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THE UK
SEPSIS
TRUST

Report on Requirements for Post Sepsis Support

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JUST ASK
"COULD IT BE SEPSIS?"

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1. INTRODUCTION

The UK Sepsis Trust (UKST) has been asked by the Rapid Response to Acute Illness Learning Set (RRAILS) and 1000 Lives Improvement Service on behalf of Public Health Wales (PHW) to quantify the burden on both individuals and healthcare systems of the unaddressed physical and mental side effects of sepsis experienced during recovery. In undertaking this work UKST has undertaken the following;

- Attended a six-week education programme for patients in Cardiff and Newport concerning health and wellbeing with focus on self-management for people with chronic health conditions facilitated by EPP Cymru;
- Attended a meeting with InS:PIRE and one of their patient sessions at Glasgow Royal Infirmary;
- Attended a Cardiac Rehabilitation session at University Hospital Wales (UHW); and,
- Liaised with members of the public in Wales who are sepsis survivors to understand what they require.

In undertaking this work the UKST has not received any payment from PHW. This work has been carried out by employees of the UKST who work on a part-time basis. Work on this report commenced in April 2018 with gathering of data.

2. BACKGROUND

A seminar was held at City Hall Cardiff to mark World Sepsis Day (13 September) in 2017, hosted by RRAILS and 1000 Lives Improvement it focused on the NHS Wales “fight against sepsis” and involved clinical leads and patients. Presentations and discussions concentrated on reducing mortality from sepsis through early recognition of symptoms and treatment and also included patient stories and their individual experiences of sepsis and recovery. At the

seminar, Health Sec Vaughan Gething committed to a collaborative project between UK Sepsis Trust Wales, RRAILS and 1000 Lives Education Programmes for Patients to look at best ways for providing post sepsis support for survivors.

Past and current research and developments have generally focused on early identification and treatment of sepsis and it has only been in the recent past (two to three years) that more interest has developed in what happens to people as they recover from sepsis. With respect to this the majority of information to date has been gathered from those people who develop sepsis and are treated in intensive care units (ICU). The UKST provides support to sepsis survivors and it is clear that post sepsis recovery is not just limited to those patients who have been treated in ICU. Post sepsis, patients often suffer with physical, emotional and psychological problems. As earlier identification and treatment of sepsis improves with research, education and better awareness; the high mortality rate associated with sepsis should improve and as a result more people will survive and so understanding recovery and offering beneficial rehabilitation is necessary to ensure that these people go on to continue their lives in the best possible way.

Current data suggests that in the UK some 250,000 people every year are effected by sepsis with around 52,000 of these people dying. In Wales the mortality rate from sepsis is thought to be approximately 2,200 annually. Each year, sepsis costs the UK NHS £2.5 to 3 billion and the Welsh NHS some £150 million. However, sepsis costs the UK economy as much as £15.6 billion annually with direct and indirect costs. Direct costs are associated with hospital stays and treatment with consumables, drugs, clinical time, bed days in hospital, rehabilitation, ongoing organ support and other access to health care. Indirect costs include lost productivity and litigation. It has already been established that early identification of sepsis and treatment is crucial to achieve better outcomes for the patient not only whilst they are being treated for sepsis but in the recovery time and process also. Early identification and treatment also lessens the burden on the NHS and economy in terms of costs.

The UKST has reviewed what is currently available to assist RRAILS and 1000 Lives Improvement Service to address how the Welsh Government and NHS can help those recovering from sepsis with respect to the physical and mental side effects of sepsis

3. POST SEPSIS RECOVERY

In the UK, of the estimated 250,000 people effected annually by sepsis, some 200,000 survive Once sepsis registries are in place in England and Wales a better understanding the number of people affected should be gained. As more awareness and education is generated around the condition and earlier intervention and treatment is given, survival from sepsis has improved. It is thought that this trend will continue as research, intervention and treatments improve. However, there are no guidelines on providing guidance and support post hospitalisation during the recovery phase. It is estimated that it takes on average between 6-18 months to recover however this is highly variable.

As sepsis affects all of the body systems (skeletal, digestive, respiratory, urinary, nervous, circulatory, endocrine, reproductive and integumentary systems) it often follows that sepsis survivors take a time to recover. Recovery can be complex depending on the initial host response, pathogen characteristic, recent medical events, treatment (timing) and individual's immunity and comorbidities prior to sepsis. It is important to note that the recovery period is not determined by a person's age, comorbidities or severity of sepsis. As noted in a paper published in Journal of the American Medical Association (JAMA) in October 2010, the new deficits of sepsis survivors were relatively more severe among patients who were in better health before the sepsis event, possibly because there was less room for further deterioration among patients who already had poor physical or cognitive function prior to the sepsis episode. It is often noted that healthy people may be expected to rebound quickly from such a serious illness, but healthier people may actually have the opposite experience (Sepsis Alliance).

It is estimated that 25% of survivors in the UK will have had amputations as a result of their sepsis, some people have long term organ damage and require ongoing clinical care and monitoring. As well as the more obvious physical impairments that people suffer such as amputations and loss of sight there are many less obvious physical impairments; these can be split into those which require medical aids as a result of more permanent or semi-permanent organ damage resulting in the need for kidney dialysis and colostomy bags for example; and into those physical impairments which are less permanent and often improve during recovery and include problems with but not limited to the following; skin/teeth/hair/nail growth problems, digestive problems, vision problems, short term memory and concentration. In addition are problems relating to fatigue and sleep and also psychological problems including Post Traumatic Stress Disorder (PTSD), loss of confidence and anxiety.

It is thought that the symptoms suffered as a result of sepsis and experienced during recovery are related to the inflammation which occurs during sepsis, changes in the microcirculation and the action of pro-inflammatory cytokines and compensatory anti- inflammatory responses may play a role. As a result, the parasympathetic and sympatric nervous systems are affected the extent of which is not yet fully understood. Studies regarding sepsis and recovery related to oxidative stress, genetics and the effect sepsis has on the citric acid cycle and on mitochondria are also not yet understood but thought to play some part.

The term often used to describe the physical and psychological problems experienced following sepsis is Post Sepsis Syndrome (PSS), however as there are no clear guidelines as to what PSS is and so for this report, we refer only to the recovery following sepsis.

Within the ICU setting where more research has been undertaken, it was suggested in a Johns Hopkins study (2013) that looked at PTSD after ICU stays that patients who had sepsis which were more likely to develop PTSD. It was suggested that the possible sepsis/PTSD connection was related to inflammation caused by sepsis; whereby the inflammation suffered in sepsis may lead to a breakdown in the blood-brain barrier, which alters the impact on the brain of narcotics, sedatives and other drugs prescribed in the ICU. The UKST note that it is not only the patients who have had sepsis and been treated in ICU that have PTSD. Inflammation suffered in sepsis therefore maybe responsible for the symptoms which affect the patient post sepsis in particular inflammation of the brain could be responsible for problems reported with short term memory loss and poor concentration, however more research is required. During sepsis the body also has an acute stress response. The effects of this can be seen in the sympathetic and parasympathetic nervous system and again the results of this can be seen in the sepsis patients as they recover and again further research is required.

It is estimated that some 40% of sepsis survivors are re-hospitalised within 90 days of discharge for potentially treatable conditions in the outpatient setting (JAMA, 2010, percentage here based larger data than just UK figures).

3.1 Symptoms encountered during post sepsis recovery

Typically, the sepsis survivor will encounter some or all of the following typical symptoms but may also have other symptoms.

More common physical symptoms encountered during post sepsis recovery;

- Fatigue/Excessive tiredness and exhaustion
- Trouble sleeping
- Poor ability to think or concentrate or find the right words
- New allergies and sensitivities
- Itchy skin and dry skin
- Brittle hair and hair loss
- Brittle nails and teeth
- Dislike of very bright/noisy and crowded spaces
- Temperature intolerances and sensitivities, often feeling very cold or sweating
- Joint pains and muscle weakness and wasting, including changes in sensation in limbs such as restless legs and swollen limbs (due to excessive fluid in the tissues).
- Dizziness on standing
- Headaches and Migraines
- Nausea
- Breathlessness in physical activity
- Taste changes and/or Poor appetite
- Changes in vision such as blurred or double vision
- Reduced kidney function
- Repeated infections and persistent sore throat

Often the physical symptoms can lead to the onset of psychological symptoms. More common psychological symptoms of post sepsis recovery:

- Mood swings, feeling snappy, irritable, or angry and upset and at times experience a low mood
- Reduced interest in things that you previously enjoyed doing and possibly losing interest in what you look like
- Worried as to the physical symptoms you may be experiencing
- Loss of confidence
- Feeling different, and not like your old self and worried as to when you might feel like your old self again
- Worrying about getting ill again and possibly feeling more vulnerable because of what happened
- Wondering what if I had not survived
- Feeling guilty/bad for the worry everyone experienced and that you survived
- Remembering some/all parts of your hospital stay, with these thoughts coming back to mind in dreams, nightmares, or “flashbacks”

- Feeling frustrated, isolated or that nobody understands. It is important for you, your family and wider support network understand that your body needs to recover, and this varies for each person.
- Impacts on relationships

3.2 What help is currently available for sepsis survivors?

- Those sepsis survivors who have experienced amputations, loss of sight/hearing and/or organ damage are followed up in clinics post hospitalisation.
- Many patients treated for sepsis in the ICU are given access to counselling and often peer support through the ICU Steps programme.
- For sepsis survivors who have not been treated in the ICU and have not had amputations, loss of sight/hearing and/or organ damage, they are generally discharged from hospital with no follow up. The infection and sepsis has been successfully treated and the patient discharged, however the daily work undertaken at the UKST and studies have shown and that symptoms experienced by sepsis survivors post sepsis are more common and affect those who have had less severe sepsis just as much (if not more) that those who have had severe sepsis and been treated in the ICU. Many sepsis survivors will suffer from a variety of the symptoms mentioned above in section 3.1.

As no general sepsis rehabilitation is currently available, some survivors will go home and find themselves struggling but feel lost and that there is nothing that can be done to help them, hoping they will feel better. Some sepsis survivors will seek help for their symptoms that they experience following sepsis. The majority of sepsis survivors want to return back to work/study and the life they had prior to sepsis but find initially they may have problems with this. On seeking support at GP's many survivors are given antidepressants, painkillers, medication for sleep, they may be put on long waiting lists for counselling and short courses of physiotherapy but this all depends what is available in the area and the understanding of the condition by the individual health professional referring them.

There are a lot of healthcare facilities available both on the NHS and privately to help people with recovery from illness however it is understanding what is needed and making these services available to sepsis survivors. The symptoms experienced by sepsis survivors must be understood and treated by doctors and other healthcare professionals who should refer patients to accessible resources which will benefit them. It does not help when the patient is referred and put on a long waiting list, they have suffered a serious illness which is classed as a medical emergency. Currently, heart attack, stroke and cancer patients are all given better access to rehabilitation programmes compared to those who had had sepsis.

In Wales, the UKST have updated their recovery leaflets and information to direct those affected to support groups, support helpline and wellbeing walks were they can learn more about the symptoms of post sepsis recovery. Although the UKST can provide information about recovery and what to expect they do not have the resources to support rehabilitation.

Due to the lack of awareness relating to the symptoms relating to post sepsis recovery many survivors are left to recover with little help and understanding which in turn can lead to further problems and slower recovery. For most survivors and their families, they expect to rebound quickly not respecting the fact that they have had a serious illness which affects all of the body, and they often do not consider that the symptoms they are experiencing as they recover are related to their sepsis. As previously mentioned above, recovery can be more challenging and more severe among patients who were in better health before the sepsis event and that healthy people may be expected to rebound quickly from such a serious illness, but healthier people may actually have the opposite experience.

3.3 Research in to sepsis recovery

To date, more research has been done relating to patients treated for sepsis in the ICU setting compared to those patients treated on other wards in the hospital. Although overall research in to sepsis recovery is very sparse.

3.4 UKST Study

To understand the recovery of sepsis survivors better in the UK, the UKST undertook a pilot study in 2017. The study comprised of 20 questions and used Survey Monkey ™ to ask the questions and data collected as a result. This was the first time that the UKST had gathered data and the aim of the study was to understand survivors better, in particular how many had been treated in ICU, how long it took people to feel better, what where the problems they had experienced during recovery and what did people find helpful to aid their recovery.

The survey was made available on social media throughout the month of August (2017). In total the UKST received 866 responses. Those answering the survey did so under their own duress, and so the answers were from a self-selected group who had access to social media. It was found that the straight forward yes or no questions were answered well where as those with multiple choice were not always answered clearly. Overall the survey was a success and the UKST intends to undertake more surveys in the future. New surveys will be better designed and will refrain from using multiple choice answers and be aimed at a larger more diverse population.

Of the 866 who responded, 62% had been treated in the ICU for their sepsis and 32% had been treated on the ward. Over 65% of the responders said that sepsis was not explained to them by the hospital staff and over 70% had been discharged from hospital with no information as to what to expect during recovery. With regard to follow up appointments some 48% were given no follow up, 7% follow up with ICU, 30% had follow up relating to a specific medical/surgical procedure/intervention and 15% had some follow up at the hospital.

The majority of those who took part in the study reported problems with the following after having sepsis; fatigue, anxiety, blurred vision, reoccurring infections, hair loss.

The majority of survivors started to feel better with in the first 12 months after having sepsis. For a few, less than 10% no improvement had been seen within a five-year period after having sepsis.

When returning to work or study most people reported problems with fatigue, anxiety, poor memory and poor concentration.

Survivors had accessed physiotherapy, psychological services and fatigue management courses, it is not known if these services were provided by NHS organisations or privately funded.

As well as the study the UKST has a support helpline and runs several support groups in various locations throughout the UK, see section 5 for more detail. From working with survivors on a regular basis the UKST are aware that the symptoms experienced during recovery are common but currently do not have numbers to quantify how many people are affected.

4. REVIEW OF REHABILITATION PROGRAMMES

The UKST has reviewed a selection of courses, to look at their suitability for sepsis survivors and whilst none of these courses are suitable in their own right as a standalone rehabilitation for sepsis survivors they all have their merits which can be drawn on in designing a specific rehabilitation programme. Each of the courses attended is discussed in this section discussing the aim of the course and its pros and cons with respect to rehabilitation for sepsis survivors.

4.1 EPP Cymru

(Education Programmes for Patients)

EPP Cymru run a six-week education programme for patients in South East Wales concerning self-management, health and wellbeing for people with chronic health conditions and for careers of people with chronic health conditions. Each session is 2½ hours long with one break. The course does not run on a continual basis and commences when there are enough people who want to attend to make the course viable. The course is free and people are referred by a primary health care provider such as a GP. The course is run by one or two EPP representatives and a volunteer, the majority of the people who run the course have themselves at some point attended and benefited from the six-week course.

There is a self-management work book that can be completed by the patient and relates to what they have learnt over the six-week period. The work book gives a recognised accreditation from Agored Crymu and can be used to show an employer that the employee is working to manage their condition and also can be used to move to other courses provided by the Open University.

The UKST attended the whole six-week course between June and July 2018, attending three sessions in Cardiff and three in Newport to see how different groups were run. The Cardiff group was larger with 15 people attending the first session, this had decreased to 10 people by week 4. The course was run in the Cardiff Royal Infirmary in a dark, poorly ventilated room on the first floor. The Newport course started with 11 people but dropped to 4 by the last week. The course was held in the Newport Sports centre in a better lit and ventilated room albeit by artificial light and air conditioning. The Cardiff session was run in the evening from 6pm to 8:30pm and the Newport course from 10:00am to 12.30pm. It is understood that numbers do generally decrease over the six weeks as people drop out due to difficulties managing their condition and not being able to attend the group due to health reasons.

It was noted that the course attendees were suffering from long term chronic health conditions and which most had been diagnosed with some time ago. A book is available to borrow for the duration of the course and handouts are also available for those who want to take them as well as a relaxation CD. It is suggested that the attendee will read a lot of information from the literature between each week at home in their own time. Using distraction techniques (to manage pain), setting and achieving weekly goals, exercising, healthier eating, communicating, medication usage, managing depression, decision making and sleeping are all areas which are addressed amongst others.

The majority of the course is given from tutors reading text to the group, then discussing this. The course is presented using flip charts. The sessions, especially those in Cardiff were run like lessons, maybe this was due to the size of the group, the Newport group being smaller was more friendly and appeared less formal.

None of the advice given is medical as none of the staff giving the course are medically trained, a lot of advice given is based on what people within the group has found works for them. It was noted that on several occasions some advice given out as general advice was not suitable for all. Many members of the Newport group in their last session wanted to attend another session in the winter to help with managing their conditions in the colder months when they often suffer more.

