time – and at the right cost". The "how" was through greater numbers of integrated services delivered in partnership and in local community settings. The resulting contract entered into with Jersey Hospice Care in 2014 is an example of that, intended to support what was then referred to as the "out of hospital" system.

The delegation of responsibility for leadership in end of life care amounts to recognition that it doesn't always have to be the Government of Jersey that sets the strategy for service design nor does it have to be the delivery provider. The decision harnessed the charity's strength as a values driven organisation embedded in the community, capable of challenging established service expectations, capable of achieving the highest standards of service delivery and articulating the voice of the patient, their families and the wider community at every stage. The result is a modernised palliative care service that supports the co-ordinated care of palliative patients across the island, by a range of different healthcare professionals who work together to meet the needs of these patients.

Under the agreement with Government Jersey Hospice Care was appointed to work across system boundaries with all healthcare providers including primary care

> *`to ensure that through education, training and services high quality palliative and end of life care would be made available to all patients with a life limiting illness at the right time and in the right place'.*

With funding support from Government Jersey Hospice Care led the introduction of the 'Gold Standard Framework', a best practice model in end of life care. Its introduction to all healthcare providers in the island made Jersey the first place in the world to offer free end of life care education to all healthcare providers in the jurisdiction. The efforts of the charity have led to awards and recognition at the highest level

> *"I would like to send my whole-hearted congratulations to the team on achieving the GSF BGS Quality Hallmark Award in End of Life Care. This marks you out as one of the leading hospices and is testament to sustained effort and commitment to ensuring that people's experience of the care they receive as they near the end of life is as good as it possibly can be. On behalf of the British Geriatrics Society, I am delighted to applaud your success in achieving this quality award."*.[11]

The partnership between Government and the charity has led to a transformation in the nature of palliative care services offered in the island; the most important outcome being perhaps that it has enabled the charity to extend palliative care services to patients with any life limiting illness (that is

11 Sarah Mistry, Chief Executive, The British Geriatrics Society

patients with a non-cancer or motor neurone diagnosis). Patients who were previously excluded from accessing such services.

The impact of offering parity is demonstrable, with the charity seeing a 205% increase in the number of patients accessing its services. The proportion of non-cancer patients has grown steadily; by the end of 2018 it had reached almost 60%. Similarly the number of patients recorded as achieving their preferred place of care and death has risen significantly. This increase is also commensurate with a reduction in the number of deaths in the hospital falling from approximately 50% of all recorded deaths to closer to 1 in 4[12] deaths, evidencing the benefit of these ‘out of hospital’ services. Critically, the feedback from patients and families who have benefited from these changes has been consistently and overwhelmingly positive and appreciative.

By doing things differently in partnership with Government, we were able to help improve the life and care experienced by so many more patients and their families. Simultaneously, saving taxpayers’ money.

12 Further information of this is available should the panel wish to consider it.