

# What do patients want?

**Vanessa Hebditch**  
**Director of Policy and Communications**  
**British Liver Trust**

13<sup>th</sup> December 2018



[www.britishlivertrust.org.uk](http://www.britishlivertrust.org.uk)

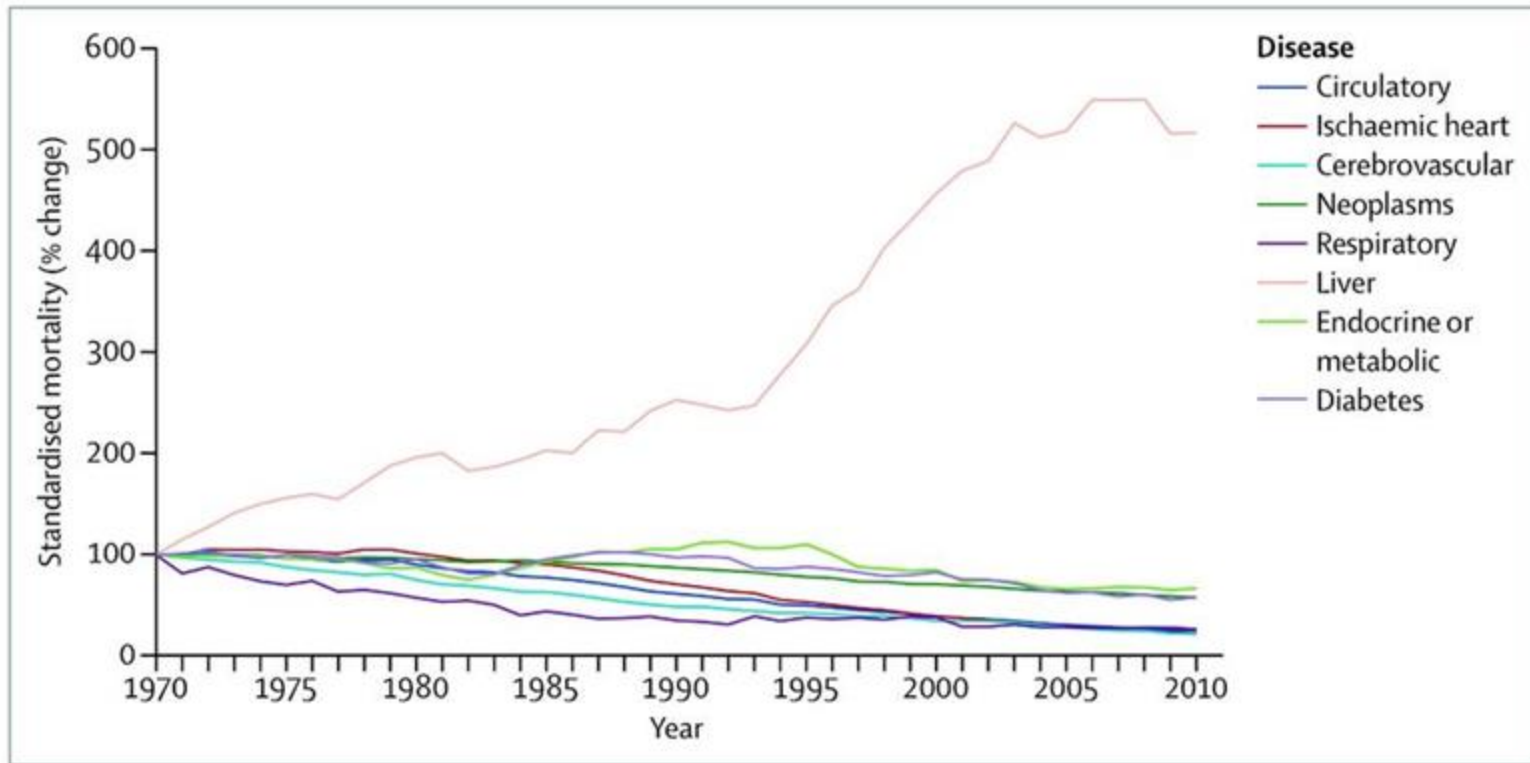


# Who we are

- Leading charity in the UK for adults with **all** types of liver disease
- Support patients and families
- Raise awareness of liver disease
- Support research
- Influence and campaign on behalf of everyone affected
- Provide a patient voice
- Focus on prevention and early diagnosis



# Liver disease in the UK



**Figure 1: Standardised UK mortality rate data**

Data were normalised to 100% in 1970, and subsequent trends plotted using the software Statistical Package for the Social Sciences. Data are from the WHO-HFA database.<sup>4</sup> Analysed by Nick Sheron (September, 2013).

