# Agenda - Health, Social Care and Sport Committee

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| Meeting Venue: | For further information contact: |
| **Committee Room 5 - Tŷ Hywel** | **Sarah Beasley** |
| Meeting date: 6 February 2020 | Committee Clerk |
| Meeting time: 09.15 | 0300 200 6565 |
| | SeneddHealth@assembly.wales |

## Informal pre-meeting (09.15-09.30)

## 1 Introductions, apologies, substitutions and declarations of interest

(09.30)

## 2 Sepsis: Evidence session with UK Sepsis Trust

(09.30-10.30) (Pages 1 - 85)

Terence Canning, Executive Director Wales, UK Sepsis Trust

John James

Joy James

Research Brief

Consultation Pack

Consultation Pack (Private)

Paper 1 - UK Sepsis Trust

## Break (10.30-10.45)

## 3 Sepsis: Evidence session with Public Health Wales

(10.45-11.45) (Pages 86 - 99)

Dr John Boulton, Director for NHS Quality Improvement and Patient Safety, Improvement Cymru - Public Health Wales

Dr Tracey Cooper, Chief Executive - Public Health Wales

Paper 2 - Public Health Wales

## 4 Paper(s) to note

(11.45)

## 5 Motion under Standing Order 17.42 (vi) to resolve to exclude the public from the remainder of this meeting

(11.45)

## 6 Sepsis: Consideration of evidence

(11.45-12.00)

## 7 Caring for our future: An inquiry into the impact of the Social Services and Well-being (Wales) Act 2014 in relation to carers: Consideration of Welsh Government response to the Committee's report

(12.00-12.30) (Pages 100 - 120)

Report - Caring for our future: An inquiry into the impact of the Social Services and Well-being (Wales) Act 2014 in relation to carers.

Welsh Government Response

Paper 3 - Welsh Government Response

By virtue of paragraph(s) vi of Standing Order 17.42

# Agenda Item 2

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# Report on Requirements for Post Sepsis Support

# - DRAFT COPY

**Date: May 2019**

# CONTENTS PAGE

# 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<br>Talks and open discussion<br>What is Sepsis<br>What may Rehabilitation look like | Individual assessment with nurse and psychiatrist<br>Talks Citizens Advice – benefits and returning to work<br>Introduction to Pacing, how it is done and help to do it<br>Exercise session/Tai Chi<br>Time to ask questions, speak to those giving talks | Individual assessment with nurse and if required physiatrists<br>Pacing, how are people getting on with this<br>Exercise session/Tai Chi<br>Talks on sleep poor concentration and PTSD and effects on relationships<br>Time to ask questions, speak to those giving talks | Individual assessment with nurse<br>Pacing, how are people getting on with this and talk on<br>Managing fatigue<br>Exercise session/Tai Chi<br>Mindfulness Intro<br>Time to ask questions, speak to those giving talks<br>Talk on Chronic pain and medications | Individual assessment with nurse<br>Pacing, how are people getting on with this<br>Exercise session/Tai Chi<br>Mindfulness<br>Talk on dietary needs and vitamins<br>Time to ask questions, speak to those giving talks | Individual assessment with nurse<br>Pacing, how are people getting on with this<br>Realistic Goal setting for coming months<br>Exercise session/Tai Chi<br>Talks -Citizens Advice – question session<br>Mindfulness<br>Time to ask questions, speak to those giving talks | Individual assessment with nurse<br>Pacing, how are people getting on with this<br>Mindfulness how is this progressing<br>Exercise session/Tai Chi<br>Review on how progressing<br>Group session on how people are coping<br>Goals for the future<br>Time to ask questions, speak to those giving talks | Individual assessment with nurse<br>Pacing, how are people getting on with this<br>Mindfulness how is this progressing<br>Exercise session/Tai Chi How is this going and a small session<br>Review on how progressing<br>Group session on how people are coping<br>Goals for the future<br>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)

Welsh Sepsis Survivors Survey 2018

## Q1 How long ago did you have sepsis?

Answered: 11 Skipped: 1

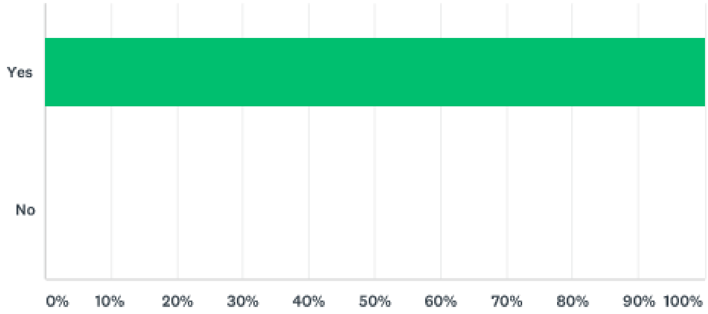
| ANSWER CHOICES | RESPONSES | |
|---|---|---|
| Date / Time | 100.00% | 11 |

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

Answered: 12 Skipped: 0

## Q3 Were you treated for sepsis in Wales?

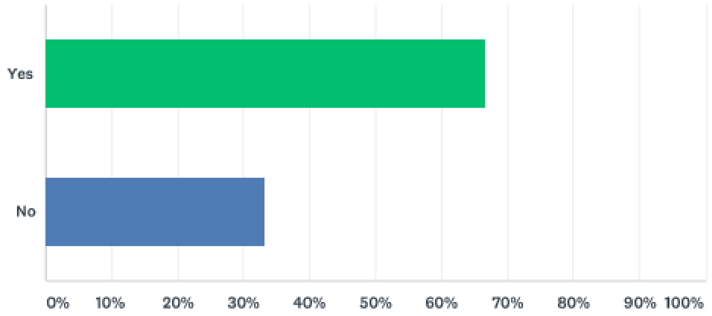
Answered: 12 Skipped: 0



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

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

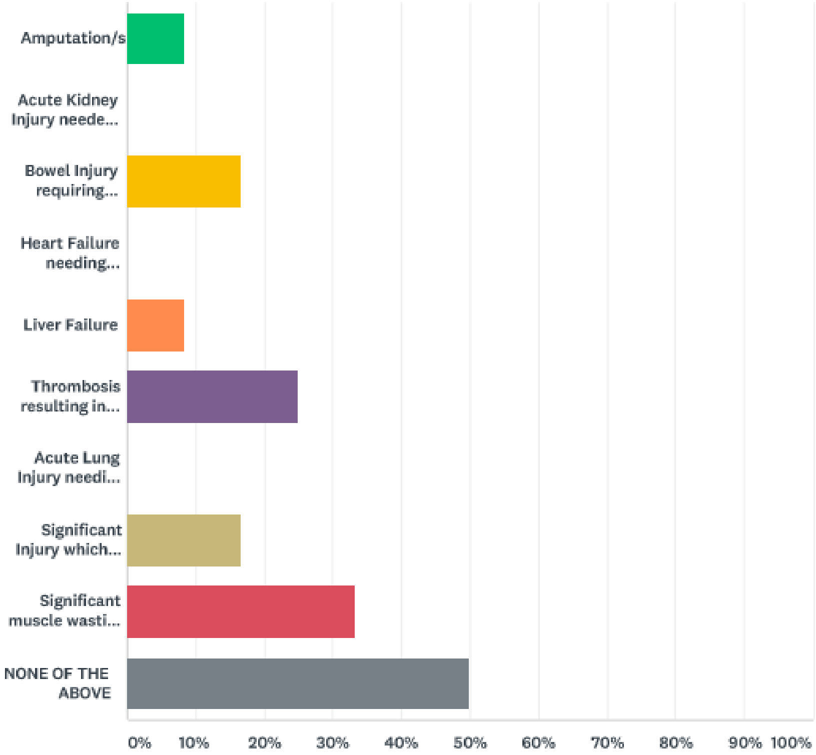
Answered: 12 Skipped: 0



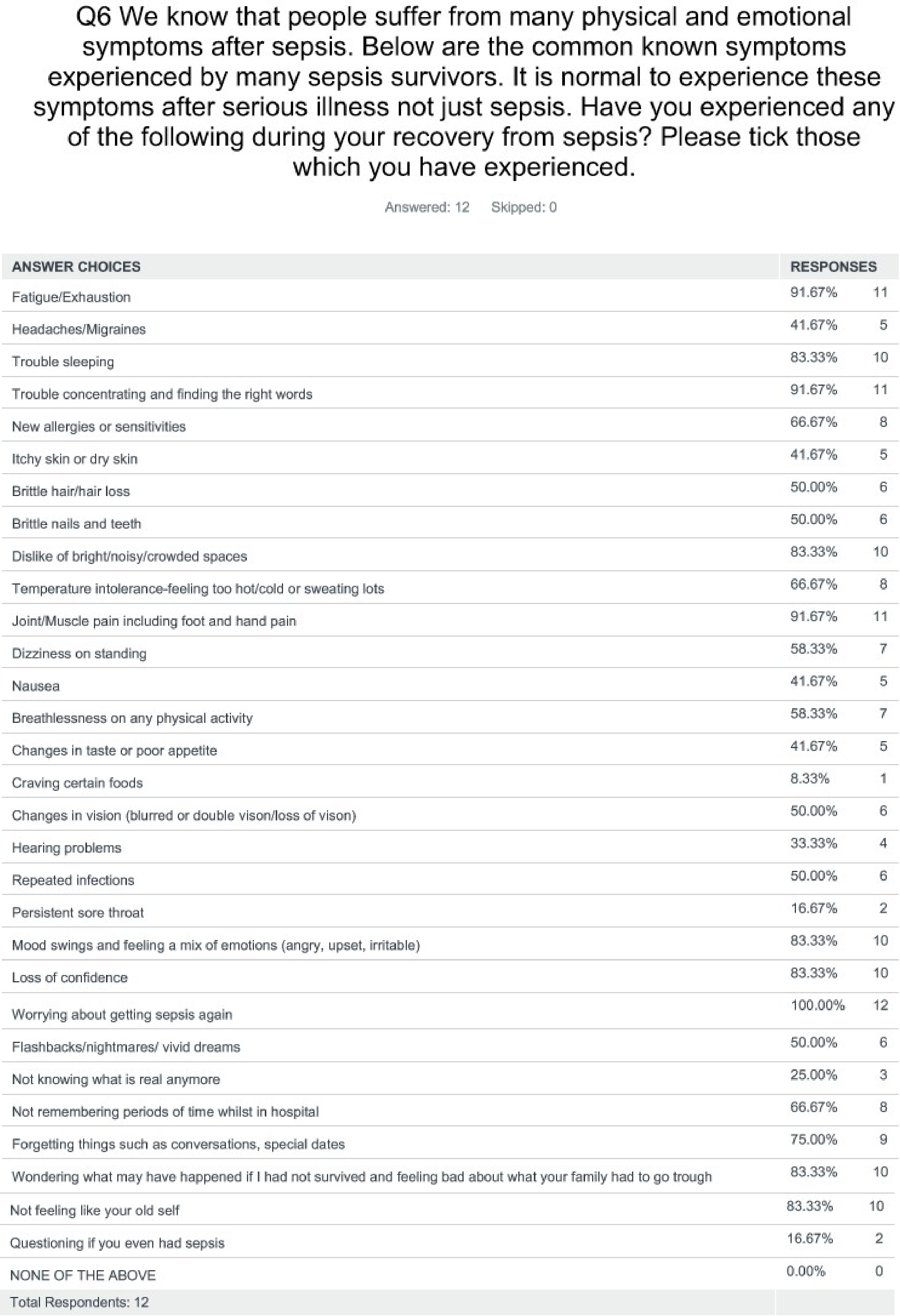
| ANSWER CHOICES | RESPONSES | |
|---|---|---|
| Yes | 66.67% | 8 |
| No | 33.33% | 4 |
| TOTAL | | 12 |

## 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 | | |



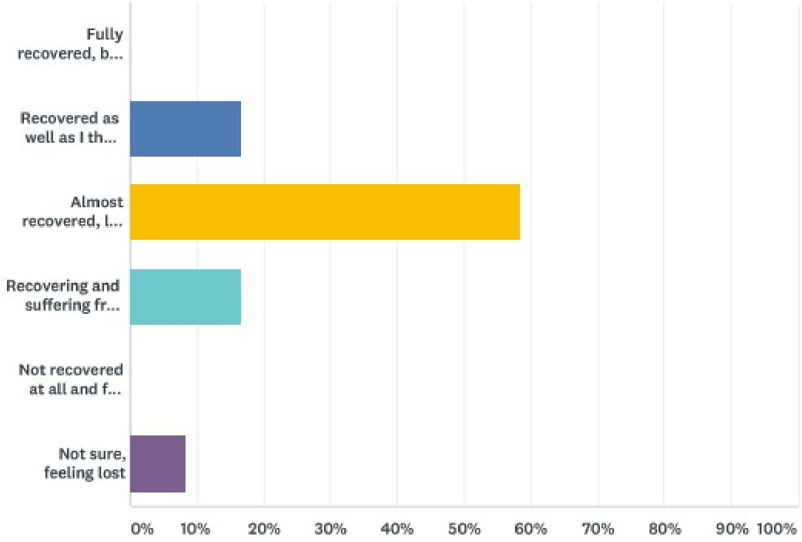
### Q6 We know that people suffer from many physical and emotional symptoms after sepsis. Below are the common known symptoms experienced by many sepsis survivors. It is normal to experience these symptoms after serious illness not just sepsis. Have you experienced any of the following during your recovery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

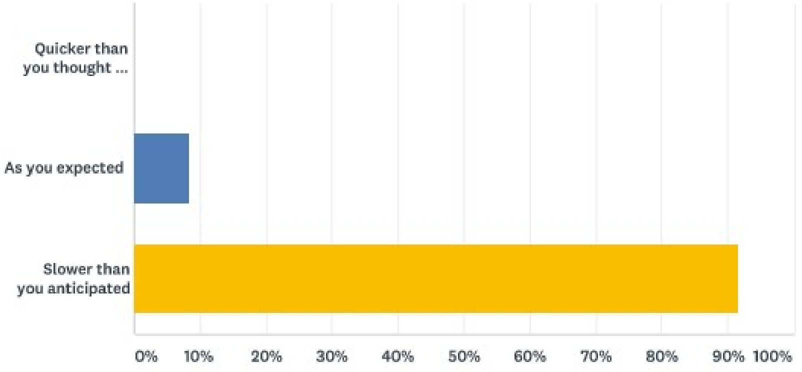
Answered: 12 Skipped: 0



| 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...

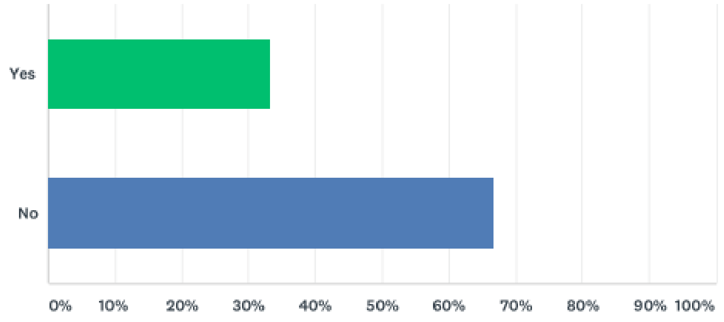
Answered: 12 Skipped: 0



| 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?

