**MINUTES of the PATIENTS’ FORUM**

**MONDAY OCTOBER 8th 2018**

**ATTENDANCE: FORUM MEMBERS AND ASSOCIATES**

Alex Thornton – Student Paramedic – Hertfordshire Uni

Amy Moore – King’s College London

Anthony Alcock - Paramedic LAS

Audrey Lucas – Enfield- Executive Committee

Barry Hills – Kent

Chris Fox -

Cllr Dora Dixon-Fyle - Southwark

Colin Hill – Berkshire

Elaina Arkeooll – Hammersmith and Fulham

James Guest – Ealing

Jan Marriott – Richmond

John Larkin- Company Secretary - Barnet

Luz Fox -

Lynn Strother – City of London Healthwatch – Executive Committee

Malcolm Alexander – Chair, Patients’ Forum - Hackney

Mary Leung – Harrow

Mike Roberts - Hampshire

Myles Simmons – Paramedic - SECAMB

Nicole Taylor – Paramedic LAS

Philip Ward – Hammersmith and Fulham

Sean Hamilton - Greenwich

Sister Josephine Udine – Chislehurst - Vice Chair

Vic Hamilton – Greenwich

**SPEAKERS**

**Ian Wilmer - Advanced Paramedic Practitioner - Critical Care**

**Sean Hamilton - Service User**

**Vic Hamilton – Carer**

**LONDON AMBULANCE SERVICE:**

ZAFAR SARDAR – LAS - EMERGENCY OPERATIONS CENTRE/UNISON

SAMAD BILLOO – LAS EOC/UNISON

**COMMISSIONER’S REPRESENTATIVE: Nil**

**APOLOGIES**

Alexis Smith - Bromley

Angela Cross-Durrant – Kingston – Vice Chair

Arthur Muwonge – Croydon

Beulah Mary East – Hillingdon

Catherine Gustaffe – Southwark

David Payne – Southwark

Dhanesh Sharma – Bexley

Graeme Crawford – Ealing

Inez Taylor – Southwark

Jan Duke – Southwark

Joseph Healy – Southwark – President of the Forum

Louisa Roberts – Tower Hamlets

Natalie Teich – Islington

Rashid Ali Laher – Healthwatch Kingston

Robin Kenworthy – Kent

Simon Mott – Tooting

Wendy Mead – City of London

**Ian Wilmer - Advanced Paramedic Practitioner - Critical Care,**

**Sean Hamilton - Service User,**

**Vic Hamilton – Carer were welcomed to the meeting.**

**1.0 Minutes of the meeting held September 10th 2018 were agreed a correct record.**

**1.1 MATTERS ARISING**

**1.2 LAS AGM** – 18 Forum members attended the AGM. Members reported that the AGM had gone well, was constructive and was more interesting and well organized than previous AGMs. The main theme had been mental health care and the speakers on this subject had been excellent. Noted that following a request to the LAS Chair for live streaming of LAS meetings, that this system had been introduced to the AGM. Progress is awaited for live streaming of all LAS Board meetings. It was also reported that the acoustics in the room were poor and some speakers were difficult to hear.

Members put a number of questions to the Board and the formal responses to these questions are awaited. A question about the Forum’s request for reintroduction of the LAS alcohol bus was answered by Paul Woodrow who described a new approach to supporting heavily intoxicated people on London’s streets.

Action: Request copy of questions put by the Forum and its members and LAS responses from Philippa Harding, LAS governance lead.

Elaina drew attention to an issue raised by a speaker at the meeting concerning the overuse of anti-psychotic drugs.

**www.patientsforumlas.net/uploads/6/6/0/6/6606397/las1.pdf**

[www.youtube.com/watch?v=7gPkL8yfh7Y&feature=youtu.be](https://www.youtube.com/watch?v=7gPkL8yfh7Y&feature=youtu.be)

**1.3 EQUALITY AND DIVERSITY - Melissa** Berry has replied to the Forum’s questions on the development of E&D in the LAS and the response is attached. She has also provided a copy of the WRES plan for the LAS (Workforce Race Equality Scheme) which is going to the LAS Board for approval.

**1.4 ACCESS TO LAS BOARD PAPERS –** The LAS continues to refuse access to hard copy LAS Board papers. The Forum has submitteda Freedom of Information request to the LAS and their response is awaited.

