Sepsis - Point of care testing

Workshop report

Discussions with clinicians and those with lived experience

May 2025

Acknowledgements:

UK Sepsis Trust for introducing us to amazing members of the public who have experience of sepsis.

To those who have lived experience of sepsis, thank you for sharing your thoughts and experiences with us.

To the clinical staff who dedicate their time to caring and improving diagnosis and treatment of patients with sepsis. Thank you for your time and your insights.

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1: Background

"Sepsis is a life-threatening condition. It can lead to shock, multiple organ failure and even death if not recognised and treated promptly. It always starts with an infection".
(The UK Sepsis Trust)

Sepsis can be difficult to diagnose with certainty: patients with sepsis may have a history of infection but not have a fever. The signs and symptoms of sepsis can be non-specific and can be missed. [1]

A company called Seroxo have developed a test that might help in the diagnosis of sepsis. The Leukocyte ImmunoTest (LIT™) assesses how white blood cells (neutrophils) are functioning. It is finger-prick blood test that can give results in 10 minutes.[2] Health Innovation Oxford and Thames Valley (HIOTV) has been commissioned to help understand the information needs of patients and clinicians that would support the use of this test if found to be useful in the diagnosis of sepsis.

2: Methodology

To explore the information needs of patients and clinicians a 2.5-hour on-line workshop was held.

Participants

A national charity, the UK Sepsis Trust, agreed to support the workshop. They contacted their members who had lived experience of sepsis[|*] to ask if they might be interested in being involved. If they were interested, they were asked to contact HIOTV. Twelve people responded and were offered a short introductory meeting with a member of the HIOTV team to explain the project and potential involvement. Eleven people took up the offer and were invited to either attend a workshop or undertake a one-to-one interview. Eight people subsequently attended the workshop and one person was interviewed.

Clinicians for the workshop were identified through existing contacts or via regional sepsis steering groups. Nine people expressed initial interest and seven attended. One clinician came from the UK Sepsis Trust.

[1] Suspected sepsis: recognition, diagnosis and early management, 2016, National Institute for Health and Care Excellence (NICE) (accessed 14 Mar 25)
[2] https://www.seroxo.com/sepsis (accessed 28 Feb 25)
[|*] Throughout this report the term lived experience and patient are both used for the group of participants who had/or had a family member with a diagnosis of sepsis in the past

Aims

The aims of the workshop were to understand the views and experiences of clinicians and people with lived experience of sepsis, in particular:

1. To understand what information is important to patients and their families if there is suspected or diagnosed sepsis.
2. To explore patient and clinician views around the LIT™ and its potential to support the diagnosis of sepsis.

Process

A briefing paper was sent to participants one week before the workshop. This included a background to sepsis, the LIT™ and questions that would be asked (questions for the workshop and individual interview are in Appendix 1).

The workshop was facilitated by HIOTV staff and one of HIOTV's public partners.

Workshop discussions were held in small groups (a clinician group and two lived experience groups), and plenary sessions with all participants.

Psychological well-being was supported by reminding people that they could leave at any point, and by having a member of the HIOTV team available to support by telephone should the need arise.

Participants were sent a follow-up thank you email, and members of the public were given details on how they could claim payment for their participation.

3: Findings

Themes that emerged from the workshop discussions are described. Although interrelated, perspectives differed between clinicians and those with lived experience.

Participants in the lived experience groups were asked to provide one word about how they felt about sepsis. Responses are presented in the word cloud below, clearly representing the significant impact on people's lives.

Is it sepsis or not?

The challenge of diagnosis, and the impact of uncertainty, was discussed by both clinicians and patients. Clinicians commented on how sepsis had been redefined in 2016 national guidance, with continued difficulties distinguishing between severe infection, sepsis and septic shock.

"The general perception of sepsis is now more severe than previously thought." Clinician

This *'blurring'* was expressed in what patients experienced, as they were not always told they were being treated for sepsis, just an infection.

Clinicians noted that patients' response to treatment can be markedly different: some recovering relatively quickly, whereas others become extremely ill and require admission to intensive care. Although patients wanted clarity, a complex and changing clinical picture can often make this challenging. For example, if a patient presents with possible sepsis they would often be treated with antibiotics before a definitive diagnosis is made.