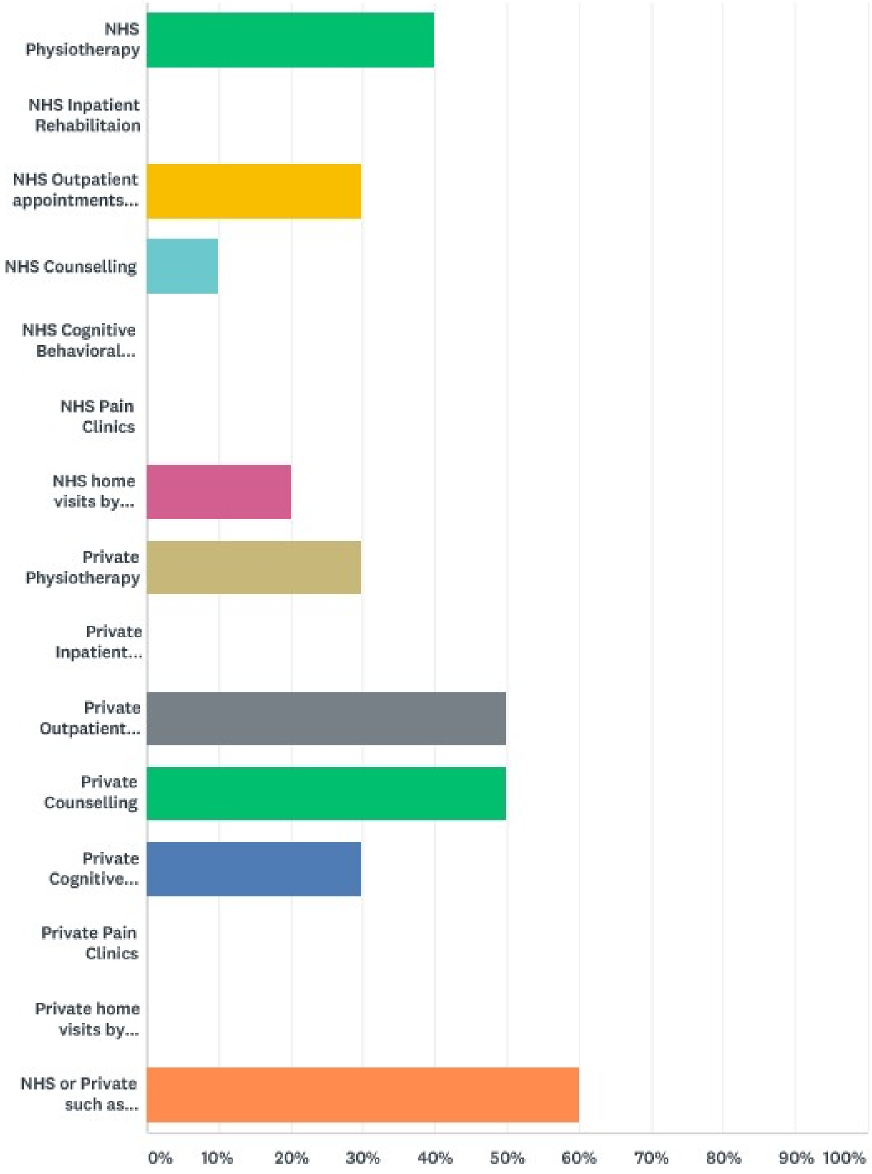
Answered: 12 Skipped: 0



| 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?

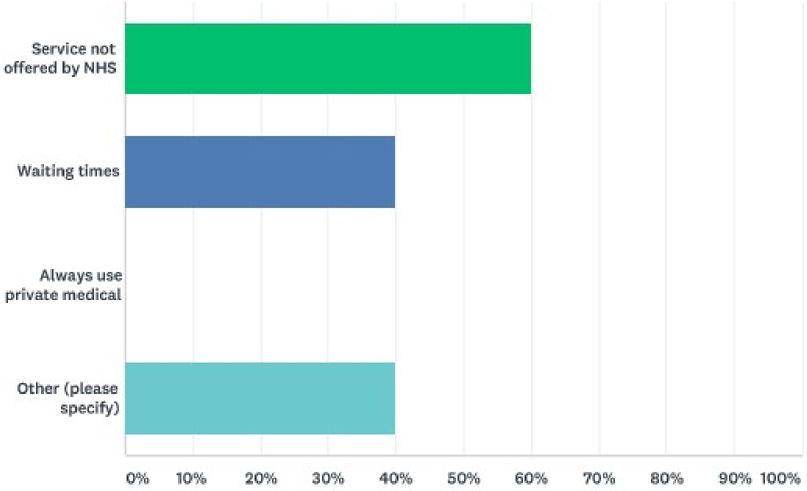
Answered: 10 Skipped: 2



| 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?

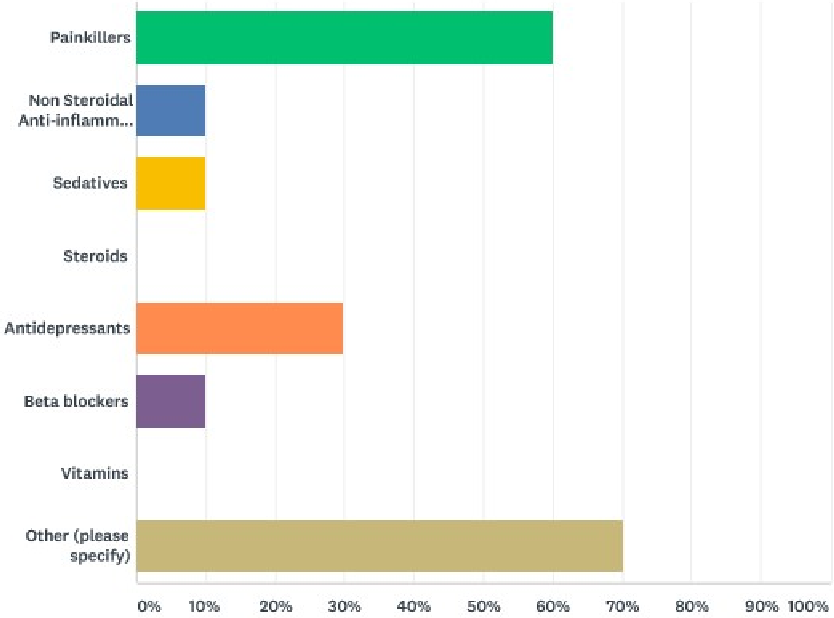
Answered: 10 Skipped: 2



| 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



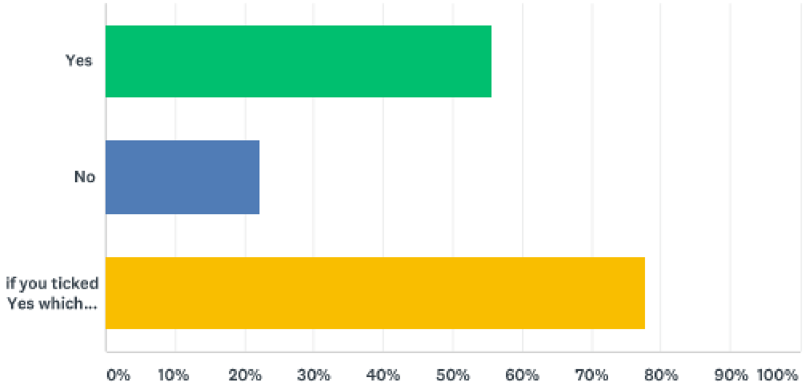
| ANSWER CHOICES | RESPONSES | |
|---|---|---|
| Painkillers | 60.00% | 6 |
| Non Steroidal Anti-inflammatories (NSAIDs) | 10.00% | 1 |
| Sedatives | 10.00% | 1 |
| Steroids | 0.00% | 0 |
| Antidepressants | 30.00% | 3 |
| Beta blockers | 10.00% | 1 |
| Vitamins | 0.00% | 0 |
| Other (please specify) | 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?

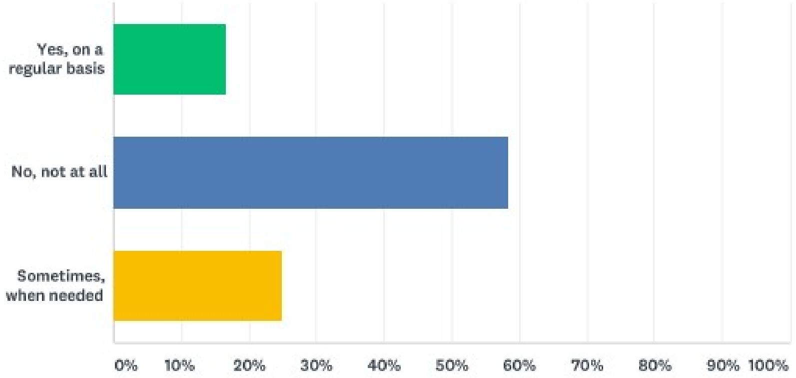
Answered: 9 Skipped: 3



| 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?

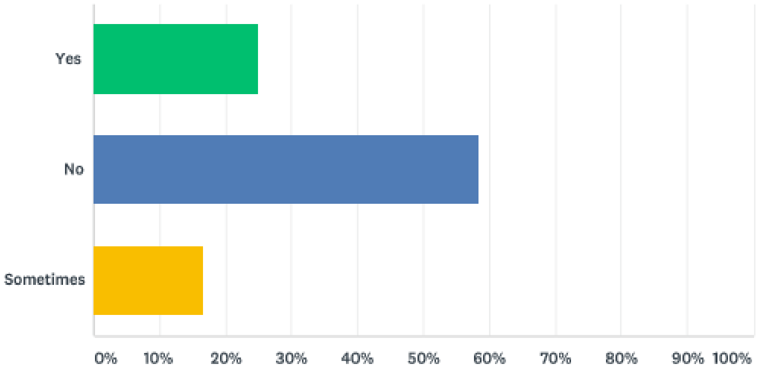
Answered: 12 Skipped: 0



| 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)

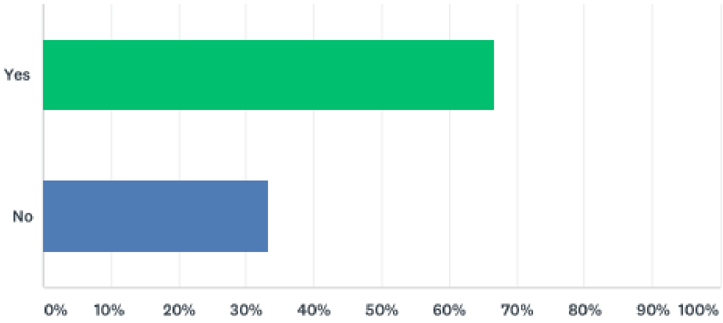
Answered: 12 Skipped: 0



| 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



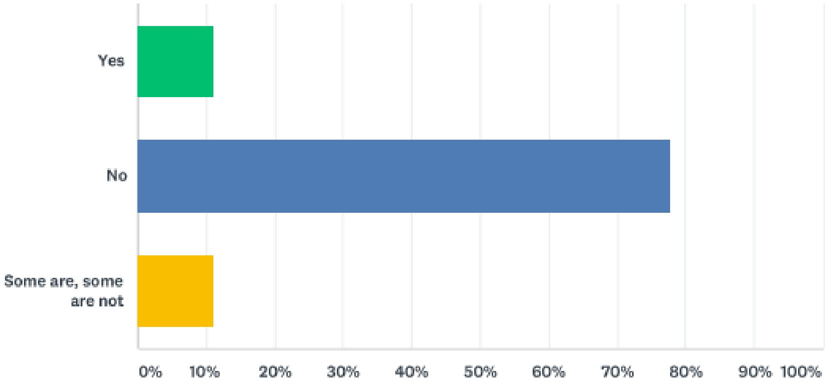
| ANSWER CHOICES | RESPONSES | |
|---|---|---|
| Yes | 66.67% | 8 |
| No | 33.33% | 4 |
| TOTAL | | 12 |

## 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?

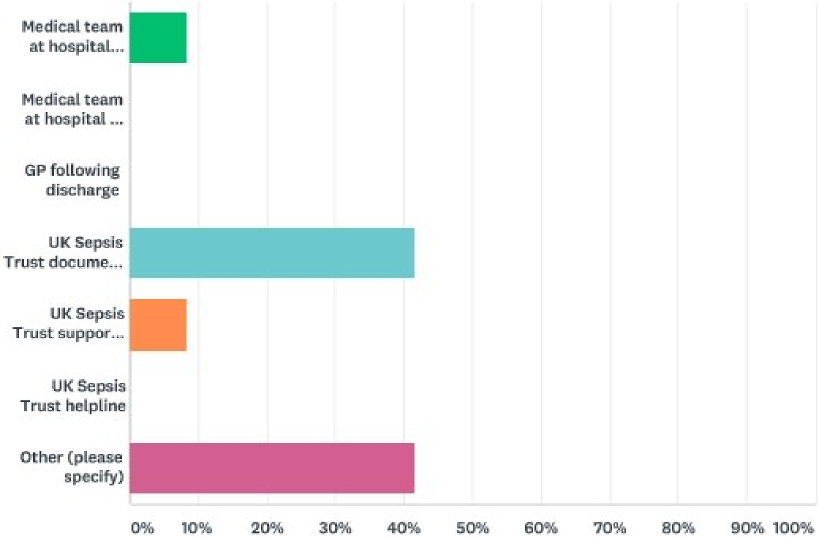
Answered: 9 Skipped: 3



| 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?

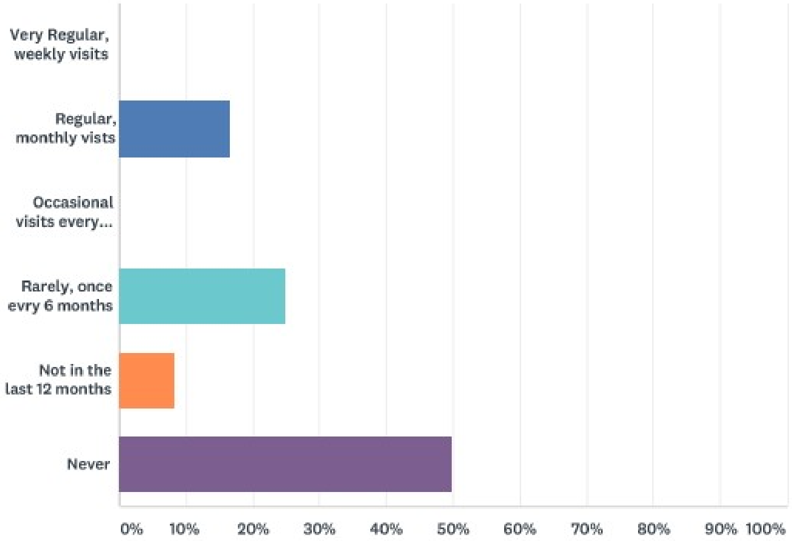
Answered: 12 Skipped: 0



| 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.

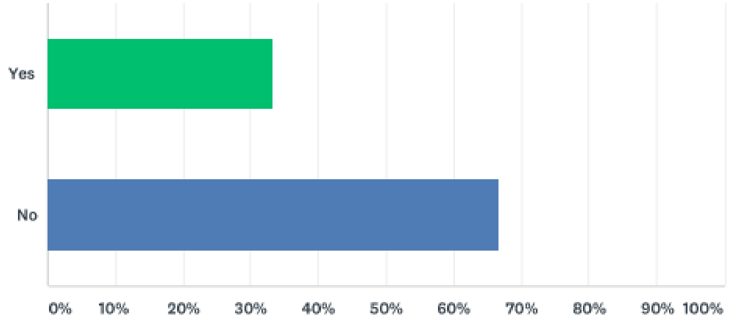
Answered: 12    Skipped: 0



| 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?

