

# “Like a curse”: Outcomes of the New Zealand 2011 People with Haemophilia and Hepatitis C Survey

Chantal Lauzon, MPH

Haemophilia Foundation of New Zealand Inc., Christchurch, New Zealand  
Contact: Ph: +64 3 371 7477; E: chantal@haemophilia.org.nz



## OBJECTIVES

Over a third of the people with bleeding disorders (PWBD) exposed to hepatitis C (HCV) through blood products in New Zealand continue to live with chronic HCV and the additional toll this has on their health and wellbeing.

The aims of the 2011 HFNZ PWBD & HCV Survey were:

- To better understand the demographics of PWBD and chronic HCV;
- To better understand the health of this community;
- To better understand the impact of HCV in this community; and
- To be able to gauge any changes in health or quality of life to the results of previous surveys of this population.

## METHODS

In October 2011, a hardcopy survey was mailed to 53 PWBD and chronic HCV currently living in New Zealand.

Respondents were asked about demographic information, employment, treatment for HCV, liver health, HCV education and support, their general health, activities and psycho-social functioning. HFNZ Haemophilia Outreach Workers provided followed-up by telephone or in person if needed.

The survey included a quality of life/wellbeing section replicated from previous surveys in 2009 and 2010 to allow for comparison over time.

In total 31 surveys (58%) were completed and returned.

## RESULTS

Over a third of respondents were aged over 61 years (39%) and only two were aged under 30 years (Fig. 1). Only half (52%) of those aged under 61 years were in full-time employment (see Fig. 2 for more data on employment status).

Figure 1. Age Range (years)