**1.5 EMERGENCY OPERATIONS CENTRE -** a) Dates for visits to the EOC at Waterloo and Bow have been requested from Pauline Cranmer for November and December. b)Advertising hoardings for recruitment to the EOC have been agreed but not yet produced.

**1.6 PATIENT SPECIFIC PROTOCOLS (PSP) –** The PSP information leaflet for patients and the public has been designed by the LAS communications department, and taken back to the Forum for final wording. It will then be placed on LAS and Forum websites and distributed through the Forum and Patients’ Forum to CCGs, GPs etc.

**1.7 PRISONS AND SECURE ENVIRONMENT –** The Forum has written to KateDavies, Director of Health & Justice Services Commissioning, concerning delays in the LAS obtaining access to patients in prisons and Immigration Removal Centres. LAS crew have also reported long delays in getting out of prisons. A meeting has been requested with her.

**1.8 DEFIBRILLATOR CAMPAIGN –** The Forum’s Defibrillator News has been distributed and the Mayor of London will raised the issue of CPR on October 16th Restart Heart Day. PHE are also now expressing interest in promoting the use of defibrillators.

**1.9 LAS COMPLAINTS AUDIT METHODOLOGY –** We have submitted a methodology for the external audit of complaints by the Patients’ Forum, but this has not yet been agreed by the LAS. Refer to Trisha Bain, Chief Quality Officer for update. Thanks to Angela Cross-Durrant for doing the ground work.

**1.10 FLU VACCINATION RATES IN AMBULANCE SERVICES –** The Forum is in contact with the Association of Ambulance Service Chief Executives (AACE) and Public Health England regarding the uptake of flu vaccination by front line staff.

**1.11 LONDON ASSEMBLY REVIEW OF THE LAS –** The LAS is due to give evidence to the London Assembly Health Committee on October 11th.

**Action:** Contact Lucy Brant the Scrutiny organiser, to update the Forum on the report and outcome process.

**1.12 WORKING WITH SOUTH EAST COAST AMBULANCE SERVICE (SECAMB)**

Noted that the LAS and SECAMB are collaborating to offset the impact of a no-deal Brexit. This includes jointly seeking sources of new ambulances.

**2.0 EPILEPSY AS A MEDICAL EMERGENCY - IMPROVING URGENT AND EMERGENCY CARE**

* **Ian Wilmer - Advanced Paramedic Practitioner - Critical Care**
* **Sean Hamilton - Service User**
* **Vic Hamilton – Carer**

**2.1 Types of Convulsion**

•First Aid

•Prolonged convulsions

•Psychogenic Non-Epileptic Seizures

•LAS treatment

•Conclusions

•Future developments

2.2 Ian described the various names for used to describe epileptic fits – which includeconvulsion and seizure (same meaning) and the range of fits:

•Epileptic convulsion (generalised, focal, absence)

•Patient with epilepsy (‘epileptic’?)

•Provoked convulsion

•Prolonged convulsions (CSE **Convulsive** status epilepticus)

•Psychogenic Non-Epileptic Seizure (PNES)

•*Syncope* (faint or cardiac)

•*Eclampsia* (during/after pregnancy)

2.3 He said that an epileptic convulsion is a seizure caused by sudden, excessive, disorderly electrical discharge in groups of brain cells, but that this phenomenon is not necessarily caused by epilepsy, whereas a patient with epilepsy has a chronic disorder characterised by a lowered epileptic seizure threshold. 1:100 people experience epileptic fits.

A provoked convulsion is an **epileptic** seizure caused by irritation of the brain e.g. head injury, stroke, alcohol, hypoglycaemia, drug overdose or infection.

2.4 A generalised convulsion involves both sides of the brain and a

generalised stiffening muscle spasm (tonic), and then rhythmic jerking of the limbs (clonic). This is also known as a Bilateral Tonic-Clonic Seizure (BTCS)

Other types of fit are described as “absence seizures” which occur when generalised awareness is suddenly lost, and the patients becomes blank and or unresponsive. “Focal” fits are limited to one side of the brain, with variable consciousness.

2.5 Generalised epileptic fits are usually short lasting and finish in under 90 seconds – they are self limiting and recovery is slow. First aid following a fit should be focussed on protecting the patient from harm, clearing the immediate area, providing padding under the person’s head and allowing the fit to resolve - and to put nothing in the person’s mouth.

It is advisable to call 999 if it the person’s first seizure, it repeats over a period of five minutes, if the person has a significant injury or if the person is unconscious ten minutes later.