"Later it may be discovered that this wasn't sepsis, so patients' think they were given the wrong treatment." Clinician

"A minority of clinicians can be too dismissive of sepsis symptoms without it being proven first." Clinician

Sharing uncertainty

The diagnosis of sepsis, particularly early on, presents genuine uncertainty for clinicians, patients and their families. There may also be genuine uncertainty about how a person's illness might progress. This uncertainty was often experienced by patients as no information being shared with them. Significant frustration, for both patients and their families, was expressed that a diagnosis, or suspected diagnosis, of sepsis was not shared. Sometimes this related to missed or delayed, diagnosis where sepsis may not have been initially suspected. This reflects some of the challenges in diagnosis described by clinicians. They also commented that it can be difficult to explain to patients that their care plan may change at any point dependent on their response to initial treatment or initial choice of antibiotics. If the plan does change, e.g. a change in antibiotics, patients can sometimes, wrongly, interpret this as an earlier error.

However, there was a perception among those with lived experience that, even when sepsis was suspected, it was not always disclosed. People described how they had only found out that they had had sepsis very late in their treatment, sometimes not until they were discharged. One person was only ever told by a family member. Confusion over diagnosis was a common theme in the lived experience discussion.

Many of the lived experience participants had experienced severe illness and are living with the continuing consequences of sepsis. Most had been admitted to intensive care and shared their uncertainty about whether they would survive.

"We want to know: Are we going to live? Are we going to survive?" Patient

Clinicians described that some staff, perhaps those more junior or those not in hospital settings, may lack confidence or experience with sepsis. Consequently, discussing uncertainties around diagnosis and outcome might be difficult or avoided. There may be reluctance to mention sepsis unless definitively diagnosed. This may be compounded by a perception that there is greater public awareness of the potential for sepsis to be life threatening. Some patients suggested that acknowledging uncertainty would be acceptable.

"It's okay to say that you're not sure" Patient

Lack of experience might also contribute to inconsistent coding[3] in medical notes, and lack of clarity in discharge summaries. Both might lead to further confusion in ongoing communication and care in the community.

Personalising information

Clinicians and patients recognised that the capacity, and desire, of patients to understand and process information, alongside the ability to make decisions about their health varies. It was noted that health literacy may be a problem so explanations need to be personalised, in a matter which can be understood. In all cases the potential for rapid progression of sepsis, can make the sharing of information a particular challenge.

"Health literacy may be a problem so it (diagnosis and treatment) needs to be explained in a manner which will be understood whilst still remaining sensitive to the patient." Clinician

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Many of those with lived experience described that the severity of their illness, affected their ability to understand what was happening to them. This was especially true if hospital admission was necessary.

[3] E.g. number codes that are used in electronic versions of patient records, to represent various aspects of patient care NHSE England (Digital) (2023) Building healthcare software - clinical coding, classifications and terminology (webpage - accessed 19 Mar 25)

"I was in too much pain to remember anything." Patient

"I don't remember anything about coming into hospital, until I was waking up in ICU. I had been in hospital for months." Patient

Lived-experience participants suggested that sometimes clinicians may assume a lack of capacity, but that the assumption should always be that the patient does have capacity.

Where sepsis was discussed as a diagnosis, many felt that not enough information was given.

"Sepsis was mentioned to my husband, but he didn't really understand what it was and what it meant." Patient

"My family were told very little." Patient

"Sepsis was mentioned when things deteriorated rapidly. My family were told that I had 50/50 chance of surviving. He didn't know anything about sepsis, and it wasn't explained to him." Patient

The lack of information experienced by patients related to both verbal and written information. Group participants and their families had found the details around sepsis complex and felt that the potential impact was poorly understood. None had been given written information to help aid their understanding and commented that resources such as those provided by the Sepsis Trust would have helped them. There was little signposting to external resources.