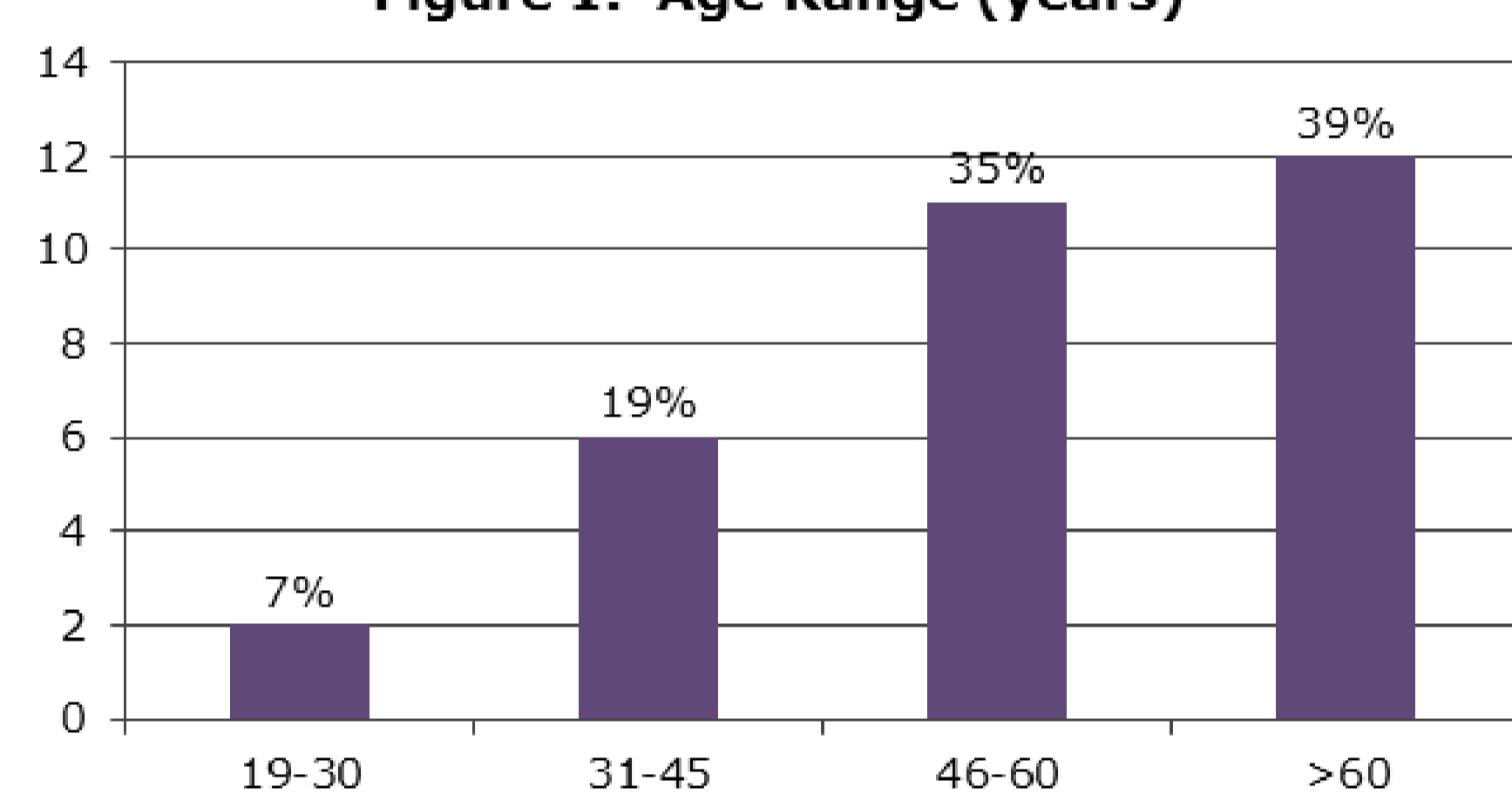
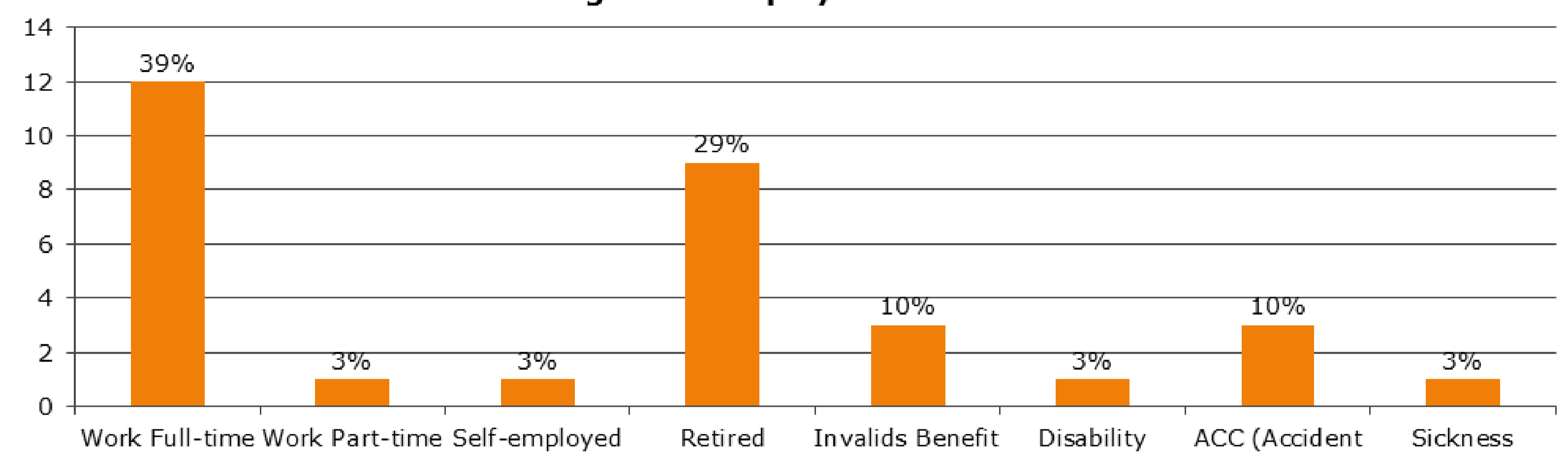


Figure 2. Employment Status



Interferon therapy had been attempted by half (52%) of the respondents (see Fig. 3) and 48% had undergone a FibroScan®. Most respondents indicated they had little or no fibrosis, however, three (10%) have cirrhosis and one liver cancer (Fig. 4).

