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Ymchwiliad i Sepsis
Inquiry into Sepsis
Ymateb gan Fwrdd Cyngor Iechyd Cymuned
Response from Board of Community Health Councils

CYNGOR IECHYD CYMUNED
COMMUNITY HEALTH COUNCIL
BWRDD CYMRU | WALES BOARD

Health, Social Care & Sport Committee inquiry into Sepsis: CHC response

CHCs are the independent watch-dog of NHS services within Wales and we seek to encourage and enable members of the public to be actively involved in decisions affecting the design, development and delivery of healthcare for their families and local communities.

CHCs work with the NHS and inspection and regulatory bodies to provide the crucial link between those who plan and deliver the National Health Service in Wales, those who inspect and regulate it, and those who use it.

CHCs maintain a continuous dialogue with the public through a wide range of community networks and direct contact with patients, families and carers. We do this through enquiries and Complaints Advocacy Service, and our visiting and other engagement activities, including public and patient surveys.

Each of the 7 CHCs in Wales represents the public and patient voice within their respective geographical areas.

CHCs routinely monitor the performance of NHS services in their area as well as respond to service developments and changes.

Our comments are largely based upon the main issues arising from complaints that our Complaints Advocacy Service has handled across Wales over the past 5 years where sepsis is a major part of to the complaint. We have identified 71 such cases. We know that there are many more cases where sepsis is part of the complaint but not the main issue.

The table below sets out the number of sepsis specific complaints where our advocacy service has been involved:

Year	Number of Complaints
2015	9
2016	11
2017	10
2018	24
2019 (to date)	17
Total	**71**

Although the numbers are small, they are increasing.

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

Around 75% of the complaints our advocacy service has been involved in relate to how sepsis has been managed in a hospital setting.

A much smaller proportion (around 15%) relate to concerns about treatment by GP practices. The remainder (around 10%) are about the management of sepsis in people’s homes, by primary care out of hours services or at other community care settings.

If we look at the complaints our advocacy service has been involved in by the specialist service area we find the following breakdown:

Area / specialism	**% complaints**
General Practice	30
Accident and Emergency	24
Gastroenterology	22
Urology	13
Cardiology	10

We do not hold information about condition specific clinical outcomes. However, the number of complaints we have been involved in where sepsis is a key issue and the patient has died are very small (less than 10 people in each of the past 5 years).

The focus of the complaints we have been involved in related largely to 3 key aspects, in order of prevalence:

- diagnosis and treatment
- fundamental aspects of care
- the information (or lack of) provided to the patient or next of kin.

Public and professional awareness of sepsis

We are aware that NHS bodies have been working to raise awareness of the symptoms of sepsis. This has included promoting the use of tool kits such as the “sepsis bundle” to support clinicians to diagnose and treat sepsis appropriately.

Some hospitals have posters displaying the symptoms both healthcare professionals and the public should look out for.

CHCs have heard from some people that:

- they were not informed that the people they cared about had sepsis. In some cases we heard that this was only found out after their loved one had died

- they do not consider the arrangements for providing antibiotics is always robust, specifically:
    - people have experienced delays waiting for microbiology results
    - people have experienced delays in prescribing, starting treatment and maintaining treatment of antibiotics
    - there is a perception that a number of antibiotics are often trialled on a “hit and miss” basis.

Some of the people who complain to us about the diagnosis and treatment of sepsis are the family or friends of people who have died. Unsurprisingly, they feel let down by the NHS.

We have heard from friends and families that some older patients in particular may not have shared their deteriorating symptoms with those caring for them as they had been assured by healthcare professionals of the appropriateness of their treatment (people often tell CHCs they don’t want to be a bother when they are in hospital).

This has led to the friends and families feeling they have let their loved one down by not themselves escalating concerns which they think might have prevented death.

We think it is really important that healthcare professionals clearly and actively monitor people who are at risk of getting sepsis so that people don’t feel it has to be their responsibility to raise concerns that the person they care for may be deteriorating.

Because sepsis sets in as a result of an infection (diagnosed or otherwise) some people have told us of their concerns that the infection itself rather than sepsis has been identified as the cause of death.

In their view delays in diagnosis and issues with the treatment of sepsis have caused or been a significant contributory factor to deterioration and death.

We hear from patients and their families that they do not always feel heard when they tell healthcare professionals that they feel their (or those they care for) condition is deteriorating.

Better communication and the on-going involvement of patients (and families where appropriate) in discussions about diagnosis, treatment and on-going care is key to addressing these concerns.

This way, people will truly experience people centred healthcare services.

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