Advance Care Planning in the context of COVID 19

What is ACP?

ACP is an ongoing process of conversations between patients, their care provider(s) and families (if the person wants this); to make clear their wishes and preferences about their future care and treatment. It is a voluntary process and takes place when a person has capacity and is only to be used when a person lacks capacity to make their wishes known. Having these conversations can reduce the distress caused by making difficult decisions at a time of life threatening clinical deterioration.

An advance care planning discussion may result in one or more outcomes:

- Statement of preferences and wishes (Preferred Priorities of Care)
- Advance Decision to Refuse Treatment (ADRT)
- Lasting Power of Attorney (LPA) for Health and welfare and/or Property and financial affaires
- Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)

Statement of preferences and wishes gives people the opportunity to talk and write down their preferences and priorities for care at the end of life. This is not a legally binding document but would be taken into consideration when decisions are made about care of the person if the person was not able to make the decision for themselves.
ADRT is a legally binding document that allows a person to say in advance what specific treatments they do not want to have, should they lose this decision-making capacity in the future.
A **LPA** for health and welfare and/or property and financial affairs is a legal process that allows a person to appoint one or more people to make decisions in these areas on their behalf should they lose capacity.
ReSPECT is a process which initiates and supports conversations and shared decision-making between healthcare professionals and their patients. Through this it creates personalised recommendations for an individual's clinical care in a future emergency in which they are unable to make or express choices. Ideally the ReSPECT process is completed ahead of any anticipated clinical deterioration but if the person was to lack capacity the discussions would take place with their family or advocate in their best interest.

What is the difference between ReSPECT & ACP's?

A ReSPECT form is a very specific type of ACP that summarises the emergency care aspect of a wider Advance or Anticipatory Care Planning process. It considers all aspects of care and treatment in an emergency. As well as decisions around resuscitation it may also include whether or not to admit to hospital and escalation of ceilings of care and treatment. ReSPECT records this information so as to make it accessible rapidly to professionals who need to make immediate decisions about care and treatment in a crisis, if someone is unable to make or express choices.

ACP more generally is completed with people who are able and willing to think ahead to a time in their illness when they may be unable to express their preferences. A Statement of Preferences and Wishes is usually longer and more detailed than ReSPECT. It is not restricted to planning for an emergency, and is likely to contain information about understanding of prognosis and personal preferences such as self-management plans, place of care preferences, thoughts about what they would want for any dependants (elderly relatives, children, pets); spiritual/religious needs/wishes; funeral plans.

How does ReSPECT fit in with existing documents and ACP?

ADRT is a legally binding document and states what people DO NOT want.

A ReSPECT form is NOT legally binding & focuses only on making recommendations about care and treatment to consider in an emergency.

A ReSPECT form can be used to draw attention to the presence of an ADRT and should contain relevant aspects within the summary recommendations for treatment and care.

A ReSPECT form will also document whether there is an LPA and other key persons to be contacted in an emergency.

ACP and ReSPECT are entirely complementary. They may be developed together, from the same conversations, or the development of one may prompt people to discuss the other.

What is the difference between ReSPECT & End of Life Care plans?

Use of and potential benefit from the ReSPECT process is not restricted to people with life-limiting illnesses or those in need of end-of-life care. End-of-life Care plans record a person's individual care and treatment needs as they approach the end of their life, and are not limited to recommendations for use in an emergency. For people approaching the end of life, the two plans can be complementary. Care must be taken to ensure that both types of plan address the specific needs of each individual.

ACP in the context of COVID 19

It is important that ACP conversations are offered to all vulnerable patients at the earliest opportunity because of the potential rapid nature of deterioration with COVID -19. Although these are difficult conversations many patients are likely to have thoughts and concerns about their situation within this crisis and welcome the opportunity to talk about them. Those with existing ACP may wish to review them in light the changes brought about by COVID 19. For anyone making and reviewing ACP at this time they can be reassured that it will be reviewed again when this crisis is over.

Consideration may be given to:

- the need for clear explanations on what will happen to their care if they deteriorate with or without COVID 19 both in staying at home or going to hospital, a hospice or care home;
- alternative caring arrangements may need to be considered in case the main carer(s) become unwell with COVID 19;
- families will not able to be with patients in hospital (which raises the potential of dying without their family);
- planning for ways of ensuring people can maintain contact during this time;
- Healthcare teams having the contact details of the main person to pass information onto about the patient. In absence of a LPA for health and welfare a patient can identify who they wish to be their named spokesperson/s;
- evidence that an LPA is valid can be done by searching the Office of the Public Guardian register online;
- an ADRT made previously it might not be valid if the person contracts COVID 19 because this circumstance would not have been predicted, they may wish to review their decisions within this context and have them recorded on a ReSPECT form;

- If funeral plans have been made alternative arrangements may wish to be considered for this period in line with government guidance on how funerals can be conducted.