2.6 With Convulsive Status Epilepticus (CSE), seizures last longer than 5 minutes or occur one after another with no recovery in between. During CSE there may be insufficient energy production, causing brain cell death possibly resulting in permanent brain damage or death. Brain damage occurs in 3-15% of CSEs and death in 32% of CSE fits that last for more than one hour.

The longer a seizure persists, the less likely the patient is to respond to drugs resulting in a higher chance death and long term disability. Delays in treatment of greater than 30 mins lead to poorer outcomes including the risk of SUDEP (Sudden Unexplained Death in Epilepsy), fluid on the patient’s lungs and aspiration pneumonia.

2.7 Psychogenic Non-Epileptic Seizures (**PNES**) are **not** accompanied by abnormal electrical discharges in the brain and are usually caused by an involuntarypsychological response to distress, and may be associated with recent or historic emotional trauma. PNES are often wrongly diagnosed as epilepsy (in 20-30% of cases) and may also be called a: ‘non-epileptic attack disorder’, ‘dissociative seizure’, ‘functional seizure’, ‘conversion disorder’ or pseudo-seizure.

* 33% of PNES have been in ITU
* 20% of prolonged seizures are PNES
* 50% of refractory seizures are PNES (poorly controlled by usual epileptic medicines)

New national guidelines are expected in 2019 and are expected to include a section on PNES.

2.8 Clinical differentiation between epilepsy and PNES is essential, is sometimes challenging - but not impossible. Diagnosis requires determination of whether the fits are consistent or fluctuating and whether they are synchronised. Other diagnostic criteria include: neurological responses, movement of the eyes, verbal behaviour and types of movement. If the clinician is in doubt the patient should be treated as CSE.

2.9 LAS assessment and treatment of patients with epileptic fits includes identification of a patient’s ‘postictal’ state, ensuring the patient is in the right position, checking airway, giving O2 if necessary and providing appropriate support. If the patient is recovering well, conveyance to hospital is not necessary, unless it is the first fit experienced by the patient.

The **postictal** state is the altered state of consciousness after an epileptic seizure. It usually lasts between 5 and 30 minutes, but sometimes longer in the case of larger or more severe seizures, and is characterized by drowsiness, confusion, nausea, hypertension, headache or migraine, and other disorienting symptoms.

2.10 Diagnosis of CSE is based on the ABC assessment ([Airway](https://en.wikipedia.org/wiki/Airway), [Breathing](https://en.wikipedia.org/wiki/Breath), and Circulation) and clinical history. The patient’s airway is checked and O2 is given if necessary. The decision whether to take to hospital depends on whether the patient is recovering, details of the patient’s history, support, location and any concerns about patient’s safety. Identification of reversible causes of CSE, e.g. raised blood sugar, is important. Medication is given if a convulsion lasts five minutes or more and the patient is taken to hospital asap, unless a reversible cause of the fit is identified. Medication is not given if the convulsion has stopped.

2.11 There are three levels of medical treatment. Paramedics can give two doses of Diazepam (via the rectal, IV or intra-osseus routes). The LAS is concerned by the

advice given in the paramedic clinical handbook (JRCALC) concerning the PR (per rectal) in adults under 70 years old; and therefore administer a lower dose.

The LAS usually gives 10mgs of rectal diazepam initially and seizures usually stop within 5 minutes and sedation lasts for a few hours. Alternatively, if the patient has been prescribed Midazolam, one to two doses can be given by the buccal route (between gum and cheek). Advanced Paramedics (critical care) can give Midazolam-(buccal), IM or IV. A&E can give Phenytoin, Levetiracetam (Keppra) or an anaesthetic.

2.12 Treatment of PNES (Psychogenic Non-Epileptic Seizures) is based on support and sympathy (not medication) and treatment as a mental health problem. There are concerns about the treatment of PNES, because the condition is poorly understood and NHS staff may not show the required level of understanding because of inadequate training.

2.13 It is rare for the LAS to be called to focal convulsions, so paramedics are unlikely to have a lot of experience in deciding whether to treat this type of fit.