The costs associated with this particular course are not known by the UKST although previously PHW has suggested that to run such a course it costs approximately £2,500 per course.

It is the UKST’s opinion that the EPP course although useful to some is not suitable for those recovering from sepsis for the following reasons:

- Recovery from sepsis is not a chronic condition. It should not be seen as a chronic condition or be allowed to progress to one unless there has been substantial organ damage or amputations as a result of the sepsis.
- It does not address the symptoms of sepsis recovery or what may be experienced and why this may happen.
- The sessions are too long, not varied enough or with enough breaks for people suffering from concentration problems and fatigue.
- There is no guidance on pacing.
- There is a poor understanding of fatigue and delayed fatigue which is one of the most recurring complaints from sepsis survivors.
- Medical help and answers to medical questions is required.

It maybe that if a sepsis survivor has developed chronic health conditions as a result of sepsis or that the patient had chronic health conditions prior to the onset of sepsis then they may benefit from this course for their chronic conditions at a later point. We don’t feel however that this will particularly help patients recover from their sepsis.

4.2 InS:PIRE

InS:PIRE is led by a team from NHS Greater Glasgow and Clyde, in partnership with the University of Glasgow, InS:PIRE (Intensive Care Syndrome: Promoting Independence and Return to Employment) began formally as a project in 2014, when it received a SHINE grant from the Health Foundation, the BMJ awarded the InS:PIRE programme an 'Innovation into Practice' award. More on the InS:PIRE implementation at the Glasgow Royal Infirmary 2014-2016 is available at http://www.health.org.uk/programmes/shine-2014/projects/promoting-independence-and-return-work-after-intensive-care-stay.

Its original aim was to improve the health and wellbeing of ICU patients after discharge from hospital, measured through return to work levels, GP visits and quality of life.

The InS:PIRE intervention comprises of a 5 week programme for those who had experienced a stay in ICU and their families, followed by a learning session for staff in week six. In Glasgow, the courses are run on a continual basis with sessions in the mornings and afternoons. Other sessions take place at other Scottish hospitals, some less frequently depending on demand. Generally, in Glasgow sessions have 18 attendees at any one time. Everyone who is admitted to the ICU ward for treatment is invited to attend the InS:PIRE 5 week programme 6-12 weeks following discharge via a letter sent from the hospital. The sessions that take place in Glasgow at the Royal Infirmary do so in large light rooms used for teaching/seminars in conjunction with Glasgow University. The rooms have modern facilities and the presentations given using PowerPoint. There are private rooms for discussions with medical professionals.

The InS:PIRE programme was set up using the Cardiac Rehabilitation programme as a model. Each session runs for 3 hours and is varied. Refreshments are provided on arrival and two short informative talks are given with question and answer sessions. The talks given include a session by the Citizens Advice Bureau, a psychologist giving a talk about brain injury, other talks include mindfulness, dietary advice, relationship issues and provide links for signposting and referrals for speech and language therapy and drug addiction. There are medical professionals available throughout the session to discuss and advise on your own personal rehabilitation. A doctor, nurse, pharmacist and physiotherapist are available for the first 3 sessions. In week 4 the physiotherapist and nurse are available. The sessions are informal. A follow up session is given. Initial studies to access the effectiveness of the InS:PIRE programme suggests that this type of intervention may improve quality of life and self-efficacy in survivors of ICU.

The UKST attended a meeting with InS:PIRE and a patient session hosted by them at Glasgow Royal Infirmary in July 2018. In discussion it was noted that the course costs around £80,000 per hospital annually to run in Scotland. Costs are based on £600 per patient and carer to attend based on 10 people attending. Overall the programme has noticed that litigation and administration involved with complaints has decreased since the intervention of the course although this has not been quantified. The reason behind this decrease is thought to be as a result of managing people’s expectations, explaining what happened to them in ICU and about recovery.

As a note, and as a comparison to other support available for ICU Survivors, the UKST note that the ICU Steps programme founded in 2005 and available within various locations around the UK is a support group which aims to support patients and their families as they recover from critical illness. It is a volunteer led organisation involving ex-patients, their relatives and ICU staff and does not have a set programme of rehabilitation unlike InS:PIRE.

It is the UKST's opinion that the InS:PIRE programme appears to be well designed for those who have been in ICU. However, many of the symptoms perceived to affect those only in ICU are experienced by those who have had sepsis regardless of the ward they were cared for in. Taking this programme as a broad template would be useful to as a basis to design a programme tailored to those recovering from sepsis.

4.3 Cardiac Rehabilitation

Cardiac Rehabilitation is very well established in all parts of the UK and has been going for over 30 years. It is set up and run in conjunction with the British Heart Foundation (BHF) strategic project which aims to support cardiovascular prevention and rehabilitation services to achieve the best possible outcomes for patients with Cardiovascular disease irrespective of where they live. Patients are requested by the hospital to take part in Cardiac Rehabilitation following a Myocardial Infarction, Percutaneous Coronary Intervention, and Coronary Artery Bypass Graft. For the audit year 2017, it was reported that around 82% of patients took part in Cardiac rehabilitation, with close to 10% taking up home-based and a smaller amount (1%) taking up structured online options. The remainder (7%) are using other undefined modes such as telephone support. It is noted that home-based rehabilitation can put the nurse in vulnerable situations and exposed to violence, drugs and dangerous dogs, these problems are often not related directly with the patient but indirectly related to the location of the patient's house. Some 62% of patients starting cardiac rehabilitation have a follow-up assessment. Cardiac Rehabilitation sessions are generally run at hospitals, and community centres. The courses run between 6 to 8 weeks and are continuously being run as there is a constant need. The session is run by cardiac nursing staff. The session includes a talk by a medical professional for example about diet, pacing, sleep management. During each session the patient has their blood pressure taken, they are also assessed for depression using a HAD scale at the start of the 6/8-week course. An exercise session with physiotherapists then follows with a warm up and cool down. At the end of the course a letter is sent to the GP to say that the patient has successfully completed cardiac rehabilitation.

The UKST attended a Cardiac Rehabilitation session at University Hospital Wales (UHW) in July 2018. After having an introduction by nursing staff the UKST attended a session on pacing given by an Occupational Therapist in a hot, windowless, disorganised room. It was noted that a general over view was presented to the patients, they were not shown how to do pacing or how it can be helpful to them. Nobody had any questions following the presentation. It was reported to the UKST that there are long waiting lists for counselling and the 6/8-week Cardiac Rehabilitation course is good to alleviate fears in the interim. It was noted that the patient does not really get to see or discuss the statistics collected from them in each session relating to their health such as heart rate and blood pressure to see how/if they are improving. All data is recorded on paper during the session.

It is not known how much it costs to run a Cardiac Rehabilitation course.

It is widely accepted that Cardiac Rehabilitation is successful. It is the UKST's opinion that parts of the course are useful in guiding what is required for sepsis survivors.

4.4 Other Courses- ICU Steps and Macmillan Hope Scheme

There are other support courses offered to others following illness which have not been widely researched by the UKST in this study, these include ICU Steps and Macmillan HOPE self-management programme.

The ICU Steps programme is a peer support programme which works similar to the SSG meeting once every two months. ICU Steps is only open to those who have been treated in the ICU. The ICU Steps programme is not run at all hospitals.

The Macmillan HOPE Scheme is offered to those patients recovering from cancer, it is run by two trained HOPE facilitators and aimed at giving Cancer suffers and survivors the opportunity to meet others in the same or similar situation to explore proactive ways of taking control of their health and wellbeing as a group and appears to be similar to the EPP Scheme although the HOPE programme runs for 2 full days, followed by a half day six to eight weeks later.

5 THE UKST SUPPORT AND SEPSIS SUPPORT GROUPS

The UKST provides support through the following mediums;

- A confidential helpline, staffed by trained nurses operated 9am-5pm Monday to Friday offering a space to talk and offering signposting for appropriate help;
- Support and information via social media and email;
- Information via our website (https//sepsistrust.org/) and printed booklets;
- Sepsis support groups supported by healthcare professionals.

The UKST runs a number of sepsis support groups (SSG) in the UK including one in Cardiff and one in Wrexham. The Support Groups are run by volunteers with support from the Sepsis Trust. The SSG are generally run once a quarter (every three months) The Cardiff SSG runs in March, June, September and December and since its inception in March 2017 it has been well attended. It is run by Tracey Laight (Support and Awareness Manager, Wales) and Terence Canning (Director for Wales) who work for the Sepsis Trust and are based in the South East Wales region, they are accompanied by at least one Sepsis Trust Support Nurse who travels from the UKST headquarters in Birmingham for the meeting and whose experience in the medical sector is with sepsis patients in ICU. The Wrexham SSG is run by volunteers and medical professionals in the area with a support nurse from the UKST in attendance until the SSG is more established. The UKST is currently only a small charity with only four employees whose job it is to run the SSG, and answer the support calls it is therefore not possible that they can attend all SSGs, leaving reliance heavily on volunteers for the time being. As awareness of sepsis grows as a result of the work the UKST are doing, more reporting in newspapers and storylines in television programmes (Call the Midwife, The Archers and Coronation Street) so has the SSGs with a rise from 10 to 21 in the past year at various locations in the UK (Sept 2017-Sept 2018).

The support groups are run as a “drop in” session in evenings or at weekends. with both survivors of sepsis attending with their families and also relatives and friends of those who have died from sepsis. The sessions are informal and are generally an education platform to find out more about sepsis, and for those who have survived what to expect during recovery. There is no structure to the sessions and there is no rehabilitation programme. Attendees often find solace in understanding it is normal to feel like they do and that they are not alone.

In addition to the SSG, the Cardiff group run a well-being walk once a month. The walk takes place on a Saturday morning at a different park each month within South East Wales. The walks are informal, and give people affected by sepsis a different environment to talk in, often talking and walking has proved beneficial for those attending. The well-being walk was set up in October 2017 and again has been successful with other SSG’s in England adopting this model.

The UKST note that group therapy in the form of the SSG is not suited to everyone and the idea of attending a support group as means of rehabilitation does not appeal to everyone. Some people benefit more from one to one discussion which is where the wellbeing walks are beneficial. However, the SSG and wellbeing walk cannot be a substitute for a properly managed rehabilitation course. The SSG and wellbeing walk are good additional services but do not monitor or specifically manage patients during recovery.

6. PATIENT PERSPECTIVE

The UKST set up an online anonymous survey open to a select cohort of survivors known to the UKST in Wales, to understand what they require with regards to rehabilitation services. The survey was open from 27th November to 18th December 2018. In total 14 people were contacted via email and asked to take part in the study, 12 responded. Limited resources and time constraints influenced the number of participants contacted. In total 38 questions were asked, not all questions were answered by the cohort. It was initially planned that the cohort would be asked the questions in a face to face interview with a member of the UKST however due to resources, time constraints and anonymity issues the questions were uploaded using a SurveyMonkey™ software and an email sent out to the cohort with a link to the survey location. Answering questions about sepsis can be emotive for many survivors and so the survey was left open for a number of days to give participants the chance to look at the questions and give them time to think about their answers and go back if needed.

6.1 Results of the 2018 Sepsis Survivor Survey

The cohort had all had sepsis in the five years between November 2012 and November 2017, they were aged between 35-65 when had sepsis with mean age of 50.75 years. All of the cohort (12) had been treated in Wales for their sepsis with two thirds being treated in ICU and a third being treated on general wards. Half (50%) of those who took part had received major surgical interventions as a result of their sepsis, including amputations, bowel injury requiring colostomy bag, liver failure, thrombosis resulting in the requirement for anticoagulant medication, significant injury requiring reconstructive surgery, and significant muscle wasting and nerve damage requiring intense physiotherapy. The remaining fifty percent (50%) did not have any surgical interventions following their sepsis however this is not to say that they were without ongoing difficulties following discharge and during recovery. To understand how many of the survivors experienced physical and emotional symptoms after sepsis we asked a series of questions details of which can be seen in the Appendix of this report (Section A). All of the cohort (12) said that they worried about getting sepsis again. The majority of those surveyed (eleven out of the twelve) had experienced the following; fatigue and exhaustion; trouble concentrating and finding the right words; and, joint/muscle pain following sepsis. Ten of the surveyed group had experienced problems with; sleeping; dislike of crowed/noisy/bright spaces; mood swings and feeling a mix of emotions (angry, upset, irritable); loss of confidence; wondering what would have happened if they had not survived and feeling bad about what their family had been through; and, not feeling like their old self. In addition, over 50% of the group had reported problems with the following physical and emotional symptoms following sepsis; new allergies or sensitivities; brittle hair/hair loss; brittle teeth and nails; temperature intolerance, feeling too hot or cold or sweating lots; dizziness on standing; breathlessness on any physical activity; changes in vison; repeated infections; flashbacks, nightmares and vivid dreams; not remembering periods of time whilst in hospital; and, forgetting things such as conversations and special dates. Just under half of the group (5) experienced; migraines and headaches, nausea; and, skin problems and changes in taste or appetite.

At the time of the survey just over 58% (7 of the cohort) felt as though they had almost recovered, with lots of improvements made but still recovering and experiencing some of the physical and emotional symptoms to some degree but not experiencing those symptoms as much as they did earlier in their recovery. Only two of those responding to the questionnaire felt as though they had recovered as well possible, they were not quite as they were before sepsis but had no problems or concerns. No-one felt fully recovered or back to how they were before they had sepsis. A total of eleven out of the twelve thought that their recovery from sepsis was longer than they had expected.

Some of those who took part in the survey had received treatment following their sepsis. A third of the survivors who took part in the survey had been called for follow up appointments following discharge from hospital. Noting that 50% of those who took part had received major surgical interventions as a result of their sepsis, including amputations, bowel injury requiring colostomy bag, liver failure, thrombosis resulting in the requirement for anticoagulant medication, significant injury requiring reconstructive surgery, and significant muscle wasting and nerve damage requiring intense physiotherapy only two of these patients received follow up appointments to discuss their sepsis (not including physiotherapy appointments). One patient who had been in ICU with no complications as a result of their sepsis was called for a follow up appointment due to their sepsis and one patient who had not been admitted to the ICU had been asked to attend a follow up appointment.

The survivors surveyed have received treatment following sepsis from the NHS and from private healthcare providers. A total of 40% of the survivors had received physiotherapy from the NHS, 30% had accessed private physiotherapy. 30% of the survivors had appointments with NHS specialists to help with their recovery, where 50% of the group had accessed private specialists to help with recovery. One person had been able to access counselling through the NHS whereas 50% of the cohort had accessed counselling privately. Two survivors had been visited at home by NHS occupational health/nurses or care workers following their sepsis. Other resources accessed by the group included private reflexology, chiropractic treatment, massage, naturopathy, podiatry and urology. Six survivors sought private health care treatment as the service they accessed was either not available on the NHS or NHS waiting times were long. This is especially the case for counselling services and Cognitive Behavioural Therapy (CBT). Three survivors had accessed private CBT; CBT is not offered by the NHS in Wales.

Prescribed medication used by the sepsis survivors as they recover include the following (but not limited to) painkillers and NSAIDS, sedatives, antidepressants, beta-blockers, antibiotics, nerve blockers and migraine medication (unspecified). Some survivors have found that medication has helped them. The majority of survivors who took part in the survey do not take medication on a long term basis, some access when necessary and a minority (2 people) take it regularly.

A third of the cohort took vitamins as dietary supplements after having had sepsis to help with their recovery these included (but not limited to); B vitamins, Magnesium, Probiotics, calcium, vitamin D, vitamin C, CoQ10, multivitamins, homeopathic medicines, iron supplements, turmeric, cod liver oil glucosamine and chondroitin. In the majority of cases the vitamins and dietary supplements were not prescribed by a healthcare professional.

Looking at how these survivors learnt about sepsis and how it may affect them, we asked them how they learnt about what sepsis was. Over 50% used the UKST website and support groups to access information, two people looked for information on the internet. Three people were told in hospital although explanation it is understood that the information given was varied. Of the four survivors that had received follow up appointments at the hospital post sepsis, sepsis was not explained to them. Sepsis was not explained to any of the survivors by their GP. Of the 12 people who took part in the survey, 50% of them had not seen their GP as part of their recovery. A third of the cohort had been referred to other services by their GP to help with recovery. Almost 60% of the cohort have never seen a healthcare professional to guide and assist with recovery from sepsis. The general consensus is that some healthcare professionals understand what sepsis is and others do not.

Three quarters of the surveyed group have attended a UKST support group, 100% of the attendees found it useful. A total of 50% have called the UKST helpline with 100% of those that had called finding it useful.