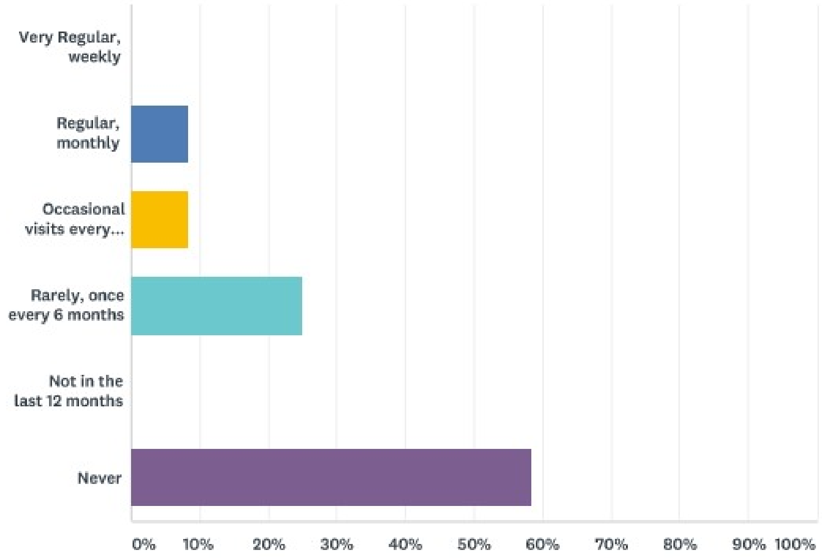
Answered: 12    Skipped: 0



| 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?

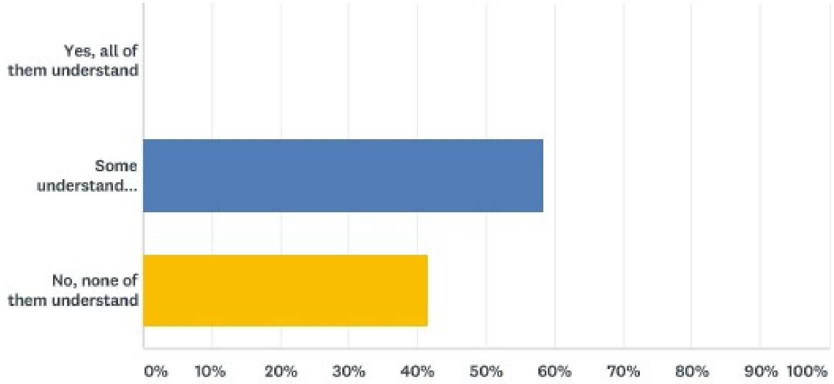
Answered: 12 Skipped: 0



| 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?

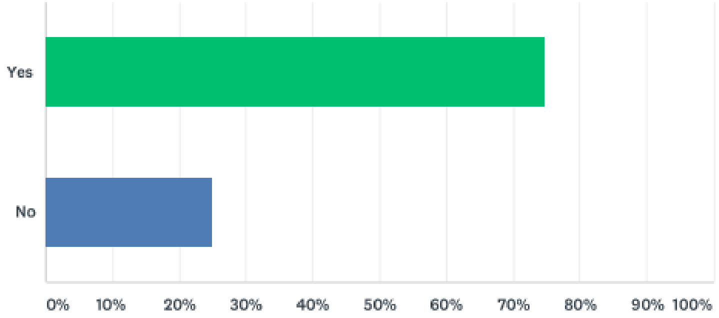
Answered: 12 Skipped: 0



| 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?

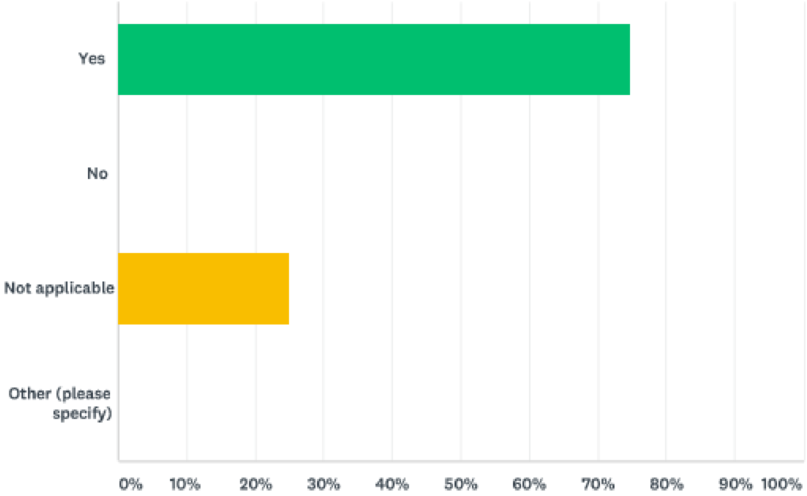
Answered: 12 Skipped: 0



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

## Q26 If yes was it useful?

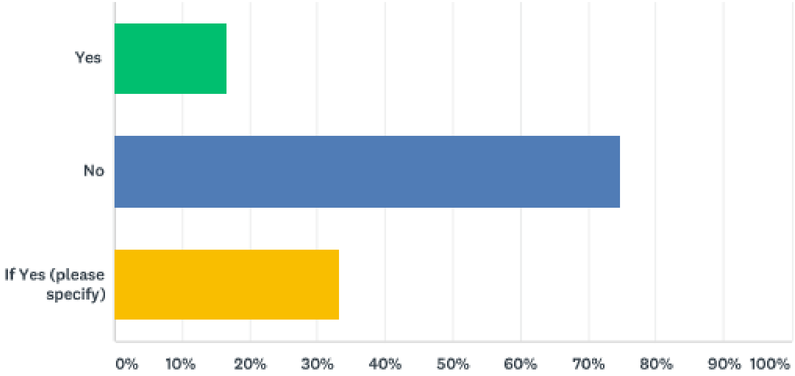
Answered: 12 Skipped: 0



| 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?

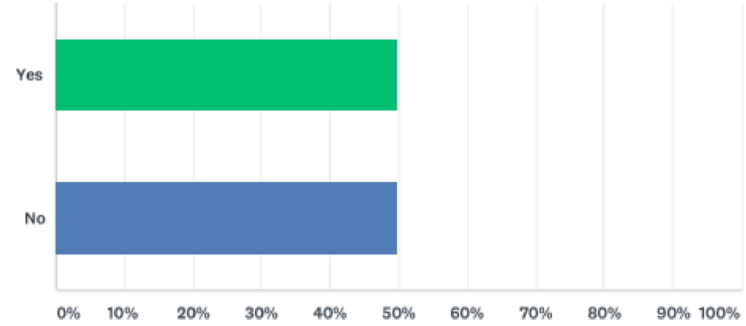
Answered: 12 Skipped: 0



| 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?

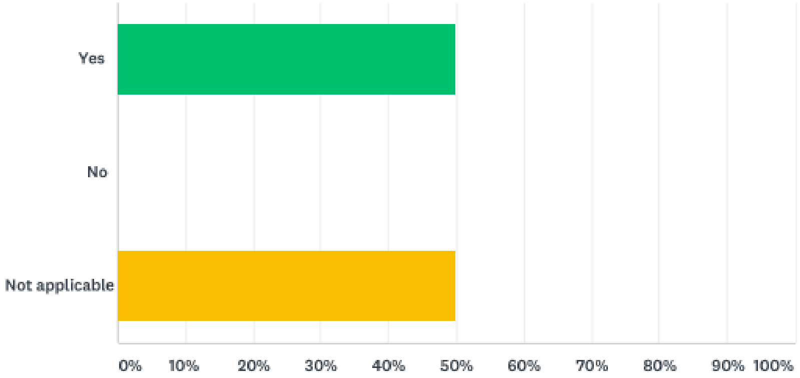
Answered: 12 Skipped: 0



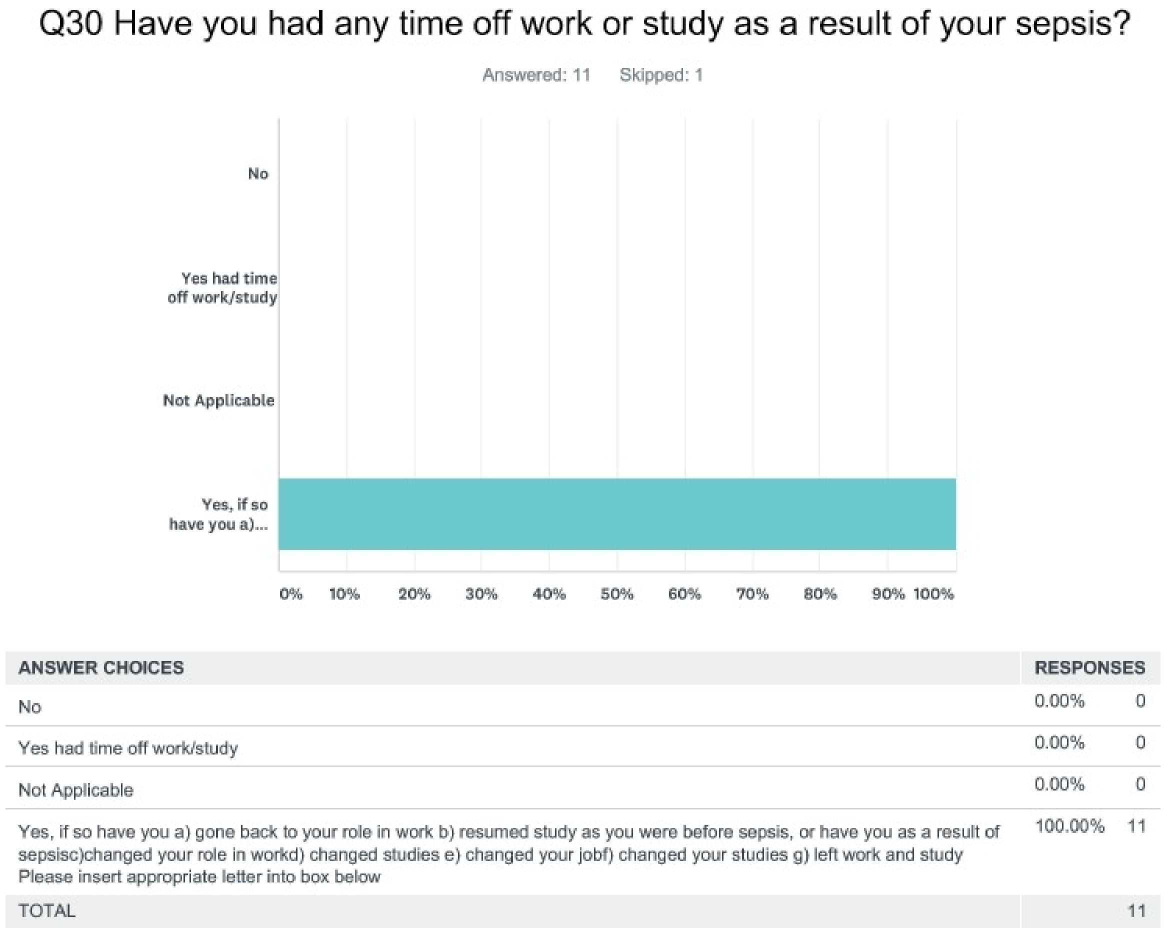
| ANSWER CHOICES | RESPONSES | |
|---|---|---|
| Yes | 50.00% | 6 |
| No | 50.00% | 6 |
| TOTAL | | 12 |

## 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 |



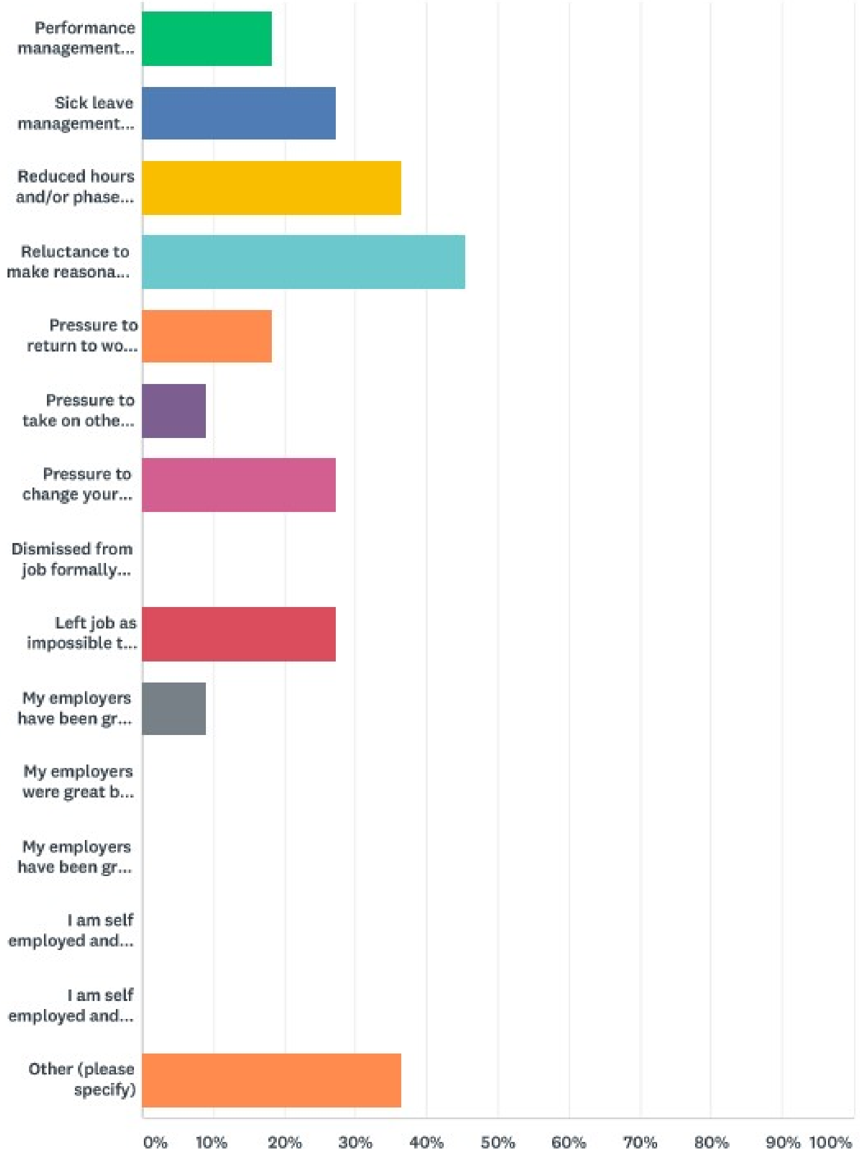
## Q30 Have you had any time off work or study as a result of your sepsis?

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?

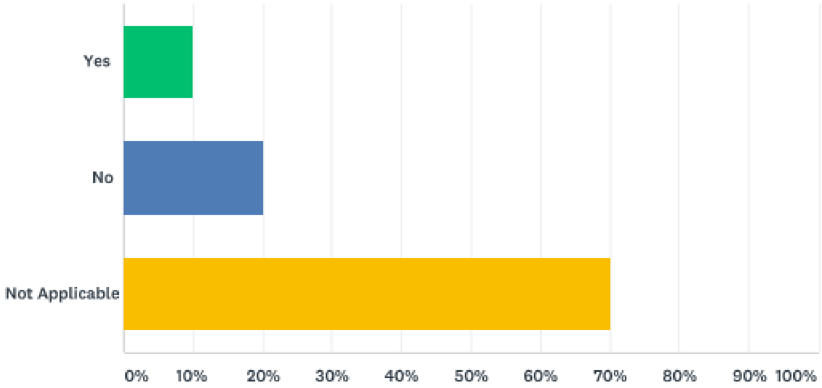
Answered: 11 Skipped: 1



| 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?

