

“HCC VOICES” – THE FIRST GLOBAL SURVEY OF PEOPLE LIVING WITH HEPATOCELLULAR CARCINOMA (HCC)

What was the rationale behind “HCC Voices”?

Multiple support groups exist for people suffering from general liver conditions and diseases. However, although HCC is the sixth most commonly-diagnosed cancer globally, and the second-leading cause of cancer deaths annually, there are very few organisations that focus solely on HCC patients.¹ As a result, HCC patients may not be receiving adequate support and information about their condition. In the absence of an international voice, there is limited information about the HCC patient journey.

In order to address these issues, London School of Economics (LSE) decided to develop the first global survey of people living with HCC to better understand their patient journey.

What was the objective of this survey?

The aim of this survey was to better understand the HCC patient experience; to learn how these patients cope with life with HCC, including their hopes, concerns, and fears; and to find out how they feel about the different medical treatments they receive, particularly the effects of later stage treatment on quality of life (QoL).

The survey contained 32 closed- and open-ended questions, which gave the patients a chance to express, in their own words, their opinions about the evolution of their illness, the challenges raised by different treatment options, including side effects, impact on QoL, issues around treatment access and their feelings about their most-recently received treatment.

Who helped develop the survey and inform patients about it?

“HCC Voices” was supported by a global partnership of liver cancer groups such as:

- American Liver Foundation
- Blue Faery – The Adrienne Wilson Liver Cancer Association
- British Liver Trust
- Canadian Liver Foundation
- European Liver Patients’ Association
- Romanian Association of Patients with Liver Diseases
- Taiwan Liver Cancer Association
- A number of liver cancer treatment units in major medical centres around the world (e.g. Singapore General Hospital, Princess Alexandra Hospital in Australia)

The survey tool was developed using an iterative process between the participating partner organisations and collaborators from the Medical Technology Research Group of the Health and Social Care Research Centre at LSE. Approval of the final survey tool was sought from the scientific advisory boards of the medical centres and patient organisations involved in the project. In some instances, independent ethics committee approval was sought. This was the case in Canada, Australia and Spain.

The patient charities involved in the project partnership were responsible for publicising the survey and encouraging patients to participate. The survey was available in 8 languages (Chinese, English, French, German, Italian, Portuguese, Romanian & Spanish) online, and in hard-copy in some medical centres.

Patients either completed the survey following self-identification or were asked to complete the survey by nurses at their doctor’s office

Who led this study?

Prof Panos Kanavos and Dr Jennifer Gill from the Medical Technology Research Group of the LSE Health and Social Care Research Centre performed the final data analysis and prepared the scientific communications related to “HCC Voices”. Dr Gill presented the overall results at a scientific poster session of the ESMO World Congress of GI Cancers, Barcelona, Spain, 30 June 2017.

Strategic Sight, a UK-based market research consultancy, created the password protected on-line survey instrument, and supported the data collection and preliminary analysis.

Sirtex supported this project with unrestricted educational grants to the participating organisations.

What was the study timeline?

The development of the survey tool started in June 2016 and the results were presented as a poster at the ESMO 19th World Congress on Gastrointestinal Cancer in June 2017.



What were the results of the survey?

Between November 2016 and April 2017 256 patients completed the survey across 13 countries, including Italy (n=62), USA (n=52), Taiwan (n=42), UK (n=32), Germany (n=23), Singapore (n=18), Canada (n=8), Romania (n=7), Spain (n=6), Brazil (n=4), France (n=1), Australia (n=1) and Argentina (n=0).

Most of the respondents were male (70%) and the median age was 64 years (range from 23 to 88 years).

Feelings upon diagnosis were negative, as one would expect following the diagnosis of any kind of serious illness. Words such as “fear”, “scared”, “worry” and “anger” were most commonly used by the patients to describe their feelings at diagnosis. Such feelings were replicated across all 13 countries indicating that, wherever your location, a diagnosis of HCC brings significant fear and anxiety.

Most patients found their specialist (85%), primary care doctor (50%) and medical websites (44%) to be good/excellent value in terms of information and advice following diagnosis, although many found patient charities to be lacking. Overall, more than two-thirds of patients (68%) did not receive enough information about their HCC at diagnosis.

Transarterial chemoembolization (TACE, 43%) followed by liver ablation (33%), surgery (29%) and liver transplant (21%) were the most common forms of treatment received by patients completing the survey. Patients found that fatigue and abdominal pain, had the biggest impact on their QoL, compared to other side effects such as nausea, skin disorders and appetite loss. Discounting surgery patients thought that TACE and sorafenib were the most challenging treatments.

Generally, patients requiring additional, later-stage treatment following surgery, transplant or ablation have TACE (which is used slightly earlier in treatment), palliative oral systemic chemotherapy in the form of sorafenib or liver-directed selective internal radiation therapy (SIRT). Sorafenib had a larger negative (81%) and smaller positive (19%) impact on QoL than TACE or SIRT, whilst moderate-to-significant side effects impacting QoL were more frequently reported by those treated with sorafenib, than those treated with TACE or SIRT. As a result, those whose most recent treatment was sorafenib were more likely to rate their current QoL as poor and less likely to rate it good or excellent than those treated most recently with either TACE or SIRT.

What are the key take home messages?

- All patients, no matter their geographic location, will confront significant fear and anxiety upon diagnosis of HCC.
- HCC patients trust information they receive from their doctor, but most feel that they need more information from other sources in order to better understand their disease and how to treat it.
- Side effects related to current late stage treatment options are negatively impacting on QoL. Those patients with incurable HCC need more, and better, treatment strategies to maintain QoL.

For more information please visit: www.sirtex.com/HCC and www.sirtex.com

1. Ferlay J *et al.* Globocan 2012. v1.0, Cancer Incidence and Mortality Worldwide: IARC CancerBase No. 11 [Internet]. Lyon, France: International Agency for Research on Cancer; 2013. Available from: <http://globocan.iarc.fr>, accessed on 13/November/2017.