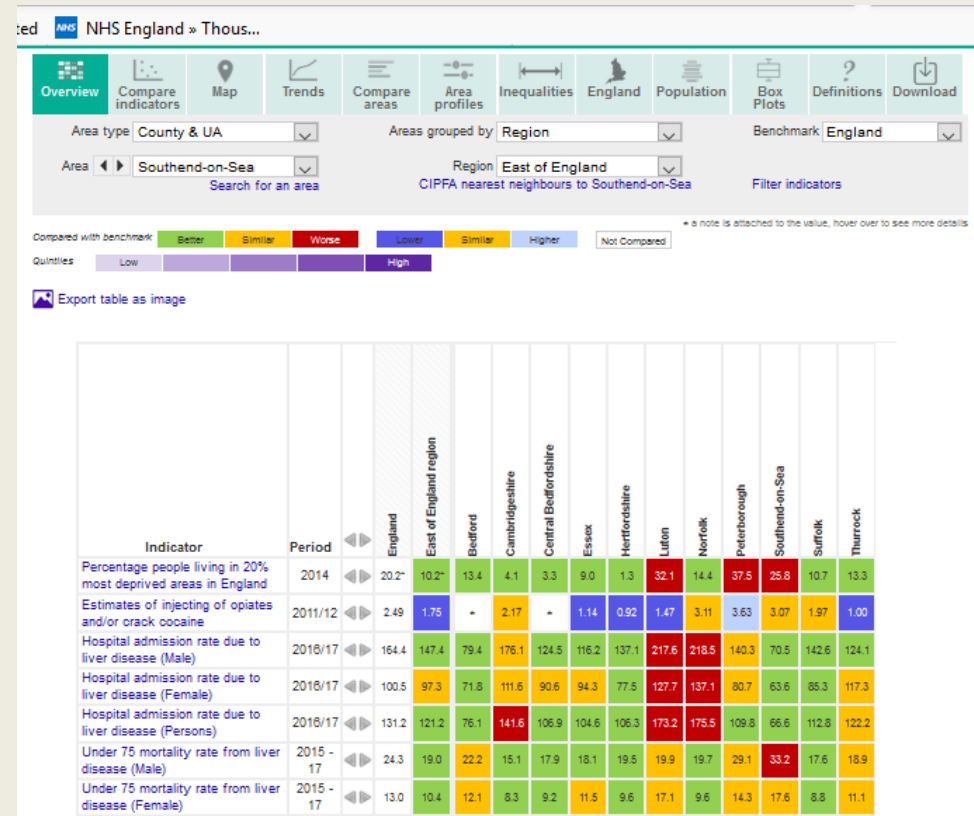
# Liver disease in the UK

- Three quarters of people diagnosed in an emergency setting
- Some regional areas of excellent care
- Some clinical areas such as transplantation where the outcomes are clearly measured and in the public domain
- Variation in when and how people are diagnosed, the information people receive on diagnosis, access to treatments, the support people are offered and their experience in hospitals and during end of life care
- Very limited patient empowerment



# Liver disease in East of England

- One in five drinking alcohol at a level that puts their liver at risk
- 62% of adults in East of England overweight or obese
- Hospital admission rate for NAFLD 4.6 per 100,000 compared with 3.0 average
- Variation in care
- [www.fingertips.phe.org.uk/profile/liver-disease](http://www.fingertips.phe.org.uk/profile/liver-disease)



