# VHL UK/Ireland Patient/Carer Survey - Summary

**Results Published June 2022**

This survey was commissioned by the Trustees of VHL UK/Ireland Charity to aid their submissions to NICE for the appraisal of belzutifan for VHL related Kidney RCC in the UK.

Belzutifan for VHL is being described by many in the medical profession as a possible 'game changer' for the treatment of VHL tumours. This drug is the first of its kind to offer a potential alternative to surgery. VHL/UK Ireland welcomed the opportunity to work with NICE on its first appraisal in the UK and the survey results will help form a vital part of this work.

Latest details about the appraisal can be found on the VHL UK/Ireland or NICE websites.

**Trigger Warning**:

Please note some of these results may be unsettling especially to newly diagnosed patients or their carers or anyone currently having a difficult time with the disease. Please note this data was collected to help understand the impact on patients and their carers to support improvements in its treatment.

Questions about this report or it's data can be directed to teamnice@vhl-uk-ireland.org

## EXECUTIVE SUMMARY

- VHL often affects many aspects of a patient's life, including their careers, travel, relationships, family planning, finances, and social activities and in most of these, more than a 10% feel these have been affected permanently.
- Carers lives can also be greatly impacted by VHL. Our data suggested carers often worry even more than patients about scans and follow appointments.
- Kidney RCC affected 51% of respondents to this survey, with at least 60% of those patients having experienced at least 1 surgery but some up to 6. Recovery from these surgeries is long and can include a high occurrence of mobility issues, pain, fatigue and anxiety/depression.
- The impact of VHL on patients and carers is significant, and lifelong.

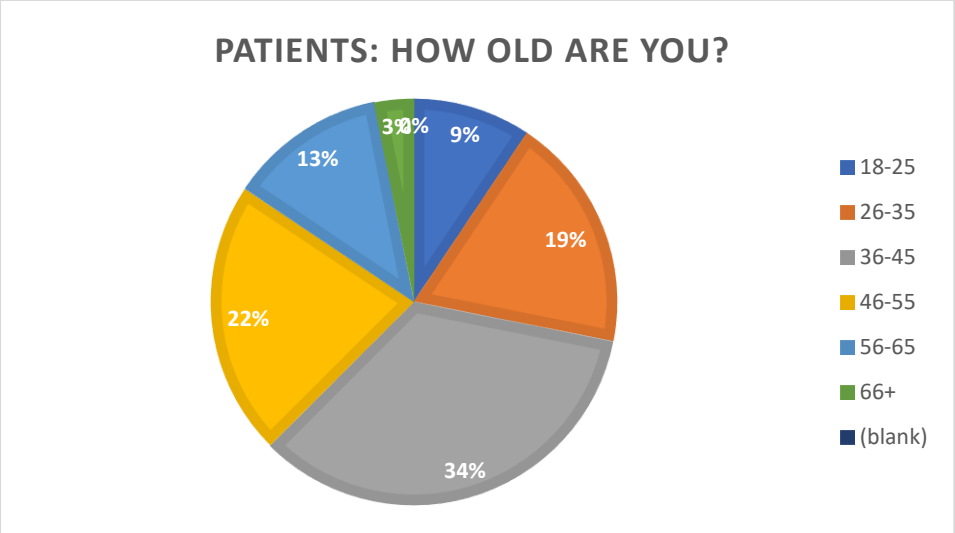
## TOTAL RESPONDANTS

The results are based on 39 responses across patients and their carers. This is how they identified their relationship with VHL

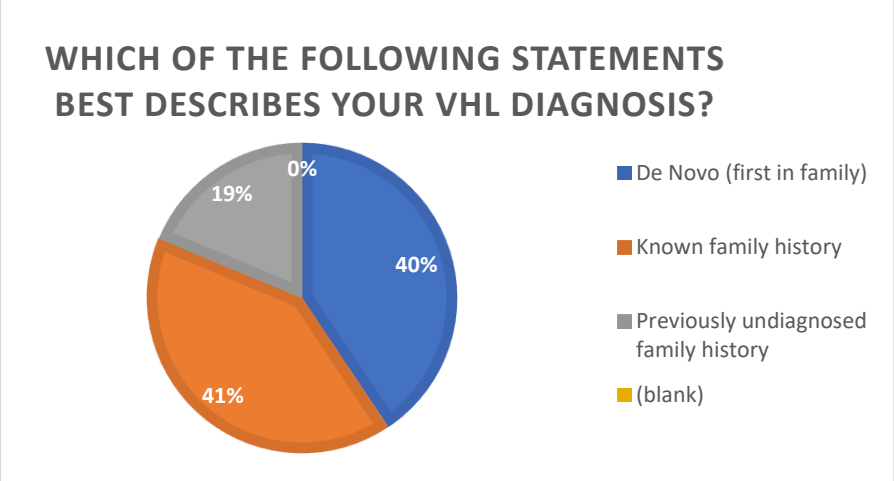
- 74% said 'I am a VHL patient/responding on behalf of a VHL Patient'
- 18% said 'I am a primary carer for someone with VHL'
- 8% said 'I am both a VHL patient and a primary carer for someone with VHL'