Clinicians recognised that the information needs of patients were very varied. They described some patients wanting to know more than others. This could include wanting to understand how they became septic, their treatment plan, and chances of a full recovery. They felt that others wanted only minimal information. The challenge of diagnosis was also a contributing factor. Uncertainty about diagnosis and disease progression sometimes influenced decisions on what information to give, and when. It was also suggested that some more elderly patients were scared to discuss this with their families or did not want them to be concerned. The clinicians agreed on the importance of informing patients if they are being screened for sepsis and following up to confirm if they do or do not.

Finding the time

All participants recognised the importance of allocating adequate time for discussion. This needed to include sufficient time for clinicians to explain and time for patients/families to ask questions. Lived experience participants often described that they were given insufficient time for discussion, and to ask questions so that they could

fully understand. Being open and transparent about recovery challenges and post sepsis syndrome was valued but information relating to it was often lacking.

Clinicians noted that family involvement in conversations can, at times, add complexity. Information needs can be different (or perceived as different), between patients and different family members.

Sensitivity is needed

Many of those with lived experience commented on "the way people delivered news". One participant remembered dwelling for days on what, and significantly how, they had been told about their diagnosis. Another described how they felt clinicians stood 'talking over them', and others commented on a "harsh bedside manner".

"The consultant said, 'you are lucky to be alive'. I didn't want to hear this. It was frightening" Patient

Specialist clinicians were felt to focus too much on their 'expert' area and were perceived to be reluctant to discuss anything outside of this, including sepsis.

"Doctors can be very focussed on their specialism and can become blinkered to see beyond this" Patient

Differences between healthcare environments

There were perceived differences between clinical settings, which could affect both the way information was given, and what information was given. For example, both clinicians and patients agreed that discussing sepsis in the community (i.e. out of hospital), would probably be very different to the discussion in hospital. This might also reflect a change in disease progression from initial signs and symptoms (initial infection), worsening and requiring hospital admission (with sepsis). Some patient's descriptions of discussions with GPs reflected this; it was felt by some that even when they were very ill before coming to hospital, clinicians did not refer to sepsis. One lived experience participant reflected that the quality and quantity of information given was higher in a specialist hospital (to which they were transferred to), compared to the smaller local hospital they initially admitted to.

4: Views on the LIT™

All participants were generally positive about the test, if it could provide quicker, more accurate diagnosis. Comments were made about the simplicity of test and the potential speed of results. Participants with lived experience liked that it was potentially non-invasive (assuming blood already taken for other tests was used).

Clinicians thought the LIT™ was most likely to be useful in addition to, rather than replacement for, existing tests.

The information required to help build trust in the test is related to answering the questions/concerns presented below – primarily relating to accuracy. The patient group shared that it was important for them to understand the trustworthiness of the test.

What does the test do?

- Would the test give specifics or just a yes/no answer? A preference around being able to say sepsis is ruled in or out.
- Can the test confirm a diagnosis of sepsis so treatment can begin?
- Could the test provide qualitative data as well as a yes/no?
- Is this test just a marker for inflammation?
- Can the test distinguish between viral and bacterial sepsis?
- Could it be used as a retest if a clinician felt that the patient was deteriorating?
- Could it predict who is the most likely to deteriorate or at highest risk of dying?

Who is the test for?

- Is there an age exclusion?
- Can it be used effectively on patients with neutrophil dysfunction, immunosuppression or on chemotherapy?
- Would the test be suitable for people who have capillary problems – e.g. some elderly patients?
- Would interpretation vary in different types of patients e.g. those who have a high white blood cell count anyway? Could the machine settings be flexed to allow for this?

Timing and processes

- When would be the best time to use to help the diagnose of sepsis?
- Who would get the test – how do we know the right patients to test?
- How often would you have to re-test the patient?
- How much of the test can we use to inform patients?
- What are the benefits for 'middle ground' patients, where it's not quite clear if it's sepsis or not. These are the people who experience the most delays.
- How could this be rolled out early in the pathway.

Practicalities

- Ease of use/interpretation of results – could any clinician run the test (regardless of role)? Would it need much training?
- How much blood is needed for the test?
- How transportable is it?
- Is there potential for digital integration, in case any readouts/bits of paper go missing? If not, how would the results be recorded in current systems?
- Is there a time limit for the blood to be tested? If the blood is kept until hospital arrival, it may degrade?
- How expensive is the test and who authorises it?
- How often does the machine need to be serviced, charged, specific storage requirements? Is there a risk of it overheating?