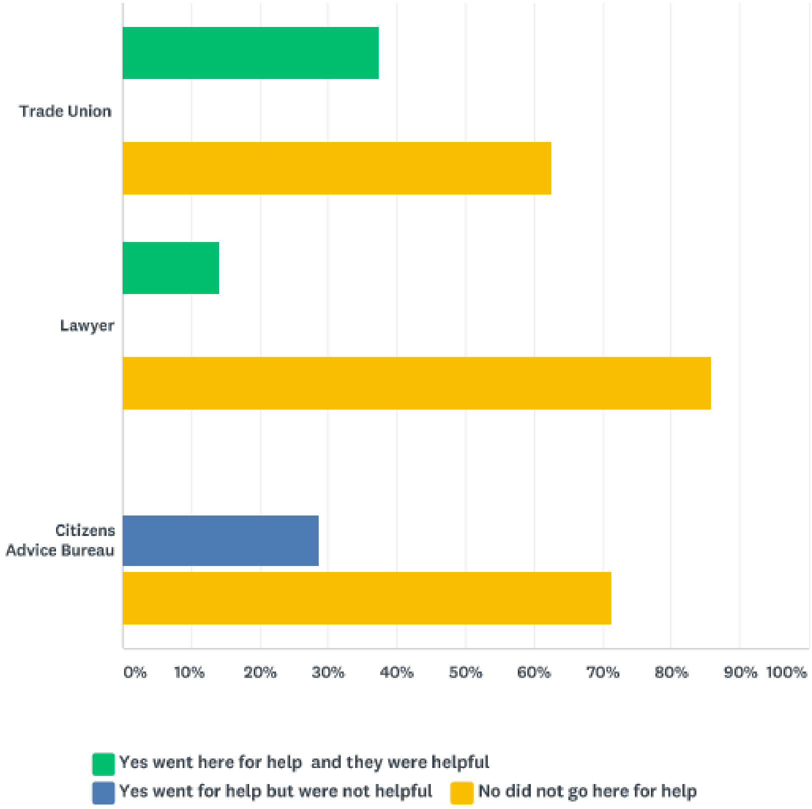
Answered: 10 Skipped: 2



| 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

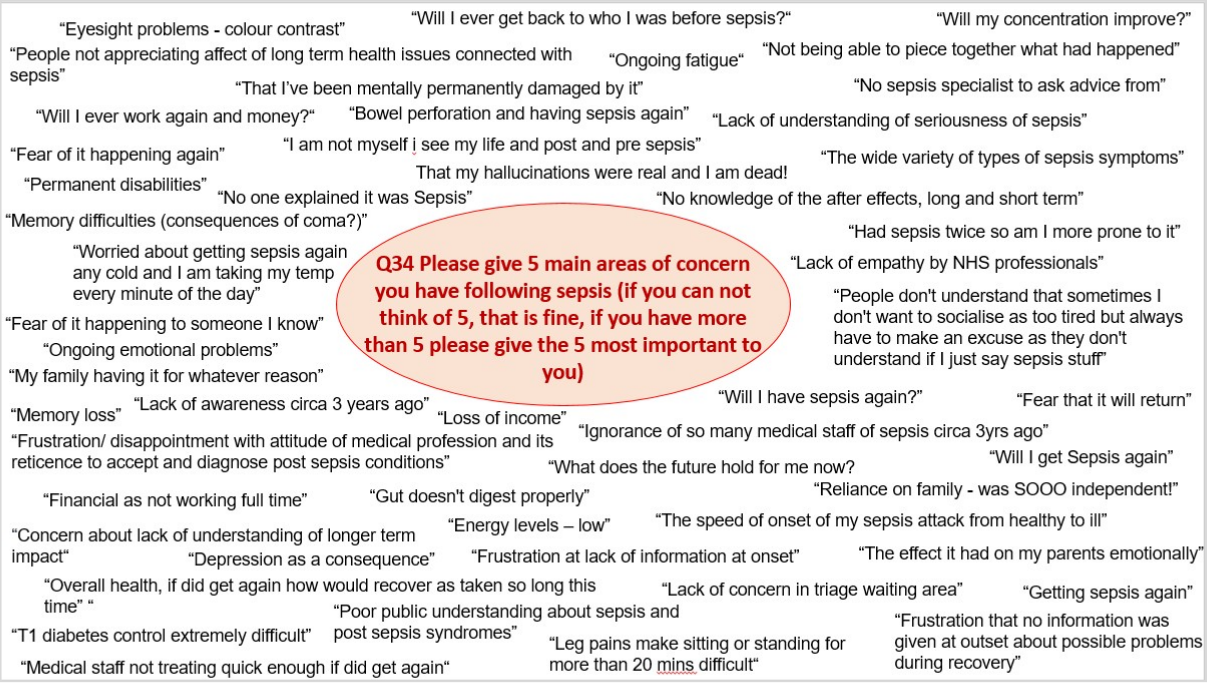


| | YES WENT HERE FOR HELP AND THEY WERE HELPFUL | YES WENT FOR HELP BUT WERE NOT HELPFUL | NO DID NOT GO HERE FOR HELP | TOTAL RESPONDENTS |
|---|---|---|---|---|
| Trade Union | 37.50%<br>3 | 0.00%<br>0 | 62.50%<br>5 | 8 |
| Lawyer | 14.29%<br>1 | 0.00%<br>0 | 85.71%<br>6 | 7 |
| Citizens Advice Bureau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

"Concern about lack of understanding of longer term impact"

"Energy levels – low"

"The speed of onset of my sepsis attack from healthy to ill"

"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"

"T1 diabetes control extremely difficult"

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

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

"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 |

**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)**

“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“

“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”

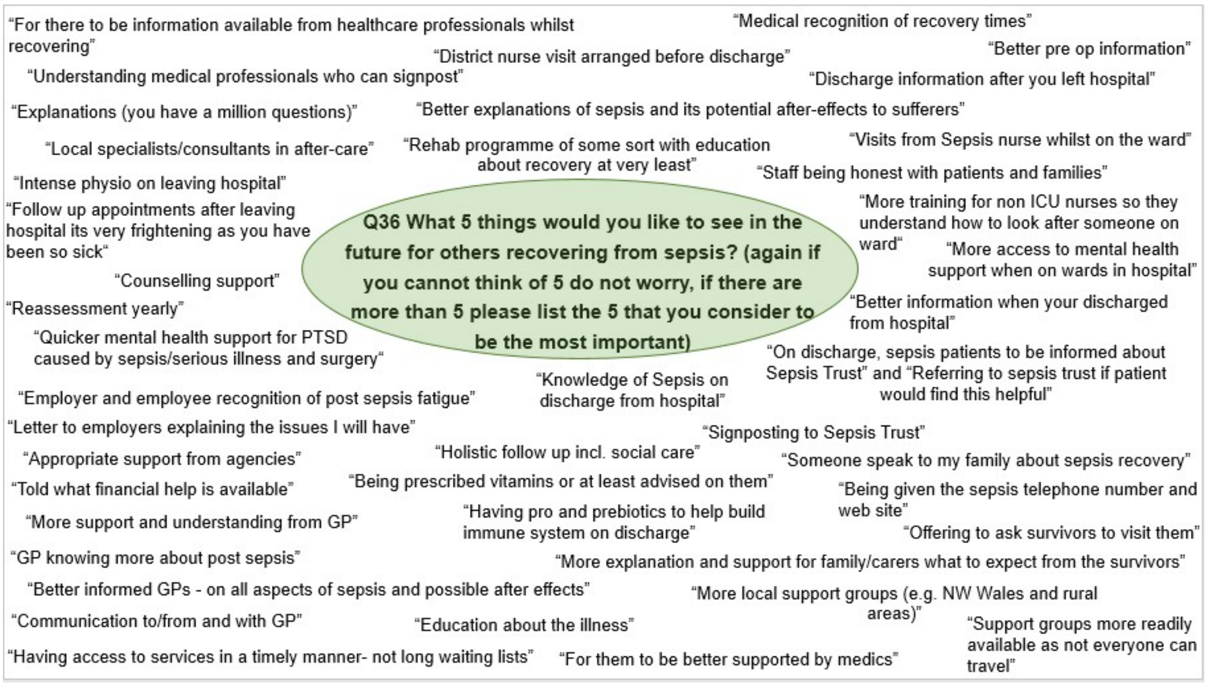
“Vitamins and probiotics, as helped more than any prescribed medication”

“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”

“Visits from Sepsis nurse whilst on the ward”

“Local specialists/consultants in after-care”

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

“Staff being honest with patients and families”

“Intense physio on leaving hospital”

“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”

“Holistic follow up incl. social care”

“Appropriate support from agencies”

“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”

“Having pro and prebiotics to help build immune system on discharge”

“More support and understanding from GP”

“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”

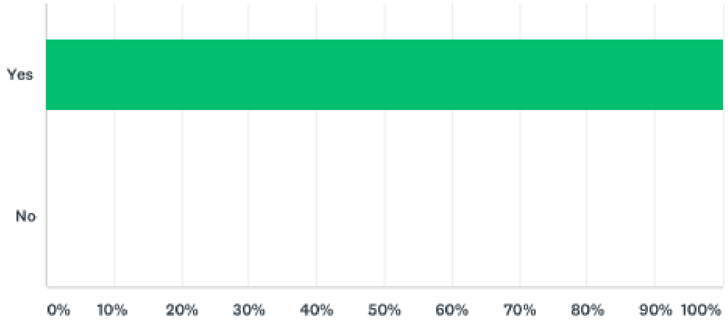
“Support groups more readily available as not everyone can travel”

“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

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

## 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.

Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon
Health, Social Care and Sport Committee
HSCS(5)-05-20 Papur 2 / Paper 2

**Iechyd Cyhoeddus Cymru**
Rhif 2 Capital Quarter, Tyndall Stryd,
Caerdydd CF10 4BZ

**Public Health Wales**
Number 2 Capital Quarter, Tyndall Street,
Cardiff CF10 4BZ

## 1 What understanding is there about sepsis incidence, how sepsis is presenting to services, and outcomes from sepsis

Sepsis is a potentially life-threatening condition triggered by acute infection or injury. In the United Kingdom (UK), there are around 150,000 cases of sepsis each year, and results in around 44,000 deaths annually. In Wales, this equates to approximately 2,200 people dying from the condition, representing approximately 13% of all hospital deaths.

Sepsis presents to healthcare services in many different ways, and at times can be difficult to recognise. Common signs and symptoms in adults include:

- Slurred speech and/ or confusion
- Shivering or muscle pain
- Poor urine output
- Severe breathlessness
- Discolouration of skin
- Feeling very unwell.

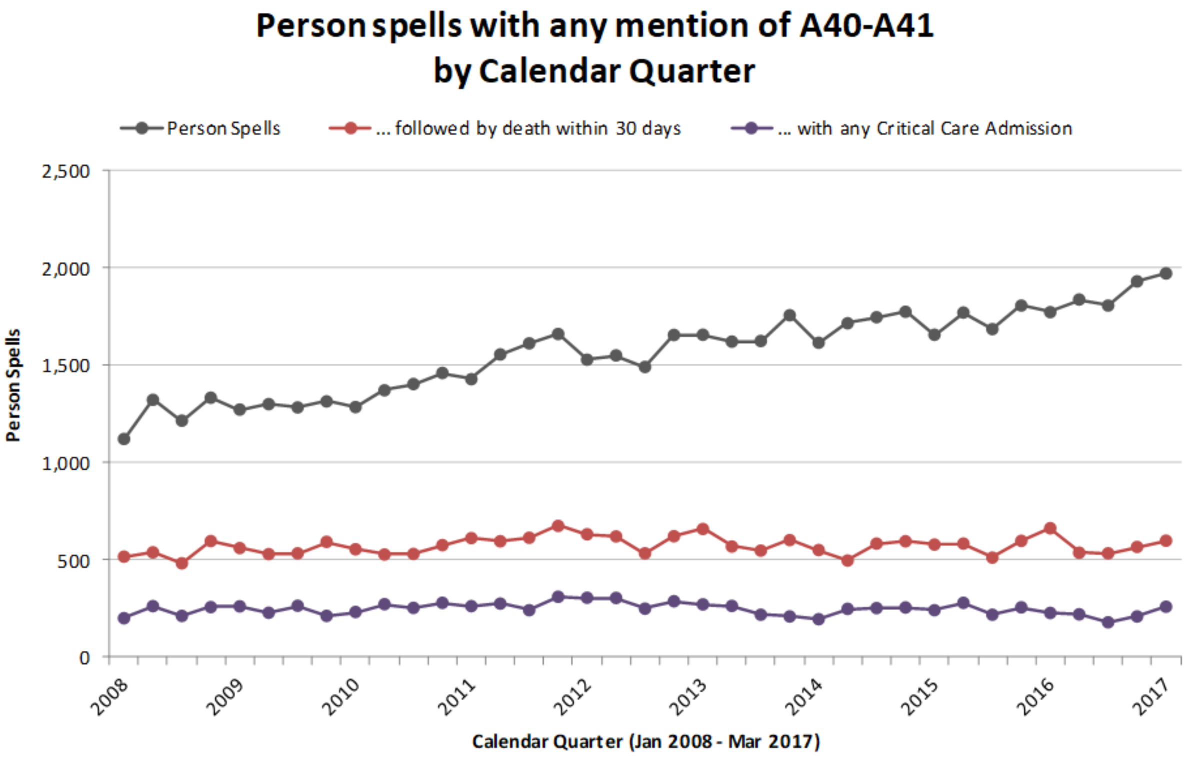
At any one time in a hospital, about 5% of all in-patients are suffering from sepsis, or severe sepsis. About 30% of those diagnosed with sepsis will die within 90 days of presentation, 30% will recover fully, and 40% will suffer permanent life-changing effects[1,2]. However, even those who recover fully, on-going psychological consequences as a result of the condition may be present. Sepsis, therefore, carries a terrible cost, not only in terms of mortality but also in the consequences that survivors may have to carry with them for the rest of their lives.

Not all deaths from sepsis are avoidable. However, there is still likely to be a sizeable proportion that are. Early recognition of the signs of sepsis is essential in achieving positive outcomes, and tools such as the National Early Warning Scoring System (NEWS) are pivotal.

The *Improvement Cymru* (formerly 1000 Lives) Acute Deterioration team in Public Health Wales have worked since 2011 to support improvement in the early recognition and effective management of sepsis across the NHS in Wales. These efforts have mainly focussed on acute hospitals because this is where most cases have presented and been recorded. In responding to ‘A Healthier Wales’ and understanding that early recognition is vital to a positive outcome, the team have recently broadened their scope to include primary and community care and are providing training and support to community nursing teams.

### 1.2 Improved National Outcomes

In October 2015, the Deputy Health Minister, Vaughan Gething, announced a significant reduction in mortality associated with two sepsis codes that had appeared to coincide with the changes made in healthcare systems occurring because of the 1000 Lives Rapid Response for Acute Illness Learning Set (RRAILS) programme. Whilst causation is impossible to attribute it does seem probable that these outcome improvements are associated with this initiative (see chart below)



## 2 Public and professional awareness of sepsis

### 2.1 Public Awareness Campaign

The issue of public awareness campaigns is challenging. Assessing the impact of any public awareness campaign is difficult. Campaigns appear to be most effective when targeting ‘at risk’ groups. This makes it difficult for addressing sepsis campaigns as it is not possible to identify ‘at risk’ groups [3].

Despite considerable work in England and Scotland, it is questionable whether the public awareness campaigns that have been run have produced any lasting evidence of raised knowledge of sepsis within the broader population.

It is also extremely difficult to maintain the delicate balance between ‘spreading the message’ to the public and possibly increasing demand on General Practice and Emergency Departments with those concerned. Consequently, in Wales, we have not undertaken any specific work with the public although have worked closely with the UK Sepsis Trust in the past.

Tracey Cooper, Chief Executive of Public health Wales, has also addressed this question in her evidence given to the Health and Social Care Committee in July 2019. An excerpt of the transcript can be seen in appendix 1.

Instead, we have focussed on raising professional awareness as part of the campaign that we have been effectively running as part of our support for 10 years.

## 2.2 Raising professional's awareness

The main vehicle for the continued improvement of recognition and treatment of sepsis in Wales for professionals has been is through participation by multidisciplinary professionals from all Health Boards and Trusts in the Improvement Cymru Acute Deterioration Programme. This has been overseen by a Rapid Response to Acute Illness Learning Set (RRAILS) Steering Group. In the coming months this will evolve to support a broader safety programme.