Looking at how sepsis affects the survivors return to work, eleven out of the twelve survivors who took part answered. All eleven had taken time off work or study as a result of their sepsis, one of the survivors had still not returned to work. Four people had returned to their job that they had before they had sepsis, one person had changed their role at work, two people had changed their job and three people were not able to continue work and/or study. Many of the survivors found employers made their return to work difficult with 45% citing a reluctance of the employer to make reasonable adjustments. Other work related issues included employers not appropriately managing performance, sick leave and phased return to work to name but a few. Only one of the surveyed survivors reported that their employers had been understanding and had no difficulties with their employers during their recovery.

All of the surveyed cohort thought that there should be a rehabilitation programme to help with sepsis recovery. Overall the majority would like to see a service run from a hospital by specialist staff with knowledge of sepsis with some input from sepsis survivors and others who can provide advice and support.

A summary of the results can be seen in the Appendix (Section A) of this report.

7. RECOMMENDATIONS

In undertaking this review of what support is required for survivors of sepsis, the UKST suggest the following;

- A rehabilitation programme is required which addresses, physical symptoms, physiological symptoms, social issues.
- The rehabilitation programme should aim to improve the health and wellbeing of sepsis survivors following discharge through education of sepsis, the recovery process and assistance with recovery.
- The rehabilitation programme should be measured through constant monitoring and patient feedback including quality of life assessment and self-efficiency assessment. In the first instance the survivor need to be evaluated at the start of any recovery programme, this can be done using a number of techniques used on other rehabilitation courses or MS/ME/pain clinics.
- Referral should ideally be through the discharging hospital or through the GP. There should be no special criteria to attend the course other than having had sepsis. Patients should attend the course around 6-8 weeks after discharge. On discharge from hospital the Patient should be given the Sepsis Trust Recovery after Sepsis booklet and card to say they have had sepsis and to contact the trust if they need support in the interim between discharge and the rehabilitation course starting.
- The rehabilitation course should be open to the sepsis survivor and either a carer or relative.
- The rehabilitation course should be run over 6 consecutive weeks with a follow up 3 months later and a further follow up after 12 months. Making 8 sessions in total. The sessions should be 3 hours long, very informal and varied with breaks.

- The rehabilitation course should be run by medical professionals with access to a specialist doctor, specialist nurses, neurologists, pharmacist, physiotherapist, psychologists/councillors and occupational health.
- Recovery resources should include physical support such as physical therapy to improve exercise capacity, strength, and independent completion of activities of daily living however it is important to understand that fatigue is a problem and pacing strategies need to be understood and learnt. Tai Chi could be considered rather than exercise.
- Mindfulness, Pacing and Tai Chi/exercises need to be taught so that the patient can come back to them as a tool for recovery. People recover at different rates and some may not be receptive to all of these at the being but taught well they could become a useful resource.
- Neurorehabilitation and psychological support such as counselling, cognitive behavioural therapy (CBT) or neuropsychiatric assessment should also be offered.
- The rehabilitation course should include presentations by non-medical people such as Citizens Advice, dieticians, UKST and others.
- Rehabilitation should be held ideally in bright, airy, well ventilated rooms set up for the course, ideally training rooms or university buildings/rooms at the hospital meaning they are less clinical.
- Data collected by medical professionals in the sessions should be collected on and managed on handheld devices where graphical plots of statistics can easily be displayed and shown to the patient as they attend the course and after they have completed it with a print out or copy sent to the patient at the end. All data should be shared with the patient.
- The rehabilitation programme needs to be able to signpost sepsis survivors for counselling, speech therapy, alcohol or drug abuse and other such services bypassing long waiting lists for all sepsis survivors giving them the opportunity to recover quicker reducing the load on the health care system and reducing the potential for chronic conditions to develop. GPs need to be made aware of what is required as part of a training scheme/awareness so they can refer appropriately.
- Equipment needed would include monitoring equipment for glucose SO2, blood pressure, physiotherapy equipment (and possibly a treadmill or cycling machine – not essential if doing Tai Chi), also as with all courses admin equipment would be required as well as projectors, refreshment facilities, toilets, access for people of all abilities and a defibrillator.

As a note, once sepsis registries are in place in England and Wales a better understanding the number of people affected by sepsis should be gained, to get the most from the registry they could perhaps be designed and adapted so that data relating to an understanding of the recovery process can be used to target rehabilitation.

An idea of a course may look something like the below model;

Week 1	Week 2	Week 3	Week 4	Week 5	Week 6	Week 6/7 (after 3 months)	Week 7/8 (after 12 months)
Private Individual Assessments including health check, discussion on medication and what are concerns, Assessment on ability to do gentle exercise Talks and open discussion What is Sepsis What may Rehabilitation look like	Individual assessment with nurse and psychiatrist Talks Citizens Advice – benefits and returning to work Introduction to Pacing, how it is done and help to do it Exercise session/Tai Chi Time to ask questions, speak to those giving talks	Individual assessment with nurse and if required physiatrists Pacing, how are people getting on with this Exercise session/Tai Chi Talks on sleep poor concentration and PTSD and effects on relationships Time to ask questions, speak to those giving talks	Individual assessment with nurse Pacing, how are people getting on with this and talk on Managing fatigue Exercise session/Tai Chi Mindfulness Intro Time to ask questions, speak to those giving talks Talk on Chronic pain and medications	Individual assessment with nurse Pacing, how are people getting on with this Exercise session/Tai Chi Mindfulness Talk on dietary needs and vitamins Time to ask questions, speak to those giving talks	Individual assessment with nurse Pacing, how are people getting on with this Realistic Goal setting for coming months Exercise session/Tai Chi Talks -Citizens Advice – question session Mindfulness Time to ask questions, speak to those giving talks	Individual assessment with nurse Pacing, how are people getting on with this Mindfulness how is this progressing Exercise session/Tai Chi Review on how progressing Group session on how people are coping Goals for the future Time to ask questions, speak to those giving talks	Individual assessment with nurse Pacing, how are people getting on with this Mindfulness how is this progressing Exercise session/Tai Chi How is this going and a small session Review on how progressing Group session on how people are coping Goals for the future Time to ask questions, speak to those giving talks

*During the course if counselling is needed the patient is referred and seen by councillors who understand sepsis and recovery almost simultaneously to the recovery course so as to complement each other and allow for the best possible improvements of the survivor.

7.1 Name for Programme

It has been mentioned to the UKST by PHW that slogans such as *Thive and Survive* help to market rehabilitation schemes. However, although the UKST have thought of a few options they suggest that ideally any name should be kept simple. The Recovery After Sepsis leaflet that was launched in September 2018 is a collaboration between medical professionals at UHW and the UKST and forms part of what the UKST would like to term the Sepsis Survivor Support Series or S4. The UKST suggest that any rehabilitation programme is part of this series. Ideas for names include *S4 Rehabilitation Programme*, *S4 Steps*, *Sepsis Steps, Assist Me Rehabilitation Programme* – (Aiding Sepsis Survivors Improve, Strengthen, Transform - Mend and Educate), and *RASP* (Recovery After Sepsis Programme).

7.2 Trials and Monitoring

Any rehabilitation needs constant monitoring however in the first instance a trial period will be required to measure how useful the programme is and if any changes need to be made. It is envisaged that trails could be conducted in the first instance in South Wales before being made available to the rest of Wales. It is possible that slightly different courses could be run at Abertawe Bro Morgannwg Swansea Moriston Hospital, Cardiff and Vale's UHW and Aneurin Bevan University Health Board Royal Gwent, the success of these groups would be monitored and evaluated prior to a final model for the rehabilitation course being adopted and rolled out over the whole of Wales.

7.3 Children

Whereby this report focuses on adult rehabilitation there is a need to look at child survivors of sepsis who often suffer development delays. It is crucial that their needs are met and they are referred as soon as possible for therapies to help their development. This may include physiotherapy, speech therapy and counselling (for parents and children) amongst other support.

8. References

- https://sepsistrust.org/
- https://www.sepsis.org/
- Hallie.C.Prescott and Derek. C. Angus 2018 Enhancing Recovery from Sepsis, A Review, American Medical Association. 2018; 319(1):62- 75.doi:10.1001/jama.2017.17687
- Derek C. Angus 2010 The Lingering Consequences of Sepsis, A Hidden Public Health Disaster? 2010;304(16):1833-1834. doi:10.1001/jama.2010.1546 https://www.sepsis.org/life-after-sepsis/post-sepsis-syndrome/
- February 2013 PTSD Symptoms Common Among ICU Survivors: Condition long linked to war veterans found in one in three ventilated patients https://www.hopkinsmedicine.org/news/media/releases/ptsd_symptoms_common_among_icu_survivors
- https//icusteps.org/
- British Heart Foundation The National Audit of Cardiac Rehabilitation Annual Statistical Report 2017

Section A

APPENDICES

Welsh Survey Summary (December 2018)

Q1 How long ago did you have sepsis?

Answered: 11 Skipped: 1

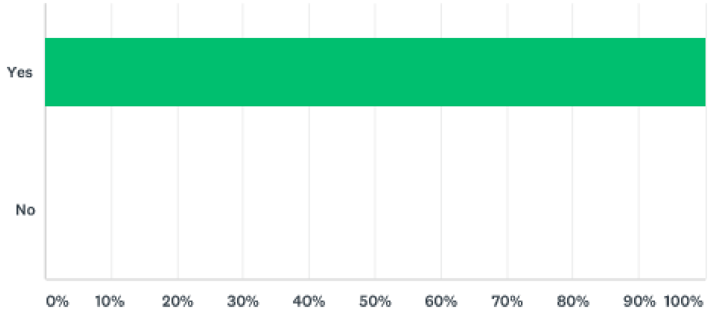
ANSWER CHOICES	RESPONSES	
Date / Time	100.00%	11

Q2 How old were you were you when you had sepsis?

Answered: 12 Skipped: 0

Q3 Were you treated for sepsis in Wales?

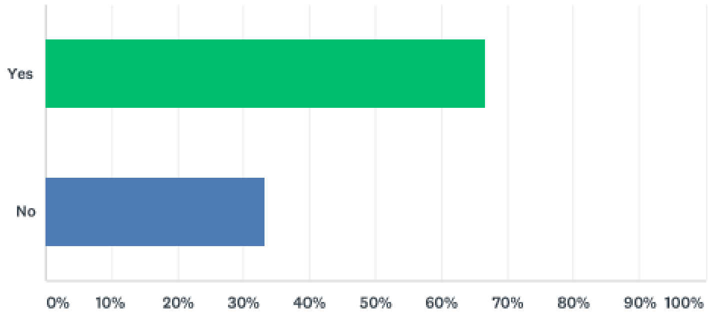
Answered: 12 Skipped: 0



ANSWER CHOICES	RESPONSES	
Yes	100.00%	12
No	0.00%	0
TOTAL		12

Q4 Whilst in hospital with sepsis were you treated in ICU?

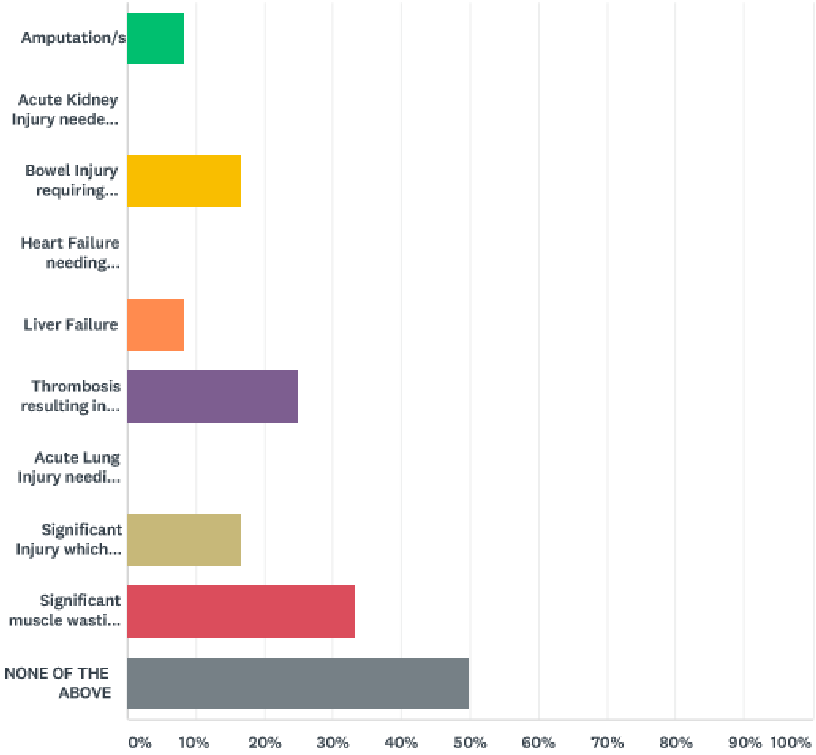
Answered: 12 Skipped: 0



ANSWER CHOICES	RESPONSES	
Yes	66.67%	8
No	33.33%	4
TOTAL		12

Q5 Did you have the following as a result of having sepsis?

Answered: 12   Skipped: 0



ANSWER CHOICES	RESPONSES	
Amputation/s	8.33%	1
Acute Kidney Injury needed ongoing dialysis	0.00%	0
Bowel Injury requiring colostomy bag	16.67%	2
Heart Failure needing medication	0.00%	0
Liver Failure	8.33%	1
Thrombosis resulting in need for anticoagulant medication	25.00%	3
Acute Lung Injury needing ongoing chest drains and oxygen	0.00%	0
Significant Injury which required reconstructive surgery	16.67%	2
Significant muscle wasting and nerve damage requiring intense physiotherapy	33.33%	4
NONE OF THE ABOVE	50.00%	6
Total Respondents: 12		

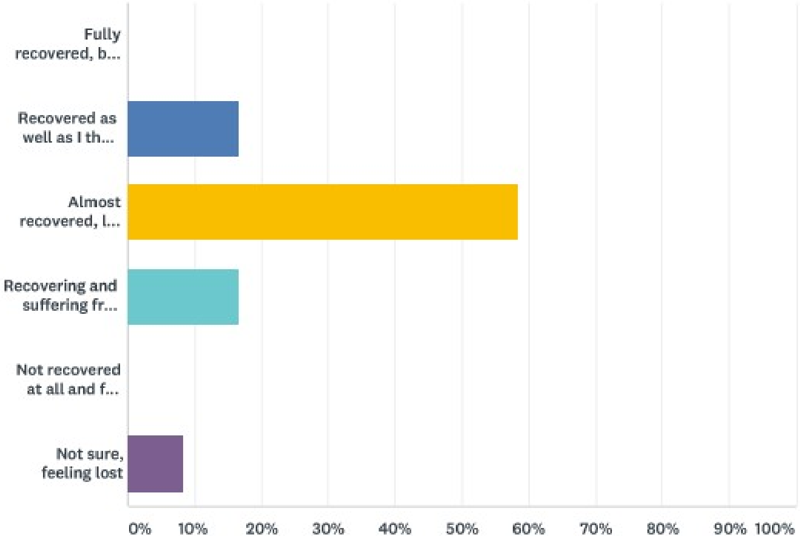
Q6 We know that people suffer from many physical and emotional symptoms after sepsis. Below are the common known symptoms experienced by many sepsis survivors. It is normal to experience these symptoms after serious illness not just sepsis. Have you experienced any of the following during your recovery from sepsis? Please tick those which you have experienced.

Answered: 12 Skipped: 0

ANSWER CHOICES	RESPONSES	
Fatigue/Exhaustion	91.67%	11
Headaches/Migraines	41.67%	5
Trouble sleeping	83.33%	10
Trouble concentrating and finding the right words	91.67%	11
New allergies or sensitivities	66.67%	8
Itchy skin or dry skin	41.67%	5
Brittle hair/hair loss	50.00%	6
Brittle nails and teeth	50.00%	6
Dislike of bright/noisy/crowded spaces	83.33%	10
Temperature intolerance-feeling too hot/cold or sweating lots	66.67%	8
Joint/Muscle pain including foot and hand pain	91.67%	11
Dizziness on standing	58.33%	7
Nausea	41.67%	5
Breathlessness on any physical activity	58.33%	7
Changes in taste or poor appetite	41.67%	5
Craving certain foods	8.33%	1
Changes in vision (blurred or double vison/loss of vison)	50.00%	6
Hearing problems	33.33%	4
Repeated infections	50.00%	6
Persistent sore throat	16.67%	2
Mood swings and feeling a mix of emotions (angry, upset, irritable)	83.33%	10
Loss of confidence	83.33%	10
Worrying about getting sepsis again	100.00%	12
Flashbacks/nightmares/ vivid dreams	50.00%	6
Not knowing what is real anymore	25.00%	3
Not remembering periods of time whilst in hospital	66.67%	8
Forgetting things such as conversations, special dates	75.00%	9
Wondering what may have happened if I had not survived and feeling bad about what your family had to go trough	83.33%	10
Not feeling like your old self	83.33%	10
Questioning if you even had sepsis	16.67%	2
NONE OF THE ABOVE	0.00%	0
Total Respondents: 12		

Q7 With regards to your recovery from sepsis how do you feel now?

