A Response by Angela Burns AM on behalf of Angela Burns and the Cross Party Group on Sepsis.

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

Sepsis is a life threatening illness caused by the body's immune system reacting in a different way to an infection.

Sepsis occurs in three stages

- Infection. Very common, rarely requiring hospital treatment and often sees a full recovery being made. Infection can affect many parts of the body and be caused by a wide variety of organisms.
- Sepsis – Occurs when the body's response to infection has started to interfere with the function of vital organs. Put simply, sepsis is a life-threatening condition that arises when the body's response to infection injures its own tissues and organs
- Septic Shock – occurs in some cases of sepsis when blood pressure falls, preventing vital organs from receiving enough oxygenated blood.

Sepsis is sometimes referred to as blood poisoning or septicaemia, but these terms are now regarded as not useful as it the effects of sepsis can affect the whole body.

Sepsis is more common than heart attacks across the UK and is a leading cause of maternal death in the ante and post-natal periods.

Current figures show that around **52,000** people died in the UK from Sepsis, with around **2600** of these in Wales. Sepsis throughout the UK kills more people than bowel, breast and prostate cancer combined. However there is little data on whether the origin of the infection was hospital, care home or primary care.

The most concerning aspect of Sepsis is that it is so often easily misdiagnosed as a simple urine infection, a virus or a transient infection.

An example of a real life situation which is mirrored in a number of cases is as follows:-

A patient presenting with what a doctor initially identified as a viral infection. They then visited an out of hours doctor who provided an anti-sickness injection. Two hours later they were in hospital having had two cardiac arrests went into septic shock and spent eight days in a coma.

A second example is that of a local Welsh women 29 who had complained about feeling unwell on a Sunday night and went to bed early. At 4am Monday morning she asked her flatmate to take her to A & E due to vomiting and feeling breathless. She was informed at

the Hospital that there was a five and half hour wait and she may be best going home and taking paracetamol. Her mother spoke to her and she was in agony and 12 hours after her first visit to A&E she returned and sepsis was now in full control. She had blood clots on her lungs, brain and kidneys. Her body was swollen, her face and nose disintegrating and turning black. She spent 6 days in an induced coma and her parents were informed that to stand any chance of saving her life they would have to amputate her limbs. Her parents agreed to the distressing decision to switch her life support off 4 days later.

Sepsis can develop from infections contracted during surgery and other invasive medical procedures such as prostate biopsy, yet the risk of this happening is rarely discussed.

There are six recognised signs of Sepsis in Adults which the Sepsis Trust UK explains as

- Slurred speech or confusion
- Extreme shivering or muscle pain
- Passing no urine (in a day)
- Severe breathlessness
- It feels like you're going to die
- Skin mottled or discoloured

2. Public and professional awareness of sepsis

Public

Public awareness of Sepsis is patchy and tends to come down to personal experience of friends and family.

However public Awareness of Sepsis has also been aided over the last couple of years by storylines in two of the UK's most well-loved soap operas.

In the Archers, Nick Grundy died having contracted Sepsis and in Coronation Street, 7 year old Jack Webster had his leg amputated as a result of contracting the disease.

These two storylines are vital in raising public awareness of Sepsis and have treated the issue with sensitivity and highlighted the causes to a different audience than a public awareness campaign would traditionally reach.

Sepsis has also been featured in the news on numerous occasions through a variety of mediums, television, radio and both written and online press. Closer to home ITV Wales news anchor Andrea Byrne used the early evening news show to highlight how she had lost her father to Sepsis and Angela Burns AM had her Sepsis story covered in the Western Mail and the Daily Mail.

The UK Sepsis Trust in Wales, working with affected families and volunteers, has worked to raise public awareness but without the back up of a national campaign they report mixed results.

As a Cross Party Group we have made repeated calls for a public awareness campaign to be launched to highlight the signs of Sepsis.

The Scottish Government launched a Sepsis Awareness public health campaign in Spring 2019, to help raise awareness of the symptoms of sepsis and raise funds for vital sepsis research.