The awareness campaign for professionals has focussed on ensuring that:

- training on the recognition, escalation and response to sepsis has been integrated since 2013 into Life Support courses that are delivered as part of mandatory training by the resuscitation training departments within each HB
- the exact numbers of staff trained at any one time will be known by each HB
- There is a focus on doctors, nurses and support workers repeating this training on an annual or bi-annual basis.

To support this training, as 1000 Lives, Improvement Cymru previously developed a suite of e-learning modules (RRAILS online) that can be accessed through the ESR and Learning@Wales. Each module takes approximately 15 minutes to complete and there would certainly be scope to make some of the modules mandatory for some professional groups. It would also be relatively easy to use this platform for the hosting of more modules on, for example, sepsis in primary care settings.

It is important to remember that Sepsis, although a major cause of harm, is not the only cause and so the training that has been developed focusses upon identifying the deteriorating patient quickly and escalating to a professional to make an appropriate diagnosis swiftly. It is this focus which we believe has resulted in the favourable sepsis outcomes that we have seen in Wales.

The Improvement Cymru Acute Deterioration programme aims to reduce avoidable harm and death from causes of acute deterioration (sepsis and acute kidney injury) in the Welsh population. The programme to date has supported acute hospitals, primary and community care settings across every health board area in Wales; offering healthcare staff standardised quality improvement tools and resources to help identify and treat their patients. The current focus is mainly on:

- Improving patient outcomes and reducing variation in practice across secondary care by conducting peer reviews to identify and share areas of good practice and areas for improvement.
- Standardising the care of acutely deteriorating patients across the whole pathway of care by introducing the National Early Warning Score (NEWS) into community settings.
- Supporting development of a systematic method of review, communication of deterioration and rapid treatment in paediatric settings.
- Supporting developmental work with post-hospital Sepsis support groups.
- Developing and maintaining a Sepsis Registry.

The RRAILS steering group, supported by Improvement Cymru, has also published guidance on the NHS Wales response to the publication of the RCP paper on NEWS 2, the standard self-assessment for the RRAILS peer review and is in the process of publishing the all Wales guidelines for Acute Kidney Injury. The work of NHS Wales is also shared more broadly via membership of the UK National Outreach Forum (NOrF) Executive Board and the International Society of Rapid Response Systems (ISRRS) third consensus statement working group.

## 3 Identification and management of sepsis in out-of-hospital settings, including use of relevant screening tools/guidance, and the referral process between primary/secondary care.

There is increasing recognition that early intervention in sepsis is associated with improved outcome. It is, therefore, paramount that there is a focus on the identification and management of sepsis in out-of-hospital settings.

In 2019, Improvement Cymru launched a programme to spread NEWS and sepsis screening in community following the successful work of piloting amongst GPs, Community Nurses and the Wales Ambulance Service. There has been considerable analysis performed into the suitability of NEWS for community usage. This analysis indicates that NEWS works well at identifying sick people but more importantly as a standardised communication tool.

Consequently, some of the tools used in secondary care have been adapted for use in community settings and care homes. All health boards and trusts have been involved in the development of the programme that aims to implement NEWS in all 160 Welsh district nursing teams by September 2020. It is expected that, in addition to providing and extending the use of NEWS as a common language of risk in Welsh Healthcare, this initiative will result in a similar positive effect upon patient outcomes for sepsis as that experienced in Welsh hospitals with the introduction of NEWS in secondary care.

In addition, a first draft of an All Wales out of acute hospital observation chart has been launched. This is compliant with the Royal College of Physicians recommendations and principles of NEWS 2. Following testing during the roll out of NEWS, it is anticipated that this chart will become standard in all non-acute hospital settings, meaning that increasing numbers of people will be identified as sick and given appropriate treatment without need for admission to hospital.

A peer review process requested by Welsh Government as a response to the publication of the PSMO report on 'out of hours' services has recently been completed following visits to 20 acute hospital sites in the seven health boards and Velindre across Wales. The final report is currently being prepared and recommendations will be used to inform future work with Improvement Cymru. The recommendations outlined include:

- Every Health Board should establish an overarching Acute Deterioration Steering Group
- Identify an operational lead for acute deterioration within each organisation, ideally with protected time for the role.
- Establish a 24/7 Rapid Response System (RRS) featuring a Critical Care Outreach
- Ensure whole hospital daily 'huddles' and ward shift handover explicitly feature information on patients at risk of deterioration
- Health Board Acute Deterioration Steering Group should agree, publicise and monitor compliance with Standard Operating Procedures (SOPs) for escalation and treatment of acute deterioration, sepsis and acute kidney injury (AKI)
- Ensure that NEWS is reliably utilised in all adult clinical areas (except maternity) both in and out of hospital.
- Demonstrate compliance with sepsis screening for all patients meeting national criteria (NEWS greater than 3 and a suspicion of infection).
- Implement and measure compliance with an Acute Kidney Injury care bundle to respond to patients identified via the AKI e-alert system
- Establish and regularly review at a hospital and Health Board level, a standard dashboard of acute deterioration metrics
- Embed standardised national training on AD, sepsis and AKI

Recommended Actions to be taken at an all Wales level:

- Create an all Wales Faculty to provide evidence to Welsh Government and to advise on future Acute Deterioration programmes
- Develop and publish a set of standards for recognising, escalating and responding to acute deterioration in secondary care and support Health Boards to self-assess against these to inform the creation of annual action plans.

- Establish a suite of role specific competencies based upon the standards to enable development and evolution of relevant education and training.
- Identify a high level dataset and reporting schedule to enable HBs to demonstrate improvements in processes and outcomes associated with acute deterioration, Rapid Response Systems and CCOTs.

## 4 Identification and management of sepsis in acute (hospital) settings

The identification and management of sepsis within acute settings continues to be a major focus of attention. There continues to be more that can be done, especially identification and management of patients on general wards rather than ED and critical care. Work to date in Wales, supported by Improvement Cymru/ 1000 Lives includes:

### ❖ Introduction of the National Early Warning Score (NEWS)

The National Early Warning Score (NEWS) has been introduced in all acute clinical areas, in the Welsh Ambulance Service Trust (WAST) and in many community and primary care settings. Wales was the first country in the UK and Ireland to implement NEWS as standard in 2013. This has had the effect of changing the national culture around acute deterioration and has hugely raised the awareness of sepsis amongst health care professionals.

### ❖ Sepsis screening and treatment

A standardised approach to sepsis screening and treatment with the sepsis 6 care bundle has been integrated with the implementation of NEWS and so the escalation process for sepsis in Welsh hospitals has been embedded in the everyday clinical protocols and procedures for many years.

### ❖ Development of Standardised tools

Working with the Health Foundation and Helen Hamlyn Institute on development of simple tools to make it easy and attractive for clinicians to comply with best practice. These include such developments as the ‘Wee Wheel’, NEWS Card and Kidney Safe Bracelet. Demand for these has been high in Wales but also in England and worldwide. For example, over 20,000 NEWS cards, which explicitly suggest that sepsis be considered for patients with a high NEWS, are in use across Wales.

### ❖ Sepsis Metrics Reporting to Welsh Government

NHS Wales, facilitated by the Acute Deterioration Programme, has developed and spread a sepsis screening and escalation tool and has worked to improve systems for delivery of the Sepsis 6 care bundle within a 1-hour window. All Health Boards now report metrics on sepsis screening and treatment to WG on a monthly basis and this data is evaluated as measurement for improvement as part of the RRAILS Steering Group meetings.

### ❖ Measurement - Suspicion of Sepsis

The Acute Deterioration team of Improvement Cymru/ 1000 Lives have continued to look at routine national data in order to understand the impact we are having on mortality from sepsis and to help identify where to focus our efforts. Unfortunately, methods that have been used in the past have become unusable due to UK-wide changes in diagnostic coding and we are having to investigate new approaches, working with colleagues from Welsh Government, to analysing this data. 'Suspicion of Sepsis' (SoS; Inada-Kim et al. 2016) is one such approach, looking at emergency admissions with an infection-related diagnosis. NHS England launched a 'SoS dashboard' in September 2019 based on this approach. We have worked to replicate this new approach using Wales's data. Having sought advice from the Public Health Wales Observatory, we are also looking at the demographics and comorbidities of these admissions to check that any positive findings aren't the result of a changing patient-mix.

### Significant improvements in recognition and treatment of sepsis at the hospital 'front door'

Following a 1000 Lives Improvement study tour to Dartmouth Hitchcock medical facility in the US, a joint RRAILS/ ABUHB team developed and established the practice of DRIPS (Data, review, improve, plot the dots, share) meetings in two emergency departments and one hospital in 2015. This method has since been spread as part of the Acute Deterioration programme and peer review process to the receiving units in eight hospitals. In every one of these hospitals the number of cases of sepsis identified in emergency departments and medical assessment units has significantly increased and the compliance with delivering sepsis treatment within one hour has increased to between 70-100% on a regular basis. This is a remarkable achievement which may well be an international first in non-electronic health care systems.

### Sepsis Box/trolley

Following the sepsis box study at Cwm Taf University Health Board, the concept of giving clinicians 'permission to act' by using a dedicated box or trolley has been adopted by most Welsh hospitals.

### NEWS Wales Application (App)

The NEWS Wales App, which enables users to calculate NEWS and suggests the likelihood of sepsis, has been re-developed by the RRAILS steering group and re-released because of popular demand, particularly from paramedics who find it an invaluable tool. It is intended that the app will play a central role in the roll out of NEWS and sepsis screening to community settings this year.

### Sepsis Guidance

NHS Wales's ability to standardise best practice at scale has been demonstrated by the publication by Richard Jones, Clinical Lead and Chris Hancock, Programme Lead for the 1000 Lives Acute Deterioration programme, of the guidance letter on the 'recognition and management of the adult with sepsis', as well as guidance on maternal sepsis, identification of sepsis by the Welsh Ambulance Service and with Dr Clare Dieppe, a position statement on acute deterioration in Children.

### ❖ Paediatric Acute Deterioration Programme

Clare Dieppe, a specialist Emergency Department Paediatric Consultant in Swansea Bay University Health Board has been appointed as Chair of the RRAILS Paediatric sub group and to lead on the paediatric acute deterioration programme in NHS Wales. 1000 Lives Improvement have published a statement outlining the expected scope and direction of paediatric acute deterioration work. With the ongoing work around the Paediatric Early Warning Score Utilization & Mortality Avoidance (PUMA) study yet to conclude, clinicians within the specialty are reluctant to develop a 'score'. They are more comfortable with an approach that improves and standardises the review and communication process.

In 2019 the Acute Deterioration programme is supporting the roll out of the Paediatric Observation Priority Score (POPS) within WAST and all NHS Wales Emergency Departments.

## 5. The physical and mental impact on those who have survived sepsis, and their needs for support

Due to earlier recognition and intervention in sepsis, short term survival has improved recently, resulting in a growing population of sepsis survivors. However, sepsis survivors appear to be at high risk of longer-term complications, worsening of chronic conditions, mental health and cognitive issues, and further hospitalisation [4]. This represents a significant burden to health and social care.

Whilst the physical and mental impact of sepsis survival is recognised, predicting complications in survivors is challenging and more data and research is needed to further understand this. As a consequence, In order to understand long-term outcomes for patients with sepsis and identify those who may need support following sepsis, a sepsis registry has been established in collaboration with the Cardiff and Vale UHB, UK Sepsis Trust, Improvement Cymru, the Healthcare Associated Infection, Antimicrobial Resistance & Prescribing Programme (HARP) and the Critical Care Network. This is the first sepsis registry in the UK to use this methodology.

The registry will be hosted by Public Health Wales as a part of its critical care surveillance programme This is complemented by the establishment of an agreed standard dataset for use by the teams as part of the expansion of Critical Care Outreach. This is ready for activation once the governance issues covering the information held in PHW are resolved.

The plan is to collect data on all acutely unwell patients, particularly those exhibiting an acute deterioration. While not all such patients will have sepsis, a significant proportion of them will. To date, no common dataset exists (e.g. from outreach teams, acute deterioration teams, etc.) on which to begin the development of an all-encompassing Acute Deterioration Registry. We have therefore taken the pragmatic step of beginning a project with a dataset that is common to all acute hospitals with a Critical Care Unit (CCU) in Wales. Currently, all CCUs submit data to the Intensive Care National Audit and Research Centre (ICNARC) using a case management system (WardWatcher) and provide HARP with surveillance data. The Sepsis Registry will utilise Ward Watcher for the required data extraction, identifying patients admitted to critical care units with sepsis and the care received (e.g. organ support delivered, lengths of stay). This will give a clear picture of what sepsis care looks like for each critical care unit, hospital and Health Board and provide outcome data for the project.

The new data extraction required from Ward Watcher should be complete by June. The data will be analysed prospectively and retrospectively. There is also a future plan to look in more detail at a sample of the patients identified to map their journey to critical care.

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## Appendix 1

**Angela Burns AM** 10:27:19

Thank you very much indeed. I wanted to understand how you measure the success of a public health campaign and how you believe we are doing on the sepsis public health campaign.128

**Dr Tracey Cooper** 10:27:36

If I take the second point first, I'm sure you may be familiar with the fact that we've been doing a huge amount of work around sepsis over the last number of years, particularly through the lens of how we prevent people deteriorating rapidly, and sepsis is part of that. So, we've been doing, if you like, a professional campaign for the last number of years, and I'll come back to the public in a second. Our 1000 Lives Improvement service interacts with the NHS, and we've been putting people through substantial training and it's now part of their mandatory training modules around early deterioration and sepsis specifically.129

**Angela Burns AM** 10:28:14

Can you just define that for us, though? When you say that you've put 'substantial numbers of people', are we talking hospital staff or are we talking about general practice? 130

**Dr Tracey Cooper** 10:28:25

It's mainly hospital staff. General practice is a really important one, because we know that a considerable number of people who will progress to sepsis are coming in at quite a late stage from the primary and community area. So, our focus has been, over the last couple of years, more around the secondary care hospital areas, but, in the last 12 months, we've increased our approach around primary and community care, providing more guidance and providing support around sepsis screening.131

Also, through our 1000 Lives team, shortly we'll be embarking on a programme for care homes, as well, because we know, particularly around urinary tract infections, skin infections and infected pressure ulcers—. So, how do we train people up more generally around quality improvement and sepsis being part of that? So, that's a really important area.132

We've also been doing a lot around the alert. A lot of sepsis can be avoided, as you know, and some sepsis can't be avoided. So, what does an alert in a hospital environment look like? What we call the early warning score in any part of an environment in a hospital is what the signs and symptoms are of someone, at the early stages, starting to manifest sepsis and what they do about it. Because, sometimes, people watch and watch and watch, and we compensate and then we deteriorate very quickly. So, we know that, through that work, we've had a significant reduction in people requiring intensive care and people deteriorating. We're doing another round of outcome measurements around how many lives have been saved as a result of this programme, obviously, because that's going to be absolutely key.133

With the improvements around reducing sepsis, though, we were actually recognised in Wales as one of the global professional campaigns of systematising an approach to sepsis through early warning in a way that other countries haven't. But obviously that needs to translate into reducing it. At the moment we have around about 2,200 deaths per year in Wales, and 13 per cent of those are in hospitals. So, again, going back to how we've systematised this, we've been doing a lot of education and training for people. I accept your point around primary and community care, which is a really important phase for us—the surveillance, detection and alert. So, now health boards are required to alert Welsh Government if there's a person that goes into sepsis, and then demonstrate how they've learned from that, which I think is really key—134