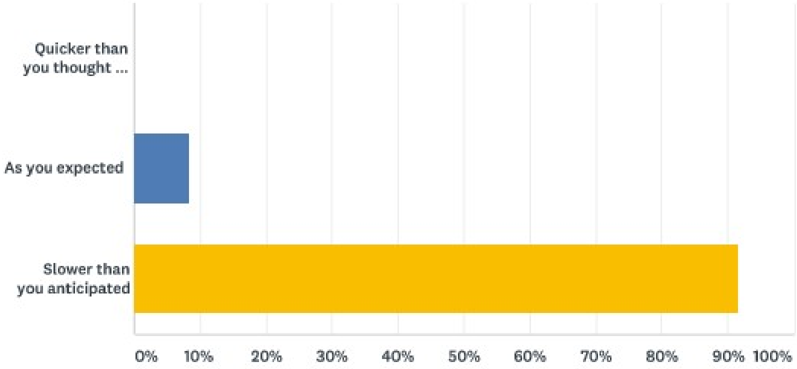
Answered: 12 Skipped: 0



ANSWER CHOICES	RESPONSES	
Fully recovered, back to my old self	0.00%	0
Recovered as well as I think I will be, not quite as I was before I had sepsis but no problems or concerns	16.67%	2
Almost recovered, lots of improvements made to date but still recovering and experiencing some of the symptoms above (see those in question 5) to some degree but not experiencing those symptoms as much as I did earlier on in my recovery	58.33%	7
Recovering and suffering from lots of the symptoms above (see those in question 5), still feel that I have some way to go to recover	16.67%	2
Not recovered at all and feel that I am making no improvements	0.00%	0
Not sure, feeling lost	8.33%	1
TOTAL		12

Q8 Time Frame - Do you consider that the time taken recovering from sepsis is/was...

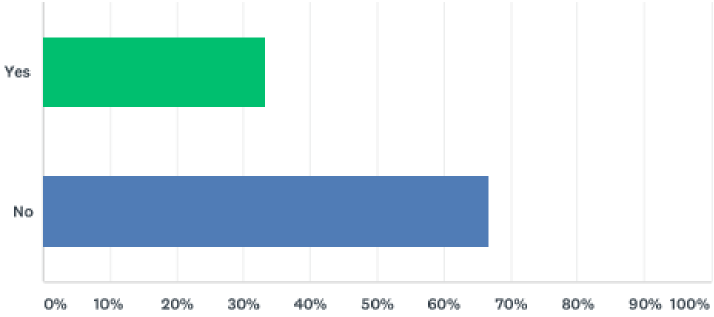
Answered: 12   Skipped: 0



ANSWER CHOICES	RESPONSES	
Quicker than you thought it would take	0.00%	0
As you expected	8.33%	1
Slower than you anticipated	91.67%	11
TOTAL		12

Q9 Did you receive any follow up appointments relating to sepsis following discharge from hospital?

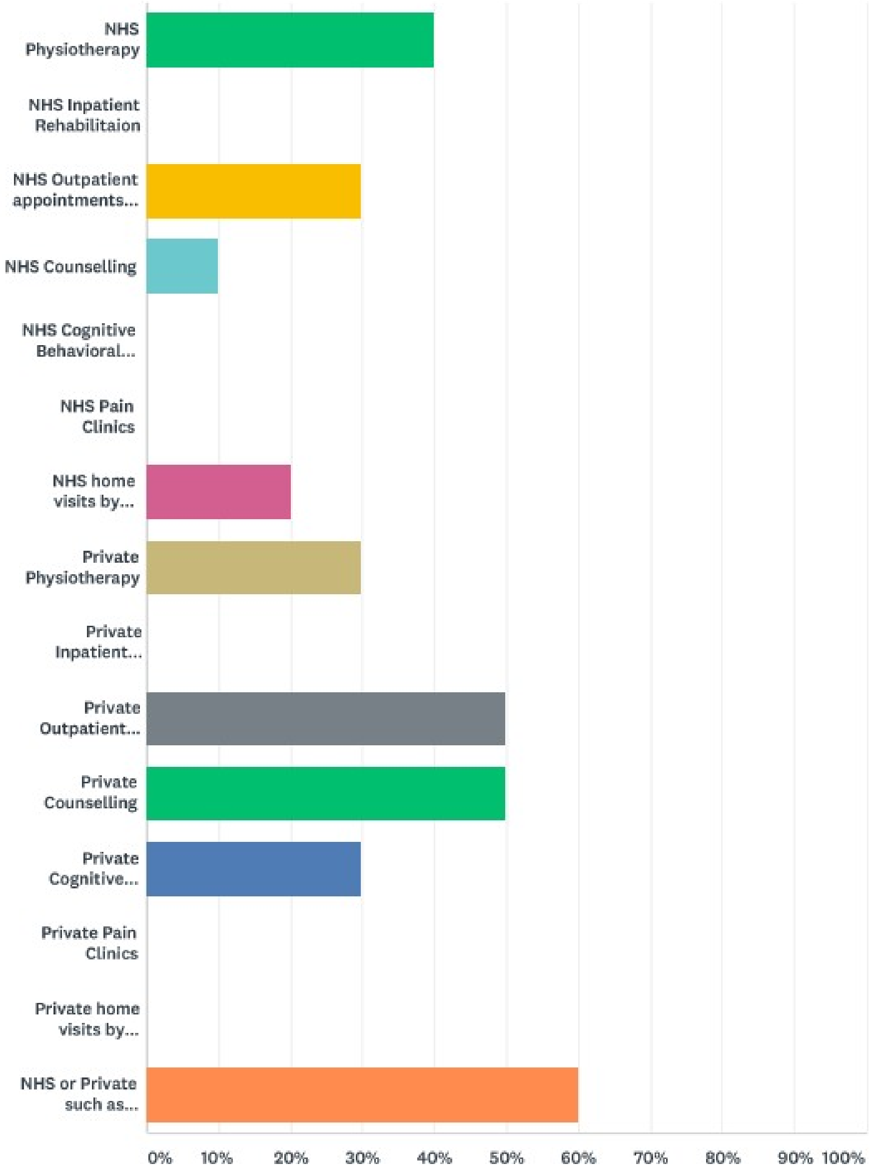
Answered: 12   Skipped: 0



ANSWER CHOICES	RESPONSES	
Yes	33.33%	4
No	66.67%	8
TOTAL		12

Q10 Have you received any of the following NHS or Private treatment since having sepsis to help your recovery from sepsis?

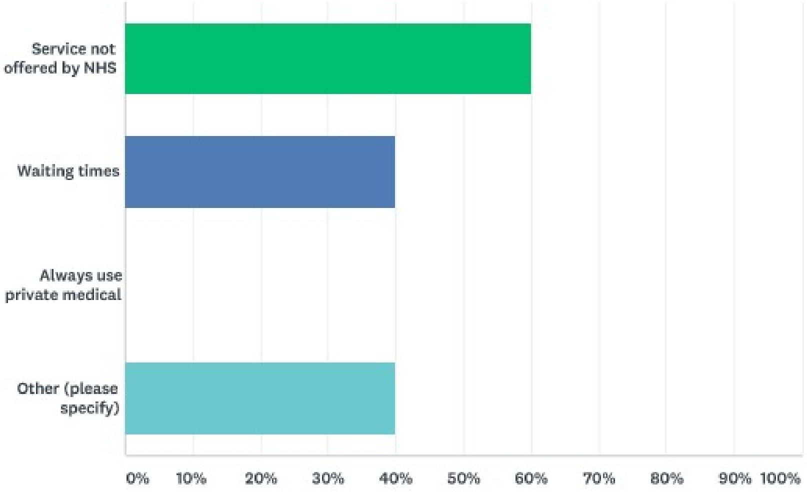
Answered: 10 Skipped: 2



ANSWER CHOICES	RESPONSES	
NHS Physiotherapy	40.00%	4
NHS Inpatient Rehabilitaion	0.00%	0
NHS Outpatient appointments with specialist/s to help after sepsis	30.00%	3
NHS Counselling	10.00%	1
NHS Cognitive Behavioral Therapy (CBT)	0.00%	0
NHS Pain Clinics	0.00%	0
NHS home visits by occupational health / nurses /care workers	20.00%	2
Private Physiotherapy	30.00%	3
Private Inpatient Rehabilitaion	0.00%	0
Private Outpatient appointments with specialist/s to help after sepsis	50.00%	5
Private Counselling	50.00%	5
Private Cognitive Behavioral Therapy (CBT)	30.00%	3
Private Pain Clinics	0.00%	0
Private home visits by private occupational health/nurses/care workers	0.00%	0
NHS or Private such as dietician, nutritionist, chiropractic, osteopath, naturopath,accupuncture, homeopath, etc. (please specify what and whether NHS or Private)	60.00%	6
Total Respondents: 10		

Q11 If you have had private medical treatment to help with your recovery from sepsis was it becouse of the following?

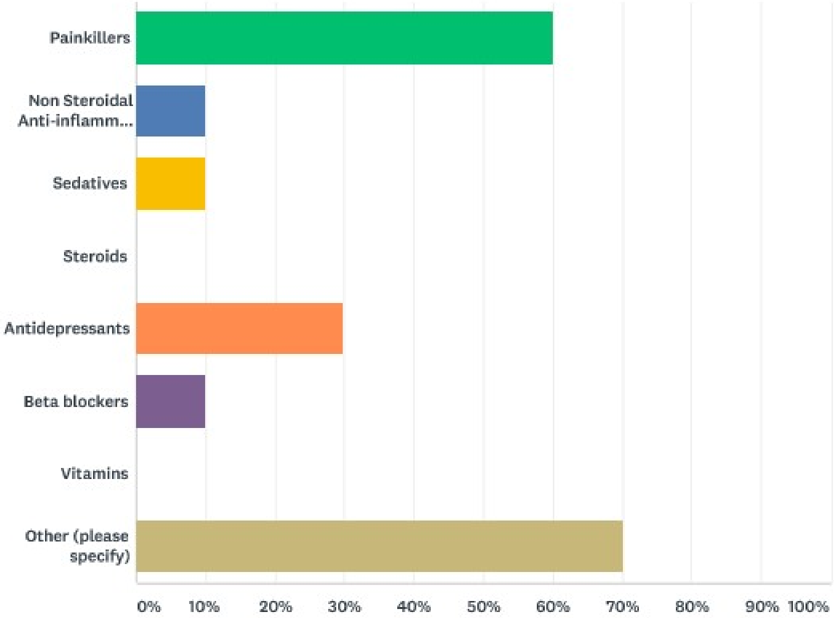
Answered: 10 Skipped: 2



ANSWER CHOICES	RESPONSES	
Service not offered by NHS	60.00%	6
Waiting times	40.00%	4
Always use private medical	0.00%	0
Other (please specify)	40.00%	4
Total Respondents: 10		

Q12 To help manage your recovery from sepsis have you been prescribed any medication?

Answered: 10   Skipped: 2



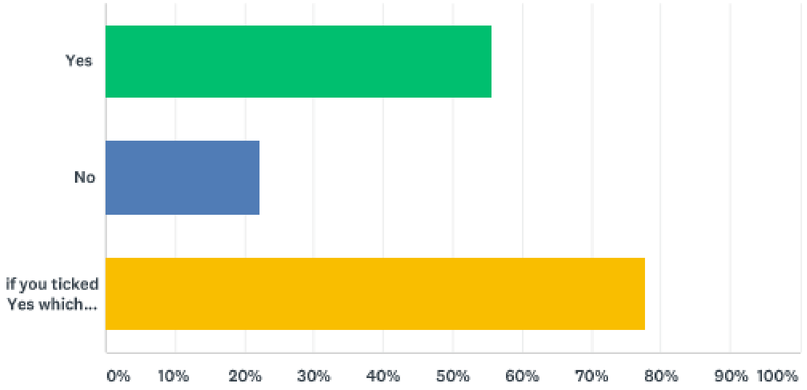
ANSWER CHOICES	RESPONSES	
Painkillers	60.00%	6
Non Steroidal Anti-inflammatories (NSAIDs)	10.00%	1
Sedatives	10.00%	1
Steroids	0.00%	0
Antidepressants	30.00%	3
Beta blockers	10.00%	1
Vitamins	0.00%	0
Other (please specify)	70.00%	7
Total Respondents: 10		

Q13 Do you know the name of any prescribed medication you were given? If so please enter just names

Answered: 10   Skipped: 2

Q14 Did you find any prescribed medication helped?

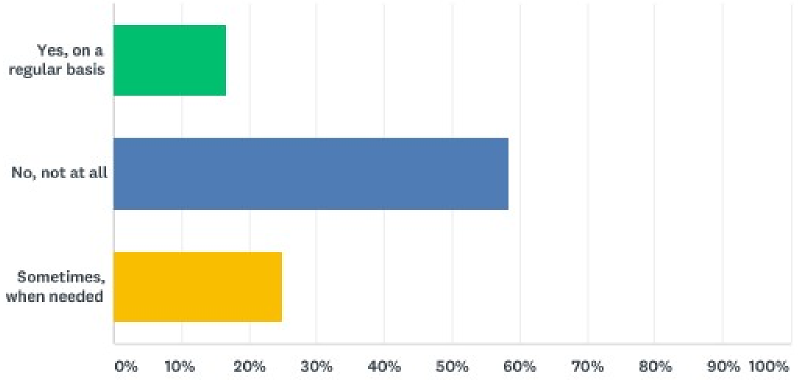
Answered: 9 Skipped: 3



ANSWER CHOICES	RESPONSES	
Yes	55.56%	5
No	22.22%	2
if you ticked Yes which helped (please specify)	77.78%	7
Total Respondents: 9		

Q15 Do you still take prescribed medication to help with your recovery from sepsis?

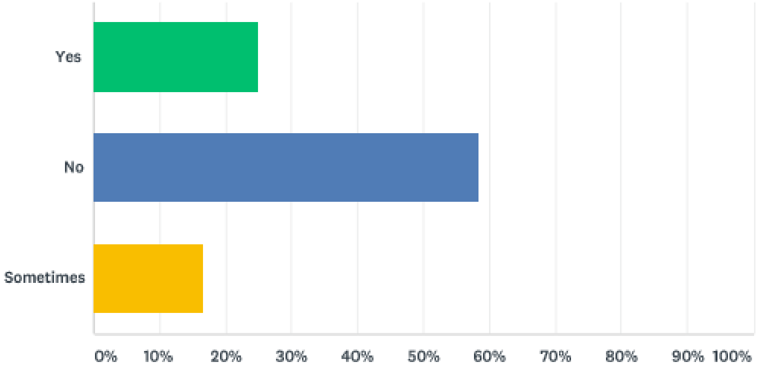
Answered: 12 Skipped: 0



ANSWER CHOICES	RESPONSES	
Yes, on a regular basis	16.67%	2
No, not at all	58.33%	7
Sometimes, when needed	25.00%	3
TOTAL		12

Q16 Do you take any over the counter medication (medication that you do not require a precription for) to help with your recovery (such as paracetamol/asprin/ibuprofen/other)

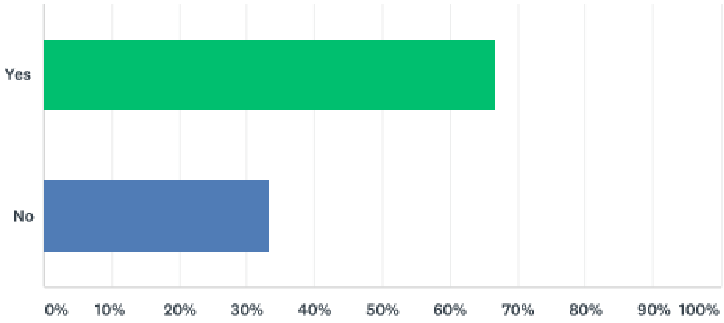
Answered: 12 Skipped: 0



ANSWER CHOICES	RESPONSES	
Yes	25.00%	3
No	58.33%	7
Sometimes	16.67%	2
TOTAL		12

Q17 Have you taken any vitamins or dietry supplements to help with your recovery from sepsis?

