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Dear Morag

Query regarding DNACPR notices for people with a learning disability

It was good to see you at the virtual Learning Disability Partnership Board in July. Thank you for bringing to our attention that concerns, initially shared at the LeDeR Steering Group, had been raised with you at Healthwatch by [redacted], a family carer representative who is an active member of our LeDeR programme.

Please forgive the length of this letter but I wanted to ensure that we provided you with as much detail as possible about the points that you have raised. I have tried to address each query in turn.

[redacted][A family carer representative] has written to Healthwatch on behalf of the Carers to raise their concerns about the issues relating to inappropriate DNACPR notices at the Acute Hospitals for people with a learning disability, reported at the LeDeR Steering Group.

During the first wave of the pandemic HWCCG were requested to undertake Rapid Reviews for notified LeDeR deaths where the indication that the cause of death was confirmed or suspected covid-19. The learning collated from these Rapid Reviews suggested that 2 or 3 Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) forms had been completed on admission to an acute hospital setting that hadn't included evidence of a mental capacity assessment or evidence that a conversation with a family member or loved one had taken place to inform a Best Interest decision.

The form content was reviewed by the Learning Disability Liaison Nurses and they concluded that the clinical decision that had been made and documented in the ReSPECT form appeared appropriate to the clinical circumstances at the time of completion and that the absence of evidence of a mental capacity assessment did not appear to have impacted on the sad outcome for the individual.

One aspect of learning identified was however that form completion in these examples should have been accompanied by a mental capacity assessment and provide evidence of engagement with a next of kin or loved one. This learning has been shared with a senior member of the acute hospital in order to inform improvements in practice. The Learning Disability Liaison Nurses have a meeting scheduled for early September with the Acting Chief Nursing Officer of NHS Worcestershire Acute Hospitals Trust (the Executive lead for Learning Disability standards within the organisation) to share these findings. The outcome of this meeting will be shared with the LeDeR Steering Group. The Acute Liaison Nurses are aware that if they did not feel that the outcome of their meeting was satisfactory they could escalate their concerns back to me as LeDeR Lead Contact.

In the week prior to the June LeDeR Steering Group meeting I had been requested to answer several questions and concerns of family carers. Jenny Hewitt had kindly coordinated a series of questions and set up a zoom meeting where we could discuss the concerns and questions raised. Two carers discussed that they had heard that DNACPR or ReSPECT forms were being discussed over the telephone and felt that this was very inappropriate. They had seen a news article in the Daily Mail and requested reassurance that local practice was not discriminatory. I requested specific details of local examples in order to review circumstances and work with colleagues to ensure appropriate action but as yet I have not received this detail. One carer discussed how she had been involved in a ReSPECT conversation prior to covid-19 that had been very respectful and helpful.

I discussed that it is important that we differentiate between DNACPR forms, which are specific to the action or inaction that is agreed to be taken if a person was to go into cardiac arrest, and ReSPECT forms which provide the opportunity for more detail about the preferences (and often the limits) of care that an individual would want should their prognosis for recovery be limited. ReSPECT forms provide a greater emphasis on mental capacity and a person's best interests. This has been seen as one of the key benefits of the roll-out of the ReSPECT programme.

In order to respond to the Carers' concerns and to help our understanding of the situation in Worcestershire regarding DNACPR notices, it would be really helpful to have some further information. Are you able to share the CCG policy on how DNACPR orders should be assessed and applied?

There is not a specific ReSPECT Policy that HWCCG has developed and issued as the implementation of the ReSPECT programme is led by national guidance. HWCCG would however expect provider services (for example local NHS Trusts) to have a Policy in place that covers ReSPECT principles and practice in order that expectations and guidance are made clear to clinicians and guide their practice.

Worcestershire were fortunate enough to be one of only a few areas that were able to benefit from dedicated resource to implement ReSPECT documentation and process. A multi-agency ReSPECT Programme Board had been in place prior to the evolving covid-19 pandemic and the CCG End of Life leads were involved in shaping the local programme and its implementation. There has been a significant emphasis on the importance of education and training as it is recognised as a fundamental component of influencing changes in practice.

The ReSPECT Programme Board has and will continue to maintain oversight of engagement with training that is available. Training was well underway prior to the pandemic but high levels of multi-agency coverage has not yet been achieved. All organisations are committed to ensuring that relevant staff access the available training and over time a strong foundation of practice will no doubt be achieved. HWCCG have committed additional resources to extend the initial implementation plan. We have no doubt that the ReSPECT Board, which includes carer representation, will ensure that any learning identified during the pandemic is fed back into organisational plans for delivery. The pandemic presented key challenges but also provided opportunity for a renewed impetus to the ReSPECT programme, highlighting the importance of getting conversations right first time

At the beginning of the pandemic numerous pieces of national guidance were issued by NHS England/ Improvement that directed practice related to care decision making and delivery.

