



Patient Organisation Submission Form

Subject of SHTG Assessment

Bacteriophage Therapy

Name of patient organisation

Antibiotic Research UK

Health/medical conditions represented

Bacterial infections – particularly those resistant to many antibiotics

Contact name for this submission

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Role of contact person

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<https://www.antibioticresearch.org.uk/patient-support/>

Date of submission

4 July 2022

Please complete the SHTG Declaration of Interest form.

Please complete this form using the accompanying guide and do not include patient identifiable information.

Accessible Language: Where not specifically required for scientific/technical explanation, please use plain language, explaining acronyms and other non-lay terms.

Please note that the information submitted on this form will be held by the SHTG secretariat in accordance with Healthcare Improvement Scotland's [policies](#). This information may be published on the SHTG website or disclosed to third parties in accordance with the Freedom of Information (Scotland) Act 2002 (FOISA).

1. Tell us about the sources you used to gather information for this submission. (See page 6 of guidance.)

Led by a small team of pharmacists, our Patient Support Service (within the charity Antibiotic Research UK) provides a web-based portfolio of resources on resistant bacterial infections, a confidential email function, and a dedicated telephone number for people to speak to our team and request information and support. <https://www.antibioticresearch.org.uk/find-support/support-for-individuals/>

Most information in this submission is qualitative and has come from:

- one to one conversations by phone and by email
- virtual patient group discussions
- emails received by the charity about bacteriophage treatment and how to access it.

Patient enquiries are steadily growing, as are visits to the webpages, particularly on resistant UTIs. All the information provided below has been shared by patients who have contacted the Patient Support Service in need of help, information, and support. Those patients quoted have given their full written permission (recorded on a form approved by the Charity's lawyer) to share their experiences. They agree to this for the purposes of improving public and professional understanding of the suffering and difficulties which face those who suffer with drug resistant infections (DRIs). They wish to see funding and development of new antibiotic and other non-antibiotic therapies prioritised to treat life-altering ongoing infection.

Bacteriophage treatment is a topic we are asked about regularly, by patients and their families desperate to find out more about it, to access treatment, and to offer to be in clinical trials- such is their sense of desperation to be well again. It is also discussed widely in Facebook community groups I belong to, such as chronic UTI, MRSA and Lyme disease support groups.

2. What is the health condition and how does it affect the day-to-day lives of patients and their carers? (See page 7 of guidance.)

This section is longer and more detailed than others, to try to put context and scale around the impact of living with resistant recurring infection, and why bacteriophage treatments are so very much needed.

Most of the patients enquiring or discussing alternative treatments such as bacteriophage treatment, have had resistant bacterial infections for months, often years and sometimes decades. They include ongoing chronic UTIs, soft tissue/bone or respiratory infections; or have persistent symptoms from infections like Lyme disease (Borreliosis). Patients who experience a drug resistant infection (DRI) endure sleepless nights worrying about whether their quality of life will continue to be diminished day by day and year by year. Some live in fear of death – especially those who have experienced sepsis or septic shock as a result of resistant infections like bacterial pneumonia or resistant UTIs. Others express that they feel life is not worth living like this, when hope of recovery has been reduced or removed for some. Two patients recently told me their doctor told them ‘It can’t be cured. You’ll just have to live with it’. They live in fear, in despair and in distress constantly.

Physical impact

The most immediate impacts of the resistant infections are pain, fatigue, listlessness, inability to cope with daily tasks and life. For UTIs, this also includes urinary frequency, burning, difficulty sitting and being forced to stay at home near a toilet – and in turn, impacts all other areas of life, work, responsibilities inside and outside the home, and social life. Most aspects of life completely stop until the infection is under control or patient is discharged from hospital to recover. Patients talk of the difficulties they face convincing friends and family that there genuinely is something wrong with them and they feel very unwell, even though they look perfectly fine. They talk about their ‘lives shrinking’ and feeling life is permanently ‘on hold’ as a direct consequence of infection which has not been successfully treated.

Other impacts of living with infection

Many experience that sense of being viewed as ‘exaggerating the truth’ and often stop trying to explain, give up mentioning their health issues with infection, and keep quiet. They suffer silently, as few of their family and friends can comprehend that antibiotics don’t always work, and that infection isn’t easy to live with. Some patients talk of losing their jobs through extended sick leave or inability to complete the work; others have lost homes, independence, even partners, as a result of the suffering from resistant infections which keep recurring and disrupting lives in every shape and form. This includes financial and economic impact, inability to care for their families and homes, intimacy reduced or stopped (usually due to UTIs). Some even talk of healthcare professionals having poor understanding of the scale of suffering and incapacity patients experience because of chronic resistant infection.

