Patient expert statement

**Cefiderocol for treating severe aerobic Gram-negative bacterial infections evaluation**

Thank you for agreeing to give us your views for this evaluation.

You can provide a unique perspective on the impact of severe, potentially life-threatening, drug-resistant infections that is not typically available from other sources.

If you would like help with your submission or somebody to read a draft for you, please contact PIP@nice.org.uk or Mandy.Tonkinson@nice.org.uk

You do not have to answer every question – they are prompts to guide you. The text boxes will expand as you type.

**Information on completing this expert statement**

* Please do not embed documents (such as a PDF) in a submission because this may lead to the information being mislaid or make the submission unreadable
* We are committed to meeting the requirements of copyright legislation. If you intend to include **journal articles** in your submission you must have copyright clearance for these articles. We can accept journal articles in NICE Docs.
* Your response should not be longer than 10 pages.

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| **About you** |  |
| 1.Your name  | Nicola Andrews |
| 2. Please specify whether you are a patient, carer, employee/volunteer for a patient organisation, or none of the above (please specify) |  Carer (to my late husband Julian Andrews 24.05.1962 – 15.07.2020). Julian had non-Hodgkin’s lymphoma and was treated with several different chemo regimens, an autologous stem cell transplant in 2017 and an allogeneic stem cell transplant (from an anonymous donor via Anthony Nolan) in August 2019. |
| 3. Name of your nominating organisation | Anthony Nolan |
| 4. Did your nominating organisation make a submission?  | Yes  |
| 5. Did you write your nominating organisation’s submission? | I offered some insights |
| 6. If you did not write your nominating organisation’s submission, do you agree with its content? We would encourage you to complete this form even if you agree with your nominating organisation’s submission, but this is not compulsory. | Yes I do |
| 7. How did you gather the information included in your statement? (For example, personal experience of a severe infection, or drawing on others’ experiences). | Personal experience of my husband suffering repeated severe infections over approximately an 18-month period. |
| Experience of infection |  |
| 8. What is it like to have a severe, drug-resistant infection? This refers to an infection which requires urgent treatment in hospital, for which there are limited antibiotics that work. These infections can be life threatening. For example, sepsis (blood stream infection), hospital-acquired pneumonia, or complicated urinary tract infection. Please include details of the type of infection you had (or that someone you care for had), if you are able to. For example, location in the body, the type of bacteria that caused the infection, and how many courses of antibiotics were used. | My husband experienced multiple hospital admissions and long courses of IV antibiotics. He suffered from multiple drug resistant klebsiella urine infections. He also had poor graft function (low blood counts) which the medical team felt the infections and related antibiotics contributed to, and some graft versus host disease.This was demoralising and often terrifying for the patient, myself and our teenage daughters. He felt ill for long periods of time and missed out on ‘normal’ life. He was told that at some point the infection was likely to become resistant to all available treatment, so he feared for his life every time it flared up. The doctors were reducing and working towards ending his immune suppressant medication (related to his stem cell transplant) and it felt like a race against time.The acutely scary part was the onset of an infection, feeling unwell, fear of sepsis and the dread of being admitted to hospital via A&E. It was worst when he woke up at night with a temperature and knew he couldn’t stay comfortably in bed. Our local hospital had limited knowledge of stem cell transplant patients especially in A&E. Having to explain his situation and needs to sceptical A&E staff was awful. During this visit he was told to use a public toilet in A&E while he was both neutropenic and too weak to walk there safely. Due to a shortage of rooms (as opposed to a bed on a ward), he was left in A&E feeling extremely unwell for over 12 hours on 3 or 4 occasions. It was truly torturous. On another occasion, he was discharged from hospital in mid-December 2019, but was back in A&E on Christmas Eve - it was a horrific experience suffering a high temperature, nausea and the rigors in a busy A&E resus with the same infection, followed by an inpatient stay over Christmas – his last Christmas alive.Sometimes the infection caused confusion/cognitive impairment. He was increasingly depressed as the infection reoccurred and was prescribed an antidepressant. On 2 occasions as he was about to be discharged, the infection came back, and he had to stay in hospital for a further course of antibiotics.During the later episodes of the infection, he experienced frequent and painful need to urinate with occasional loss of bladder control necessitating incontinence pants which was embarrassing and upsetting. He experienced delays to tests and mixed messages as he was admitted and treated at 2 different hospitals – our local hospital and his transplant hospital. The antibiotics themselves caused unpleasant side effects like nausea, diarrhoea and drops in his haemoglobin levels. meropenem for an infection.The infection also meant he was prescribed additional medication – tamsulosin and hyoscine butylbromide to try and mange his urinary symptoms. This was unpleasant as he was taking so many tablets each day, at some points around 60 tablets. He also needed IV fluid on many occasions.He passed away from a brain bleed attributed to his low platelets. At the time he had also been prescribed meropenem for an infection.His quality of life was awful for his last year alive, particularly a 2-month hospital stay during the early period of the covid pandemic |