Figure 3. Outcome of last interferon-based treatment (tx) for hepatitis C

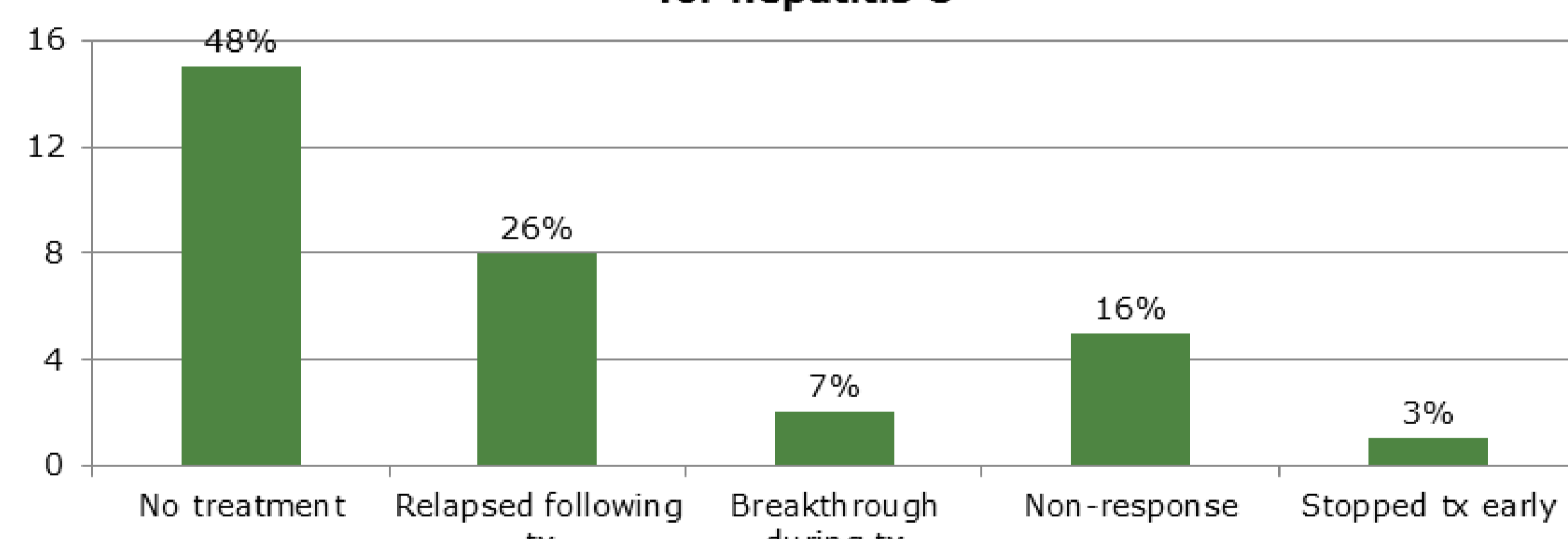
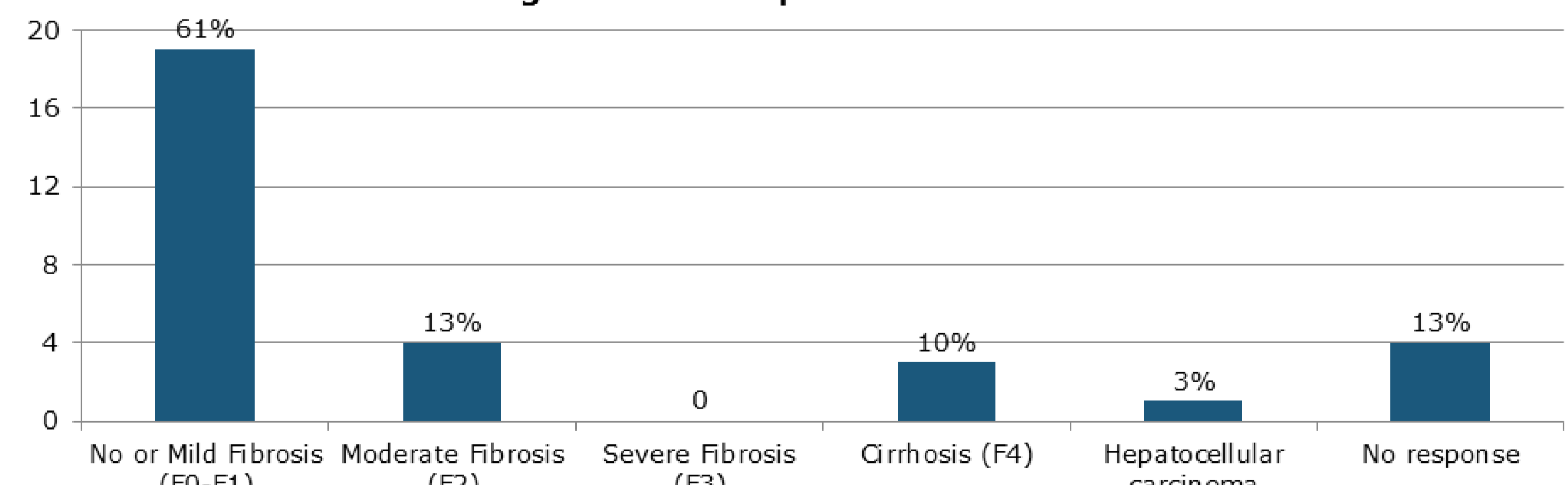
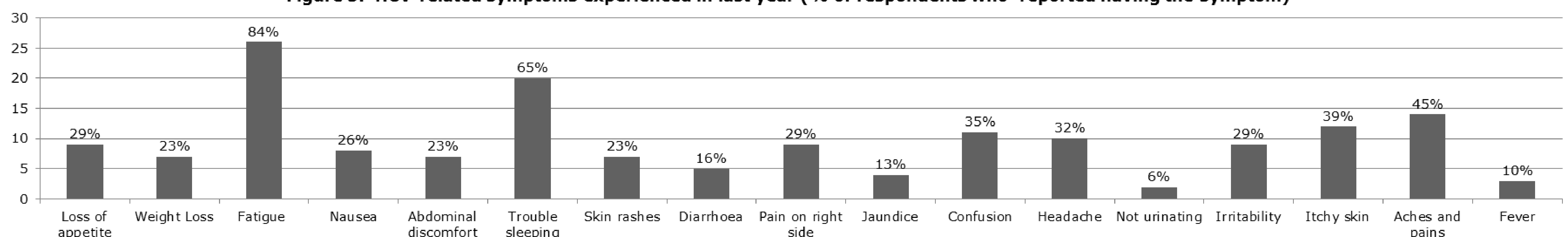


Figure 4. Self-reported Liver Health



Fatigue affected 84% of respondents and was the symptom which most impacted on their lives for 65%. In general, half of the respondents (51%) reported feeling good or very good, although most reported having physical limitations, especially in relation to vigorous activity (81%). The survey showed that the majority found daily tasks harder to complete, both because of pain (49% at least some of the time), and also loss of energy (67% at least some of the time). Anxiety or worry about the effects of HCV affected 81% of respondents.

Figure 5. HCV-related symptoms experienced in last year (% of respondents who reported having the symptom)



Most respondents (58%) felt they were well informed about HCV, preferring HFNZ Outreach Workers and publications, and their general practitioner as sources of information on HCV.

## CONCLUSIONS

Compared to previous wellness survey scores, PWBD and HCV in 2011 generally reported similar levels of overall health, although less severe limitation on vigorous activities (48% in 2011 vs. 65% in 2010), and less impact from loss of energy (68% vs. 75%) and pain (48% vs. 56%) on daily tasks than in 2010. Although most 2011 respondents reported making positive lifestyle choices to support their liver health (healthy diet [87%], abstinence from alcohol [45%], no smoking [68%], regular exercise [50%]) living with HCV, and especially the associated fatigue, encumbers both daily living and social activities/hobbies.

