Understanding the hepatocellular carcinoma (HCC) patient landscape: Results from the 1st global survey of people living with HCC

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**Background**
- Multiple support groups exist for general liver conditions & diseases
- However, there are few organisations focusing solely on HCC
- It is possible that HCC patients are missing out on valuable support and information
- There is limited information on the global patient journey due to lack of patient surveys
- Aim: To develop a global survey in order to better understand the HCC patient experience and to compare the effects of later stage treatment on quality of life (QoL)

**Method**
- 7 patient charities and >15 medical centres in 13 countries developed the survey, which was approved by scientific advisory boards
- hcc-voices.com contains 32 closed- and open-ended questions on demographics, diagnosis, and treatment (side effects, QoL, treatment access and most recent treatment)
- Patients either completed the survey following self-identification or were asked to complete the survey by nurses at their Dr’s office
- Available in 8 languages (Chinese, English, French, German, Italian, Portuguese, Romanian & Spanish) online, and in hard-copy in some medical centres, from 1st November 2016 to April 2017

**Results**

**Demographics**
- 256 respondents between November 2016 and April 2017
- Male = 178 (70%) Female = 78 (30%)

**General Treatment Effects**
- What HCC treatments have you received at any stage since your diagnosis?
- How have patients rated their general treatment effects?

**Impact of Most Recent Treatment**
- Excluding surgery what has been the most challenging HCC treatment?
- How has your most recent treatment affected your QoL?

**Conclusions**
- Most patients undergoing palliative oral systemic chemotherapy report more side effects that have a significant impact than those treated with liver-directed SIRT or TACE
- Increased side effects lead to more reports of reduced QoL
- Those with incurable HCC need better treatment strategies to maintain QoL

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**Significance**
- Understanding the HCC patient landscape
- Comparison of HCC treatments
- Impact of side effects on QoL