Answered: 12 Skipped: 0



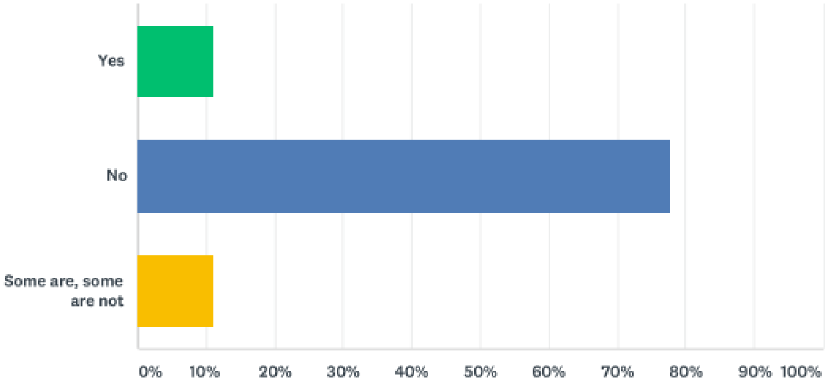
ANSWER CHOICES	RESPONSES	
Yes	66.67%	8
No	33.33%	4
TOTAL		12

Q18 If you answered Yes, to question 17, what vitamins and or supplements are you taking or have you taken, please list just the names of vitamins/supplements

Answered: 8 Skipped: 4

Q19 Are your vitamins/dietry supplements precribed by a health care professional?

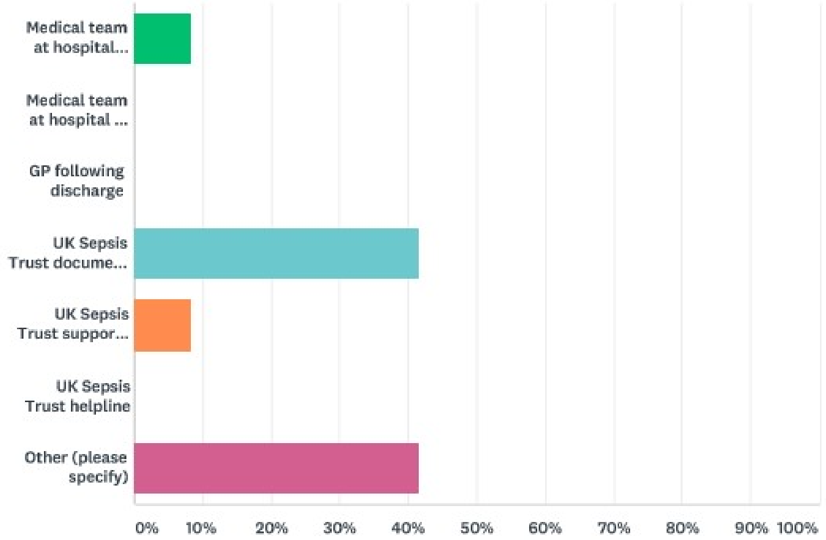
Answered: 9   Skipped: 3



ANSWER CHOICES	RESPONSES	
Yes	11.11%	1
No	77.78%	7
Some are, some are not	11.11%	1
TOTAL		9

Q20 Who explained sepsis to you?

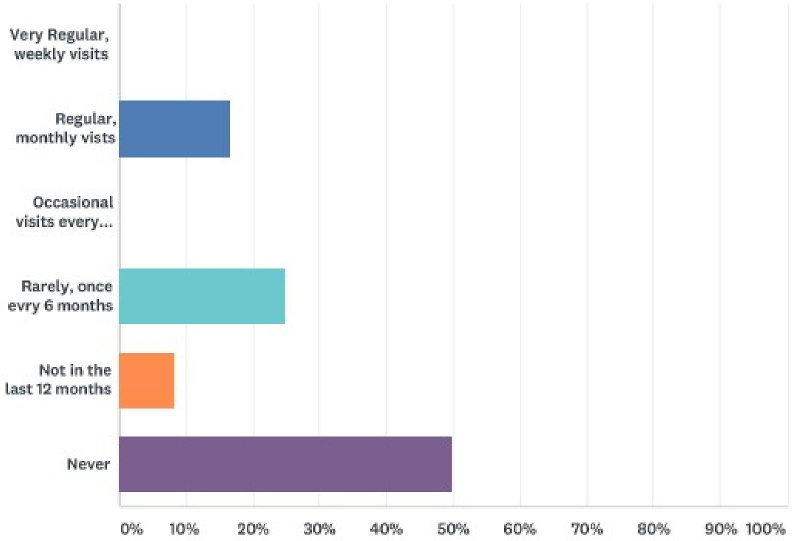
Answered: 12   Skipped: 0



ANSWER CHOICES	RESPONSES	
Medical team at hospital during inpatient stay	8.33%	1
Medical team at hospital in a follow up outpatient appointment following discharge	0.00%	0
GP following discharge	0.00%	0
UK Sepsis Trust documents and website	41.67%	5
UK Sepsis Trust support group	8.33%	1
UK Sepsis Trust helpline	0.00%	0
Other (please specify)	41.67%	5
TOTAL		12

Q21 Do you see your NHS GP as part of your sepsis recovery? This question is not about how many times you see your GP for other heathcare concerns, just those realted to your sepsis recovery.

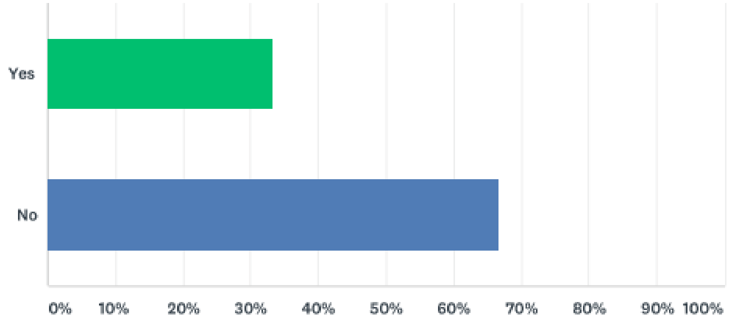
Answered: 12 Skipped: 0



ANSWER CHOICES	RESPONSES	
Very Regular, weekly visits	0.00%	0
Regular, monthly vists	16.67%	2
Occasional visits every 2-3 months	0.00%	0
Rarely, once evry 6 months	25.00%	3
Not in the last 12 months	8.33%	1
Never	50.00%	6
TOTAL		12

Q22 Has your NHS GP reffered you to other services to help with your recovery?

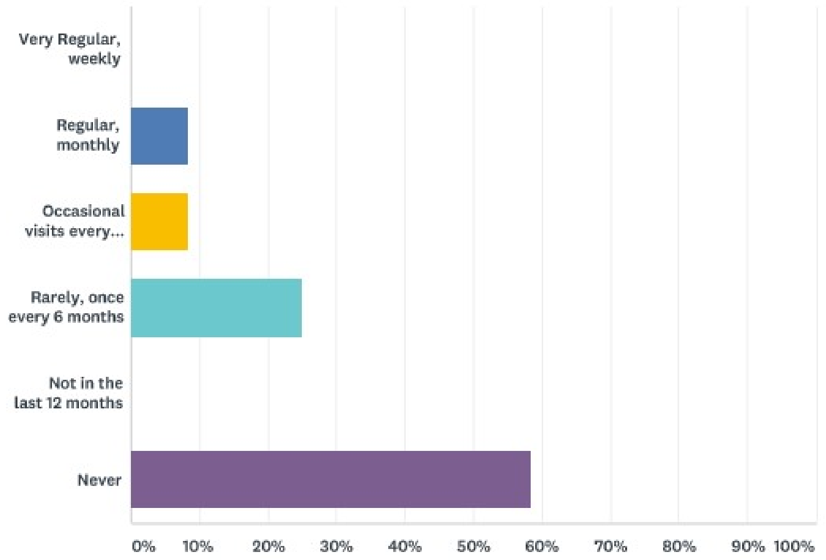
Answered: 12 Skipped: 0



ANSWER CHOICES	RESPONSES	
Yes	33.33%	4
No	66.67%	8
TOTAL		12

Q23 Do you see other healthcare professionals as part of your sepsis recovery?

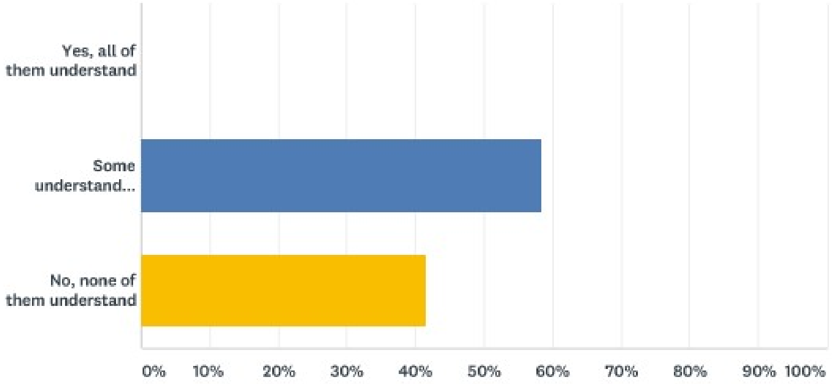
Answered: 12   Skipped: 0



ANSWER CHOICES	RESPONSES	
Very Regular, weekly	0.00%	0
Regular, monthly	8.33%	1
Occasional visits every 2-3 months	8.33%	1
Rarely, once every 6 months	25.00%	3
Not in the last 12 months	0.00%	0
Never	58.33%	7
TOTAL		12

Q24 Do you feel that that your recovery post sepsis is understood by healthcare professionals?

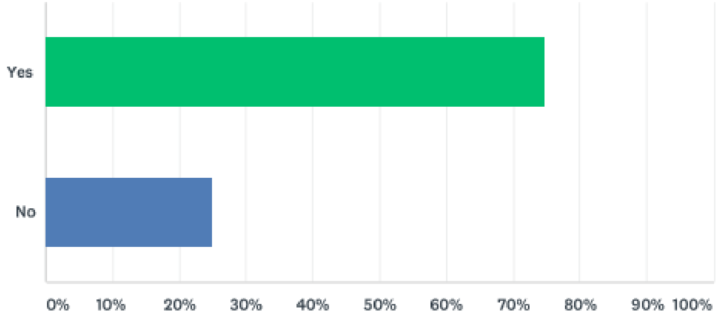
Answered: 12 Skipped: 0



ANSWER CHOICES	RESPONSES	
Yes, all of them understand	0.00%	0
Some understand others do not	58.33%	7
No, none of them understand	41.67%	5
TOTAL		12

Q25 Have you been to a UK Sepsis Trust Support Group?

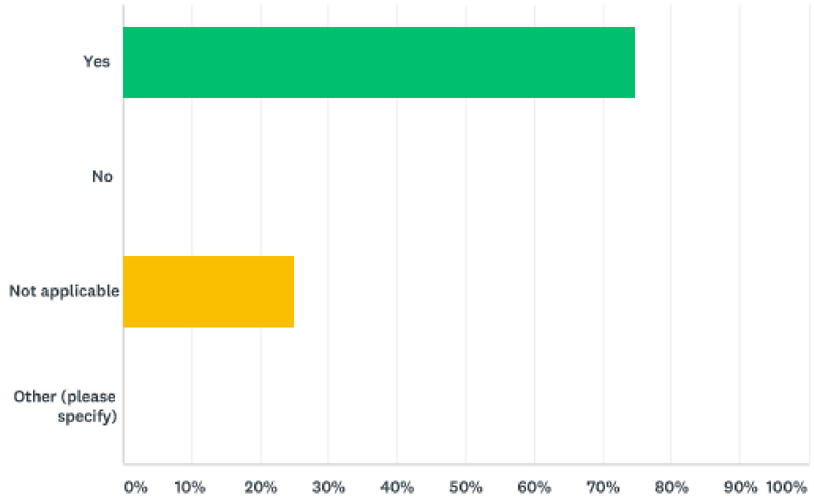
Answered: 12 Skipped: 0



ANSWER CHOICES	RESPONSES	
Yes	75.00%	9
No	25.00%	3
TOTAL		12

Q26 If yes was it useful?

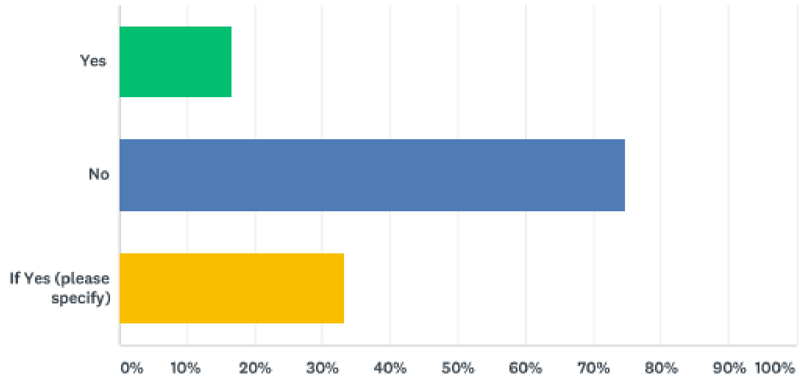
Answered: 12   Skipped: 0



ANSWER CHOICES	RESPONSES	
Yes	75.00%	9
No	0.00%	0
Not applicable	25.00%	3
Other (please specify)	0.00%	0
TOTAL		12

Q27 Have you been to any other Support Groups following sepsis such as ICU Steps?

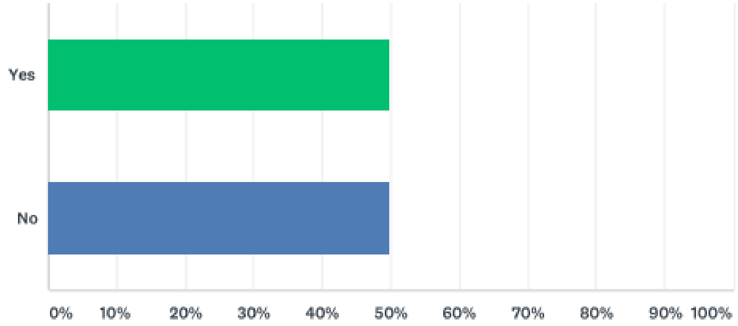
Answered: 12   Skipped: 0



ANSWER CHOICES	RESPONSES	
Yes	16.67%	2
No	75.00%	9
If Yes (please specify)	33.33%	4
Total Respondents: 12		

Q28 Have you called the UK Sepsis Trust helpline for advice/support following sepsis?

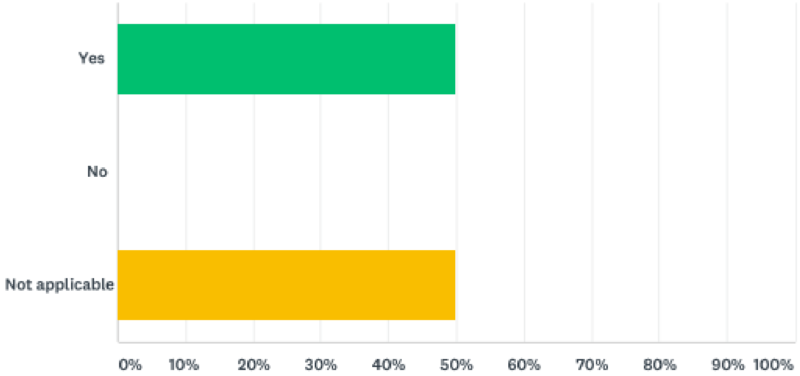
Answered: 12 Skipped: 0



ANSWER CHOICES	RESPONSES	
Yes	50.00%	6
No	50.00%	6
TOTAL		12

Q29 If you have called the UK Sepsis Trust helpline did you find it useful?

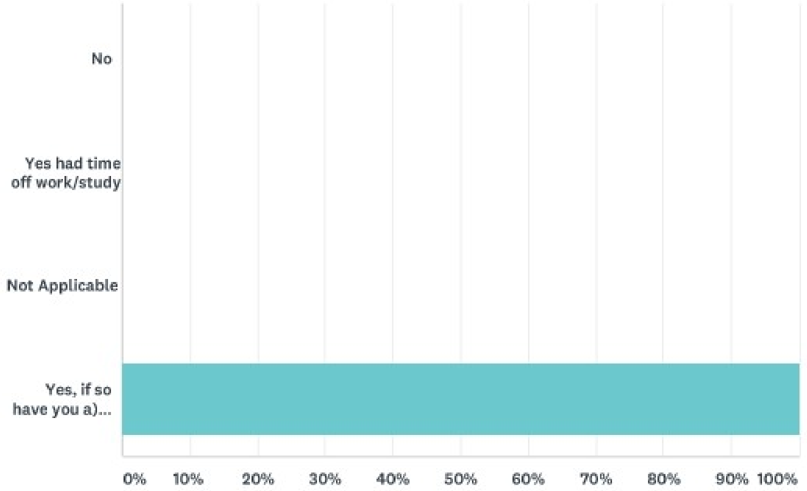
Answered: 12 Skipped: 0



ANSWER CHOICES	RESPONSES	
Yes	50.00%	6
No	0.00%	0
Not applicable	50.00%	6
TOTAL		12

Q30 Have you had any time off work or study as a result of your sepsis?