What other information would be useful?

All participants reiterated the question of whether the test would completely rule in or out, a diagnosis of sepsis. Clinicians expressed interest in whether it could be used to predict those more/most likely to deteriorate.

Lived experience participants reinforced that they needed to be advised on what the test was for, along with any other tests. They would want to know if it was a test to specifically look for sepsis.

"Matter of fact normalise it – provides reassurance to patient who hasn't a clue what's going on" Patient

"If you had a fracture, you would say that you are going to x-ray to see if you have a fracture in your arm. Just tell them – we are going to do a finger prick to look at the cells in your blood – always close the loop of communication, tell them and their family what the result of the test was" Patient

They were broadly content that they could simply be told that the test was one of a series of tests and how these would be used in combination.

Those with lived experience were interested to understand practicalities including:

- When, and how often, the test would be taken?
- When would they get the results?
- Would it be painful?

There was no preference to receive verbal or written information specific to the LIT test. There was, however, a clear desire for more information regarding tests and diagnosis of sepsis.

Where should it be used in the patient pathway?

Clinicians suggested that it might be most useful using the LIT early in the pathway, such as in the Emergency Department for the 'middle group' of patients who often experienced delays in diagnosis. They also reflected that it might be useful in retesting some patients, particularly those that they felt were not improving/responding to initial treatment. This assumed that the test would not provide a definitive result.

Lived experience participants also championed use early on in patient pathways. Not limited to the Emergency Department, they also suggested use by paramedic crews, and in the community/GP settings, to promote pre-hospital diagnosis.

"The clock is always ticking" Patient

This was reflected in some personal accounts of diagnoses not being made before admission to hospital, where the individual felt that it should have been.

5: Summary

The impact of sepsis on individuals is significant both physically and psychologically. There are often challenges in reaching a clear diagnosis of sepsis, with a blurred line between sepsis and infection. Even when a sepsis diagnosis is reached, patients experience is that it might not always be shared or is shared late in the hospital stay. Information is highly valued by patients and their families; however, in their experience it is often lacking. Both clinicians and those with lived experience recognise that information giving is a skill including how and when information is conveyed. It is of key importance to patients to find time to discuss and to support a fuller understanding. Information giving may sometime be impeded by actual or perceived lack of capacity.

Both clinicians and those with lived experience were positive about the LIT™ test if it provided a way to speed up or enhance the diagnosis of sepsis. This included possible access in pre-hospital settings. However, questions were raised about accuracy, potential exclusions, and practical considerations. Going forwards it will be important to:

- Generate evidence to address queries where it does not already exist.
- Develop both patient/family and clinician facing information that answers the questions raised.

Appendix One – Breakout Session/Interview Questions

Breakout Session 1 (25mins)

Aim: To understand what is important to patients and their families with respect to **information** in the sepsis pathway. (**information needs**)

Clinician Group - What is your experience of diagnosing patients with sepsis?

- What works and what doesn't work at the moment?
- What do you think patients and their families need to know?

Patient Groups

- What was important for you/your family to understand when you became unwell?
- What information were you given at the time?
- What information was useful and what could have been better?

Breakout session 2 (25 mins) (groups included

Aim: To explore patient and clinician views around using the LIT to support diagnosis in the sepsis pathway

- What do you think about what you heard about this blood test? Explore positive and negative views, any concerns?
- What information would you need to know about this blood test for you to feel you could trust it?
- Do you feel that patients should be given specific information about the LIT test when their blood sample is taken for sepsis screening in and emergency setting?

Clinician specific question

- Where do you feel the LIT fits in the clinical pathway and how would it's use change decision making for clinicians and experience for patients?
- The test can be set to be very sensitive and so potentially give false positives or set to a lower sensitivity and having more false negatives? What are your thoughts on this? NB reiterate that this is not the only test in pathway (this needs to be said in the plenary intro about the test).