An NHS Health Development Agency report entitled "The effectiveness of Public Health Campaigns" identifies *Providing basic, accurate information through clear, unambiguous messages as being a key element for success in changing behaviour.* However it is notoriously difficult to measure the effectiveness of a campaign, especially when it is focussed on awareness raising as opposed to changing behaviours. Making best use of mass media is key when awareness of a health issue is important to its resolution.

A 2015 report by Public Health in Research and Practice on the effectiveness of social media campaigns states that there is "strong evidence that public health social marketing campaigns conducted through main stream media can have a direct and positive impact on behaviour" but it also states that there is a role for social media but not in a standalone way.

A study in the Journal of Palliative Medicine about the impact of Public Health Awareness campaigns published in 2017 highlights the **Just Ask** campaign run by The UK Sepsis Trust which focussed on goals of care planning. Although accessible to the public the campaign's target audience was clinical practitioners. It is notable that the report highlights that shorter social marketing campaigns in term of time have a larger impact on behaviour change. Additionally it can make a difference who fronts the campaign or who is branding it as evidence shows that older adults are more sceptical of a campaign branded by the government or politicians and are more receptive to professionals such as Doctors or celebrities to impart the message. A third key component of an effective marketing public health campaign is the need to use experiences and stories of other people, be it through traditional or new forms of media. A feature documenting my personal experiences carried in a national newspaper received a great deal of feedback and I know helped to save at least 7 lives.

The Welsh Government have repeatedly told us that they are sceptical of the effectiveness of Public Health campaigns and this is an assumption that we need to challenge. A well run, well targeted campaign can have a major impact on its intended audience.

Making use of a short debate in the Assembly Chamber Angela Burns was able to highlight a public health campaign on Sepsis that made use of Ambulances in certain Ambulance Trusts in England. The Sepsis Six points were highlighted and the question was asked "Could it be Sepsis?". Despite numerous requests there is no willingness to run a similar targeted campaign here in Wales which is of great concern to the Cross Party Group on Sepsis.

Professional

The Cross Party Group undertook two investigations in order to gather a couple of investigations into how well Sepsis is understood within a different fields.

We sent out a short questionnaire to every GP surgery in Wales, around 450. We received 11 responses. The data obtained from this project was minimal, but the key messages back from the GPs was that they could not identify Sepsis champions within their Health Board nor a specific rehabilitation team with their Health Board. They also said they would welcome more support in identifying sepsis and there was a mixed view in terms of a tool kit being available.

A similar questionnaire was issued to Social Services departments at Welsh Local Authorities – Again the response was poor and highlighted the haphazard approach to identifying Sepsis in Council run care homes and the lack of clarity when it came to treatment pathways.

A GP from Hywel Dda Health Board area stated that *"I have noticed that Sepsis recognition has gained more airtime in post graduate medical education in the last year or so."* He goes on to say that *"there appears to be more teaching and pointers on sepsis recognition including the use of computer tools and checklist".* However he expresses concerns that there is a need to undertake more detailed training to better identify paediatric cases. The GP concludes his observations by stating *"The importance of sepsis and in particular public education of the warning signs cannot be overstated".*

Awareness is also important for paramedics and the Cross Party Group on Sepsis have called for Sepsis protocol cards to be issued for call handlers to help them check for signs of Sepsis when 999 calls are being made. These cards already exist for 35 or more conditions spanning from severe headaches to stroke and can help ensure that Sepsis is considered as an option. The Cross Party Group heard from the Welsh Ambulance Service and were told that such a call would not be accepted as it may impact on other diseases being missed or going unrecognised. The Group pointed out that diseases such as cancer or stroke already have clearly defined pathways and identifying signs, something which Sepsis is still lacking.

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.

We need to consider the support and training that is required to reduce the risk of Sepsis. As many as 80% of Sepsis cases originate in none hospital settings.

Examples of how a Care Home has introduced measures to reduce the risk of Sepsis.