For children the treatment is the same as CSE, but for adults the treatment programme is currently unclear and new guidelines are required. Advanced paramedics do have clear guidance for treatment of focal convulsions, which includes treatment with Midazolam

**2.14 In conclusion Ian said that:**

a)    It is felt that too many recovered patients who have had a fit are

being taken to A&E

b)    Care of PNES (Psychogenic Non-Epileptic Seizures) is not well

understood by front line paramedics and is care is probably sub-

optimal.

c)    LAS has not introduced the national recommended dose of rectal

diazepam, because of their concerns the dose is too high. Ian does

not agree.

d)    Paramedics don’t have IM Midazolam in UK

e)    The recommendations for focal convulsions in adults are unclear.

New national adult convulsion guidelines are expected next year, and if the draft is accepted will include:

* A section on PNES
* IM Midazolam for CSE – not IV
* A section on focal seizures in adults

In the long term - Advanced Paramedic Practitioners may explore the option of giving alternative second line medications.

**Ian Wilmer was thanked for his excellent presentation.**

2.15 Vic and Sean Hamilton described their experiences of urgent and emergency care for the treatment of epilepsy. Sean has epilepsy and Vic his father is his carer. Sean finds it very difficult to go out without his father in case he has a fit. Vic described the family situation where both his son Sean and has wife have epilepsy and sometimes they suffer fits at the same time.

Sean described his experience of hospital A&E departments, which he said sometimes made his condition worse. He said there were many co-morbidities with epilepsy and that medical diagnosis of epilepsy can be difficult and can be confused with other conditions – he said that different doctors may give a different diagnosis for the same symptoms and may be unclear about diagnosis of a true seizure. Sean said that it can be very hard to explain his condition to other people, particularly because he loses awareness of what is going on around him when he has a fit. Bystander anxiety can make it worse, whereas his father’s voice calms him.

2.16 Sean described his experience of seizures on trains, where people have ignored him, walked over him and assumed he was drunk. He said he can consequently no longer travel around without his father. Referring to responses from the train crew and the police, he said that the protocol can be confusing and attempts to remove a fitting person from a train can worsen the situation. He said that the LAS and transport police have a lot to learn about responding to people who have fits on trains and in stations.

Referring to the steps needed to prevent admission to hospital following a fit, Sean said that it would be useful if ambulance services could coordinate their vehicles so that a patient who is safe to go home after a fit, which has occurred away from the person’s home, could be taken by interconnected ambulance services and then safely discharged home. He suggested that NHS Digital could support the development of a more interconnected ambulance service.

**Vic and Sean were thanked for their excellent contributions to the meeting.**

**2.17 In response to questions from the Forum Ian Wilmer and Fenella Wrigley (Medical Director) gave the following answers:**

Q1) When there is a call to EOC for a patient suffering epilepsy/convulsion, are paramedics always sent?

A1) If the caller reports that the patient is unconscious and still convulsing, then a paramedic is part of the pre-determined response profile – a paramedic is automatically sent if available at a reasonable distance.

Q2) Do technicians/EACs have the competence and skills to respond to epilepsy/convulsion patients? What role do they have for these patients?

A2) Most patients with epilepsy have stopped convulsing before the LAS arrive, and therefore EAC/EMTs should be able to provide the care they need. If the patient is having a provoked convulsion from the most common cause (low blood sugar) the EAC/EMT can treat most of these with the medications they have available (glucose gel between fits and Glucagon injection during fits). Occasionally IV glucose may be required, and this is a paramedic only skill. If the patient is having a psychogenic non-epileptic seizure (and this is recognised) EAC/EMTs can provide all the care required. If the patient had their own prescribed buccal Midazolam with them, then an EAC/EMT can administer that to them. It is only in the small number of cases of prolonged convulsions (Convulsive Status Epilepticus), where the patient does not have their own medication, that a paramedic is required. This is why a paramedic is part of the planned response to these patients.

Q3) How many serious incidents (SI) per year since 2000 have been related in any way to epilepsy? We appreciate that it might be difficult to obtain such a large set of data, but would be interested to see what is available.

A3) We cannot provide this information for the last 18 years. However, we have looked back over the past 12 months and there has been one SI declared relating to Epilepsy.

Q4) How many datix/LA52 have been entered in relation to epilepsy calls over the past year?

A4) There have been 29 incidents logged on Datix in regards to calls/incidents we have attended.

Q5) Have there been any PFD (preventing future death) notices from coroners in relation to epilepsy and what recommendations were made to prevent future deaths?

A5) None

Q6) Are you aware of PFDs (preventing further death notices) in relation to epilepsy from other AS in the UK?