General Practice were issued with national guidance to move to remote consultation for all but the most critical functions and to significantly reduce the need for face to face appointments. This guidance was issued with a view to significantly reduce the risk of exposure to covid-19, particularly for those who were vulnerable due to age or a pre-existing long-term condition.

HWCCG were conscious of the potential unintended consequences of this guidance. An STP Ethics Forum was established that included lead clinicians. This Forum provided lead clinicians with the opportunity to review all aspects of evolving guidance and consider how best to support the interpretation and implementation of guidance in a manner that minimised any potential risks. This included a communication to all GPs across Herefordshire and Worcestershire to re-emphasise the content of a statement from the Royal College of General Practitioners, regarding the need to ensure that advanced care plans, ReSPECT forms or DNACPR specific decisions continue to be made on a highly personalised basis. I hope this provides some reassurance that we communicated our expectation that ReSPECT conversations would, despite the pandemic and more remote way of working, continue to be highly personalised.

Worcestershire CCGs (prior to the merger of Worcestershire and Herefordshire CCGs from 1st April) and provider organisations worked together ahead of the pandemic to take a proactive approach to ensuring that as many people as possible were provided with the opportunity to discuss an advanced care plan or ReSPECT form.

General Practice had prioritised a focus on those living in care home settings to maximise the quality of care for those believed to be at increased risk of poor outcomes should they contract covid-19. It was recognised that for some individuals a hospital admission would not be in their best interests and alternative provision, where well planned, would likely enable personalised end of life care of better quality.

Prior to the formal ‘lockdown’ the NHS national team declared a level 4 major incident. All areas were required to plan to ensure that acute hospitals (and in particular intensive care facilities) had sufficient capacity to meet the projected level of local need. Planning was informed by analytical modelling of the potential number of coivd-19 cases that we might expect to see and of course by

the experience of other parts of Europe who were a few weeks ahead of the UK. Local planning included several initiatives and we are pleased to confirm that neither acute care or intensive care facilities were overwhelmed. The Learning Disability Liaison Nurses tracked the care of a number of individuals with a learning disability who required acute or intensive care facilities, and this has included some great examples of recovery.

The Voluntary sector (including Social Prescribers based within General Practice) and local clinicians were engaged in contacting households where the system believed there to be a vulnerable individual, to determine their level of need for health and social care. This was mainly focused upon practical issues such as the need for medication or food supplies. AS part of the conversation the individual was also asked if they had a ReSPECT form in place and whether a conversation with a clinician to develop a ReSPECT form would be welcomed. It is possible that some family carers of people with a learning disability were contacted by Social Prescribers and that part of that conversation was to enquire about whether a ReSPECT form conversation would be helpful.

Social Prescribers would not have been undertaking the conversation to discuss the content of a ReSPECT form, although they may have initiated a conversation about the ReSPECT process. It is possible that any concerns raised about initiating such a conversation may not have been responded to with the appropriate level of sensitivity had the conversation been initiated by a skilled clinician with wider experiences of contacting families in distressing circumstances

If this was the case we would be keen to know about these circumstances in order to support improvements in practice and ensure that staff also feel supported to get these conversations right.

How does the CCG assure that this policy is being followed in hospitals and what has been done to address the issues raised at the LeDeR Steering Group, particularly in relation to people with a learning disability?

The implementation of the ReSPECT programme is overseen by the multi-agency ReSPECT Board. Evaluation of the impact of implementation across our hospital environments and the audit of completed forms has commenced across both counties. This will continue into the autumn and winter as new CCG appointments come into post. Any gaps or learning identified will be reported into the ReSPECT Board in order that the system can agree on effective action to share positive practice and to drive improvement.

The examples of concern shared with us regarding hospital practice were from LeDeR Rapid Reviews undertaken ahead of a fully completed LeDeR Review. When the full LeDeR Review is completed we will have more detail available to enable appropriate recommendations and agreed system action to be put into place.

LeDeR Rapid Review detail available so far appears to indicate that the timescale between the persons admission to hospital and the identification of a poor prognosis was very quick, leaving little time to enable the comprehensive conversation that we would all expect. We also know that in any other circumstances discussions of this nature in an acute hospital would often be undertaken by Consultant Intensivists (Consultant colleagues who specialise in working with individuals and communicating with families when there is a deterioration in health that may benefit from intensive care). We know that during the first wave of the covid-19 pandemic many other clinicians from other specialties were required to set aside their usual workload and support the expansion of respiratory and intensive care provision. It may therefore have been the case that the skill set of the clinician who was required to lead a ReSPECT conversation / decision was not what was required.

We have learnt from other neighbouring areas that in the first days and weeks of the pandemic there were examples of misinterpretation of the use of a frailty score to inform an individual's treatment plan and consider the extent to which, if they were to require ventilation, they might be successfully be weaned off and able to recover. We have not been made aware that such decisions were made within our local system and would be keen to learn of them if this were the case.