## VHL PATIENT RESPONDENT DATA:

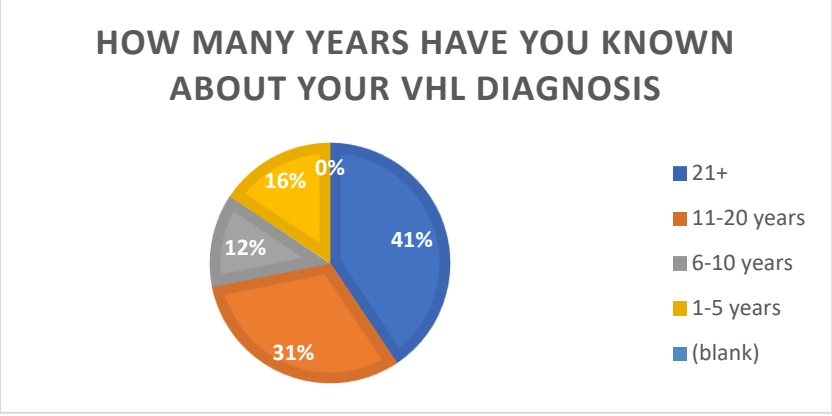
Patients' response data was collected from 32 participants in the survey, 75% of respondents were between the ages of 26 and 55.




Of 32 patients' 41% were the first to be diagnosed in their family. 40% has a known family history, 19% had an undiagnosed family history were VHL is suspected but unproven.

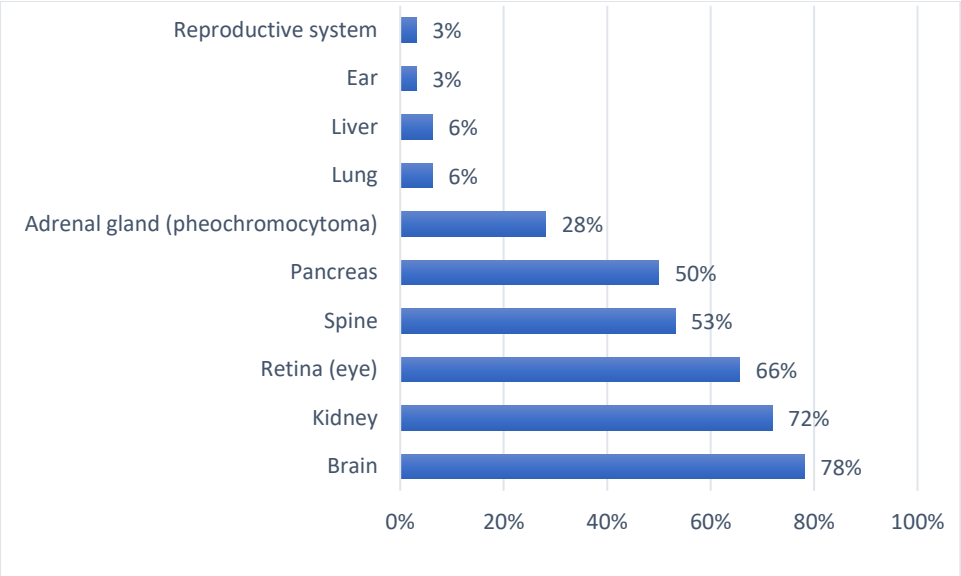



84% of respondents have lived with VHL diagnosis for 6+years.