A6)  None

**2.18 Audrey Lucas** asked about treatment for the massive headaches that can follow fits. Ian replied that the response depends on how long the fit has lasted and added that after a fit patients often experience headaches, sleepiness and muscle ache. Ian said that patients who experience fits lasting a long time (5 minutes plus) should go to hospital, but for shorter fits going to hospital, despite side effects of the fit is not necessary – observations by the LAS crew should however continue until the patient is safe to discharge.

**2.19 Mike Roberts** described having a fit in WH Smiths and being seen by a crew from SECAMB service. He described feeling groggy after the fit and it taking 3.5 hours to recover. He said that the fit followed a motor bike accident.

**2.20 Elaina** **Arkeooll** described the importance of Patient Specific Protocols for patients who suffer severe episodes of epilepsy, which require specialized care. Ian agreed but pointed out that PSPs are linked to addresses not people, and if the person has a fit away from their home, the PSP would not be useful unless the person was carrying a copy with them.

**2.21 Alex Thornton** a paramedic student from Hertfordshire University said that the guidelines for care and treatment of patients with epilepsy are not very specific. He asked if a paramedic would be criticized by the coroner or, if a patient who had been fitting was left at scene and later died. Ian replied as follows:

The new adult convulsions guidelines due out next year should help. The general view is that most 'simple' convulsions, in patients known to have epilepsy, who have not injured themselves, and have recovered, do not need to go to hospital. Giving very specific guidance for who is safe to leave at home can be a challenge. In answer to the coroner question, it depends on the patient. If the paramedic has considered the history, risk factors and family support, and done a reasonable patient assessment; then a paramedic would not be criticised. Ian said that the critical questions to consider are: was your decision reasonable and what would a group of your peers think? If there were clear signs that the seizure was caused by meningitis or a cerebral bleed and you hadn't recognised that, then yes you probably would be criticised.

**2.22 James Guest** asked whether it was useful to place a pencil or similar object in a person’s mouth when they are fitting to stop them from breaking their teeth? Ian said using a pencil is now regarded as too risky and potentially harmful.

**2.23 Ian Wilmer** was asked whether fluorescent lights and flash photography are liable to induce a fit in a person with epilepsy. He confirmed this was the case for some people and added that all patients are different and that there are 60 different types of epilepsy, so people will respond differently to different stimuli.

**2.24 Jan Marriott** thanked Ian for his expertise in the field of epilepsy and asked for more information about caring for a person after a fit. He replied that the support needed after a fit varies enormously, e.g. children may take a long time to recover from a fit. Ian said that each person’s needs are different and that it is important to respond to their specific needs rather than use standard procedures.

**2.24 Sister Josephine** asked if there were specific care pathways for the different types of epilepsy. She also asked for more information about the misdiagnosis of mental health problems as epileptic fits, and the risk of wrongly treating the patient with drugs for an epileptic fit.

**2.25 Ian Wilmer** replied that there are care pathways for convulsions in adults and children in the JRCALC guidelines (Joint Royal Colleges Ambulance Liaison Committee), which are followed by all front line ambulance staff. He added that time is needed for a full assessment, to ensure that the patient is either taken to hospital or safely left at scene. Ian said that new guidelines will be produced in 2019, which should include methodology for differentiating between fitting in mental illness (PNES) and epileptic fits. He said this is expected to reduce the incidence of harm caused by incorrect administration of epileptic drugs. He added that the guidelines are also expected to recommend either buccal or intramuscular use of Midazolam, rather than IV. Ian said that the JRCALC guidelines are advisory, not mandatory and that they are not the most up to date guidelines, in terms of promoting medical advances in pre-hospital care and treatment of epilepsy.

**2.26 Elaina Arkeooll** asked Sean if he had a PSP (Patient Specific Protocol). Sean said he does not, and that he has a complex type of epilepsy, which can be difficult for doctors and paramedics to diagnose and to identify causative factors for fits.

**2.27 Myles Simmons** explained that a PSP (ReSPECT/Coordinate my Care) can be developed jointly by doctors and patients as a care plan, to ensure that the patient gets the right care, first time from the LAS and other providers across the country. Myles agreed to provide some more detailed information.