| 9. How long did you (or someone you care for) spend in hospital receiving treatment for the drug-resistant infection? | A total of around 8 months over an 18 month period. Julian had 11 (I believe) hospital inpatient stays over 18 months prior to his death - these were almost all due to his infection. On a couple of occasions, he was admitted for other reasons, but his stay was extended both times as his infection inevitably flared up. His courses of IV antibiotics started off short – 3 days - but were gradually extended until they were 14 days every time he needed treatment. Each time he was in hospital for between 4 and 60 days. He spent more time in hospital than at home in the last year of his life.He also had 2 inpatient stays at our local hospice who had agreed to administer IV antibiotics to try and avoid the need for further hospitalisation during covid. He was not admitted for end of life care but did pass away unexpectedly while under hospice care. |
| Were you (or someone you care for) required to isolate in hospital (that is, to be in a room on your own) to reduce the risk of passing on the infection to other patients? How long for? | Yes - Julian needed his own room and hospital staff wore PPE due to his low immune system and transplant. Julian was neutropenic every time his infection flared up, however these precautions may also have been taken to prevent the spread of infection to other vulnerable patients |
| 10. Did the resistant infection impact other treatments? For example, did the infection delay acceptance for an organ transplant, or any other surgeries? | One round of R-CHOP chemo was delayed. Julian’s transplant wasn’t delayed, however the drug resistant infections became much worse after transplant.My understanding from Julian’s consultant is that the infections were a contributor to his supressed blood counts – he needed frequent blood and platelet transfusions. The low platelets meant other investigations were cancelled including a lumbar puncture and an endoscopy. |
| 11. What do carers experience when caring for someone who has had a severe, drug-resistant infection? | It was very stressful caring for my husband, I was constantly worried about him, and looking after him, and this impacted on my career, social life and mental and physical health. I would like to emphasise that the impact of this kind of infection is felt by other family members, not solely the main carer. Our two teenage daughters were impacted greatly by seeing their Dad constantly ill, upset and in pain. Also not having their mum around as I was visiting him in hospital so frequently. They had to manage their A levels and GCSEs while he was in hospital.We had to constantly be on alert for him developing a temperature and consequently needing to go to A&E – it wasn’t really safe for him to be left alone in the house so myself or one of my daughters had to be at home. Our relationship was affected as I had to persuade him to do things he really didn’t want to (such as take his temperature, take medication, attend hospital) when he was feeling unwell.It was particularly heart-breaking witnessing Julian’s confusion and depression. As Julian was an inpatient at 2 different hospitals, information was sometimes confusing, and we worried that tests and information were being missed or not fed back to us. I felt the added pressure that I had to be on top of all his care - asking questions and researching what a test was for and what it involved, for example. We sometimes felt lost as sometimes explanations were lacking and no one person knew everything that had happened to him. Hospital visiting was time consuming and upsetting with the expense of train travel to London or parking at Watford. Support from friends and family dwindled as it became so common for Julian to be unwell.My daughters and I have been left with long term anxiety and stress. We are constantly on edge, anticipate problems with situations and fear illness. |
| Current treatment of severe drug-resistant infections in the NHS |  |
| 12. What do patients or carers think of current treatments and care available on the NHS? | The treatments that Julian was offered – ertapenem, meropenem and temocillin – never successfully treated the infection, it kept recurring sometimes only days after treatment was stopped. It was demoralising and worrying being offered the same treatment repeatedly, knowing that it previously hadn’t been effective and that another hospitalisation via A&E was likely to follow, also knowing the unpleasant side effects of the anti-biotics.It would be life changing and in many cases lifesaving, if alternative treatments were available |
| 13. Is there an unmet need for patients who have a severe, drug-resistant infection requiring urgent hospital treatment? | Absolutely. If an alternative drug is available that is effective, it will save lives. It will also save much pain and heartache for patients and their families plus reduce hospital stays and the related impact on the NHS. |
| Advantages of Cefiderocol  |  |
| 14. What do patients or carers think are the advantages of cefiderocol? | This drug could offer an alternative hope and lifeline for patients with drug resistant infections. |
| Disadvantages of Cefiderocol  |  |
| 15. What do patients or carers think are the disadvantages of cefiderocol? | Individually, patients may suffer bad side effects to the drug, but I personally believe this is outweighed by the chance of it being effective against infection. An opportunity to take an alternative medication would have been welcomed by my husband. |
| **Patient population** |  |
| 16. Are there any groups of patients who might benefit more or less from cefiderocol than others? If so, please describe them and explain why. | I only have personal experience and knowledge of my husband’s situation. |
| Equality |  |
| 17. Are there any potential [equality issues](https://www.nice.org.uk/about/who-we-are/policies-and-procedures/nice-equality-scheme) that should be taken into account when considering severe drug-resistant infection and its treatment? | I am not personally aware of any |
| Other issues |  |
| 18. Are there any other issues that you would like the committee to consider? |  |
| Key messages |  |
| 19. In up to 5 bullet points, please summarise the key messages of your statement: | * Additional antibiotic treatment options can save lives
* It’s terrifying for patients knowing treatment options are limited
* Ineffective treatments mean patients have a poor quality of life, feeling unwell with multiple hospital admissions
* Carers and family members live a life of fear and stress
* It’s not only carers, but other family members e.g. teenage daughters, whose lives are irreparably affected by the fear and practicalities of living with a patient with a drug resistant infection
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Thank you for your time.

Please log in to your NICE Docs account to upload your completed statement, declaration of interest form and consent form.

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