> * Housekeeping staff 'damp' dust. We do not use 'sticky' polish but dust with a damp cloth with disinfectant on it. This not only keeps the dust down (instead of floating in the air and then remanding somewhere else) but ensures that there are no sticky polish surfaces for bacteria to find a home. We also document the monitoring of our cleaning and this highlights any problem areas or areas of noncompliance. We can then get to the root of the problem and solve it.
> *We provide Infection Control training to all our staff on an annual basis, this not only goes over the basis of good infection control but also reminds staff of the most basic of requirements.....handwashing!!! This is something that we teach and then

'drill' into our staff so that they fully understand the reasons for our nagging! We also carry out hand washing audits (both observation and using a 'light box' to highlight poor practise).
*Our infection control is audited annually and remedial actions taken where necessary.
*Appropriate cleaning materials and then training and updating by the companies on an annual basis. If any product is changed or altered they also come and educate the staff in-between if necessary.
* A rigid uniform policy which not only includes correct uniform but also things such as a 'no jewellery' policy and no acrylic or 'false ‘nails and no nail varnish. This is one that has to be monitored frequently but with the help of a light box you can show staff who think they have washed their hands thoroughly how their chipped nail varnish can hold bacteria
*All of our bins are foot operated so contamination does not occur when staff have dried their hands and paper towels go into the bins.

In 2011 all health care providers were asked to ensure that all staff were to undertake **ANTT training (Aseptic Non-Touch Technique).** This entails an E learning programme (videos and a multi choice assessment) followed by a clinical tuition session and a clinical based assessment. Staff have to obtain 80% in the written assessment before they can go any further. The Cross Party Group were concerned to learn that aseptic technique is no longer taught at the start of their training. In 2016 Public Health Wales found that ANTT had not being widely adopted and issued another request to health care providers that it was. Now the Welsh Government is insisting on 'all' staff having this training. The message here is very muddled and we need to ensure that we have the checks required to make sure that this extra training is happening.

From the limited response that we have had to our survey and conversations that we have had professionals it is obvious that there is no clear route between primary and secondary care providers when it comes to Sepsis patients. Messages are not passed on or are lost in the system.

It is acknowledged that Sepsis is often misdiagnosed whether it be in a GP surgery or hospital and it is this misdiagnosis which can have fatal consequences. There is a lack of a universal tool widely available to help identify sepsis. However reports earlier this year highlighted that a rapid Sepsis Test is being developed by Strathclyde University which can produce results in 2 ½ minutes. There is a hope that it can be used in GP surgeries, A&E and at patients bedsides. Also in existence is a C-reactive protein (CRP) test which is a blood test marker to identify inflammation which can be an early indication of a Sepsis infection. The majority of current tests for Sepsis can take 48 hours to provide results.

Time is of the essence when it comes to treating Sepsis as every hour that passes without treatment sees the chance of mortality increasing by 8%.

In Hospital settings the National Early Warning Score (NEWS) system is used to assess potential Sepsis cases. This is an aggregate score made up of six physiological parameters,

with the aim of improving detection and response to clinical deterioration in acutely unwell patients. Parameters measured are:

- Respiratory Rate
- Oxygen saturations
- Systolic BP
- Pulse rate
- Level of consciousness (AVPU score)
- Temperature

The system appears to be well understood and is made regular use of, not only in Primary Care but also secondary care settings. One Welsh Nursing home stated that having employed NEWS they saw a 30% reduction in Hospital admissions.

Last year a new *Out of Acute Hospital News Observation chart* was launched for testing to support healthcare professionals working in community settings to identify early signs of sepsis.

It is in acute settings that progress appears to have been made, albeit slowly. Many A&E departments have Sepsis 6 trollies which have the tools to identify and treat Sepsis on discovery as well as offering a reminder to staff to consider it when making a diagnosis.

A problem does remain in the Triage area of A&E where patients may present with another problem and the signs of Sepsis may be ignored. The cross party group have heard from Sepsis survivors who have been discharged from Triage without a Sepsis diagnosis only to be rushed back in to A&E later the same day when Sepsis has struck. The challenge is to identify Sepsis at the earliest stage.

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

It is not just about surviving Sepsis but surviving sepsis well.