**2.28 Sean Hamilton highlighted the following issues:**

a) Problems with public transport. He said that some transport providers are proactive in supporting him, but others are problematic.

b) The failure of NHS bodies to share comprehensive medical notes about him, so that if he has a fit away from his home area it may be difficult to get the most appropriate urgent and emergency care.

c) It is essential for understanding to develop in the community about the best way of supporting and assisting people who have epilepsy, especially when they have a fit. Understanding an individual’s specific needs would help families and demystify epilepsy.

**https://www.epilepsysociety.org.uk/emergency-medication#.W93u7JP7SUk**

**See also appendix 1 relating to a detailed description of ReSPECT**

**3.0 Risks to the LAS associated with a ‘no-deal’ Brexit**

3.1 The Forum has written to the LAS and 25 other NHS Trusts regarding their preparations for a no-deal Brexit. A brief reply has been received from the LAS and a detailed paper will be put to the November LAS Board meeting. The questions put to the LAS were as follows:

In relation to your preparations for possibility of a no-deal Brexit, and in the absence of NHSE guidance on preparations for this risk:

1)   What percentage of your staff are citizens of other European Economic Area (EEA) countries?

2)   What percentage of the EEA citizens you identify in Qu 1 are classified as paramedics, doctors, nurses and other front line staff groups?

3)   Can you supply your strategy (or action plans) for retaining staff who are EEC citizens, and describe how you assist them in relation to their legal status and rights issues?

4)   What percentage of EEA staff do you expect to leave the Trust by March 2019?

5)   Can you supply your long term strategy (or action plans) for recruitment of staff to replace EEA staff who leave the Trust?

6)   Have you identified which medicines and medical devices are most likely to be affected by supply problems as a result of a no-deal Brexit?

7)    Can you supply your strategy (or action plans)  designed to ensure that patients are not subject to harm as a result of delay or disruption to the medicine and medical devices supply chain caused by a no-deal Brexit.

**4.0 AMBULANCE RESPONSE PROGRAMME - ARP**

4.1 Noted that when the ARP was introduced, NHS England informed the Forum that full compliance with the 4 new targets was expected. It has become clear that the failure to meet targets continues, (like the previous system-categories A and C). Noted also that formerly the average number of calls to the EOC in 24 hours was 1000 and now has risen to 5500. It is clear that LAS resources do not match demand.

4.2 Samad Billoo explained that while people are waiting for a response to their 999 calls, that new calls are constantly coming in with a higher priority, which must be responded to. Delays in appropriate responses can also be due to incorrect assessment and to practical issues like road works.

**4.3 Myles Simmons** explained that in the Cat A&C system (the previous system), getting the wrong resource to the patient within 4 minutes was regarded as a success, whereas getting the right resource to the patients in ten minutes and saving the person’s life was regarded as a failure to meet targets, because the response exceeded 8 minutes.

**5.0 SUPPORT FOR INTOXICATED PATIENTS**

5.1 Noted that the Forum has written on several occasion to Dr Johal on this subject but received no reply. An FOI will be sent to Brent CCG, the commissioner of the LAS. The CCG has deteriorated considerably in its commitment to patient and public involvement and the issue will be raised with the CQC if the poor performance continues.

**6.0 LAS PERFORMANCE DATA**

The data set was noted.

**7.0 Meeting closed at 7.30pm.**

**APPENDIX**

**ReSPECT (Recommended Summary Plan for Emergency Care and Treatment**

Here are some details regarding the ReSPECT form. This system is not used by local CCGs in London or hospitals, hospices or GP centres. ReSpect facilitates the production of recommendations (care plan) for a person’s clinical care in a possible future emergency, in which they may lack capacity or be unable to make or express choices about treatment options. It provides health and care professionals responding to that emergency with a summary of recommendations to help them to make immediate decisions about that person’s care and treatment

The plan is created through conversations between a person and their health professionals. The plan is recorded on a form and includes their personal priorities for care, and agreed clinical recommendations about care and treatment that could help to achieve the outcome that the patient and doctor most want. It also specifies those that would not help, and those they would not want. A specimen form can be found at the following web address: <https://learning.respectprocess.org.uk/#modules> and Web Learning app -<https://learning.respectprocess.org.uk/>

**Why ReSPECT?**

For many years there has been debate over the use and design of DNACPR forms, together with a recognition of their limitations. The ReSPECT process was created following a systematic review of DNACPR decisions and documents. An approach that focuses only on withholding CPR in people who are dying or for whom CPR would offer no overall benefit has resulted in misunderstandings, poor or absent communication and poor or absent documentation. ReSPECT aims to encourage patient and family involvement in decision-making, to consider recommendations about CPR in the context of broader plans for emergency care and treatment, and to record the resulting recommendations on a form that would be used and recognised by health and care professionals across the UK.

