

# LSE Research Online

## J. L Gill, A. Baiceanu, P. Clark, A. Langford, J. Latiff, A. Wilson, P. – M. Yang, E. Yoshida & [P. Kanavos](#) HCC patient voices survey

### Survey

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## **HCC Patient Voices Survey**

Welcome to your Survey

Many thanks for considering taking part in the first ever global survey on patients who have been diagnosed with Liver Cancer. The purpose of the study is to better understand how Liver Cancer affects day to day life for people who have been diagnosed with the disease. Specifically, we would like to better understand how you have obtained and accessed information about your disease, how your day to day activities and outlook on the future has been affected, and the experiences you have had during different treatments you may have received.

Participation is voluntary and all answers are dealt with in the strictest confidence. The survey will be open until the end of March 2017. The research agency Strategic Sight Ltd is managing the survey and their details can be found by clicking on 'Legal Info' below. A report will be available at the end of the survey and we hope this will provide new insights for patients and healthcare professional on how to improve care for patients living with Liver Cancer.

By clicking on Begin below, you are consenting to take part in this research. Many thanks.

If you do have any questions, please contact us at [question@hcc-voices.com](mailto:question@hcc-voices.com)

Q1 What is your gender?

- Male
  - Female
-

Q2 To which ethnic group do you belong?

- White Caucasian
  - Latino/Hispanic
  - Middle Eastern
  - African
  - Caribbean
  - South Asian
  - East Asian
  - Mixed
  - Other
  - I'd rather not say
- 

Q3 Which type of liver disease did you have before you were diagnosed with Hepatocellular Carcinoma (HCC)?

- Chronic Hepatitis B
  - Chronic Hepatitis C
  - Non-Alcoholic Fatty Liver Disease
  - Other
  - None
-

Q4 In what year were you born?

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Q5 How long has it been since you were diagnosed with HCC?

- Less than 1 year
  - 1 to 3 years
  - 4 to 6 years
  - More than 6 years
- 

Q6 How did you learn you had HCC?

- From my GP (General Practitioner or Primary Care Doctor)
  - Oncologist
  - Hepatologist
  - Gastroenterologist
  - Emergency Room Physician
  - Other \_\_\_\_\_
- 

Q7 Which 3 words best describe your feelings when you learned you had HCC?

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Q8 Do you feel you received enough information about HCC and its treatment at the time you were diagnosed?

- Yes
  - No
- 

Q9 What treatments have you received since you were diagnosed?

- Liver Transplant
  - Surgery (removal of some or all cancer)
  - Liver Ablation (treating the cancer with extreme hot or cold)
  - External Radiotherapy (treating the cancer with an x-ray beam)
  - Internal Radiation Therapy (SIRT or radioembolisation - treating the cancer with implanted radioactive beads)
  - Transarterial Chemotherapy (TACE - chemotherapy delivered directly to the cancer)
  - Chemotherapy tablet (sorafenib/Nexavar)
  - Intravenous Chemotherapy (given directly into a vein)
  - Alternative medicine
  - No treatment offered
  - Treatment recommended, but declined
- 

Q10 Of the treatments you selected, in which order did you receive them?

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Q11 Did you take part in a clinical trial?

Yes

No

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Q12 If yes, do you remember anything key about the trial - name, treatment etc?

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Q13 Are you currently under treatment, or have you any new treatment scheduled - if so which one?

Yes, treatment: \_\_\_\_\_

No

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Q14 Which best describes your current situation?

I am fully active; I can do everything I did before I had HCC.

I am still active, but I can't do all the things I used to do.

I can get around a bit and take care of myself most of the time, but I can no longer work at my current/previous job.

I can take care of myself a little bit, but I have to rest in bed or in a chair most of the time.

I require a caregiver and I'm in bed or in a chair almost all of the time.

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Q15 During your diagnosis or treatment where have you gone for advice or counsel and how useful have you found it?

	Not Used	Limited Value	Good Value	Excellent Value
Internet - Medical Sites	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Internet - Forums / Chat Groups	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Patient Charities / Organizations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Friends / Family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Psychological Support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Alternative Medicine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Healer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Primary Care Doctor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Church / Religion / Religious Groups	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Specialist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nurse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q16 Thinking about your present or most recent medical treatment, what has been its effect on the following:

	Significant Negative Effect	Negative Effect	Improved Somewhat	Improved Significantly
Your daily activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your level of energy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your outlook for the future	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your general mood	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your family / carers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your 'quality of life'	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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Q17 If you were working at the time you started treatment did the side effects prevent you from working?

- Yes
- No

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Q18 What else would you like to say about how this treatment has affected your everyday life?

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Q19 Excluding surgery - which of the treatments you've received for your liver cancer has been the most challenging?

N/A - I've not received any treatment other than surgery

Most challenging: \_\_\_\_\_

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Q20 Why was it so challenging?

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Q21 Thinking specifically about side effects that you may have experienced during treatments, could you rate the impact they had on your quality of life?

	I did not experience this	Minor problem that I could manage myself	Moderate problem that disturbed my daily routine	Significant problem that required a doctor's attention
Abdominal pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Skin disorders (including painful hands and/or feet, blistering, rash etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nausea and/or vomiting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Diarrhea	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fatigue	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Weight loss	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Alopecia (hair loss)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Loss of appetite	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q22 How long did these side effects last?

	1 to 2 days	Up to 1 week	More than 1 week, up to 4 weeks	Most of the time	All of the time
Abdominal pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Skin disorders (including painful hands and/or feet, blistering, rash etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Nausea and/or vomiting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Diarrhea	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fatigue	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Weight loss	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Alopecia (hair loss)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Loss of appetite	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q23 Compared to the way you felt before you were diagnosed with HCC how do you feel about the following?

	Better than before diagnosis	Similar to before diagnosis	Slightly worse than before diagnosis	Significantly worse than before diagnosis
How tired I feel	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My ability to exercise	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My memory	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My concentration	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My appetite	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How well I sleep	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My relationship with my friends and family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My overall physical condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My overall mental condition	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q24 How would you rate your quality of life today?

- Excellent
  - Good
  - Fair
  - Poor
  - Other: \_\_\_\_\_
- 

Q25 If you could change one thing to improve your quality of life, what would it be?

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Q26 Thinking about the future, how do you think further treatments that you might need could affect your everyday life and things you want to accomplish?

- No impact
  - Minimal impact
  - Significant impact
- 

Q27 Have you used supplementary health insurance during your HCC treatment?

- Yes
  - No
- 

(if 'No' survey skips to Q34)

Q28 Were all the treatment options covered by your insurance plan?

Yes

No

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(if 'Yes' survey skips to Q34)

Q29 Was your treatment chosen based on what was covered by your insurance policy?

Yes

No, details: \_\_\_\_\_

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Q30 Did you have to pay out of pocket for any of the treatments?

Yes

No

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Q31 If yes, were you reimbursed?

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Q32 Did your doctor have to make a special request to the hospital administration for your treatment?

Yes

No

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Q33 If yes, did you have to wait longer before starting treatment?

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Q34 Were you referred to a different hospital because the treatment option that your doctor wanted you to have was not available in the hospital?

Yes

No

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End of Block

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