Impact on mental health

For most people I speak to, the impact on mental health is severe. Many are suffering or been treated for depression and/or anxiety and this worsens with each episode of DRI. The physical suffering is already terrible, but the fear of not recovering or being able to resume aspects of 'normal living' causes severe depression. This is only exacerbated by the unspoken fear that one day there will be no antibiotic left to treat their DRI – and the outcome is too terrible for them to put into words. But they are all thinking about it. Living with a chronic drug resistant Infection feels like a life sentence to each of them, but one which they believe the general public have no understanding or concept of, until it happens to them or one of their family.

Seeking alternative treatments

Many of the patients I support speak about trying every possible natural means of dealing with the ongoing infections; from special diets, to natural or herbal treatments, to infection avoidance strategies too eg avoiding sex to prevent a DR UTI flaring up. Many will undertake their own research in a desperate effort to find something that may help them. Many have asked us about bacteriophage treatment and where to access it.

Patient quotes

We can share many examples of patient experiences of the impact of living with a drug resistant infection. Here are a few; others can be found on our website at <https://www.antibioticresearch.org.uk/find-support/patient-stories/>

RW told me “ In 2018, I had laparoscopic surgery to diagnose and treat endometriosis, and I contracted an infection from the catheter, that developed into urosepsis. It wasn't treated correctly and that is why I'm suffering from a multidrug resistant urinary tract infection (*Citrobacter koseri*). When I was released from hospital and trying to access the right care to get better, it quickly dawned on me that I was one step away from sepsis, two steps away from death. That was a frightening reality for me. My GP did everything she could in her power and gave me lots of short rescue courses of various antibiotics, which didn't work at all. Unfortunately, two years and four months on, I've made little headway, and I don't see myself coming off antibiotics for a very long time because I keep on having horrible symptom flares, which are incapacitating and stop my life. I have pain when urinating, urethral burning, loin pain, dizziness, general feeling unwell. I get these horrific shooting pains in my lower region that are just tremendously painful and reduce me to tears. No one can see it, friends and family can't see it, I can present like I'm fine and look okay, but that is not the truth of what's going on in my mind. I suffer silently, just like the infection is invisible, my suffering is mostly silent and invisible. As we know, antibiotic resistance is a global serial KILLER, therefore, I hope the NHS and the government will thoroughly review all the statistics regarding patient's cause of death and ongoing infections, and in light of these facts prioritise and develop new solutions to combat drug resistant infections. “

Lisa's experience involves a constantly infected PEG fed site and a resistant recurring pneumonia related to scoliosis of spine. Lisa has said “Experiencing recurring infections where I end up in hospital or unwell have proved to be another 'knock' to me in my life – as it affects me being able to do my volunteer job. I may be disabled and not able to do paid

employment, but losing that opportunity to give back, and to undertake the volunteering role which gives my life so much purpose and meaning can be extremely difficult to deal with. When illness and infection remove that, it has a major impact on all aspects of my life. I become more anxious and more depressed when this happens – as it's another reminder that I'm not well and am disabled. But I remain determined not to let either bacterial infection resistant to antibiotics, or other conditions define me or prevent me from making a useful contribution to society and to life".

Mary recorded a video of why ongoing resistant UTIs are ruining her otherwise healthy and fit lifestyle here: <https://www.antibioticresearch.org.uk/stories/marys-experiences-with-recurrent-antibiotic-resistant-infections/>

Mary said "My recurrent urinary tract infection has left me prone to more infections. Intermittently, some antibiotics no longer work. I feel a burden to my family and my GP practice and unreliable as a wife, mother and friend as I never know when I might be ill.

It makes you feel desperate, debased, humiliated and apart from your family and friends. They can't help you, and you feel that no one wants to talk about bladder problems. Why would they?! It's embarrassing and makes you feel subhuman. I have, at times, had suicidal thoughts – thinking that my family might be better off without me and my recurrent urinary tract infection".

Mary has had to cancel her holiday three times this year due to infection flaring up and is unable to participate in her usual outdoor/walking activities or enjoy her new grandchild.

These quotes are representative of many patients we speak to about the invisible suffering, helplessness, and deadly impact of resistant recurring infection.