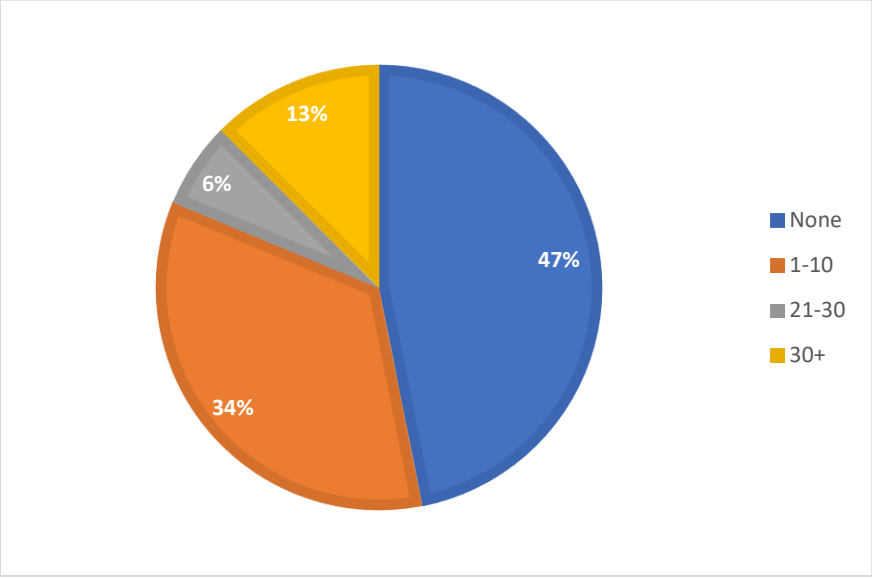
**Treatment, monitoring and manifestations:**

Respondents were asked, ‘which of the following areas of your body have been affected by VHL *primary* tumours in your lifetime? Please include any that have been treated/removed’



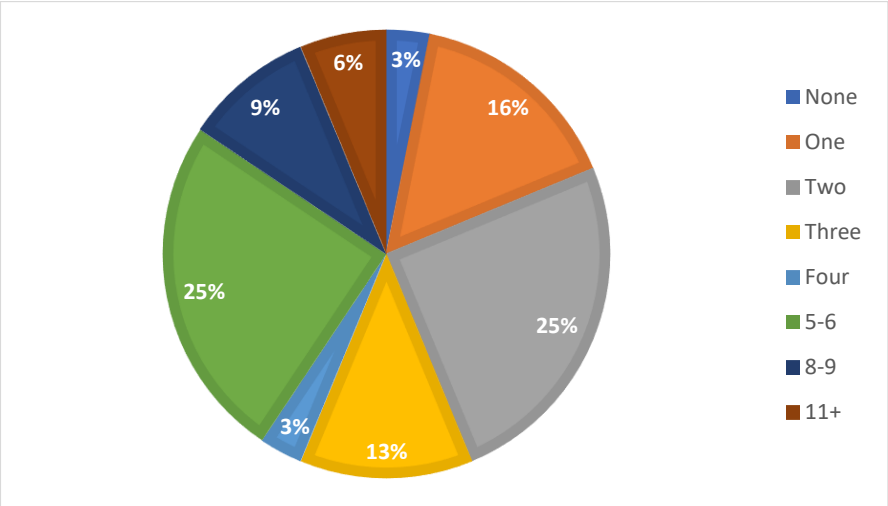

How many laser treatments have you had on your eyes in your lifetime?

53% have had at least one laser treatment.



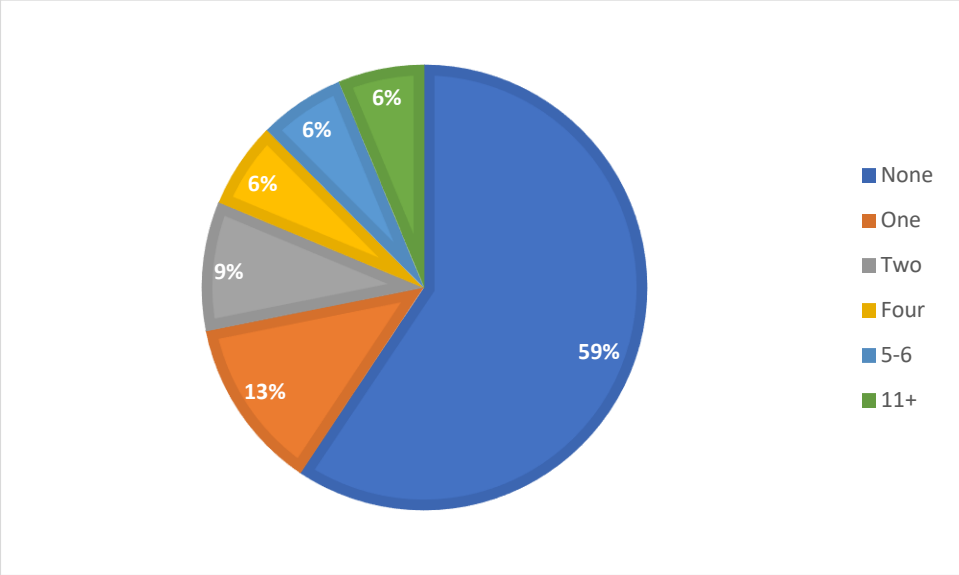
To date, approximately how many VHL-related surgical procedures have you had in your lifetime, requiring a GENERAL ANAESTHETIC?