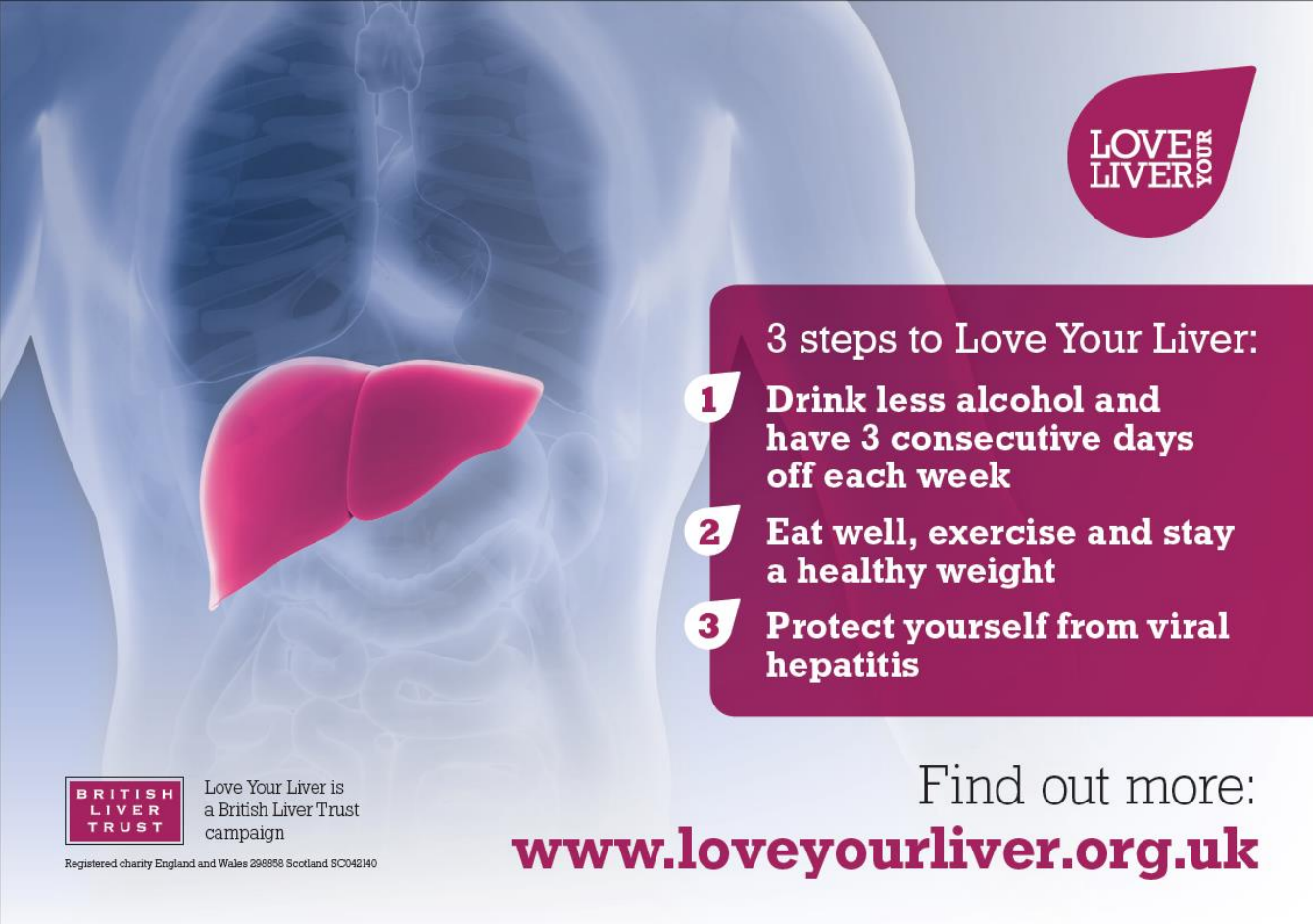
# What do patients want?



[www.britishlivertrust.org.uk](http://www.britishlivertrust.org.uk)



# Awareness of the risk factors



**LOVE YOUR LIVER**

3 steps to Love Your Liver:

- 1** Drink less alcohol and have 3 consecutive days off each week
- 2** Eat well, exercise and stay a healthy weight
- 3** Protect yourself from viral hepatitis

Find out more:  
[www.loveyourliver.org.uk](http://www.loveyourliver.org.uk)