3. What do patients and carers want from the health technology? (See page 8 of guidance.)

Those enquiring about bacteriophage treatment have usually become so desperate for successful treatment they have done their own research into what it is, how useful it has proved, where it can be accessed and how they can get onto a bacteriophage programme. The key reasons they want to access bacteriophage treatment are:

1. Antibiotic therapy has failed; most patients have had months and years of antibiotic treatment, are now living with the horror of an ongoing resistant or persistent bacterial infection where no antibiotic (or other therapy/approach) has been able to eradicate or cure it
2. There are no/very few new antibiotic treatments coming to market, nor are there many in the development pipeline. Antimicrobial resistance (AMR) is rising every year so current treatments options are conversely reducing. Patients understand that AMR is likely to be the next pandemic which increases their desire to see non-antibiotic therapies made available.
3. Antibiotic therapy has caused severe and sometimes irreversible damage to the gastrointestinal system, and can no longer be tolerated by the patient – so it becomes a desperate search for alternative options to treat the recurring/ongoing infection and reduce the impact on their lives.
- 4 Many patients have reached the point where they feel no existing NHS services, help, support or treatment is going to provide the means to successfully treat the infection so they have turned to private medical services and often worldwide options such as seeking treatment abroad eg Private Bacteriophage treatment in Georgia.
5. Many patients feel desperate since ongoing infection has put their lives on hold, and they feel they are not believed by clinicians (often as old inadequate diagnostic testing does not detect the bacteria). Despite experiencing symptoms, some clinicians have suggested to patients its 'in their heads'. This in turn pushes them towards alternative options which they hope will give a 'once for all' treatment.
6. Many sufferers have lost their jobs and livelihoods due to the infection causing ongoing illness; so they are often the individuals least able to afford private treatment. They wish to see bacteriophage treatment made available free at the point of care under the NHS; delivered locally or even nationally; by clinicians and healthcare professionals who understand and believe the impact of drug resistant infection.
7. They understand there is always risk with new treatments and newly-developing therapies. They have assessed that risk and feel worth taking as the life they live is so limited, so dependent on others, their illness is so misunderstood, and their fear of sepsis and eventual treatment failure leading to death is very real. These are considered bigger risks to the patients.

One example of this is a 26 year old mum called EC. She has suffered ongoing resistant UTIs for around 9 years, but has recently been told there is only one intravenous antibiotic left which can bring the ESBL bacterial infection under control. She has suffered sepsis several times. Her family often drive her hundreds of miles to see specialists both in major NHS hospitals and privately but no solution has been found. Her father has contacted me in desperation to find other therapies and treatment options, since the urologist and specialist have said they have no more ideas or options given the damage already caused to her renal function. Every time she is admitted to hospital with severe infection they wonder if options will run out and death is imminent for this young mother. She and her family are desperate to find alternative options, like bacteriophage treatment, to treat this life-threatening UTI.

4. What difference did the health technology make to the lives of patients that have used it? (Leave blank if you didn't make contact with anyone who had experience of the health technology.) (See page 9 of guidance.)

Many patients seeking bacteriophage treatment in the UK have failed to find where the trials are, or where therapy is being offered. That is a huge barrier.

I have spoken with two patients who have sought bacteriophage treatment in Georgia. Both used crowd-funding to gather funding for this treatment option. One patient MH is now three weeks into treatment, having flown to the Georgia clinic earlier this year, It is too early to know the results. MH has already lost her job, her independence, and her marriage as a direct consequence of years of an ongoing resistant chronic UTI.

The second patient, CS, had to put her booked trip to Georgia on hold as the war in Ukraine began, and is still waiting, desperate to go as she cannot tolerate antibiotic treatment any longer. She says her life is currently 'shrinking' every day as she cannot leave the house, has lost her job as an English teacher, cannot attend her daughter's engagement party, go out with friends, attend events. She is extremely upset and worried she will not be able to attend her own daughter's wedding due to this ongoing infection. CS has admitted to feeling suicidal, and desperately hopes bacteriophage treatment will soon be made possible for her. She is still prepared to travel to Georgia for bacteriophage treatment when allowed, to provide opportunity to recover, to attend the wedding and resume her life again.