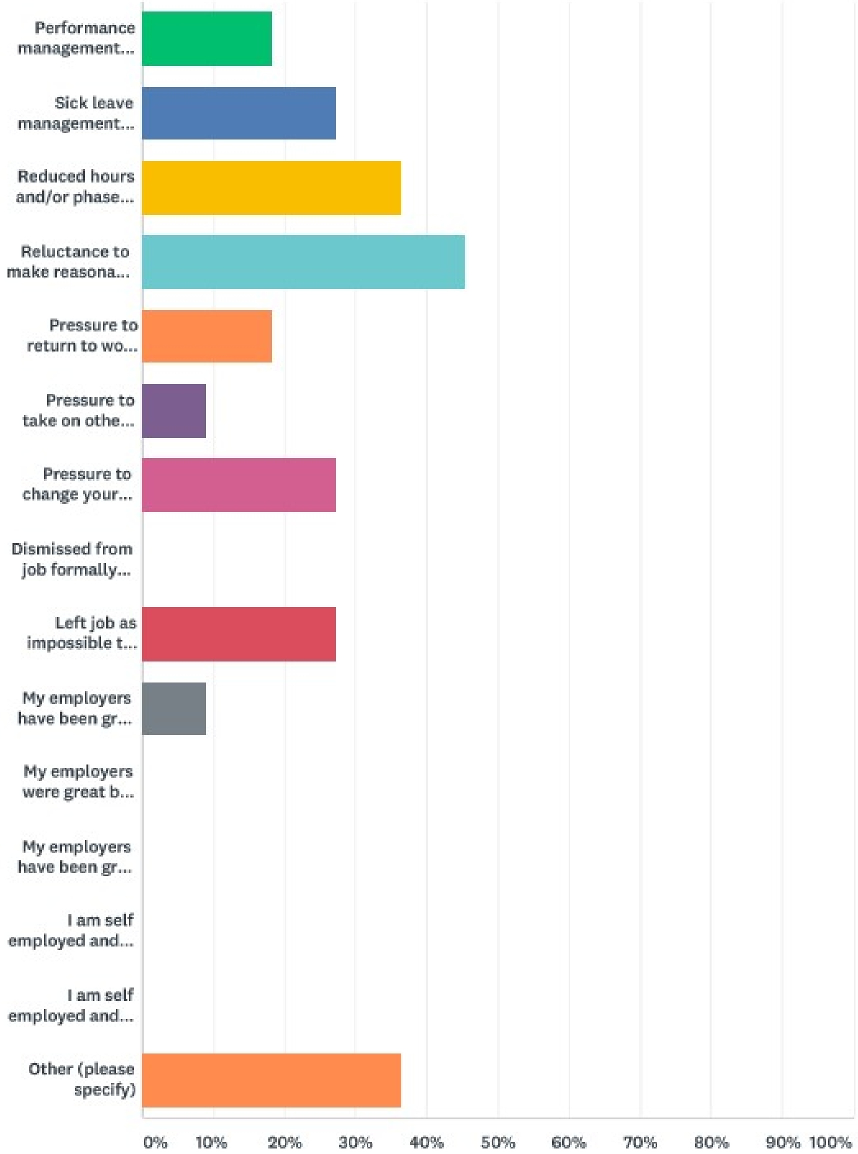
Answered: 11   Skipped: 1



ANSWER CHOICES	RESPONSES	
No	0.00%	0
Yes had time off work/study	0.00%	0
Not Applicable	0.00%	0
Yes, if so have you a) gone back to your role in work b) resumed study as you were before sepsis, or have you as a result of sepsisc)changed your role in workd) changed studies e) changed your jobf) changed your studies g) left work and study Please insert appropriate letter into box below	100.00%	11
TOTAL		11

Q31 If employed, following your sepsis have you experienced any difficulties with employers?

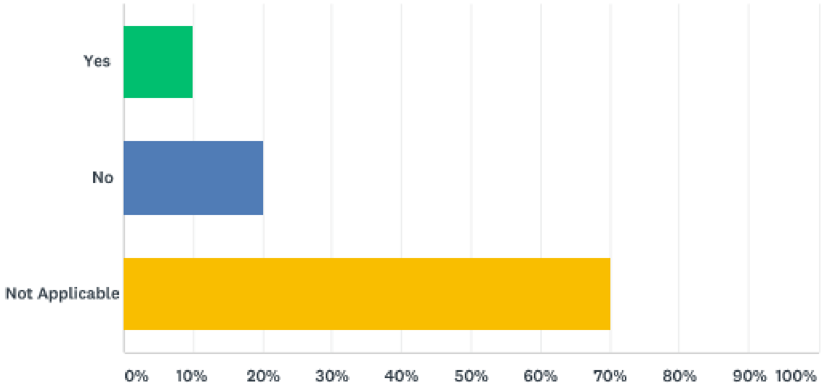
Answered: 11   Skipped: 1



ANSWER CHOICES	RESPONSES	
Performance management issues	18.18%	2
Sick leave management issues	27.27%	3
Reduced hours and/or phased return to work issues	36.36%	4
Reluctance to make reasonable adjustments	45.45%	5
Pressure to return to work before you are fit to	18.18%	2
Pressure to take on other roles/tasks not suitable for you	9.09%	1
Pressure to change your contract	27.27%	3
Dismissed from job formally, unfairly or constructively	0.00%	0
Left job as impossible to work there anymore	27.27%	3
My employers have been great and really understanding, I have had no difficulties with employers during my revovery after sepsis	9.09%	1
My employers were great but I decided to leave or change employment after sepsis as I had a different/new perspective on life	0.00%	0
My employers have been great but my work collegues have not been understanding of my situation and recovering from sepsis	0.00%	0
I am self employed and have other issues regarding employment benifits, self employment insurances and income due to taking time off to recover from my sepsis	0.00%	0
I am self employed and have not had any problems regarding work following my sepsis	0.00%	0
Other (please specify)	36.36%	4
Total Respondents: 11		

Q32 If you left your job have you found new employment?

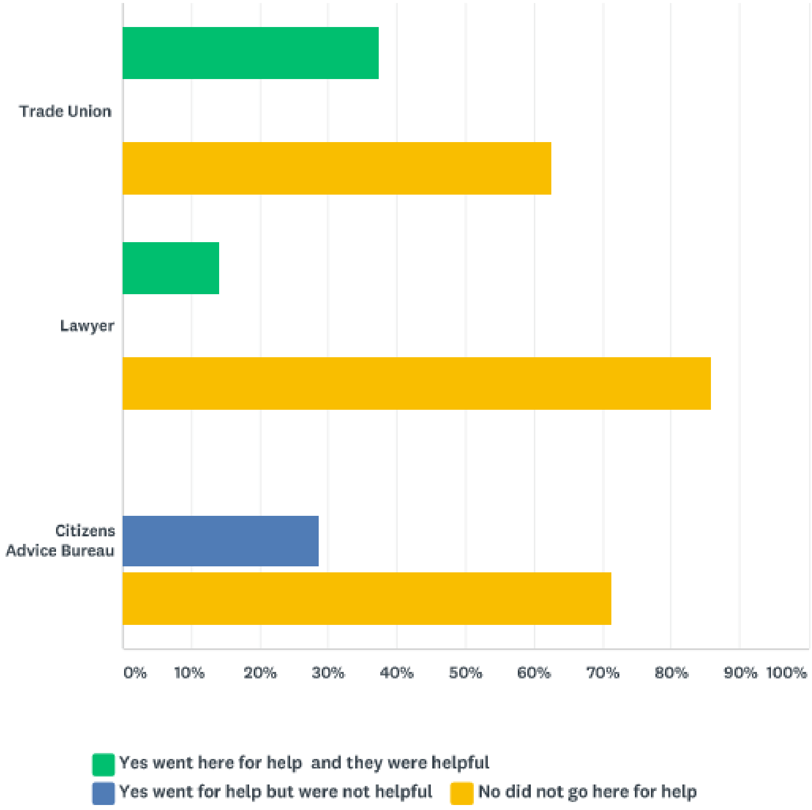
Answered: 10 Skipped: 2



ANSWER CHOICES	RESPONSES	
Yes	10.00%	1
No	20.00%	2
Not Applicable	70.00%	7
TOTAL		10

Q33 If employed and had employement issues following return to work, did you enlist the help of the following and were they helpful?

Answered: 8 Skipped: 4

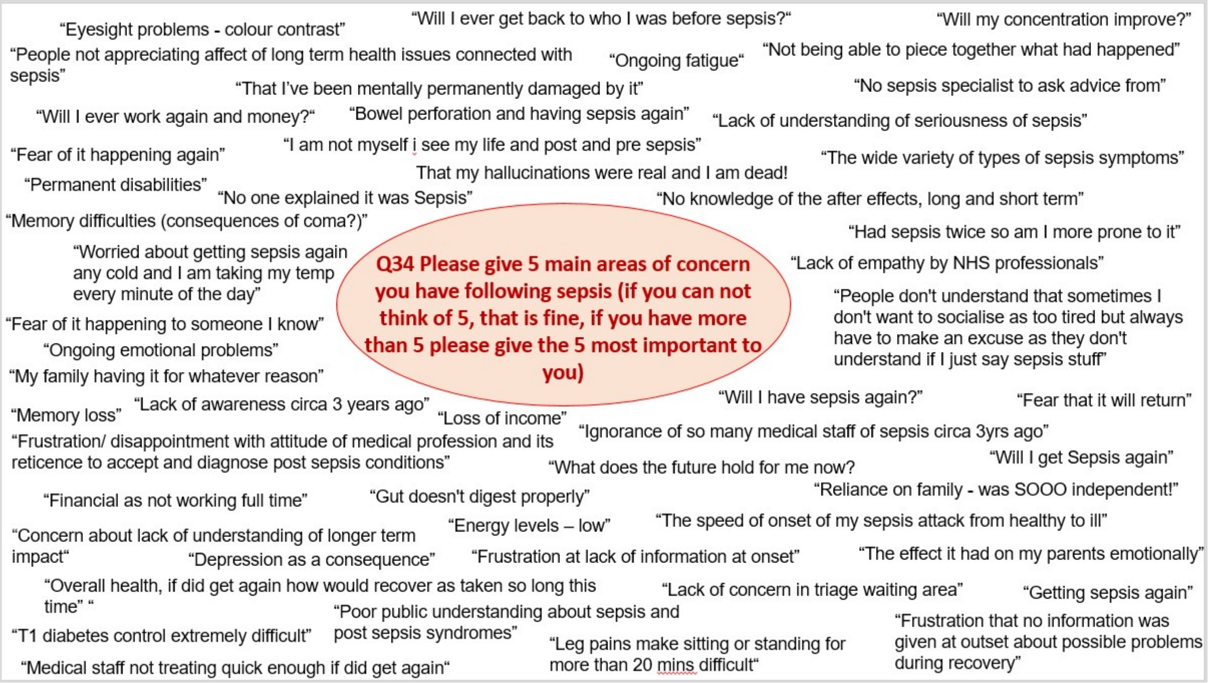


	YES WENT HERE FOR HELP AND THEY WERE HELPFUL	YES WENT FOR HELP BUT WERE NOT HELPFUL	NO DID NOT GO HERE FOR HELP	TOTAL RESPONDENTS
Trade Union	37.50% 3	0.00% 0	62.50% 5	8
Lawyer	14.29% 1	0.00% 0	85.71% 6	7
Citizens Advice Bureau	0.00% 0	28.57% 2	71.43% 5	7

Q34 Please give 5 main areas of concern you have following sepsis (if you can not think of 5, that is fine, if you have more than 5 please give the 5 most important to you)

Answered: 12 Skipped: 0

ANSWER CHOICES	RESPONSES	
1-	100.00%	12
2-	100.00%	12
3-	91.67%	11
4-	75.00%	9
5-	66.67%	8



Q34 Please give 5 main areas of concern you have following sepsis (if you can not think of 5, that is fine, if you have more than 5 please give the 5 most important to you)

“Eyesight problems - colour contrast”

“Will I ever get back to who I was before sepsis?“

“Will my concentration improve?”

“People not appreciating affect of long term health issues connected with sepsis”

“Ongoing fatigue“

“Not being able to piece together what had happened”

“That I’ve been mentally permanently damaged by it”

“No sepsis specialist to ask advice from”

“Will I ever work again and money?“

“Bowel perforation and having sepsis again”

“Lack of understanding of seriousness of sepsis”

“Fear of it happening again”

“I am not myself i see my life and post and pre sepsis”

“The wide variety of types of sepsis symptoms”

That my hallucinations were real and I am dead!

“Permanent disabilities”

“No one explained it was Sepsis”

“No knowledge of the after effects, long and short term”

“Memory difficulties (consequences of coma?)”

“Had sepsis twice so am I more prone to it”

“Worried about getting sepsis again any cold and I am taking my temp every minute of the day”

“Lack of empathy by NHS professionals”

“People don't understand that sometimes I don't want to socialise as too tired but always have to make an excuse as they don't understand if I just say sepsis stuff”

“Fear of it happening to someone I know”

“Ongoing emotional problems”

“My family having it for whatever reason”

“Will I have sepsis again?”

“Fear that it will return”

“Memory loss”

“Lack of awareness circa 3 years ago”

“Loss of income”

“Frustration/ disappointment with attitude of medical profession and its reticence to accept and diagnose post sepsis conditions”

“Ignorance of so many medical staff of sepsis circa 3yrs ago”

“Will I get Sepsis again”

“What does the future hold for me now?

“Financial as not working full time”

“Gut doesn't digest properly”

“Reliance on family - was SOOO independent!”

“The speed of onset of my sepsis attack from healthy to ill”

“Energy levels – low”

“Concern about lack of understanding of longer term impact“

“Depression as a consequence”

“Frustration at lack of information at onset”

“The effect it had on my parents emotionally”

“Overall health, if did get again how would recover as taken so long this time” “

“Lack of concern in triage waiting area”

“Getting sepsis again”

“Poor public understanding about sepsis and post sepsis syndromes”

“Frustration that no information was given at outset about possible problems during recovery”

“T1 diabetes control extremely difficult”

“Leg pains make sitting or standing for more than 20 mins difficult“

“Medical staff not treating quick enough if did get again“

Q35 What 5 things do you think would help your recovery/rehabilitation from sepsis? (if you cannot think of 5 do not worry, if there are more than 5, list the most important 5)

Answered: 12 Skipped: 0

ANSWER CHOICES	RESPONSES	
1-	100.00%	12
2-	100.00%	12
3-	91.67%	11
4-	75.00%	9
5-	41.67%	5

“Early diagnosis and appropriate guidance on rehabilitation at outset, not 6 months down the line”

“Rehabilitation”

“Dedicated support via NHS”

“An outpatient department for Sepsis”

“Having more support from NHS after discharge from hospital”

“Initially having quicker treatment when went to hospital”

“More information at diagnosis & discharge” and
“Having explanation of sepsis when in hospital and what to expect in recovery“

“Having a rehabilitation course specific to sepsis”

“Access to counselling, and understanding what you have been through in hospital“

Q35 What 5 things do you think would help your recovery/rehabilitation from sepsis? (if you cannot think of 5 do not worry, if there are more than 5, list the most important 5)

“Counselling”

“Physical rest”

“Sign posting to possible support available”

“Medical staff sitting down and explaining situation to self and family whilst in hospital”.