97% have had a least one surgical procedure requiring a General Anaesthetic, 41% have had 5 or more.

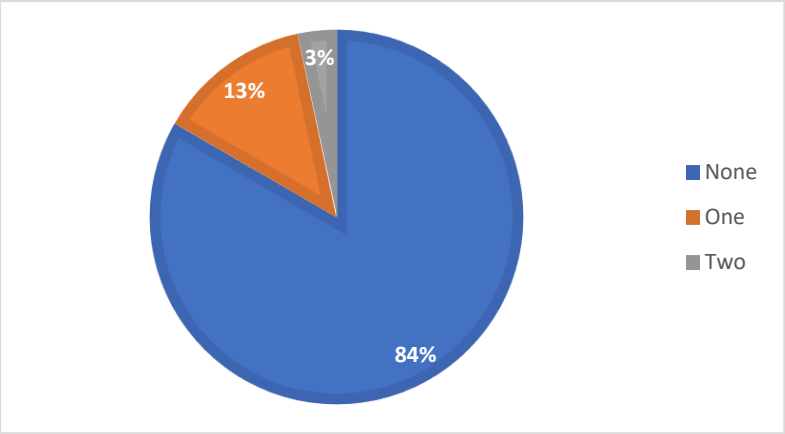



To date, approximately how many VHL-related surgical procedures have you had in your lifetime, requiring a LOCAL ANAESTHETIC? (NOT INCLUDING GAMMA KNIFE/ EYE LASER)

41% have had a least one surgical procedure requiring a local anaesthetic.

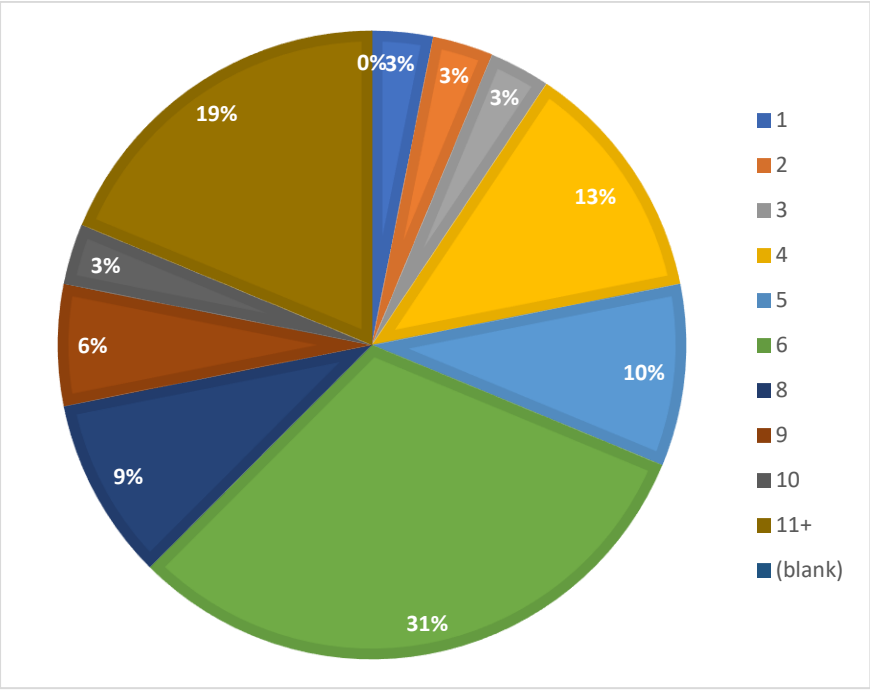


Approximately how many VHL-related Gamma Knife procedures have you had?