**10:30**

**Angela Burns AM** 10:30:58

Can I just ask you—? Because I'm conscious that the Chair will breathe down my neck in a minute. Can I just ask you a couple of questions on that bit of it, before we get to the public health element of it? Do you monitor how many people contract sepsis and survive, but survive poorly—i.e. they have multiple issues, they may have lost a number of limbs, they may have had mental health issues as a result, they may have had brain incapacity as a result? Because you're right; in pure terms, there is a small—and I emphasise the words 'very small'—reduction in the number of sepsis deaths. But what I cannot find out—and I'm the chair of the cross-party group on sepsis, and believe me, I've burrowed through data, but I cannot find out—is how many people are surviving, but you wouldn't necessarily say they had a great quality of life afterwards. Are you able to provide that kind of figure work? Do you measure that anywhere? Because of course that is whether or not we're being successful.135

**Dr Tracey Cooper** 10:32:01

Absolutely. The short answer is that I'm not aware that we are—. We look at it, as you say, at that point of time, for that episode, that the patient didn't deteriorate, didn't die from sepsis. The extent to which we then do the follow ups—because it may not be just that they're in the hospital stage of subsequent complications; it could be further down the line. I'm not aware that we do, but I'm very happy to go and research it and get back to you.136

**Angela Burns AM** 10:32:30

I'd be really interested in that. Also, when it comes to the analysis of the data, it would be very helpful to find out where people are being referred from, because we have a clear—. I think the RRAILS programme is actually very good, and I think it has made substantial changes to the way sepsis is managed within a hospital environment. However, again, what we're unable to really track well is how many people are admitted to hospital having not been handled appropriately in either a care home setting or in a GP setting. I've done quite a bit of research with GPs who—. It's very difficult. You don't know if this person's got flu, or it's going to go into sepsis, or they've got a urinary tract infection and it's going to develop. But again we could have a commonality, particularly in care homes, about who gets looked at in a care home or not looked at in a care home, particularly if it's not a medically based care home, and is left then too long and is suddenly taken in as sepsis. So, I'd like to have a feel for that, and then I'd like to have just a brief word on whether or not you think a public health campaign to explain to people what they need to look at, the signs of sepsis, or just being sepsis aware, or asking, 'Could it be sepsis?'—whether or not you think that would be of benefit.137

**Dr Tracey Cooper** 10:33:51

We know that 80 per cent of people who attend hospital and become septic originate from primary and community care. So, we have historically been targeted at the hospital, probably because it's actually easier to try and control people. As I was saying earlier, we recognise that, actually, primary and community care is key. My background is as an emergency medical physician, and I was a regulator in a different country, so the quality of care in care homes was fundamental to us, and I would suggest it's about building an understanding quite quickly around deterioration that could be from sepsis. It may be as a result of something else, but actually, it's the fact that sometimes people aren't detected as clinically deteriorating.138

The other challenge is about primary care, and the thresholds for calling a GP into a care home setting. So, part of the conversation we're having even around immunisation and vaccinations and flu, potentially, is whether there are opportunities to train other people up—registered nurses in care homes and others—around those early signs of deterioration. So, we are developing a quality improvement programme—not solely sepsis, but sepsis is part of that—around care homes, for that very reason, because we know it's like a rotating door. I'm very happy to give you more detail or meet with you if that would be helpful to give you some more information on that. 139

In relation to the public health campaign or public campaign around sepsis, it's a really interesting one. We have similar discussions around many campaigns, actually. You may be aware that in 2016 England launched a public sepsis campaign. Scotland did some work as well. What we don't know—we haven't been privy to it; it may be working through—is the evidence that, actually, that made a difference to reducing the incidences of sepsis and the outcome of care as a result of sepsis. We've had discussions on and off, I'd say for about a year or so, with Welsh Government officials about this very issue. We get asked quite a lot about doing public campaigns, understandably, on areas. What I would say is that there are campaigns around a lot areas that people invest a lot of public money in and, actually, that may not be the way of really getting to the people who can make a decision to control something, to prevent something. 140

**10:35**

**Angela Burns AM** 10:36:22

I do totally understand that and, of course, I think one of the dangers with politicians is that we all have a little hobby horse. I'm prepared to admit that mine is sepsis, so I completely get that—you can't rush off and do campaigns around everything. However, sepsis does kill more people per year than the top three cancers. Now, you could ask almost anybody anywhere in Great Britain what cancer is, and they will tell you. You can go almost anywhere in Great Britain and say to people, 'Do you know what sepsis is?' and a huge number will not know what on earth you're talking about. Now, you cannot drive down a road in England—if you pass an ambulance it will have the sepsis warning signs. Every ambulance. I've travelled around and I've taken photos of the things to prove to Wales that there are small things that we could do. To be frank, it's—what do you call it—an orphan event; it's not one of the big ones. We all get cancer and we all understand what it means, but it's killing people. But worse than killing people—and I mean worse than killing people—is that it leaves people devastated afterwards. Very few people walk away from sepsis clean and clear. There are multiple amputations. There is always a side effect. I've yet to meet a sepsis survivor who's had it and has been A-okay afterwards. So, again, on the public health and the benefits in the long term, the pick-up that the state has to do is phenomenal, so I don't quite understand why we wouldn't want to start elevating this up the process, because of those very sort of lifestyle changes that will happen. 141

**Dr Tracey Cooper** 10:38:15

Yes. I would say it's a priority for us. It's been a continued, very focused piece of work for 1000 Lives, and we've increased progress on that. I'd be delighted to meet and have a conversation about this, because it used to be one of my bugbears in a former world. Yes, it's about what are the messages to which audience. I think one of the challenges is that people may go to their GPs, and at that point it may not be picked up. So, it is about making sure that, actually, we don't just focus on one at the cost of another. It's what the best—we were talking a bit about behaviour change earlier—what's the best message for the public through what medium, what's the best message and guidance, support and direction to professionals through what medium. But I'd love to meet up and have a more detailed discussion about it. 142

**Angela Burns AM** 10:39:06

Right. You're on. Just one last very small question—and again, other Members here may be more aware of this than I am. I'm chair of the group, but it was only at the last group that I heard of the early warning score. Now, that's supposed to be a public health initiative. So, essentially, we all have a card—I don't know if everybody else is aware of this—and basically it says what is your normal baseline: what is your normal temperature, what is your normal blood pressure, what's your normal— 143

**Dai Lloyd AM** 10:39:42

Pulse rate.144

**Angela Burns AM** 10:39:43

—pulse rate; you know, all of the things, so that if your score—. And it's on a card, so that if you then are unwell there's a baseline that a medical professional will be able to judge you from. I think that's a brilliant idea, and if everyone in Wales had one then you've got something to start measuring people on. But I'd never heard of it. How far out is that? Why isn't that kind of thing being more promoted in public health? Because that would be a good baseline for a gazillion illnesses.145

**10:40**

**Dr Tracey Cooper** 10:40:14

Certainly, the national early warning score, we've embedded it in—again, it's more hospital based—for the last number of years. It is absolutely fundamental to start to understand if someone is going to clinically deteriorate in exactly the way that you've just said, particularly if it's a pregnant woman whose physiology is different. We've investigated a sepsis case of someone who sadly died in another country because the clinicians, the people looking after her, didn't understand that her body responds differently in the third trimester than it does when you're wandering around the streets. So, we have a national early warning score that is mainly—and the approach has been—in hospital. It's also about what an obstetric early warning score is and what a paediatric early warning score is. Actually, there's some good stuff that's happened, which again I'm happy to discuss with you. The challenge of having it out and about with you is that your body changes. So, my baseline today could be—. When I'm running, which I really need to do later today, my baseline would be different. The important thing is, while you have observations, if you go to your GP periodically or if you're in a hospital—the only way they can do that is baselining what's normal for you at that point in time and what are the red flags.146

# Agenda Item 7

## Written Response by the Welsh Government to the Report of the Health Social Care and Sport Committee's Inquiry into the Social Services and Well-being (Wales) Act 2014 and its impact on carers

I would like to thank the members of the Health Social Care and Sport Committee for their report. Its recommendations clearly highlight the concerns of carers and others, as well as the challenges ahead. I have set out in previous statements that the Welsh Government values very highly the contribution that carers make in their caring role, and our commitment as a government to support them.

In relation to the committee's recommendations, I am pleased to confirm that in regard to the majority of the recommendations, we are already planning or taking action to improve the support and experiences of carers. I have set out below my responses in detail to the Committee's individual recommendations. I look forward to discussing this response with you in due course.

**Recommendation 1 -** The Welsh Government must, as a matter of priority, demonstrate stronger national leadership in the delivery of rights and services for carers under the Act. As a starting point, it must prepare, within 6 months, a clear action plan for addressing the failings of implementation highlighted in the evidence we received. In doing this, it must consult key stakeholders and carers. It must also set out a clear timetable for delivery of the actions identified in its plan

**Response - Accept**

The Welsh Government is providing strong national leadership in developing better support for carers. Since the introduction of the 2014 Act and its implementation from April 2016, we have worked to develop the rights of carers and focus on how we have the greatest impact for carers across Wales.

As well as working in partnership with carers to develop the 3 national priorities for carers, published in November 2017 we also agreed as part of that work to establish a new Ministerial led strategic forum. Established in 2018, the Carers Ministerial Advisory Group brings together key stakeholders – local authorities, health boards, carers' organisations and others, to consider the needs of carers, now and in the future.

At the Carers Ministerial Advisory Group (MAG) meeting in mid-May 2019, I set out my thinking as to how we can take our national priorities for carers forward into 2020 and beyond through a comprehensive national plan. I subsequently announced on 21 November 2019, Carers Rights Day, our intention to develop a new national plan for carers. It will help to drive forward the strategic agenda and work in combination with our existing three national priorities for carers. The new plan will set out the key drivers and actions we will need, and how we can all work together as government, statutory authorities, health boards, commissioners, Social Care Wales, carers' organisations and others, to deliver real impact in carers' lives.

The content and structure of the new plan has already been the subject of discussions with the MAG membership, commencing at their meetings in October and November 2019. This included considering feedback about carers' needs assessments, how we can improve carers' knowledge of their rights under the 2014 Act, and where they can access information, advice and assistance.

This thinking will be taken forwards at the next meeting of the Carers MAG on 29 January 2020. I want us to be in a position to hold a public consultation later this year, and have a new plan in place before end of 2020.

Financial implications – none. Any additional costs will be drawn from existing programme budgets.

**Recommendation 2** The Welsh Government must plan now for the anticipated rise in the number of unpaid carers. It must take a long term view of what the needs of carers will be in the future and how, along with local authorities, local health boards and the third sector, it will meet those needs. The Welsh Government must clearly set out how it will achieve this and report back to us on progress in 6 months.

**Response - Accept**

Wales has an ageing population and more of us will be in a position of caring for our loved ones, with many living with more complex, long term health conditions. The 2011 Census estimated there are c. 370,000 carers, which is by now likely to be an underestimate. In 20 years there are estimates that one in three of us will have caring responsibilities. Demographics forecast that over the next 20 years (in 2040), 1 in 4 of us will be over 65, with those aged over 75 projected to increase from 9 per cent of the population in 2018, to around 14 per cent in 2040.

At a strategic level our Well-being of Future Generations (Wales) Act means all public bodies listed in the Act must think about the longer term, working better and smarter with individuals and communities, as well as each other, to prevent strategic problems developing and escalating, as well as adopting a more joined-up approach. We have also prioritised social care in our national strategy – Prosperity for All – and A Healthier Wales which emphasises the need for an integrated health and social care system. These strategies will now be supported by our new national carers plan.

The key mechanism for planning is the Population Needs Assessments and guidance is being prepared by government to inform the next round of assessments. We have clearly set out in Part 2 of the 2014 Act that local authorities and health boards have responsibilities to:

- understand the characteristics and needs of their local population, including carers, by conducting a population assessment of people in need of care and support, and carers in need of support;
- provide or arrange the provision of a range and level of services, including preventative services to carers and are accessible within the community; and
- ensure that carers can readily access information, advice and assistance about the type of support available in their community, and as importantly, helps them to understand how the care and support system works in their area.

Financial implications – None.  There will not be any additional discrete costs. Any additional costs will be drawn from existing budgets.

**Recommendation 3** The Welsh Government must ensure that the Ministerial Advisory Group is supported and resourced to be an effective forum. It must be of sufficient status within the Welsh Government to raise the profile of caring and carers' needs across government policy areas, including local government, health, housing and transport. As such, it should be chaired by a member of the Welsh Government. It should be transparent, and should publish agendas and minutes of its meetings. The Deputy Minister must report back to this Committee within 6 months on the actions that have been taken to address these issues

**Response -  Accept**

Our ministerial advisory group for carers was created in mid-2018 in response to calls from a wide range of stakeholders for a strategic and high level forum whose members can engage with, challenge and influence current and future policy. The group's status and commitment of Ministers is demonstrated by the frequent attendance of the Deputy Minister for Health and Social Services, to hear the considerations and feedback of the members.  They have met five times between summer 2018 and December 2019 and will next meet on 29 January 2020.

Having considered the progress of the work of the MAG, I have appointed Mr Arwel Ellis Owen, former Chair of Social Care Wales, as Chair of this group. With his expertise and experience he will provide clear, impartial and strategic leadership of the MAG at a key point in its work programme – notably development of the new national plan.

We will publish the agenda and minutes of the meetings so that everyone can read about discussions and the development of the new national plan.

Financial implications – none.  Any additional costs will be drawn from existing programme budgets.

**Recommendation 4** The Welsh Government must, as a matter of priority, give effect to its commitment to undertake a major publicity drive to raise awareness of the Act and carers' rights under it. This should raise the profile of caring, improve identification of carers, promote the benefits of needs assessments under the Act, and encourage take-up. It should also signpost people to appropriate information, advice and assistance about caring. The Deputy Minister must report back to this Committee within 6 months on progress.

**Response -  Accept**

I was pleased to inform the committee members of our intention to launch a new carers' rights awareness campaign, when we met in mid-February 2019. We launched the campaign on Carers Rights Day, 21 November, the first phase in a targeted campaign in 2019 and into 2020.  We also launched material to inform older people of their rights and used social media to highlight the launch.

The initial phase of the campaign will focus on all ages of carers, with key messages within a poster and leaflet, which informs people that they can contact their local authority to find out more, and where appropriate, access a carers' needs assessment. Information from this first phase will be used to inform the campaign in 2020-21, including information targeting young carers.

We will be collecting data and information on use of our website pages hosting the poster and leaflet, as well as officials receiving regular evaluation reports and seeking feedback from carers networks such as the members of the Wales Carers Alliance.

Financial implications – none. Any additional costs will be drawn from existing programme budgets.

**Recommendation 5** The Welsh Government must ensure that those health and social care professionals most likely to come into contact with carers, including GPs, are able to identify carers and signpost them to appropriate services. The Welsh Government must ensure that specific training is provided for this.

**Response - Accept**

Local authorities have the responsibility for ensuring their workforce is suitably trained to deliver services such as information, advice and assistance and support for carers, but as part of its remit Social Care Wales provides information, resources and training for social care workforce professionals that includes how to support carers, and most importantly, how to hold that critical conversation with a carer, when undertaking a carers' needs assessment.

A senior official from Social Care Wales is a member of the Carers MAG and the development of training and information resources for this critical workforce will feature in the new national plan.

Since 2016-17 we have been providing direct funding to local health boards to support carers and in 2018-19 and 2019-20, £1m has been focussed on supporting carers when in contact with GP services, and when the person they care for is discharged from hospital. For 2020-21 I will ask LHBs to use their allocation in a more flexible way, given our development of the new carers' national plan.

Health Education and Improvement Wales (HEIW) and Social Care Wales (SCW) are jointly leading the development of a workforce strategy for health and social care, in partnership with NHS Wales, Local Government, the voluntary and independent sectors as well as regulators, professional bodies and education providers. The workforce strategy is a key enabler, in delivering the ambition of 'A Healthier Wales' and on 12 November 2019 the Minister for Health and Social Services announced a £127.8m investment package to support education and training programmes for healthcare professionals in Wales, an increase of 13% compared with 2019/20.