“Talk to recovering sepsis survivors”

“Professional help with pacing and managing the symptoms”

“Better information from medical professionals”

“Mental rest”

A "sepsis consultant"

“Better understanding of post sepsis syndrome”

“call back after a month to discuss recover”

“Empathy from NHS staff”

“Better understanding about amputations from sepsis - it is NOT the same as amputation from diabetes”

“Not being told by GP *“that perhaps my symptoms are in the mind”*

“More information when I left hospital”

“Being given leaflets to read at my leisure”

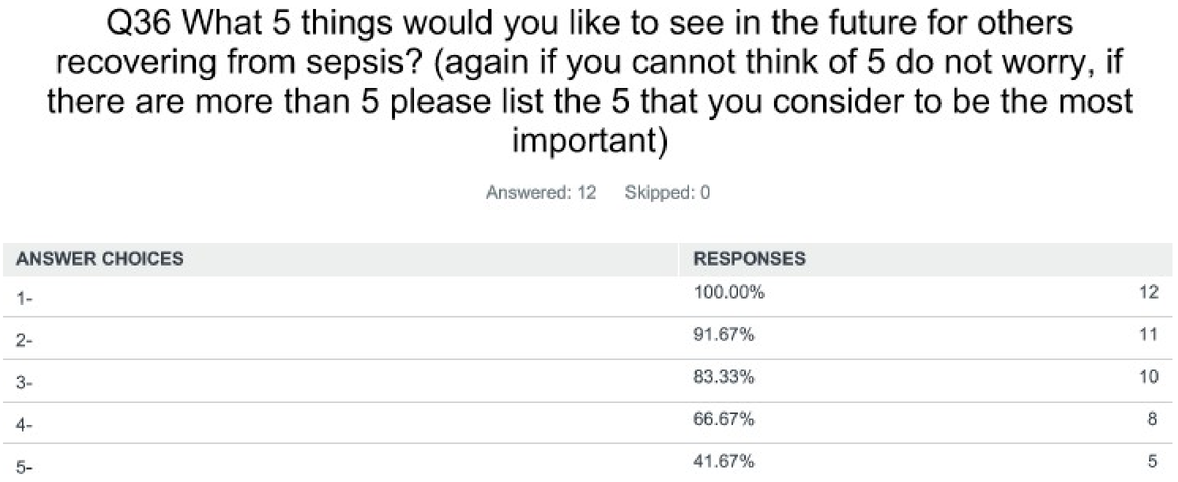
“Better mental health support”

“Information about support organisations”

“Better discharge notes from hospital to GP where sepsis is secondary to other surgery/illness”

“Vitamins and probiotics, as helped more than any prescribed medication”

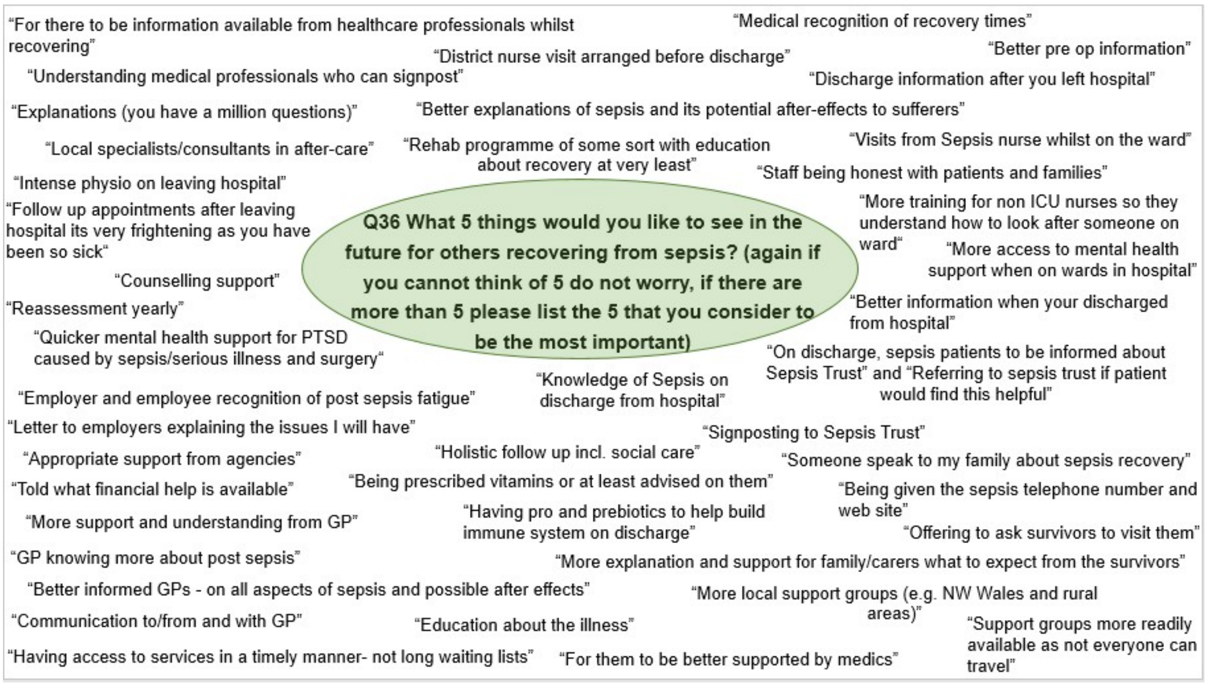
“A joined up approach for sufferers”



Q36 What 5 things would you like to see in the future for others recovering from sepsis? (again if you cannot think of 5 do not worry, if there are more than 5 please list the 5 that you consider to be the most important)

Answered: 12 Skipped: 0

ANSWER CHOICES	RESPONSES	
1-	100.00%	12
2-	91.67%	11
3-	83.33%	10
4-	66.67%	8
5-	41.67%	5



Q36 What 5 things would you like to see in the future for others recovering from sepsis? (again if you cannot think of 5 do not worry, if there are more than 5 please list the 5 that you consider to be the most important)

"For there to be information available from healthcare professionals whilst recovering"

"Medical recognition of recovery times"

"Better pre op information"

"District nurse visit arranged before discharge"

"Understanding medical professionals who can signpost"

"Discharge information after you left hospital"

"Explanations (you have a million questions)"

"Better explanations of sepsis and its potential after-effects to sufferers"

"Local specialists/consultants in after-care"

"Rehab programme of some sort with education about recovery at very least"

"Visits from Sepsis nurse whilst on the ward"

"Intense physio on leaving hospital"

"Staff being honest with patients and families"

"Follow up appointments after leaving hospital its very frightening as you have been so sick"

"More training for non ICU nurses so they understand how to look after someone on ward"

"More access to mental health support when on wards in hospital"

"Counselling support"

"Reassessment yearly"

"Better information when your discharged from hospital"

"Quicker mental health support for PTSD caused by sepsis/serious illness and surgery"

"On discharge, sepsis patients to be informed about Sepsis Trust" and "Referring to sepsis trust if patient would find this helpful"

"Knowledge of Sepsis on discharge from hospital"

"Employer and employee recognition of post sepsis fatigue"

"Letter to employers explaining the issues I will have"

"Signposting to Sepsis Trust"

"Appropriate support from agencies"

"Holistic follow up incl. social care"

"Someone speak to my family about sepsis recovery"

"Told what financial help is available"

"Being prescribed vitamins or at least advised on them"

"Being given the sepsis telephone number and web site"

"More support and understanding from GP"

"Having pro and prebiotics to help build immune system on discharge"

"Offering to ask survivors to visit them"

"GP knowing more about post sepsis"

"More explanation and support for family/carers what to expect from the survivors"

"Better informed GPs - on all aspects of sepsis and possible after effects"

"More local support groups (e.g. NW Wales and rural areas)"

"Communication to/from and with GP"

"Education about the illness"

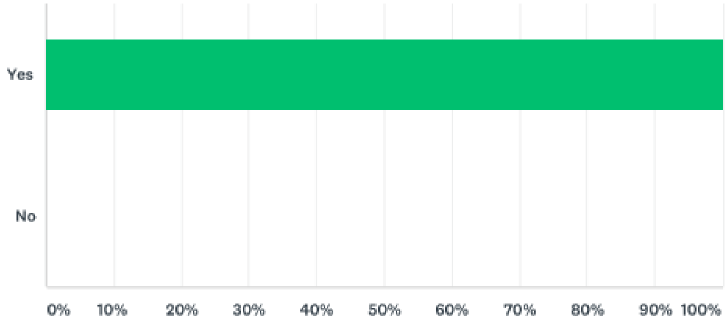
"Support groups more readily available as not everyone can travel"

"Having access to services in a timely manner- not long waiting lists"

"For them to be better supported by medics"

Q37 Do you think that those who have had sepsis would benefit from a rehabilitation programme?

Answered: 12 Skipped: 0



ANSWER CHOICES	RESPONSES	
Yes	100.00%	12
No	0.00%	0
TOTAL		12

Q38 If you answered yes to question 37, what would you like that programme to look like? There is a word limit.For example please say where you think it should be run, who should run it, what medical staff if any should be available, how many sessions and over what period of time and what you would like to see included.

Answered: 12 Skipped: 0

ANSWER CHOICES	RESPONSES	
Where should it be run from?	100.00%	12
Who should run it?	100.00%	12
What medical staff if any would you like to be involved?	100.00%	12
Length of each session and overall duration of programme?	100.00%	12
What would you like to see included?	100.00%	12
Anything else?	66.67%	8

Q37&Q38 Do you think that those who have had sepsis would benefit from a rehabilitation programme?

Q38 If you answered yes to question 37, what would you like that programme to look like? There is a word limit. For example please say where you think it should be run, who should run it, what medical staff if any should be available, how many sessions and over what period of time and what you would like to see included

Where should it be run?

- Somewhere local (Cardiff) with parking
- By hospital to ensure capture all Sepsis patients
- Any area centre where a group could meet with fellow sufferers
- Hospital training/conference rooms
- Local hospital
- Connected to the hospital
- Locally, across Wales
- Hospital once well enough. Home visits initially
- In local hospitals
- In the community but from people who have supported you
- Local hospital/health centres
- Specialist area at hospital

Who should run it?

- Medical professional for technical knowledge, sepsis survivor for experience, anyone who can provide advice/support to survivors
- Specialist Nurses
- Previous sufferer with a medical back up/speaker
- Hospital
- Health professional
- Mixture of professionals and sepsis survivors
- Sepsis Trust in conjunction with medical professionals
- Physio, counsellors, OT
- Specialist staff
- Qualified professionals but people with understanding
- Sepsis survivors supported by appropriate professionals
- NHS

What medical staff is any should be involved?

- It might be helpful to have a guest speaker at each session, which may include some group interaction and Q&A. My mum goes to a tinnitus group that works in this way and she has found it helpful.
- Physio, Counsellor, social services,
- Sepsis trained
- Specially trained nurses and psychiatrist
- Counsellors, physio
- ICU nurses, physio, counsellors
- PSS /ME/CFS... specialist, sepsis nurse, dietician, counsellor, physiotherapist
- Physio, counsellors, OT
- Nurse practitioners, appropriately trained medical staff physiotherapists occupational therapists, social workers
- The people who helped you recover
- Nurses
- Nurses, doctors and pharmacists, physios, dietitians, neurologists, psychotherapists

Length of each session and duration of course..

- 1 -2 hour at a time over a period of time
- Professional input required
- 1 hour max for newly post sufferers
- 2 hours, 3 months
- 30 minds
- meet every other month about an hour and a half and last half hour just chat to people
- Up to 2 hours, possibly for up to 2 years but until the 'sufferer' feels confident with his/her rehabilitation
- Depends on stage of recovery - max 2hrs, but probably 10mins initially
- Dependant on need of patient
- Depends on level of need as to how much you can cope with
- Variable as everyone is so different.
- 2 to 3 hours once a week over 8 weeks

What would you like to see included?

- Explanation of sepsis recovery what to expect/ simple exercises just to keep your body moving/ sign posting to helpful groups or activities/
- Group meeting with shared experience of new and recovered patients
- Should cover physical and mental recovery
- Time to talk, Time for exercise
- Presentation from different people and organisations
- Explanations of sepsis and how it can affect the body, strategies for pacing recovery, dietary advice, emotional support, sign-posting to other agencies, advice on coping with life-changing circumstances, local peer support network
- Physio, counselling, OT
- Practical advise regarding health and wellbeing.
- Physio, listening, occupational therapy, some may need life skills (I couldn't lift a kettle for months)
- Impact of sepsis, what you can expect, self help options, sources of info
- Explanation of sepsis and what to expect in recovery, help with getting benefits so CAB, how to do pacing, mindfulness, what to eat, advice on supplements, advice on relationships and how both patient and carer see things, exercise, PTSD,

Anything else?

- It would be nice to have more activities that survivors could go to, do something but also talk and meet other survivors. I think sometimes doing something gets you out the house, meet others with a common illness and can talk or listen if you like there is no pressure.
- Not time limited
- Online forums might suit the weakest
- Progressing to fund raising activities for Sepsis Trust
- I go to a sepsis group and I feel it is not run right we sit in a circle I feel like I should stand up and say hi my name is ... and I am a sepsis survivor its weird. also so people feel very uncomfortable speaking in public
- There needs to be someone available to ring (e.g. a sepsis specialist nurse) in the early stages of recovery
- Advise about what benefits could be applied for and practical help with applying for them
- Sensitivity that this horrible illness is not the same as support needed by an aging person

Appendix 1

Across Wales and the rest of the UK, despite the efforts of charities such as the UK Sepsis Trust and events such as World Sepsis Day, people are still dying or being left with life-changing physical and psychological damage from an illness they've either never heard of or are unaware of the need for a rapid diagnosis and treatment.

The need for awareness and the impact of slow recognition:

Case Study – Sepsis Survivor Helen [redacted]

'Following a major operation In December 2016 I was discharged from Cardiff Hospital and sent home to recover, however, 3 days later imy condition was declining, and my husband took me to see my GP who immediately recognised referred me straight to my local hospital (Neville Hall, Abergavenny). – ***So far, so good.***

On arriving at the hospital, I provided a full history and was triaged. The nurse first informed us that they had no ability to admit me, following which she then eventually examined me and told me to wait for the Doctor. On his arrival the Doctor re-examined me and discharged me with anti-nausea medication. – ***Failure one:*** *I was 96 hours post major Op and clearly showing symptoms of Sepsis, but was sent home.* ***Greater public awareness of Sepsis at this stage*** *would have enabled either myself or my husband to have raised the possibility.*

Having received the diagnosis on the Monday, my husband left for work, in the belief that the medication prescribed by the Doctor should be beginning to take effect. However, soon afterwards I began to feel worse, my father came to see me, and I then put myself to bed. ***A clear opportunity missed –*** *With myself and my husband so close to the situation,* ***had my father been made aware of the signs and symptoms, perhaps he would have either encouraged us to constructively challenge the Doctors diagnosis, or sought medical help at that point.***

I awoke a few hours later and found myself struggling to breath. I felt as if I was dying, but somehow managed to dial 999. Despite being violently sick in front of the paramedic, he was reluctant to take me to hospital. ***Failure two*** *- another opportunity missed. Again, my history and signs and symptoms should have been ringing alarm bells in the paramedics' mind and could have presented another opportunity for my family to raise a concern. Thankfully this failure was short lived, because although I have little recollection of the event my condition deteriorated again and I was admitted into Neville Hall Accident and Emergency.*

Following admission, I remained in A & E for a number of hours whilst they ran some tests. It was at this point that my husband (who was a patrol medic in the military) challenged the medical staff and raised concerns about my oxygen levels, but he was politely offered an explanation and decided to defer to the medical Team. ***Failure Four.*** *By this stage I had been triaged three times, had seen a minimum of 10 health care professionals, all of whom had* ***failed to identify the clear signs and symptoms of sepsis****, and the concerns raised by my husband had been dismissed.*

It was at this point that my luck changed however, but not a result of an awareness of Sepsis. It was because a bed had now become available on a ward and although I was assessed to have no surgical issues I was admitted for observation. By now many of the hospital's lights had been dimmed, but on arrival at the ward the Doctor who had sent me home earlier in the week was on duty and as I was being moved on to a ward bed he intervened (by chance) and requested that I was placed in an examination room, - presumably so that he could take a few minutes to understand his patient's needs. – ***This action saved my life.***

Under normal lighting it was obvious that my abdomen had become bloated and that my skin had begun to change colour. In fact, I had gone into kidney failure, and the Senior Consultants who were summoned and informed my husband that my other major organs were also beginning to shut down, as a result of Sepsis. The emergency surgical team were immediately called and I went into theatre at approx. 2 am. I awoke a number of days later in ITU, having *had life changing surgery (I now have a Stoma), but fortunately oblivious to everything that had happened, and at that point naive to what lay ahead.*

Two years on I am still living with the consequences of the lack of awareness and a delayed correct diagnosis. Through the Sepsis Trust I regularly speak to people who have either survived or lost loved ones more recently than my experience which evidences a continued need for action. ***Given the significant numbers affected by Sepsis each year what could change that? To me and the other Sepsis survivors the answer is obvious – A public awareness campaign.***

Through my involvement with the Sepsis Trust I regularly volunteer to speak to groups of health care professionals about my experience, whilst also sharing my story with colleagues and acquaintances - I am proud to say that I've been informed of ***three diagnosis*** *as a result of those people remembering my story. However, myself and my fellow survivors cannot speak to the entire population of Wales and remembering that Health professionals are also members of the public I believe that it's safe to say that if a campaign had increased awareness in the minds of the health professionals who treated me and my family and friends who supported me after my operation that a conversation would have been had before life changing surgery became the only option.*

The Burden of Sepsis

A public awareness campaign by Welsh Government will help people to understand what sepsis is and the need for early, rapid screening, diagnosis and treatment. The **annual cost** to the UK economy of sepsis care is currently estimated at between **£10.5 billion and £15.5 billion**. The costs and risk of adding to the workload of front-line clinicians will be more than offset by earlier treatment, which will prevent deterioration and the need for critical care, and ultimately reduce the burden of long-term health problems for survivors. This will reduce the need for support service and primary care health services for sepsis survivors, helping them to return to work and contribute to the economy.