The full LeDeR Review for each case will be examined in detail in due course and it is important that we do not at this point to jump to any conclusions about any underlying factors or lessons. I hope you trust that HWCCG are fully committed to understanding any aspect of learning that may be identified through the LeDeR process and will work with partners to address any gaps or concerns until we are assured. All LeDeR deaths reported up to the end of June 2020 will be completed by the end of December 2020 and we would be happy to involve Healthwatch in our Steering Group where the themes of lessons and agreed system actions will be shared.

The LeDeR programme includes a number of priority workstreams that are helping to drive improvements in practice and health outcomes. For 2020/21 HWCCG LeDeR is working closely alongside the Primary Care Team to support a national Quality Improvement module for Learning Disabilities as part of the Quality Outcomes Framework in General practice. This will provide a key opportunity to share examples of good practice and lessons identified by the LeDeR programme and its partners.

We are also interested to know more generally about the current policy in terms of sending out and completion of DNACPR forms and / or ReSPECT forms in care homes, so if you are able to give us any information about this, that would be great. If they are being sent out to care homes, what assurances are there that they are being completed / signed off by a relevant health professional and are able to involve family members as appropriate? Especially in terms of the current pressures on health services and limitations of care home residents to have face to face contact with professionals and families.

HWCCG are leading an STP wide implementation programme for ReSPECT. Any existing DNACPR forms are being phased out and replaced by ReSPECT documentation at the earliest opportunity for each person. As part of this programme of work ReSPECT forms have been made available to care home settings. ReSPECT forms are not yet nationally available in electronic format and are only available as a printed paper copy. Version 3 of the form will be available from mid-September and has been updated to further guide the level of personalisation about decisions reached. Completion of the form will enable trusted individuals known to the person (including care staff) to initiate the detail of conversations with individuals and their families ahead of the review and final 'sign off' of a ReSPECT form by the persons lead clinician. Sometimes this might be a specialist consultant but most frequently this is the persons GP.

Information about the national programme and its principles are available here https://www.resus.org.uk/respect

The usual preference would be to complete a ReSPECT form following a series of face to face conversations. The covid-19 pandemic has however altered usual working practices and so some forms have been initiated remotely. In some parts of the county local Hospices have provided a significant amount of training and support to Care Homes to enable appropriate and sensitive conversations about ReSPECT to be initiated. We appreciate that as the pandemic evolved not all care homes may have been able to access training and support available in as timely a manner as they would like due to the capacity of each Hospice to respond to requests for support. Learning review events are being coordinated by the CCG in partnership with the local authority, to review the experience of care homes during the pandemic. The approach taken is framed by a semi-structured interview and this includes a section on the experience of how ReSPECT principles were managed. Key learning from these events will be reported back into the ReSPECT Board where any identified action across agencies can be agreed.

The principles and process of the completion of ReSPECT forms extend beyond the rather simplistic focus of the historical DNACPR forms and so should support vulnerable individuals and their loved ones / families to have confidence in their capacity to have a voice in informing and deciding how they may be treated in an emergency situation. We know that you would agree that this is of vital importance for those with a learning disability and so we need to understand the detail available if there are examples where the process has been misrepresented or misused in any way.

I know we also touched on the issues of where forms are kept and communicated to others on Tuesday and them being kept up to date is also a potential issue.

The ReSPECT Programme Board is aligned to a wider End of Life workstream for HWCCG and the STP system. Additional posts within the CCG have recently been appointed to and this will further strengthen the implementation of the necessary training and implementation that is required to embed high quality processes and principles for ReSPECT across HWCCG footprint. The coordination and sharing of relevant information about preferences and decisions (including Best Interest decisions) is a critical factor within this programme and central to its benefits and effectiveness.

The STP Digital workstream is working closely with the End of Life workstream to ensure that the availability of the right information at the right time in the right place is enabled as speedily as possible so that personalised care preferences influence decisions that need to be made at critical points in a persons life.

We share your concern regarding the importance of ensuring that the inappropriate completion of ReSPECT forms does not disadvantage or discriminate against people with a learning disability. With the availability of specific examples we can be clear about how we can influence practice and any further improvements required. We have been provided with specific examples where ReSPECT forms within an acute hospital setting were not believed to be completed to a good standard and we have taken initial action to review this with a view to understanding the influencing factors in more detail to enable the system to collectively address this.

Where there are concerns about aspects of care delivery that HWCCG and the LeDeR programme can influence we are absolutely committed to ensuring that the circumstances are reviewed in sufficient detail to enable learning to be extracted and robust plans to be put in place to ensure that improvements are made.

I hope that this adequately answers the questions you have posed Morag. If it would be helpful to have a further conversation please do not hesitate to contact me.

Yours sincerely

Rachael Skinner
Associate Director of Nursing and Quality