**Who developed the form?**

ReSPECT has been developed by a Working Group comprising more than 30 representatives of the public and of professional organisations from a range of care settings and clinical specialties. Members of the Working Group have given a vast investment of time and energy to the project thus far. Much of the funding and facilitation of the project has been provided by the Resuscitation Council (UK), with support from the Royal College of Nursing. Invaluable design work has been provided by HELIX, through funding from the Oak Foundation. A substantial grant from Macmillan Cancer Support will provide public-facing and educational materials to support implementation of ReSPECT. Including AACE

**Who benefits from ReSPECT?**

This process can be for anyone, but it is especially relevant for people with:

* particular health needs that may involve a sudden deterioration in their health with a life-limiting condition
* advanced organ failure,
* advanced cancer
* frailty
* epilepsy
* diabetic crisis
* at foreseeable risk of death or sudden cardio-respiratory arrest who want to complete the ReSPECT process and documentation for other reasons

**Can the ReSPECT form be used wherever the person is?**

Yes. For example, once it has been adopted in a health community it can be used in the person’s home, in hospitals, hospices, care homes, nursing homes and during ambulance journeys. For that reason, it is important that the person keeps it with them, and that it is readily available for professionals who may need to see and use it. The person should take it with them if they go out or travel away from their home, and make sure that their family, friends or carers know about it, and know where to find it in an emergency. Clinicians should help people to understand the importance of this. If the person moves from one place to another (e.g. to or from home, hospital, hospice, care home, nursing home or from one hospital ward to another) it is good practice to review the ReSPECT recommendations to ensure that they remain valid, but a new form will not be not needed unless the recommendations change.

**What happens to DNACPR forms or Treatment Escalation Plans (TEPs) that are already in existence?**

Existing DNACPR forms and TEPs will continue to be effective and do not need to be replaced immediately. When healthcare communities implement the ReSPECT process there must be a robust plan to ensure that existing DNACPR forms or TEPs remain valid for a substantial period of overlap. ReSPECT is not just a replacement for a DNACPR form; the aim is to promote recording an emergency care plan by many more people, including many whose ReSPECT forms will recommend active treatment, including attempted CPR if it should be needed.

**Is a ReSPECT form legally binding?**

As with current DNACPR’s - No. The ReSPECT recommendations are to guide immediate decision-making by health and care professionals who respond to the person in a crisis. However, they should have and be prepared to justify valid reasons for overriding the recommendations on a ReSPECT form.

**Why is there no section on the ReSPECT form for the signature of the person or their relatives/legal proxy?**

As with current DNACPR’s a ReSPECT form records clinical recommendations for emergency care arising from patient-centred discussions, and is neither an ADRT nor a ‘consent form’. It does not require signature by the person themselves or, if they already lack capacity when it is completed, by their representatives. Asking a person with capacity to sign a form would be likely to be misinterpreted as suggesting that it has a legal status that is not the case. The recommendations on the form are to guide immediate decision-making by professionals present at the time of a crisis in which the person does not have capacity to make or express decisions. It is the responsibility of the health professionals completing the form to sign it, as they would sign any clinical documentation or record of discussion. By so doing the clinician confirms that they have both complied with capacity and human rights legislation, and complied with best practice in communication and shared decision-making, or where the latter was not practicable or appropriate to state the reasons.

**Who can create one, and who should it be for?**

Anyone involved in the care of the patient can initiate the process, where this seems to be likely to be helpful. It does not have to be the GP or the hospital doctor and may, for example, be a specialist nurse involved in the person’s care. Technically, ReSPECT could be completed for any patient at any time but, realistically, it will be used mostly for those whose health might deteriorate acutely. Initially, many will be completed during an acute admission to hospital, but as time goes by it is hoped that more people will have them completed when they are relatively stable, so that their ReSPECT forms can guide decision-making when they become acutely ill and hospital treatment is considered.  Initiation of ReSPECT across a range of community, hospital outpatient and inpatient settings will offer people the maximum opportunity to think ahead and plan for their care in a future emergency. These documents will be created and signed by a range of clinicians working in both acute and community settings. Not by Ambulance Clinicians working in the Ambulance Service although paramedics working in the community, for example in GP surgeries may complete them.