**BRITISH LIVER TRUST**

Love Your Liver is a British Liver Trust campaign

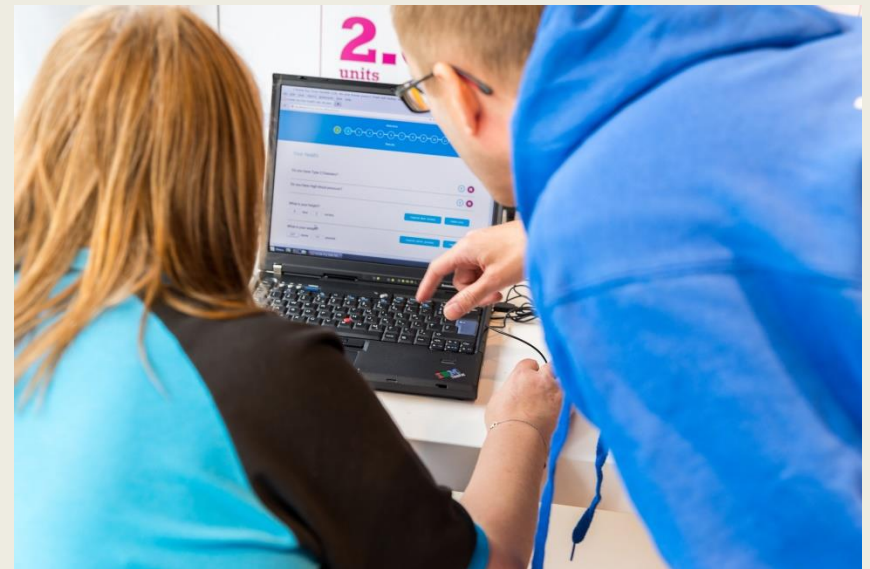
Registered charity England and Wales 298858 Scotland SC042140





[www.britishliverdisease.org.uk/screener](http://www.britishliverdisease.org.uk/screener)

- Online screening tool
- Asks people about their risks
- Over 190,000 people completed so far



[\*www.britishlivertrust.org.uk\*](http://www.britishlivertrust.org.uk)





# Early Diagnosis



[www.britishlivertrust.org.uk](http://www.britishlivertrust.org.uk)



# Roadshow impact

- 1 in 5 roadshow attendees show a reading indicating risk of liver damage
- 2000 people screened at roadshow during 2018
- Need to use this as a catalyst for improving early detection in the local community



# Our work – supporting general practice

- Three year partnership with the RCGP
- Tool kit for GPs ([www.rcgp.org.uk/liverdisease](http://www.rcgp.org.uk/liverdisease))
- Educational workshops
- New guidelines for commissioners – launched April next year
- Raising awareness through journals and publications
- Development of new Read codes
- Dissemination of new guidelines for LFTs



# Patient voice

- Nurse led helpline
- Online forum
- Support groups
- Feedback through website, social media
- ‘Love Your Liver’ ‘Roadshow’
- Patient review of resources and services
- Patient representation
- Surveys





# Calls to the Helpline

“I’ve spoken to several different doctors and I’m very confused about advice”

“Which hospital is best?”

“How do I get dietary advice”

“My doctor has told me I’ve got a fatty liver but told me not to worry”

“I don’t understand what I’ve been told or what the tests mean”



# What do patients want?

## Patient Centred Service

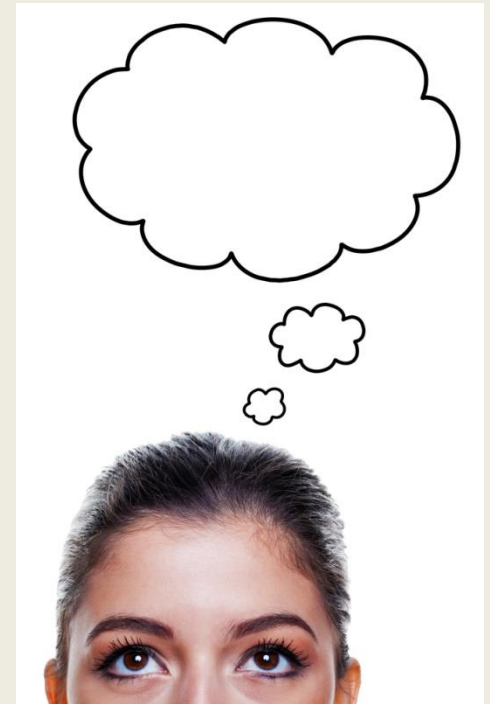
- Responsive
- Listens, understand and respects their needs
- Involves patients and carers
- Continuously improving
- Good communication – that is two way



# In summary

**Patients want early diagnosis followed by care that is**

- high quality
- safe and effective
- accessible and timely
- provided by clinicians and nurses with a specialist knowledge





# Thank you and any questions?

Email us at [info@britishlivertrust.org.uk](mailto:info@britishlivertrust.org.uk)

Stay in touch – sign up to our newsletter or follow us



@LiverTrust



British Liver Trust



[www.britishlivertrust.org.uk](http://www.britishlivertrust.org.uk)