Sepsis survivors are often left with life changing disabilities such as loss of limbs, an inability to concentrate and focus and extreme tiredness.

Mental Health Impact

There are two key mental health issues - Post Sepsis Syndrome (PSS) and Post Traumatic Stress Disorder (PTSD).

PSS is a condition that affects up to 50% of sepsis survivors. They are left with physical and/or psychological long-term effects, such as:

- Insomnia, difficulty getting to sleep or staying asleep
- Nightmares, vivid hallucinations and panic attacks
- Disabling muscle and joint pains
- Extreme fatigue

- Poor concentration
- Decreased mental (cognitive) functioning
- Loss of self-esteem and self-belief

These lasting physical issues can be explained, but there is more to PSS that cannot yet be explained, such as the disabling fatigue and chronic pain that many survivors experience. Others complain of seemingly unrelated problems, like hair loss and crumbling teeth that may occur months after their discharge from the hospital.

PSS is as yet not fully understood.

PTSD

A well recognised disorder from ICU survivors and now many sepsis survivors also report symptoms of PTSD. Researchers have already recognised that a stay in Intensive Care is a trigger for PTSD, which can last for years. It can be partially explained as a consequence of inflammation caused by sepsis. This inflammation 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.

No matter how ill someone is after having sepsis, survivors have described it as: "*You never feel safe. Every time some little thing happens you think, "Do I need to go to the hospital or is this nothing?*"

There remains a fear of repetition, for example a patient who contracted Sepsis having had dental work may go on associating Sepsis with such procedures and avoid obtaining treatment. This fear can also be seen by Sepsis survivors and their close family being hyper vigilant when it comes to their health with any ache, pain or tiredness being considered a sign of Sepsis returning. Mothers who have experienced Sepsis whilst pregnant can worry that if they give birth again, Sepsis may follow.

It is not just about surviving of Sepsis, but ensure that people survive well.

Sometimes PTSD has in the past being mislabeled as 'simply' depression or anxiety when in fact it is much more.

Physical Health Impact

Contracting Sepsis is like being involved in a Road Traffic Accident, you have no warning of it, no symptoms and can literally wake up from a coma to find that limbs have been amputated and your life changes forever. There is no real pathway for recovery from Sepsis and this must change. Presently, the only specific post sepsis support is provided by 3rd sector organisation, The UK Sepsis Trust, which operates a helpline, literature and facilitates support groups.

There is a lack of clear communication between Hospitals and GPs when it comes to patients who are discharged. Sepsis is often not recorded and Sepsis survivors often have to alert GP's about their Sepsis history.

One of the GP responses states that they “would be in favour of enhanced local primary care access to rehabilitation services for those affected by sepsis particularly simple physiotherapy and mental health support.”

One of the members of the Cross Party Group, a former health care professional, had three limbs amputated due to Sepsis and was left to struggle to obtain multidisciplinary assistance in making the life changes that they needed to so they could continue to live independently. There is a lack of joined up thinking between agencies which can cause difficulty and delay in getting home adaptations undertaken and obtaining mental health and physical health support.

The Sepsis Trust has a small, but increasing number of support groups across the UK, with an established group in Cardiff. These groups are not only important for sepsis survivors, but also their families. The UK Sepsis Trust has produced a ‘Recovery After Sepsis’ booklet which is a great help to patients, families and health professionals and they would like to collaborate on distribution of this to sepsis survivors.

Other illnesses such as Cancer see the NHS working in close collaboration with charities such as Tenovus and Macmillan but this does not run true for Sepsis charities.

The Sepsis lead for the Cardiff and Vale University Local Health Board is leading on developing a sepsis registry for Wales to get reliable data on the incidence and mortality from sepsis and to see what data we can gather on sepsis morbidity so as to be able to target NHS resources appropriately with the aim of being able to recognise and treat sepsis early to reduce the incidence and severity of post-sepsis syndrome.

The reality is that mental and physical health are intertwined and we need to address both the physical and psychological effects of Sepsis to aid a patients recovery.