Financial implications – none. Any additional costs will be drawn from existing programme budgets.

**Recommendation 6** The Welsh Government must ensure that the formal needs assessment process for carers is clarified and standardised across local authorities. It must be able to demonstrate how it has achieved this and should report back to this Committee within 6 months on progress

**Response - Accept**

The 2014 Act places clear duties on those exercising functions under the 2014 Act to begin with the assumption that the adult is best placed to judge their own well-being.

The carers' needs assessment process is clearly identified in the dedicated Part 3 Code of Practice (assessing the needs of individuals) which must be applied by all local authorities when they undertake an assessment with an individual or carer. This code sets out a process for assessing the needs of an individual for care and support, or support in the case of a carer, and a process of assessment that will apply to everyone – children, adults and carers, as well as a process of review and re-assessment, that will apply to assessments.

All practitioners must work with people to identify what matters to them, and identify an individual carer's strengths and capabilities. This is central to the system. It is an approach to assessment and care planning that recognises that needs can be met not only through the provision of services, but through active support and assistance to enable people to meet their own needs e.g. helping carers access local services themselves.

Care and support plans evolve from effective assessments about what matters to the person, and the outcomes they want to achieve. This is a model of assessment and care planning that requires the assessment process to start with the person themselves and understand their strengths and capabilities and what matters to them and how their family, friends and local community play a part in their life to help them reach their personal outcomes.

Financial implications – none. Any additional costs will be drawn from existing programme budgets.

**Recommendation 7** The Welsh Government must ensure that those social care professionals responsible for delivering needs assessments are trained to provide an improved user experience for carers. Training should include an emphasis on appropriate language to be used around assessments, breaking down barriers to engagement with social services and ensuring that carers are able to access the support they are entitled to under the Act. The Welsh Government must evaluate the impact of this training

**Response - Accept**

In 2018, Social Care Wales commissioned the Institute of Public Care to engage with carer stakeholders and statutory bodies, including officials from Welsh Government and representatives from Carers Trust Wales, Carers Wales and the All Wales Forum for Parents and Carers, to develop a new carers' needs assessment toolkit of resources.

Published in spring 2019 these resources are specifically intended to support social care professionals to deliver carers needs assessments and care and support plans for carers where eligible needs are identified. These are developed with the carer as an equal partner, and with the goal of enabling carers to live the life they want to achieve. They previously launched an e-learning course in autumn 2018, to help professionals across the health, social care and public sector to understand the needs and issues that affect all ages of carer. This is available on the NHS Wales e-learning platform and is intended to complement existing training resources, and to work alongside the carers' assessment toolkit.

Skills in respect of working with carers was included as a new priority in the Social Care Wales Workforce Development Programme (SCWWDP) grant for 2019-20. Data is being sought from the regions on their training activity and is part of the grant reporting process during 2019-20.

The "What matters conversation" is flexible and person centred, so language can be adapted to facilitate the conversation, including when it comes to a formal carers needs assessment. We would not expect a social care professional conducting a carers' needs assessment of a young carer, to use the same language as with an adult. It is vital that local authority employees and others who are engaging with carers, including carrying out a carers' needs assessment, truly enable the conversation to be led by the individual.

Financial implications. None. Any additional costs will be drawn from existing programme budgets.

**Recommendation 8** The Welsh Government must require an evaluation of the effectiveness of the needs assessment process. The method of this evaluation is a matter for the Welsh Government, but it should be done on an annual basis and the results should be published.

**Response - Accept in principle**

The 2014 Act takes a proportionate approach and local authorities or their commissioned services employed to carry out assessment, should only carry out assessment when and where needed, providing support to individuals and carers through other means where appropriate. However, the key focus is on the outcomes of those conversations, and the impact on the life of the carer and their ability to continue in their caring role, as well as having a life alongside their caring role.

Formal evaluation of the 2014 Act is ongoing over a 3 year period. Commencing in 2019-20 it will be an examination of the extent to which people have "voice and control", therefore analysing the key principles embedded within the 2014 Act. Our new Performance and Improvement Framework will help us obtain evidence and identify where there may be gaps in our knowledge or data collection.

Quantitative data collected from local authorities is currently published on an annual basis and this includes data in relation to assessments of need for care and support. From April 2020 onwards, the data collected will inform the quantitative data component of the new Performance and Improvement Framework. This will provide a range of data and evidence to measure and monitor performance at a local and national level, to drive improvement across the social care sector and inform national policy.

Financial implications – None. If appropriate, the costs of such analysis and any associated monitoring would be met through existing programme budgets.

**Recommendation 9** The Welsh Government must set out the maximum time that it believes a carer should wait to receive a needs assessment; and

**Recommendation 10** The Welsh Government must require local authorities to report back on waiting lists for needs assessments. The Ministerial Advisory Group may provide an appropriate forum for reviewing these reports.

**Response - Accept in principle**

We recognise and accept that a number of carers are telling us they are waiting for a statutory carers' needs assessment. There is a need to collect more appropriate and meaningful data. I will use that data and more immediate work with the Carers MAG to identify how more timely responses can be delivered, as well as a range of solutions that enable local authorities to deliver timely, effective statutory assessments that are responsive to the support carers need, when they need it.

Financial implications – none. Any additional costs will be drawn from existing programme budgets.

**Recommendation 11** The Welsh Government must ensure that refusal rates of needs assessments are kept under review. The Ministerial Advisory Group may provide an appropriate forum for this work

**Response - Accept**

We all need to understand why carers are choosing to refuse their rights to an assessment of their need for support. The formal evaluation arrangements we have put in place has already started to provide the evidence for this. The number of assessments refused by adult carers is currently collected through the Adults receiving care and support data collection. Figures for 2016-17 onwards have been published annually and since 2016-17 the data on the number of carers who refused assessments has remained relatively stable. This data will be included in the new data requirements for the Social Care Performance and Improvement Framework, from April 2020 onwards.

We recognise that there may be more carers for whom it would be appropriate to have a formal needs assessment from their local authority. However, when seeking to understand this data and in addition to caveats on data quality, it is important to note that carers who do not need support (at that time), or whose needs are currently being met through information, advice and support services, or who already have a support plan in place and whose needs have not changed, it is not therefore expected that they would need a carers assessment in any given year.

Asking individuals their reasons for refusing an assessment can be difficult because many may not wish to give this information and often only a very small percentage of individuals return any qualitative survey issued by an organisation asking for feedback.  In light of this the I will ask the Carers MAG to consider whether research beyond that already under way, for example in Measuring the Mountain, to sample and obtain such qualitative data, is appropriate, The MAG will also consider any risks around sampling and scaling up, and how this would impact on local authorities carrying out a carers needs assessment.

Financial implications. None. Any additional costs will be drawn from existing programme budgets.

**Recommendation 12** The Welsh Government should ensure that emergency planning is a core component of all needs assessments to ensure that specific arrangements are in place for a time when the carer is unable to continue to care.

**Response - Accept**

Part 3 of the Code of Practice requires all local authorities to ensure all carers needs assessments include a detailed conversation about how to achieve the outcomes of the carer and what support they may need in different circumstances.  These circumstances include situations where there is an emergency.

Within health boards and local authorities there are examples of different approaches to helping carers in such circumstances, for example a number of authorities offer emergency carer ID cards.  We would also encourage local authorities to share good practice. For example, Ceredigion local authority offers an Emergency Carers Fund, available to support unpaid carers in any situation that the carer considers an emergency.  In 2018/19 the fund was used to look at a more innovative ways of supporting carers and the person they care for, until either longer term arrangements could be made with each party, or until the crisis was resolved in the short term.

The Welsh Government has also been undertaking an informal consultation, including local authorities, about a new draft policy framework for urgent and emergency care.  The draft policy framework describes a new six goal approach intended to help local service leaders to do things differently, better and faster for people who want or need to access urgent and emergency care. This will include:

1. Co-ordination, planning and support for high risk or vulnerable people - and their carers - who are more likely to need urgent or emergency care; and
2. Advice and signposting for people, family members and/or their carers who want or need urgent support or treatment.

Financial implications. None. Any additional costs will be drawn from existing programme budgets.

**Recommendation 13** The Welsh Government must ensure equitable provision of services for carers across Wales, including respite services. As a starting point, it must ensure that a baseline range of support services for carers, based on eligibility criteria, is provided by all Local Authorities. The Welsh Government must introduce a mechanism to monitor delivery of this support. It should report back on progress within 6 months.

**Response - Accept**

Through the population needs assessments, local authorities and local health boards are about to jointly evidence needs for care and / or support in their area and use that evidence to provide or arrange services and support to meet those needs. At the individual level the national eligibility criteria set out in the 2014 Act provides for a consistent approach to meeting the care and support needs of all individuals in Wales, including carers. Central to this approach is the spirit of co-production, working with the individual, carer and family to understand their needs, capacity and resources and the outcomes they wish or need to achieve. Needs can be met not only through the provision of services but also through active support and assistance to enable people to meet their own needs.

Every local authority will have a different level and range of provision available from across the public, third and private sectors, making it impossible to ensure an identical level of service provision or provider. However, we are discussing with local authority social services representatives how greater consistency can be achieved and reported on including by building upon existing mechanisms such as reports provided to the Regional Partnership Boards. This would engage all of the partners who are involved in supporting carers, not just local authorities.

Financial implications. None. Any additional costs will be drawn from existing programme budgets.

**Recommendation 14** The Welsh Government must publish information on expenditure by local authorities on respite services. This should cover each financial year since the government's investment of £3 million of recurring funding began in 2017-18.

**Response - Reject**

Health and social care overall is a priority for us and will continue to be so, with figures from HM Treasury showing we are investing 11 per cent, or almost £300 more per person in health and social care combined, than in England.

The overall budget for health and social care in Wales is just over £9 billion per annum and with the mainstreaming of carers rights under the 2014 Act, all carers have and can expect to access services provided by local authorities and health boards, as can an individual with care and support needs. This includes access to respite provision where appropriate.

As was raised in my evidence to the Committee, and in a detailed discussion of the Carers MAG in October 2018, there is considerable debate about what respite now comprises, as it moves away from the "traditional" model of overnight care in for example a care home for the individual with care needs, or an overnight sitting service, which enables their carer a night's uninterrupted sleep. We also know that individuals who access direct payments can use this mechanism to access and purchase forms of respite, which may take many different forms.

In the absence at present of an agreed definition and a consistent data source we cannot accept this recommendation to publish a national data set.  Our focus in this area will be on working with partners to understand the value of different respite models in terms of outcomes for carers.

Financial implications. None. Any additional costs will be drawn from existing programme budgets.

**Recommendation 15** The Welsh Government must ensure that the impact of its £3 million recurring investment for respite services is evaluated. This work must identify the quality and quantity of the services provided, as well as capturing information about gaps in provision.

**Response -  Accept in principle**

As part of the right for carers to have their need for support assessed and a right for eligible needs to be met, this can include an assessed and eligible need for respite care.  However, it is important that this is delivered through a person-centred approach.  We do not support a universal provision of one particular type of support – that would not be based on the assessment of need and tailored to the individual.

The Carers MAG held a detailed discussion in October 2018 about the different forms of respite provision and feedback from carers, including discussion of the Older People's Commissioner for Wales Rethinking Respite report.  It is clear from a range of sources that many carers, including young carers, wish to have respite in the form of family breaks / holidays.  As a consequence of these discussions I met with the Chief Executive of Shared Care Scotland to hear more about their Short Breaks Fund and Respitality Schemes.  We will also be taking part in and co-funding a bi-lateral conference between Wales and Scotland in May of this year, to enable academics, officials and other key bodies to exchange ideas and learning.

The number of adults with a care and support plan who received services including respite care and recreational, leisure and lifelong learning opportunities during the year is currently collected through the Adults receiving care and support data collection (this would include carers though they cannot be specifically identified within the data currently collected).  Figures for 2016-17 onwards have been published annually. We will continue to collect relevant data and information, to inform us about the ongoing need for carers' respite, and the impact for the individual.

Financial implications. None. Any additional costs will be drawn from existing programme budgets.

**Recommendation 16** The Welsh Government should ensure that a minimum standard of advice and support is provided across Wales to those carers wishing to make use of Direct Payments. This should form part of a baseline range of support services on offer to carers.

**Response - Accept**

All conversations with carers, as part of a carers' needs assessment must include the offer of direct payments to meet eligible needs. Direct payments can be used to meet any identified eligible need and individuals can choose to meet their eligible needs partially through a direct payment, whilst the remainder is managed and arranged by their local authority.

Our code of practice specifically requires that appropriate, accessible information and support is available to everyone. That support must be available when people are making the initial decision about whether direct payments could benefit them as well as throughout the period they continue to receive a direct payment. Local authorities commission external support or provide this service in-house.

Working with direct payment recipients, third sector partners, local authorities and Social Care Wales, we have developed a dedicated on-line presence and published a range of resources to promote and support the use of direct payments. It is a comprehensive resource aimed at both practitioners and direct payments recipients, cover the basic information they need to know, and signposting to more detailed advice where needed. https://socialcare.wales/service-improvement/direct-payments-a-guide

Financial implications. None. Any additional costs will be drawn from existing programme budgets.

**Recommendation 17** The Welsh Government must ensure that all young and young adult carers are able to access the support and services they need. In doing so, it must address the specific concerns raised by young carers in evidence to this committee. It must ensure that the support and services for young and young adult carers are person-centred, age-appropriate and flexible to meet their specific needs. There must also be a strong connection between schools and carers' services. The Welsh Government must clearly set out how it will achieve this, and must report back on progress within 6 months.

**Response - Accept**

Under the 2014 Act there is no difference between the rights of an adult carer or a child carer and as part of all local authorities' duties in the 2014 Act, it is crucial to ensure that carers of all ages are supported in their caring role and that they are supported in their own life outside caring. If the carer is a child, the assessment must have regard to his or her developmental needs and the extent to which it is appropriate for the child to provide the care.

The Population Needs assessments provide the data on which regional partnership boards and partners should be designing services for carers, as well as seeking their input. This should include young carers. Recognition of the needs of young carers and how to support them must be embedded across services and support provided by local authorities, health boards and others.

We know that the majority of local authority young carers' services are commissioned from the third sector, delivered by organisations such as Barnardo's, Action for Children and Carers Trust Wales. They offer a level of expertise and knowledge around the needs of young people in general, but also most critically the affect that the caring role can have on an individual child. It isn't just young carers services that need to be appropriately designed and funded, which is why we funded

Carers Trust Wales, in 2018-19, to develop a new Good Practice for Commissioners guide. Launched in autumn 2019, its purpose is to assist a wide range of different commissioning organisations, including local authorities, to better understand the needs of carers.

The particular issues and experiences of young carers, and young adult carers, will be part of the work and considerations of the Carers MAG and our new Engagement and Accountability Group as we develop our new carers' national plan. These groups will be considering the evidence submitted to this committee including these recommendations.

We clearly recognise the need for a strong connection between schools and their local young carers' services so that young carers are fully supported. As part of this, we are aware that some schools have identified a lead for young carers to oversee the support young carers receive and signpost to young carers services but we recognise this can be applied more consistently. This work is being further developed in schools and supported by Regional education consortia leads for equity and wellbeing.

Financial implications - None. Any additional costs will be drawn from existing programme budgets.

**Recommendation 18** The Welsh Government should strengthen the existing Code of Practice for Local Authorities about what is considered to be an “appropriate” level of care for a young carer to ensure that the position in Wales is at least equal to that in England and Scotland

**Response - Accept**

There is no difference or disadvantage for young carers in our 2014 Act. Our Codes of Practice are clear about the assessment process as well as meeting eligible needs, with clear information in particular around the process and practice, considerations that need to be followed when undertaking a needs assessment of a young person who may have care and support needs, or a young carer who may have their own care and support needs.

