CYHU

CAN YOU HEAR US?

Community Feedback Summary

June 2020

LEARNING FROM
LIVED EXPERIENCE

Key Summary

Can You Hear US? (CYHU) is an organisation representing the lived experience of people with Neurofibromatosis Type 2 (NF2). Our services aim to empower patients to regain a sense of control over their lives and promote self-management strategies through education, peer support, and engagement.

An essential element in NF2 life is that of coordinated care through the UK NF2 Specialist Service. CYHU is unaware of any assessment of the impact this service has on the lives of NF2ers and their families (beyond the scope of the NFTI-QoL) however, anecdotally, as an organisation we have seen much evidence demonstrating the extent to which this service has positively empowered the clinical lives of those affected and it's life changing impact.

To ensure more constructive feedback was provided, CYHU sought to understand the experiences of the patients we work with, in context of their NF2 Specialist Clinic engagement, to provide insight to user experience within the service. To ensure wider access to feedback was achieved, CYHU concluded that an online survey was most appropriate for the needs of the CYHU community and allowed for anonymous responses. For the purposes of this document, we refer to those directly living with NF2 as 'patients'. Family members and caregivers are referred to as non-patients.

The survey was posted in 2 CYHU run facebook groups for both the UK NF2 Network consisting of family members, caregivers, and a number of patients (N=192) and the UK Patient exclusive group (N=117). Cross referencing was conducted to ascertain the number of patients in both groups and duplicate numbers leaving a total assumed non-patient respondent potential at N=118.

In total, 41 responses were received. 3 responses were identified as non-patient responses and due to the significantly low rate (less than 1%), non-patient responses were removed from analysis. Response rate was assumed as respondents from the patient only group, although we accept some marginal error due to unknown patients in the non-patient specific group, leaving 38 responses (approximately 32% response rate) included in the analysis. Age ranges consisted of U18 (1), 19-24 (1), 25-29 (9), 30-39 (11), 40-49 (9), 50-59 (4), 60+ (3).

Further to respondent profile and qualitative feedback, the survey contained statements covering 4 specific domains related to patient experience; Service Responsiveness, Clinician Communication, Access, and Decision Making. Responses were collected using a 5-Point Likert Scale to provide an ordinal measurement of opinions and beliefs and to avoid closed questions which can result in positive response bias. Each section included further opportunity to make comments. Additionally, two opportunities were provided at the end of the survey to provide general feedback and feedback specifically related to COVID issues. Participants were asked to consider only experiences in the last 3 years prior to Covid-19.

It is estimated that around 1,000 people are living with NF2, in England, at any one time (Nerve Tumours UK) therefore, a rough estimate shows that the CYHU online community accounts for approximately 11% of the NF2 population (Assumed England service users as no service exists in Wales and separate services exist in Scotland). The lack of fixed data however, means that we cannot provide accuracy.

When asked what was most important to respondents when using the service, responses were ranked in the following order. An 'other' option was offered but not utilised:

1) Clear and accessible medical information (34%)
2) Friendly and approachable staff (29%)
3) Fast response to queries and concerns (24%)
4) Regular contact between clinical appointments (13%)

The results showed a strong overall satisfaction with the NF2 Specialist Service and many noted the significant role the service played in their lives, including how much they value the service however, there are some key areas that should be considered and reflected upon. Inconsistency between services was highlighted in qualitative feedback and indicated a potential need for a policy of standardised service across the UK network. We understand that separate Trusts & Foundations operations may limit this and we acknowledge that the feedback in regards to inconsistency may be linked to patient expectations however, we recommend this be explored and clarity provided in both service standards and patient guidance to manage expectations

Key Findings

- Respondents felt strongly that they were treated with respect and dignity and given opportunities to ask questions
- Uncertainty around patient expectation, particularly in relation to what they should and shouldn't contact their clinical teams about
- Mixed responses to the perception of feeling pressured to make decisions around care and being 'told' what to do
- Feelings of being overwhelmed during appointments and the impact on a patient's ability to have clear discussions
- Desire to utilise more digital communication support options during appointments
- Need for clarity and communication of patient rights
- Concerns about lack of access and privacy in relation to psychological support

Further feedback and COVID related feedback

- The desire for ophthalmological presence in MDTs
- Welcome/information packs for patient clarity
- Patient 'check in' process
- Inclusion of more digital support resources
- Clarity around service activity in light of COVID
- Information provided around safety and future appointments

It was well acknowledged that the NF2 teams are experiencing incredible challenges during COVID-19 and the need for changes was widely understood and appreciated. Whilst it is also acknowledged that general guidance has been provided via Nerve Tumours UK, there is still apparent confusion over risks, potentially exacerbated by inconsistency of information provided by each clinic.

Summary of Recommendations

Following the results of the feedback to this survey alongside conversations occurring in the CYHU community, we recommended the following actions.

- Explore consistency issues across services
- Consider emotional and communication issues during appointments and their implications on informed consent
- Investigate viability in increasing digital access to clinical appointments. Ensure all communication support options are available to patients in accordance to the Accessible Information Standard
- Provide clarity around patient expectations of service provisions
- Reflect on relationship dynamics between clinicians and patients and the potential impact on patient empowerment
- Publish a COVID strategy to provide patient clarity
- Consider the introduction of patient experience assessment process
- Ensure psychological support offer is communicated clearly