5. Additional information you believe would be helpful for SHTG to consider. (See page 9 of guidance.)

Our team covers the whole of the UK, but that includes many Scottish patients too. Here are some of the pertinent issues and information that these Scottish patients have shared:

- Some have had to regularly travel to London to be seen at a specialist NHS clinic eg Whittington Hospital- a Tertiary Centre for Lower UTIs because there is no Scottish option or equivalent. This emphasises the need for Scottish-based treatment options.
- One Scottish patient with recurring infection travelled from the North of Scotland to a Central belt hospital in desperation for treatment due to a new specialist up North refusing further antibiotic treatment and leaving the patient to cope with chronic severe infection symptoms and no treatment options. This damaged her trust in health professionals for the short and long term. It emphasises the need for alternative treatment options where antibiotic treatment continually fails and patient /professional relationships are being adversely affected.
- Most of the enquiries we receive (60-70%) are about chronic UTIs, from females between the age of 30-75 years but often consulting male urologists/urogynaecologists. Some patients have described resistant UTIs as an area of health inequality. Maree Todd MSP and Minister for public health and women's health recently said "*Women's health is not just a women's issue. When women and girls are supported to lead healthy lives and fulfil their potential, the whole of society benefits.*" This provides yet another reason for bacteriophage therapy to be offered as a treatment for chronic, resistant infection in Scotland giving equitable treatment for these patients where there are few/no other alternatives.

About Antibiotic Research UK

We are a small charity set up in 2014. We are a member of The Association of Medical Research Charities (AMRC) and the only charity dedicated to undertaking research into antibiotic resistant infections. Our mission is to tackle the global threat of drug-resistant infections by:

- Driving and enabling innovative and collaborative research to ensure future generations have access to effective treatments.
- Supporting patients and families that are affected by drug-resistant infections.
- Working in partnership with key stakeholders to raise awareness and reduce the spread of drug-resistant infections.

Antibiotic Research (UK) established the country's first dedicated Patient Support (PS) Team in February 2019 realising the need for better patient information, support, advocacy for

those suffering with resistant bacterial infections. It also recognised the lack of patient voice in decision making within AMR strategies. The charity uniquely fills that gap.

6. Please summarise the key points of your submission in up to 5 statements. (See page 9 of guidance.)

Access to Bacteriophage treatment in Scotland is earnestly sought and supported by patients for the following reasons:

- A drug resistant infection (DRI) is for many patients we speak to, a chronic condition and a potential death sentence which is invisible and which they must live with. Many have taken numerous courses of antibiotics over months, years, even decades but with no success in eradicating the causative bacteria. Some sufferers are now unable to tolerate antibiotic treatment. Both groups of patients now desperately seek alternative options, delivered within the NHS and ideally within a reasonable distance of home.
- Resistant infection is considered by patients to be an illness of inequalities - lack of acceptance or affirmation of the patient's ongoing suffering by family and even health professionals; the need to travel from Scotland to clinics in England, or even abroad, to access treatment; and the extremely high proportion of women silently suffering with crippling recurring UTIs.
- Symptoms often include severe pain, fatigue, lethargy, brain fog, leading to severe depression and anxiety as their lives 'shrink' and quality of life decreases. Recurring and resistant infections dramatically reduce quality of life for sufferers and their families. They severely affect mental health. Some patients say life is not worth living like this and admit to having suicidal thoughts.

- Ongoing DRIs result in an economic burden on individuals due to many being unable to work due to infection. It is also an economic burden on NHS services and social services due to the need for ongoing health care, social care, as well as welfare benefits. DRI has a huge impact on carers and families too; in practical terms looking after the patient, homes and children; in providing financially; and the loss of freedom to undertake leisure trips/celebrations/outings/holidays together which significantly affects all members of a family too.
- Over reliance on poor microbiological testing methods means patients often feel they are “not believed” by healthcare professionals or by family and friends, even when symptoms are experienced despite tests saying ‘no bacteria found/identified’. This is especially true where poor sensitivity testing for UTIs, along with treatment failure using antibiotics, has driven patients to research and access private treatment, including bacteriophage treatment abroad.

For all these reasons, patients enthusiastically support the introduction of bacteriophage treatment options in Scotland.

7. Please give us details of anyone outside your organisation that had a role in preparing your submission. (See page 10 of guidance.)

No one else.

8. Do you consent for your submission to be posted on the SHTG website? (See page 10 of guidance.)

Yes

No

Thank you for completing this form. It will be given to SHTG members to inform their development of an Advice Statement for this technology.

Please return the form to:

his.shtg@nhs.scot