The assessment process starts with the individual carer, whatever age they are, in order to understand their own strengths and capabilities, what matters to them, and how their family, friends and local community play a part in their life, to help them reach their personal goals and well-being. A young carer's needs assessment will not judge the way they are looking after the cared-for person (unless their safety, or the person they are caring for is at risk), nor must it assume a carer will want to continue in their caring role.

The purpose of a carers' needs assessment is to work with the individual, carer and family and other relevant individuals to understand their needs, capacity, resources and outcomes they want to achieve, then to identify how they can best be supported to achieve them. It is not about making any value judgements on what a young carer or adult carer provides for the individual with care needs, but to consider their needs holistically.

Financial implications – None. Any additional costs will be drawn from existing programme budgets.

**Recommendation 19** The Welsh Government must update and strengthen existing guidance for schools about identifying and supporting young carers, to ensure awareness throughout all schools of the demands on young carers. It should encourage and create opportunities for the sharing of best practice of support services for young carers within schools.

**Response – Accept**

We recognise the importance of supporting schools to identify young carers and to provide appropriate support to meet their needs in terms of educational attainment, emotional health and learner well-being. The development of our new Curriculum for Wales which contains a much stronger focus on well-being, and on creating ambitious and capable learners, has the potential to address some of the barriers experienced by young carers.

To help young carers we introduced a practical toolkit to help schools support them. Carers Trust Wales produced two guides – 'Supporting Young Carers in Schools: Guide and toolkit', and "Supporting Young Carers in Schools: A Step-by-step Guide for Leaders, Teachers and Non-teaching Staff". These were written in association with teachers and school staff to help make the identification and support of young carers in schools as easy as possible. They also developed a toolkit aimed at 'Supporting Students with Caring Responsibilities who are in further education.'

We recognise the importance of supporting schools to identify young carers, and provide appropriate support to meet their needs in terms of educational attainment, emotional health and well-being. In 2019-20 we are providing funding to Carers Trust Wales for a suite of training, resources and guidance to support young carers and their teachers. These resources will be available for use by schools in summer 2020.

Financial implications - None. Any additional costs will be drawn from existing programme budgets.

**Recommendation 20** We believe that the young and young adult carers' ID card scheme should be a national scheme, delivered by all local authorities with appropriate support from the Welsh Government and accessible to all young and young adult carers. The Welsh Government should ensure this is achieved as a matter of priority. It should report back on progress within 6 months.

**Response - Accept**

We want a national scheme to be in place so that all young carers aged up to 18 can benefit, wherever they live.

We are working with local authorities and local health boards using a phased approach to national coverage of an ID card scheme over the next two financial years. This first stage of the phased roll out which will start this financial year will involve up to 7 local authorities acting as 'Early Adopters' to trial and evaluate different potential components of a national scheme. Alongside these Early Adopter local authorities there will be a cluster approach where local authorities of similar locality, urbanisation and demographics can group together. The exact date of commencement of the full national scheme depends on the outcome of this testing stage with early adopter authorities, but our aim is to have a full national scheme in place for 2022.

Throughout this development and testing phase we are continuing to fund Carers Trust Wales, who have worked with national and regional GP, pharmacy and education bodies, to raise public service professionals' understanding of the needs of carers. This will continue as the scheme is rolled out, so that the professionals coming into contact with the cards, know what they mean and how to respond appropriately to the young carer.

Financial implications - None. Any additional costs will be drawn from existing programme budgets.

**Recommendation 21** The Welsh Government needs to ensure the standardisation of information, advice and assistance for carers across local authorities and local health boards. This must include bilingual provision of these services. As part of this, the Welsh Government should convene representatives from local government, health boards and the third sector with the aim of developing an approach that will secure these improvements for the service user. We ask the Deputy Minister to report back to us on progress within 6 months.

**Response - Accept**

Improvement in public services is always possible and we agree that this applies to the conversation between a carer, and a local authority or health provider, when seeking information, advice and assistance (IAA). Our Carers MAG has representation from statutory bodies, the health boards and carers organisations and will be consulting more widely as part of the national plan development process. As part of their discussions they have been considering how to help individuals identify as carers, which is critical before ensuring they know where and how to access IAA.

Local authorities have a clear duty in the 2014 Act under the key principles of the 2014 Act and the statutory Code of Practice (Part 2 - General Functions). Local authorities' IAA services must publicise information about how the care and support system operates in the local authority area; the types of care and support available; how to access the care and support that is available; and how to raise concerns about the well-being of a person who appears to have needs for care and support.

IAA is intended to focus on prevention and early intervention and deliver a wider range of community-based services through partnerships and multi-agency working. The introduction of IAA has been a significant change for local authorities and the approach is still embedding. IAA approaches therefore vary across local authorities and have recently been subject of scrutiny by the Welsh Audit Office (WAO). Their Front Door to Adult Social Care report will be a key document in helping to drive improvement in the quality of IAA.

Welsh language standards for local authorities, who have a duty to provide IAA, were made in 2016.  We expect all statutory bodies to meet the requirements set for them under Regulations.

Financial implications – None.  Any additional costs will be drawn from existing programme budgets.

**Recommendation 22** The Welsh Government needs to work with local authorities to better promote the availability of information, advice and assistance for carers, including clear details of how to access it. This should be done as part of the publicity campaign referred to in Recommendation 4**.**

**Response – Accept**

Local authorities are represented via the Association of Directors of Social Services, on our Carers MAG and will therefore be involved in discussions as to the content of our new national plan.  This will include considering how best to target information about carers access to their rights under the 2014 Act.

Not all IAA is provided by a local authority, and a key source of information about such preventative and wellbeing activities is the DEWIS Cymru website.  More organisations are registering their activities all the time and making DEWIS a key resource for everyone.  We are working with local government, health and third sector partners to further develop and enhance this resource as part of a single national directory of services.

Financial implications – None. Any additional costs will be drawn from existing programme budgets.

**Recommendation 23** The Welsh Government needs to ensure that staff providing information, advice and assistance as part of each local authority’s central advice and information point have up-to-date information about rights and services for carers under the Act, and that refresher training will be provided where necessary. We note the work being undertaken by Social Care Wales, the Welsh Government and local authorities to develop a competency framework to support the development of information, advice and assistance workers. We ask that the Deputy Minister updates us on progress with this project.

**Response – Accept**

We know not every local authority uses a model of a single point of access for people to obtain IAA, as illustrated by the WAO’s Front Door to Adult Social care report.  However, we expect all local authorities to have in place and fund an appropriate up to date employee strategy and training offer for their staff, wherever they work.

In 2019 we commissioned Social Care Wales to work with local authorities to develop a new competency framework, to support the knowledge, skills and competencies required by local authorities for their information, advice and assistance (IAA) workers.  They are expecting to complete and launch the new competency framework in early 2020.

Financial implications – none. Any additional costs will be drawn from existing programme budgets.

**Recommendation 24** The Welsh Government must ensure that the independent evaluation of the Act considers whether the funding for carers' services has been sufficient to deliver the policy intentions of the Act. It must also consider the funding that will be necessary in the longer term to deliver the rights and services promised by the Act

**Response – Accept in principle**

The formal evaluation of the 2014 Act is looking at two major areas – the implementation of the Act and the impact of the Act. The primary focus of the evaluation is on the difference that the 2014 Act has made to people in need of care and support, and carers in need of support, so the majority of the evaluation will be focussed on these areas. We will not be looking at funding of services specifically, as part of the formal evaluation which commenced in November 2018, and which will run for three years.

The Carers MAG is the key forum where issues of funding can be explored in more depth, and as part of our considerations as we develop the new national plan. It may advise a change to the existing evaluation of the Act but there may be other options such as commissioning a more bespoke piece of research.

We are committed through our national strategy, Prosperity for All, to developing innovative funding models to ensure additional funding is available for social care in the longer term to help meet the demands it will face. This is part of our wider consideration of alternative ways of funding public services in Wales.

To take this work forward an Inter-Ministerial Group on Paying for Social Care has been established to provide the policy input into the consideration over how such potential additional funds may be raised and distributed, and the priority areas of social care where any funding raised in this way would be most effectively invested. The group's work will be informed by the findings of research we have recently commissioned to analyse the potential options to utilise any additional funding that may be raised.

Funding implications – None. Any additional costs will be drawn from existing programme budgets. Assessment of potential future funding implications in relation to changes in government policy which might impact government budgets and statutory bodies or other organisations, will be considered as part of the ongoing development of carers policy, which we are taking forward in co-production with stakeholders

**Recommendation 25** The statutory sector is heavily dependent on the third sector for delivery of vital services to carers. That dependency needs to be reflected in both the provision of adequate funding for the third sector, and the meaningful involvement of the sector in planning and decision-making around that funding. We believe this matter should be explored by the Ministerial Advisory Group. We ask the Deputy Minister to provide us with an update on this work within 6 month

**Response - Accept**

An element of the terms of reference when establishing the Carers MAG and identifying members, was to consider existing and future funding streams across all sectors. The third sector plays a vital role in delivery and it is most important that we consider how levels of funding and our policy and operational decisions can affect that wider picture. We will include discussion of this recommendation on a future Carers MAG agenda in 2020.

Co-production runs throughout the 2014 Act. All partners involved in the development and delivery of social care services are expected to co-produce services to bring about the changes envisaged in the 2014 Act.

At an organisational level, Welsh Government is already seeing some good examples of co-production through the RPBs' delivery of the Integrated Care Fund (ICF). Service users and carers are key partners in the work for the RPBs and we expect RPBs to proactively engage with people and support them to inform the shape of services in the region. It is important that citizen engagement occurs at a range of different levels and not just around the RPB table with a few 'expert citizens.'

Financial implications – none. Any additional costs will be drawn from existing programme budgets.

**Recommendation 26** There is a need for a long-term, sustainable and streamlined funding arrangement for third sector organisations delivering essential services to carers under the Act. We believe that funding should be provided on a three-yearly basis as a minimum. The Welsh Government must move towards this as a matter of priority.

**Response – Accept in principle**

Our existing Third Sector Sustainable Social Services (SSS) grant scheme has been very successfully operating on a three year cycle, from 2016 and was extended by a year so now ends 31 March 2020. It has provided funding to a diverse range of organisations, including carers' organisations to deliver activity that supports the implementation and embedding of the key principles of the 2014 Act. This has included raising awareness of carers' rights under the 2014 Act.

Following on from our current successful scheme we opened a new Third Sector SSS grant scheme for applications, during summer 2019. Bidding organisations were notified of the outcome before end of 2019. The next three year scheme, which will contain three carer-specific projects, will commence from 01 April 2020.

Austerity over the past 10 years has had a significant negative long term impact on our ability to plan and fund multiyear grants or programmes, however, we have consistently sought to protect health and social care spending.

Looking ahead at our ability to plan for the longer term, a Comprehensive Spending Review (CSR) was announced by HM Treasury at the end of August 2019. At the time of writing, this full multi-year Spending Review is now due to take place later this year.

At present, the UK Government has delivered a Spending Round for one-year only. We recognise and are therefore sympathetic to calls from our public sector partners for budgeting over a longer period, in order to support forward financial planning. It is always our ambition to provide long-term clarity over budgets, whenever possible, however, this must be balanced with realistic and sensible planning assumptions. The UK Government's austerity agenda coupled with the uncertainty regarding Brexit constrains our ability to do this.

Financial implications – none. Any additional costs will be drawn from existing programme budgets.

**Recommendation 27 -** The Welsh Government should provide a comprehensive and accessible list of available funding sources for support for carers to be delivered by the third sector. This should be done as soon as practicable.

**Response – Accept**

A mapping exercise was undertaken by officials in 2018 and details of the sources of funding available under each Regional Partnership Board footprint and where these entered the system, were issued in September 2018. This exercise did not include all funding to third sector bodies who provide services relating to carers, either nationally or locally. However we will look to expand on this exercise to provide a fuller account of funding streams and we are looking into how we can improve the accessibility of Welsh Government grants, including raising awareness, particularly to the third sector.

Financial implications – none. Any additional costs will be drawn from existing programme budgets.

**Recommendation 28** The Welsh Government should consider making available a single funding stream for carers' services. This should replace the current system of individual grants. It should be accompanied by a monitoring and reporting mechanism to ensure it is delivering value for money

**Response – Reject**

The vast majority of funding we provide to local government for social care, including carers, is delivered through the un-hypothecated local government settlement.

The £4.5 billion settlement is considered by local authorities alongside other sources of income such as specific grants and locally-raised income from council tax, fees, sales and charges and is spent according to local needs and priorities.

Standard Spending Assessments (SSAs) are used to distribute settlement funding to local authorities with nearly 30% of total SSA being distributed on the social care part of the formula.

Local authorities, as autonomous and democratically accountable bodies, are statutorily responsible for managing their financial affairs.

We believe that local authorities are best placed to judge the local needs of their communities and to fund services accordingly. The funding system we have in place gives them the flexibility to make those decisions. We offer considerable flexibility to authorities to exercise autonomy and responsibility in managing their finances.

Financial implications – none. Any additional costs will be drawn from existing programme budgets.

**Recommendation 29** The Welsh Government must take a stronger lead on a national approach to data collection on carers to ensure that appropriate and meaningful data is collected across all sectors in a coordinated and consistent way. We believe this should be a function of the Ministerial Advisory Group, which should develop national guidelines to determine what data needs to be collected, how it should be collected and how it will be used following collection. The data should be published, and should be used to inform future service and financial planning. We believe that the Performance and Improvement Framework is an important part of this work, and we ask that the Deputy Minister provides us with an update on progress.

**Response - Accept**

We recognise the importance of having effective and meaningful information and statistics and have therefore spent considerable time on developing a new Performance and Improvement Framework, which will improve the way that data is collected, in relation to the Social Services and Wellbeing (Wales) Act 2014 and thus our understanding of the impact of the Act, including its impact on carers.

The development of the new national action plan, which is being led by the Carers MAG, will be considering a wide range of elements that can inform the content of the future plan, including existing data, what future data will be collected, as well as research evidence such as the Measuring the Mountain project, which published its Phase 1 report in summer 2019. Bringing together an overview of the data and material that can inform how we work across sectors to improve the information, advice and support for individual carers.

Financial implications – none. Any additional costs will be drawn from existing programme budgets.

**Recommendation 30** We endorse the recommendation from Estyn in its report of May 2019 that the Welsh Government should produce reliable, nationally collected data to help identify young carer.

**Response - Accept**

We welcomed Estyn's Thematic review report "Provision for young carers in secondary schools, further education colleges and pupil referral units across Wales". We remain committed to collecting data, which in due course will provide valuable information to enable us to better address the educational and support needs of young carers.

Some data on assessments for young carers is currently collected and published annually. From April 2020 onwards, the quantitative data component of the Performance and Improvement Framework has a section on young carers which includes information on IAA and assessments.

Financial implications – none. Any additional costs will be drawn from existing programme budgets.

**Recommendation 31 -** The Welsh Government must provide an update on progress of implementation of the Welsh Community Care Information System within 6 months

**Response – Accept**

There are currently 14 organisations that have gone live on WCCIS, with 18 signed contracts in place. There are approximately 11,500 users using WCCIS across Wales. Wrexham went live in November 2019. Hywel Dda University Health Board have committed to a launch for Community Nursing and for integrated Social Care teams within the Ceredigion Authority area in December. Swansea Bay University Health Board are currently finalising a Full Business Case for the implementation of WCCIS.

Welsh Government has recently committed additional funding to support the national programme, regional deployment by Local Government, and NHS implementation of WCCIS functionality. This funding is being made from the Digital Priorities Investment Fund and the Integrated Care Fund, as part of additional A Healthier Wales funding.

The Welsh Audit Office (WAO) is currently reviewing WCCIS and its report is expected in mid-2020. The Welsh Government welcomes the review and is working with the WAO to identify areas within the WCCIS programme that can be supported to further accelerate and assure roll-out.

Financial implications – none. Any additional costs will be drawn from existing programme budgets.