Further details can be found here :
http://allcatsrgrey.org.uk/wp/download/health_economics/YHEC-Sepsis-Report-17.02.17-FINAL.pdf

Campaigns (1) – Do they work?

Case Study – Stroke: The FAST Campaign

On **Friday 29 January 2016** Welsh Gov released a news report with the headline
"More people in Wales surviving stroke shows new report"
In essence the report shows that more people are surviving and fewer people are now dying from stroke. The report also highlights how awareness campaigns and better prevention have helped to reduce the number of people having strokes, while faster interventions have increased people's chances of surviving and returning to independence as quickly as possible. Amongst the key findings it is stated that:

- For strokes time matters.
- There is an improved awareness of the symptoms of stroke as a result of campaigns such as FAST or Lower Your Risk of Stroke. These are supporting people to recognise when they are having a stroke and take appropriate action quickly

Dr Andrew Goodall CEO NHS Wales

"*I want to pay tribute to the NHS staff who have played a vital role in making continued and sustained improvements to services.*

*"Our annual report shows that by focusing on a number of areas and through prevention, **awareness-raising and education; effective and timely treatment**; research and supporting those living and dying from a stroke, we are delivering quality care for people. We will continue to build on this progress."*

Like Stroke, Sepsis is also **time critical** illness with risk of mortality increasing by 8% for each hour that a septic patient does receive antibiotics. **Lack of sepsis awareness** in the communities often means sick individuals are **slow to access health care** which causes delays in diagnosis and treatment which can be fatal or result in life changing outcomes. It should be highlighted that, for all the brilliant work that NHS Wales and PHW have undertaken in the care setting, 70% of sepsis cases are community acquired.

For stroke an estimated 7,000 people will have a stroke each year in Wales and there are more than 65,000 stroke survivors living in Wales.

For Sepsis and estimated 8,000 people will have sepsis each year in Wales and there are more than 2,000 deaths.

The question is ….if an education and awareness campaign has been successful for stroke then why would it not be similarly successful for sepsis?

Full report on improvements in stroke can be found here:

https://gov.wales/newsroom/health-and-social-services/2016/160129stroke-report/?lang=en

Awareness in action

Case study – "That's the poster which saved your life"

At a recent UK Sepsis Trust support group meeting, Angharad Harris told us how her partner James Brannagan owed his life to her swift action. Angharad is a mental health nurse whose job takes her to UHW and Royal Gwent. Her awareness of sepsis was purely gained from passing sepsis posters each day in her work place. This was later to become crucial when her partner James became ill with what they thought was a chest infection. James was deteriorating and developed sickness and a fever and confusion. James has no recollection of what happened next. Angharad took control rang an ambulance and insisted that her husband was seriously unwell. Based on the 'just ask' poster was convinced he had signs of sepsis and strongly stated this. Jayne was right. James was admitted with in septic shock. He was in hospital for a few weeks and was later told by his consultant that he was, in all likelihood, about 5 hours from death. Angharad is certain that but for seeing those posters she would have waited. If she had worked in a different building or, like most members of the public, worked in a non-health environment where she wasn't exposed to sepsis awareness she wouldn't have known the signs.. She would have waited. On leaving the hospital Angharad walked passed the posters again but this time with James and said 'That's the poster which saved your life". Helen and James are the lucky ones. There are over 2000 people each year who are not so lucky like Rachel Day (aged 29), Chloe Christopher (17), Lucy Ellis (16) and Amy Whiting (5).

Campaigns – Does WAG support campaigns?

We have covered the successful FAST campaign above and given that just yesterday (12/3/2019) Public Health Wales announced their #loveyourcervix campaign you would have to conclude that they do. Like the Minister for Health and Social Services we also believe in building a healthier Wales. We also believe that prevention is at the heart of a healthy Wales but to able be prevent anything happening you have to be aware of the possibility that it may happen in the first place. Otherwise, as a consequence, you do nothing and the worst thing you can do with sepsis is to do nothing at all.

‘***Prevention is at the heart of a healthy Wales***” - Vaughan Gething (Building a Healthier Wales (12/3/2019)

We, as petitioners and in collaboration with the Sepsis Trust and WAG are very happy to work on the prevention of sepsis to protect unaware members of the public from its potentially catastrophic outcomes.

Better Support for Sepsis Survivors

Some individuals develop sepsis so severe that they can become desperately ill very quickly and might need treatment in an ITU / HDU. Up to 80% of patients survive sepsis. Many will return to a normal or a ‘near normal’ life within 18 months of being ill. However, some survivors will have long term problems, occasionally having life changing effects like amputations which might impact on both them and their family.
These long-term problems can be divided into physical and psychological, and often start during the acute phase of your illness. Collectively, they are known as Post Sepsis Syndrome (PSS).

PHYSICAL LONG-TERM PROBLEMS	PSYCHOLOGICAL LONG-TERM PROBLEMS
Poor mobility Breathlessness / chest pain Fatigue Loss of appetite Taste changes Dry skin Brittle nails and teeth Hair loss Oedema (excessive fluid in the tissues, which look swollen) Joint stiffness or pain Muscle wasting Changes of sensation in limbs (tingling, numbness, pain) Poor kidney function (which may need dialysis) Repeated infections	Anxiety Insomnia (difficulty sleeping which can also be a result of pain or breathlessness) Flashbacks, panic attacks and nightmares Depression PTSD (Post Traumatic Stress Disorder) Poor concentration Short term memory loss

Formal support for survivors of sepsis and their families is non-existent. Many leave hospitals without an explanation of what they have suffered, potential impact or signposting. UK Sepsis Trust runs quarterly support groups in North and South Wales, however, these are dependent on fundraising income. There is no funding from WAG although the support groups and telephone support helpline are staffed with former consultant nurses. In Cardiff, volunteers also run monthly ‘well-being’ walks and participants have advised that meeting similar people has helped their recovery and understanding of Sepsis.

We are calling for a timescale for the Sepsis registry that the Health Minister announced on World Sepsis Day 2018 and a Wales wide strategy for survivors and families impacted by Sepsis.

Appendix 2

Response to petitions committee – Sepsis Public Awareness Campaign Wales

Having read the letters and responses that resulted from the first meeting of the petitions committee we feel no real reason to add a great deal more than what follows to our previous response. We feel the original points remain relevant, valid and, to a degree, unanswered. With that in mind, we would refer the committee back to reconsider them in light of the answers offered.

However, in relation to this particular response of the Minister for Health and Social Services to the letter of Janet Finch- Saunders AM, we are very appreciative to have the opportunity to add the following:

The cabinet minister's response continues to focus on the great work that government has undertaken within healthcare via the 1000 lives programme and the intention to roll out NEWS. Nobody associated with this petition doubts this, in fact, we both recognise and applaud it. However the petitioners are not asking for improvements and education within healthcare, they are asking for better education for the public and better support for sepsis survivors. As per the petition the call on the Welsh Assembly Government is:

" …to undertake a Sepsis Public Awareness Campaign to reduce unnecessary deaths and improve outcomes for survivors and all affected. In memory of Chloe Christopher and everyone who has been affected by Sepsis in Wales"

We know that Public Health Wales is looking Post Sepsis Syndrome (PSS) along with the UK Sepsis Trust in Wales and, of course, we welcome this and will watch this particular space keenly.

However, for us as petitioners, this does not address the call for a public awareness campaign.

It seems the reasons against, though we recognise as being challenging, can be basically summarised as two-fold.

1. It is complex and important to strike the right balance with messages about the appropriate use of antibiotics and the risk of creating public anxiety.

Stating that a campaign is complex and requires the right balance is surely true of most healthcare campaigns at the outset? We see this more as a challenge to overcome and an opportunity to responsibly address the issues than a reason not to have a campaign at all.

Rolling out NEWS to primary care and care homes etc is extremely commendable but it is quite esoteric and the benefit of the common language of NEWS will only help members of the public once they have accessed healthcare. The issue is when members of the public do not access healthcare or do so extremely late when their NEWS score may well be telling them they are severely unwell, possibly critically. These are the situations we are trying to avoid, these are the situations which the rolling out of NEWS and improved education within healthcare do not address.

There is a focus on the 'worried well' being an issue with a campaign but what about the 'unworried unwell'? These people do not know to access healthcare and wait to get better. These are the community tragedies. Surely the 'worried well' are a consideration of any previous campaign and, one would hope, there is the knowledge, expertise and benefit of experience from previous healthcare campaigns within WAG and PHW to be able to develop a strategy to counter and mitigate this.

2. There is no evidence to suggest campaigns lead to improvement to justify the public money required to fund the campaign.

The petitioners accept that measurement of the success of campaigns must be quite difficult but again we would suggest this is a challenge to overcome rather than a reason not to do. Again we would hope that there was enough experience to take an approach which considers this and could be addressed in collaboration with expert stake holders.

Also while Wales takes this stance against a sepsis campaign Scotland seems to disagree. Ironically, on the same day the Minister for Health and Social Services was writing to tell us that campaigns may not be the way forward, Scotland were actually doing the exact opposite and launching a sepsis campaign fully supported by the Chief Medical Officer and Scottish Govt.

Chief Medical Officer Catherine Calderwood said:

"While deaths caused by sepsis have fallen by 21% since 2012, thanks in part to the work of the Scottish Patient Safety Programme, it is still vital that people are aware of this potentially fatal condition. The key in treating sepsis is catching it quickly so that is why it's important to know the signs. If someone has two or more of the symptoms and they are getting rapidly worse, it is important to seek urgent medical advice.

"Following our first campaign from 2018, we know that more than three out of four people are aware of the dangers of sepsis but we want to further increase public awareness to spot the signs and this campaign will help us do this. It will also help to focus on continuous improvement across Scotland ensuring there is safe and consistent care for all sepsis patients."

Further detail can be found here:

https://www.gov.scot/news/raising-awareness-of-sepsis/

The video can be viewed here:

https://www.facebook.com/200786289976224/posts/2239199719468194?s=557625890&v=e&sfns=cl

This is clearly not a campaign that would have cost a lot of money and while it's not perfect it does deliver a very simple message in very simple language. As mentioned earlier the public do not know about NEWS have no relationship with it and will not be using it as reference point to access healthcare. The process we need is for the sick / deteriorating patient to present to healthcare where the health professional then uses NEWS as a reference point for diagnosis and treatment or escalation if required. If the patient wasn't severely unwell at this stage IE well enough to go home and self-monitor or be monitored by parent or guardian then maybe this is the stage to introduce the basics of NEWS to the patient/public. This would be the 'safety net' as we know that some patients who ultimately end up in septic shock were not triggering on NEWS when they first accessed healthcare, for example, at the GP surgery. It's often the deterioration that is missed because people are not aware enough to act. They wait.

Could we not also look at others countries and learn from their successes and failures? Rather than viewing this as something we think might fail, should we not see this as an opportunity and have the confidence to back our celebrated and rewarded sepsis experts to get this right and deliver the kind of campaign that Wales, NHS Wales and Welsh Government can be proud of?

N.B. Just as a footnote to the last discussion, Leanne Wood AM who was very supportive did note that she was surprised by re small number of signatures supporting the petition. The reason for this was we had initially started an ipetition which we later discovered was no longer a former submittable to Welsh Assembly Government. For this reason only the paper signatures were submitted. We had over 800 signatures online before we had to close it.

https://www.ipetitions.com/petition/sepsis-public-awareness-campaign-wales

Appendix 3

Sepsis awareness in action– When the system works well from community to care.

Case Study – Matthew [redacted]

Matthew is a legal professional man just over 50 years old who has kindly volunteered to share his story below:

I had a Prostate biopsy on Thursday the 25th July 2017.

As part of the procedure, I signed the usual patient agreement highlighting perceived risks, including, I later recalled, an infection rate (later revisited and understood) put at 1 in 40 (2.5%). This was not foremost in my mind but nevertheless **'flagged'** with me.

On Sunday the 28th, I travelled to London with my wife to visit our son for dinner and stayed overnight at an hotel. That evening I felt as if I was coming down with flu like symptoms. The following morning I felt generally unwell but walked to breakfast and to some shops although I had to sit down and ask my wife to 'collect' me on the way out. Eventually, while feeling much worse, I drove home. On arriving back in Cardiff that Bank holiday Monday night, I went straight to bed thinking I would sweat it out overnight.

When I woke up on the Tuesday morning, I felt very unwell and debated whether to turn over and try to sleep it off, but having had the biopsy and the **'flag' of infection**, I told my wife that I thought I ought to go straight to my GP, Helen [redacted]. My wife Karen was on her way to the gym, but clearly realised that not being one to go to the GP, there must be something wrong and she asked whether she should accompany me, not that at that stage she was going to let me go on my own. I felt so ill I said yes and again this reinforced her thinking as to the seriousness.

I prepared myself to do battle with the **receptionist** to let me see Helen straight away without an appointment but in fairness she **saw how I looked** and called her as we walked in. The **GP** Helen examined me and **was concerned enough to immediately telephone the Heath** to tell them that I was coming straight in and to expect me with a couple of named individuals she asked for. She actually misdiagnosed me as being in retention but was clear that I needed to be admitted immediately. My wife Karen took me straight to the **emergency assessment unit where I was met by a small team who set me up with initial treatment.** My consultant (for prostate investigations) Prof. Howard [redacted], who was away at the time, had somehow been advised and arranged for one of his registrars to see me in the unit. **Within half an hour he had put me on the triple antibiotic as I went into toxic shock and sepsis.**

I was later admitted to the urology ward under Howards direction, and had the fluid and antibiotic treatment regime while waiting for the blood culture growth results to establish the underlying infection, which turned out to be E-coli, confirmed 4 days later. In the meantime I had various issues with blood pressure and at one stage (not very clear to me now) I was given a ‘last chance’ 2 dose antibiotic which thankfully stabilised me at the time. I am very grateful that I had continuous visits from Howard’s team, particularly his registrar.

Having established the E-coli, I was discharged with appropriate antibiotics for that infection.

Looking back now**, I was lucky that I and others, especially Helen and Howards registrar, took the right decisions at key points and that following admission to the emergency assessment unit, I was put on the drip immediately and then constantly monitored and given the last chance dose when my blood pressure collapsed (the nurse at first thinking the monitor was faulty, until she tried the second one with the same result!).**

What I did not anticipate was that being discharged did not actually mean recovered. I returned home very ill and it took me at least 3 to 4 weeks to begin to get over the infection and months to recover strength and lost body weight from the sepsis. In addition, the sepsis had destroyed the muscle and supporting structures around a shoulder replacement I had completed in late December 2016, so much so that I had to have 2 further operations, a twice postponed (due to infection risk) attempted repair, which failed followed by a reversal replacement in December 2017.

It is only in hindsight that I realise how lucky I was to have acted on or had assistance at key moments. As I was told at the time, if not, or if I had turned over to sleep it off that morning, **if I had not acted I would have likely died within the hour.**

Matthew’s story serves to highlight the positive outcomes which are the likely result of people being well enough informed to make the right decisions at the right times. It also further highlights the key roles of everyone involved – Himself, his wife, the receptionist, the GP, the staff at UHW.

In Summary:

- Post biopsy, Matthew was informed of the risk of infection (Awareness = ‘safety netting’) before discharge back to community.
- Back in the community Matthew realises he is unwell and remembers the ‘safety netting’ advice and along with his wife decides to see his GP (patient awareness = timely action).
- At the surgery the receptionist also plays a key role. Recognising Matthew looks unwell she acts quickly and alerts the GP (recognition = escalation action).
- The GP also realises Matthew is unwell and immediately pre- alerts UHW (recognition = escalation action)
- Due to the pre-alert at UHW the team is waiting to treat and IV antibiotics and fluids are administered as well as blood cultures being taken within 30 mins (quick diagnosis = quick treatment)

- Matthew is discharged after just 4 days of in-hospital treatment. His recovery is slow but he is ok. The outcome could have been very different had he not acted early.

When everyone is informed and everything is aligned like this, we are confident that if people in the communities who react like Matthew reacted this will lead to better outcomes. They just need enough knowledge about their health to do so.