On average, in a 'normal' year, how many medical appointments related to VHL do you attend per year? (Include all hospital appointments, scans etc)

78% attend 5 or more appointments a year, 19% more than 10 a year:



## PATIENT IMPACT DATA

Below is the percentage of patients who say **SYMPTOMS** of VHL tumours has affected decisions on the following areas of their lives **at some point** (either rarely, occasionally, frequently or permanently):

- Mild Mobility Issues 56% (9% permanently)
- Severe Mobility Issues 53% (13% permanently)
- Change in sensation in at least one area of the body 59% (25% permanently)
- Inability to work or study 63% (9% permanently)
- Inability to do housework/ daily chores 66% (3% permanently)
- Inability to do leisure activities 69% (6% permanently)
- Issues affecting family or personal relationships 63% (6% permanently)
- Pain 72% (13% permanently)
- Anxiety 78% (3% permanently)
- Low Mood 88% (6% permanently)
- Clinical depression 41% (0% permanently)

| | Ever | Frequently | Permanently |
|---|---|---|---|
| Mild Mobility Issues | 56% | 13% | 9% |
| Severe Mobility Issues | 53% | 6% | 13% |
| Change in sensation in at least one area of my body | 59% | 6% | 25% |
| Inability to work or study | 63% | 6% | 9% |
| Inability to do housework/ daily chores | 66% | 9% | 3% |
| Inability to do leisure activities | 69% | 16% | 6% |
| Issues affecting family or personal relationships | 63% | 16% | 6% |
| Pain | 72% | 13% | 13% |
| Anxiety | 78% | 31% | 3% |
| Low Mood | 88% | 25% | 6% |
| Clinical depression | 41% | 9% | 0% |

Below is the percentage of patients who say **TREATMENT** of VHL tumours has affected decisions on the following areas of their lives **at some point** (either rarely, occasionally, frequently or permanently):

- Mild Mobility Issues 72% (16% permanently)
- Severe Mobility Issues 53% (13% permanently)
- Change in sensation in at least one area of the body 69% (28% permanently)
- Inability to work or study 69% (13% permanently)
- Inability to do housework/ daily chores 69% (3% permanently)
- Inability to do leisure activities 72% (6% permanently)
- Issues affecting family or personal relationships 59% (9% permanently)
- Pain 81% (16% permanently)
- Anxiety 78% (9% permanently)
- Low Mood 81% (6% permanently)
- Clinical depression 34% (3% permanently)

| | Ever | Frequently | Permanently |
|---|---|---|---|
| Mild Mobility Issues | 72% | 6% | 16% |
| Severe Mobility Issues | 53% | 3% | 13% |
| Change in sensation in at least one area of my body | 69% | 6% | 28% |
| Inability to work or study | 69% | 6% | 13% |
| Inability to do housework/ daily chores | 69% | 13% | 3% |
| Inability to do leisure activities | 72% | 16% | 6% |
| Issues affecting family or personal relationships | 59% | 16% | 9% |
| Pain | 81% | 6% | 16% |
| Anxiety | 78% | 22% | 9% |
| Low Mood | 81% | 19% | 6% |
| Clinical depression | 34% | 6% | 3% |

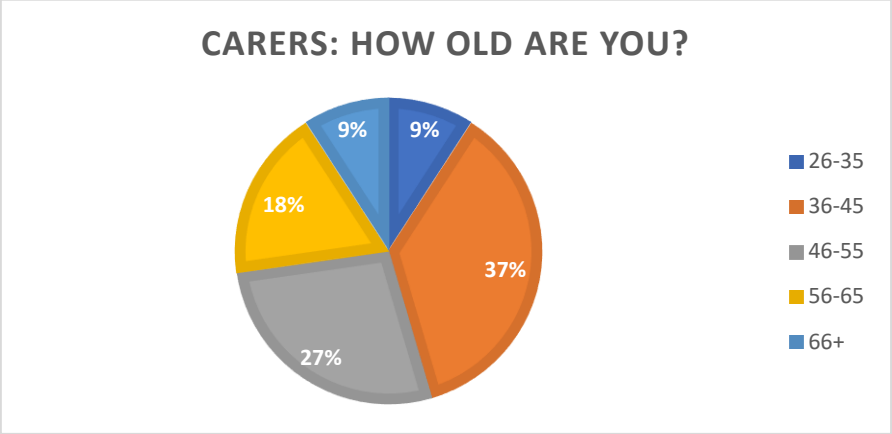
Below is the percentage of patients who say VHL has affected decisions on the following areas of their lives **at some point** (either rarely, occasionally, frequently or permanently):

- Career – 69% (22% permanently)
- Travel – 75% (13% permanently)
- Relationships – 69% (16% permanently)
- Family Planning – 75% (28% permanently)
- Finances – 69% (9% permanently)
- Social Activities -78% (6% permanently)

The number of patients who have ever experienced worry about scans and follow up appointments is 94% (22% permanently)

**CARERS**

11/39 respondents were carers for someone with VHL, the most common age range of carers was age 36-45 (36%)




Key findings:

- 73% of the carers were looking after someone under the age of 45
- 64% of the VHL patients they look after attending 5+ appointments per year. 82% of carers attended all of these.

