



## Empowering and educating patients diagnosed with cirrhosis

**Project leaders:** Heather Marcinkowski, Jennifer Clancy and Louise Campbell

**Duration:** November 2015 – June 2017

**Keywords:** Education, cirrhosis, liver, empowerment

### Project background

The liver unit at St Mary's Hospital, London, delivers a wide range of services to individuals diagnosed with liver disease.

Liver disease is a significant challenge facing the health service, the fifth-largest cause of mortality in the UK and the only one of the major diseases – alongside cancer, stroke, heart disease and diabetes – that has seen an increase over the past decade. Severe liver disease, or cirrhosis, is associated with an increased risk of developing liver cancer and ultrasound is used for early detection. However, at St Mary's there was a non-attendance rate of between 24% and 48% for the six-monthly screening procedures, which has implications for resources and for patient outcomes. Patients reported significant increases in anxiety associated with the scans and many seemed to have limited understanding of the importance of screening.

### Aims and objectives

The aim of this project was to improve the quality of life for individuals who have a diagnosis of cirrhosis. To achieve this, the objectives identified were to:

- Gain insight of patients' understanding of liver cirrhosis, its side-effects and the purpose and value of the six-monthly screening programme
- Empower individuals to improve engagement with their care and so to improve their health outcomes and wellbeing
- Design and implement a nurse-led clinic for educational purposes and create a link for patients if they have any concerns
- Evaluate the effectiveness and usefulness of clinic

### Implications for practice

- It is important to consider enabling factors as well as barriers when looking at the causes of events (for example non-attendance)
- A combination of small, practical changes and increased information can have a dramatic effect and save money

*This project was supported by the FoNS Patients First Programme in partnership with The Burdett Trust for Nursing*

### Online

Further information about the project can be accessed from:

[fons.org/library/report-details?nstd=73157](https://fons.org/library/report-details?nstd=73157)

### Key activities and outcomes

#### • Data collection

The first priority was to gather baseline data about the number of patients diagnosed with cirrhosis, the number of ultrasound screening appointments missed and the reasons for people not attending. It was decided that the next step should be to explore these reasons with patients via a telephone call.

Patients reported a number of barriers to attendance:

- 45% had not received an appointment letter
- 77% did not know the reason for the screening
- 20% would have found a text reminder useful
- Other obstacles included: the language used in the letter; 'just forgot'; medical reasons; confusion about the difference between an ultrasound and a fibroscan; and administrative difficulties (patients had cancelled but been unable to rebook)
- Incidentally, patients reported that the appointment letter stated 'US' not 'ultrasound', which also created confusion

It was also recognised that patients who did attend would be able to provide valuable information about what had encouraged and enabled their attendance. Although contact was made post-attendance, not enough people responded for meaningful conclusions to be drawn.

#### Introduction of a nurse-led cirrhosis clinic

The cirrhosis clinic offers a one-hour, face-to-face appointment with the patient and their significant others. The senior nurse who runs the clinic discusses what cirrhosis means, its potential complications, signs and symptoms, recommendations for changes in diet and lifestyle, and the monitoring regimen – for example scans, endoscopy and blood tests. There is also the opportunity to address any questions or concerns the patients have.

#### Re-audit of non-attendance rates

After the introduction of the clinic, a further audit was undertaken, which revealed a noticeable reduction in non-attendance rates for ultrasound screening.

#### Going forward

- Patients are now finding it easier to rebook
- The team finds it useful to continuously update the database of patients with cirrhosis
- A letter is sent out after the first missed screening scan explaining why ultrasound scans are needed and giving contact information for the nurse specialist
- There has been closer interdepartmental working. For example, the team has had discussions with the radiology department about the wording of appointment letters
- The team plans to continue the nurse-led clinic, especially for people who are newly diagnosed