ACP- Recording and Sharing

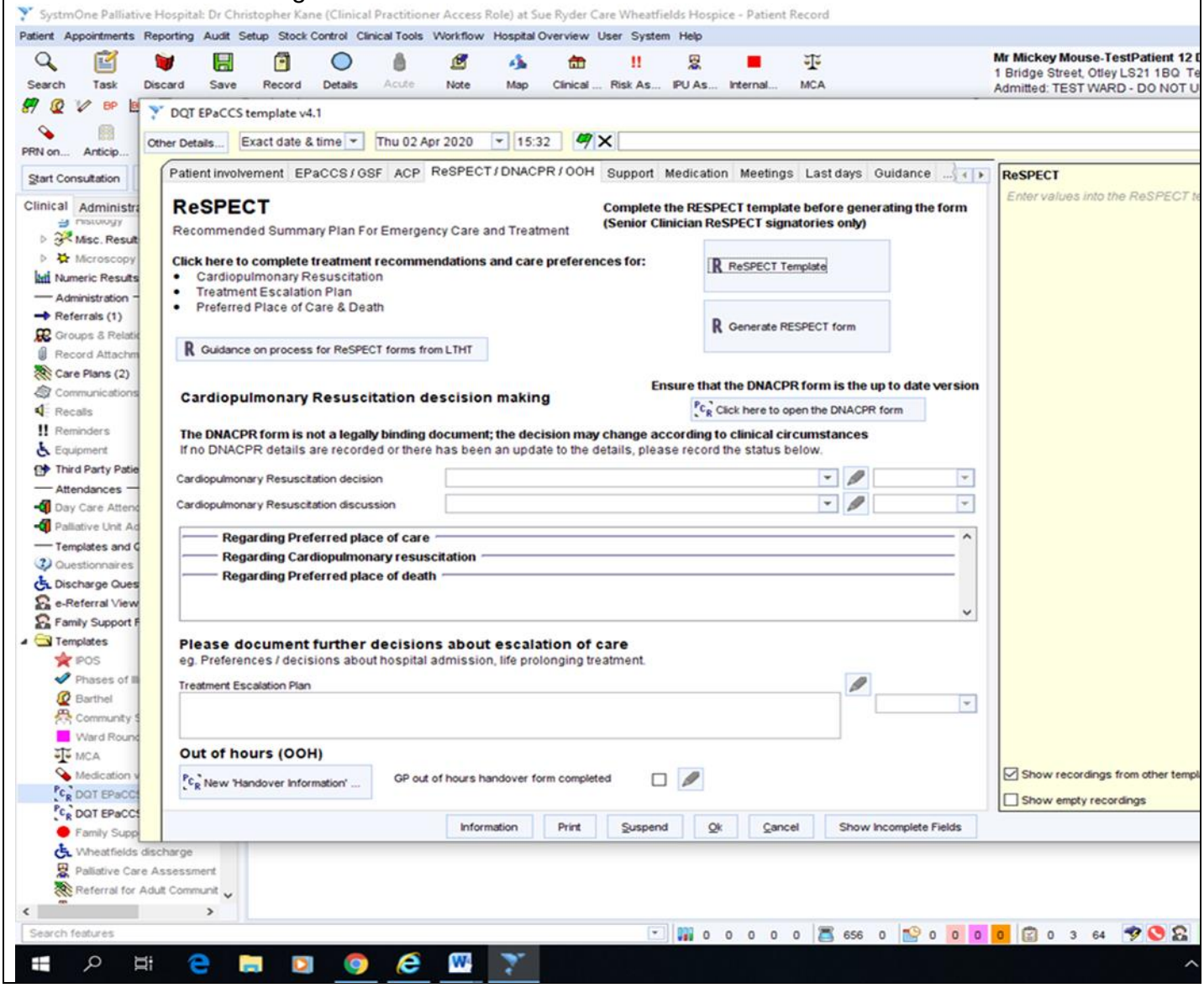
Following any ACP discussions it is important that those who are close to the patient and those involved in their care know:
WHAT the Advance Care Plan includes?
HOW it is captured, are there are any particular documents?
WHERE they are kept?

There is not one overarching document at the current time which everyone uses to capture everything in detail, but it is important to record key decisions on a central database – Electronic Palliative Care Co-ordinations Systems (EPaCCS)on SystmOne or Emis; Leeds Care Record.

EPaCCS has the ability to record areas such as: preferred place of care; preferred place of death; mental capacity; if there has been a discussion with family; the existence of a LPA and also where any ACP documents are kept e.g. ADRT/ Statement of preferences and wishes.

There are various documents where people may record their Statement of preferences and wishes (Preferred Priorities of Care), so if someone has completed a paper version it can be shown to the healthcare professional for transcribing onto an electronic system. An individual may have both paper and electronic ACP records in existence; any updates must be replicated across all formats.

ReSPECT can now be generated on EPaCCS



Resources

More in depth information can be found on the Leeds Palliative Care Network (LPCN) website in a dedicated section to Advance Care Planning:
https://leedspalliativecare.org.uk/professionals/resources/advanced-care-planning/

It would be useful to read this guidance alongside other documents found on the LPCN COVID 19 information for professionals page**:**
https://leedspalliativecare.org.uk/professionals/covid-19-support-for-professionals/

Planning Palliative Care
ACP Discussions About Goals of Care
EPaCCs ReSPECT COVID 19 Update