Carers were asked how often VHL affected THEIR decisions on the following:

| | Ever | Frequently | Permanently |
|---|---|---|---|
| Career | 55% | 9% | 18% |
| Travel | 73% | 18% | 18% |
| Relationships | 45% | 18% | 0% |
| Family Planning | 27% | 9% | 18% |
| Finances | 55% | 9% | 9% |
| Social activities | 64% | 18% | 9% |

Carers were asked how often THEY experience the following due to caring for someone with VHL?

| | Ever | Frequently | Permanently |
|---|---|---|---|
| Inability to work or study | 73% | 27% | 0% |
| Inability to do housework/ daily chores | 64% | 9% | 0% |
| Inability to do leisure activities | 82% | 27% | 0% |
| Issues affecting family or personal relationships | 82% | 18% | 0% |
| Anxiety | 82% | 27% | 0% |
| Low Mood | 91% | 0% | 0% |
| Clinical depression | 36% | 0% | 0% |

Carers were asked how the following re scans and follow up appointments:

| | Ever | Frequently | Permanently |
|---|---|---|---|
| How often do you think THEY worry about the following... Scans for VHL | 73% | 36% | 9% |
| How often do you think THEY worry about the following... Follow up appointments for VHL | 73% | 36% | 9% |
| How often do YOU worry about the following... Scans for VHL | 91% | 27% | 18% |
| How often do YOU worry about the following... Follow up appointments for VHL | 91% | 27% | 18% |

**VHL RELATED KIDNEY RCC**

20/39 (51%) of respondents said they (or the patient they care for) had been formally diagnosed with VHL related Renal Cell Carcinoma (Kidney RCC).

- 35% of these said they have 1 or less than 1 fully functioning kidney
- 85% of these patients have had a least 1 kidney surgery, 25% have had 2 or more, 5% have had 5+
- Of those patients who have had kidney surgery, 70% said their longest stay after surgery was more than 5 days
- NO RCC patients had ever been offered any alternative to surgery as a treatment
- Kidney surgery (treatment) presents patients with significant post operative symptoms
- The presence and treatment of Kidney RCC nearly 70% of patients anxiety and/or depression at some stage

Respondents were asked how often they (or the patient you care for) experience the following due to SYMPTOMS of VHL related Kidney RCC?

| | Ever | Frequently | Permanently |
|---|---|---|---|
| Mild Mobility Issues | 33% | 0% | 6% |
| Severe Mobility Issues | 33% | 0% | 11% |
| Mild Pain | 50% | 11% | 0% |
| Severe Pain | 33% | 0% | 6% |
| Fever | 22% | 0% | 0% |
| Fatigue | 50% | 28% | 6% |
| Headache | 44% | 17% | 0% |
| Change in weight | 44% | 6% | 6% |
| Nausea | 22% | 6% | 0% |
| Anxiety and/or depression | 67% | 17% | 6% |

Respondents were asked how often they (or the patient you care for) experience the following due to TREATMENT of VHL related Kidney RCC?

| | Ever | Frequently | Permanently |
|---|---|---|---|
| Mild Mobility Issues | 72% | 6% | 6% |
| Severe Mobility Issues | 50% | 11% | 6% |
| Mild Pain | 89% | 6% | 0% |
| Severe Pain | 72% | 11% | 0% |
| Fever | 28% | 0% | 0% |
| Fatigue | 78% | 22% | 6% |
| Headache | 50% | 11% | 0% |
| Change in weight | 50% | 11% | 0% |
| Nausea | 39% | 6% | 0% |
| Anxiety and/or depression | 67% | 6% | 6% |

Several personal testimonials regarding VHL related Kidney RCC were shared with the charity and will be included in our submission to NICE. Some touch on the physical aspect or the impact on their quality of life but the most common hardship is lifelong stress, worry and anxiety that living with VHL RCC brings.