**Evaluating the impact of information and support for people with Nystagmus in the digital age: A patient and carer questionnaire study**

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**Abstract**

**Background:** Nystagmus is a disorder of rhythmic, involuntary oscillations of the eyes and can be classified as either infantile or acquired. Whether it occurs in isolation or as a part of other visual or neurological disorders, it causes significant visual dysfunction and problems with social functioning. In this study we seek to understand ways in which people with nystagmus are currently supported across the UK and identify any geographical variations or disconnects between current practice and best practice, as judged by patients and their carers.

**Methods:** A nationwide, qualitative, cross-sectional, questionnaire study of people with nystagmus and their carers. Recruitment was achieved through specialist clinics, charity events, online advertisements and social media calls. Data was gathered using five, age-appropriate questionnaires which were completed and returned to the research team between November 2016 and August 2018.

**Results:** 184 respondents were included (89 carers, 47 patients aged 4-10 years, 5 aged 11-14 years, 4 aged 15-17 years and 39 >18 years). Notably, respondents rated social media as the best source of information they have received, even compared with face-to-face consultation with medical professionals. Additionally, only 33% of respondents had been offered visual impairment support. Notably, patterns of clinical practice and patient experience emerged according to geographical location, particularly provision of initial information and ongoing VI support.

**Conclusions:** This study highlights a significant variation in the support and information received by people in the UK with nystagmus. It also supports the role of charities and increasingly, social media in the provision of patient information. The study also highlights the need for standardized guidelines for the management of patients with nystagmus, particularly with regard to support and information.

**Key Words**

Nystagmus, support, information, visual impairment, charity

**Introduction**

Nystagmus is a disorder of rhythmic involuntary oscillations of the eyes1,2 and can either be infantile or acquired. Infantile nystagmus can be idiopathic or be associated with other eye diseases, neurological syndromes or low vision3,4, 5.Nystagmus is thought to affect 24 people per 10,000 in the UK, and treatment options are currently limited for the vast majority1. A range of visual impairments are seen in children, extending from driving standard vision to severe visual impairment6. Importantly, visual impairment can be underestimated by using static visual acuity tests alone as ‘real-world vision’ relies on the ‘speed of seeing’7 and various other factors for people with nystagmus. For example, static visual acuity tests do not take into account moving targets, judgement of speed, real-world lighting conditions or complex visual scenes. Furthermore, real-world vision in nystagmus is known to be affected by factors such as changes in vision due to head position, tiredness and stress7,8. For these reasons, inconstant levels of support and information are often reported by patients11.

It is known that there is a strong correlation between visual impairment and reduced social functioning1,3, 4, 9. Poor public understanding of nystagmus has been shown to negatively impact those with the condition10. Several studies have also demonstrated a correlation between interaction with low vision services and improvement in quality of life3,9,10.This study aims to gain insight into the current provision of information/support in the UK and its perceived benefit, in order to help shape the development of guidelines for information and support for nystagmus.

**Materials and methods**

The study has been granted ethical approval by HRA and East Midlands - Leicester South Research Ethics Committee (REC) reference 16/EM/0418. Data was anonymized by using a patient coding system. Data was stored on a password protected research computer and backed up onto a password protected hard drive. Hard copy consent forms, with the corresponding unique study identifier were stored in a locked filing cabinet in a locked research office.

Participants were identified through regional nystagmus clinics, via charity events and by website adverts through support charities including the Nystagmus Network, Albinism fellowship, Gift of Sight, and RNIB. Questionnaires were posted to participants with instructions and included a pre-stamped addressed envelope. Geographical boundaries were purely assigned according to standardised geographical regions in the UK rather than based on established clinical networks or deaneries

Inclusion criteria included people with nystagmus and their carers of any age that were eligible for care in the National Health Service. Exclusion criteria were people who felt unable to understand the questionnaire.

Informed consent was obtained from either the participant or parent/guardian either in a face-to-face interview with the research team or via a postal pack. Participants were made aware of their right to withdraw at any time.

Previously validated questionnaires12,13 were evaluated but none deemed appropriate for the objectives of this study. Bespoke questionnaires were created in collaboration with the Nystagmus Network charity and encompassed open and closed questions to evaluate specifically the impact of information and support. Five separate questionnaires were devised with age and group appropriate questions (appendix 1-5) and data was collected between November 2016 and August 2018.

Information collected included if the individual was certificate of visual impairment (CVI) registered (registered sight impaired), had contact with the Visual Impairment teacher service (VI teachers), or if they had contact with other visual impairment support such as that supplied independently by schools or other charities

**Results**

The survey was advertised as described in the paper and respondents were asked to contact the study team via a dedicated email address. 251 respondents made contact and of these, 184 returned completed questionnaires and consent forms giving us a recruitment rate of 73% of those who made contact. A total of 184 respondents were included in the study, comprising of 89 carers (of children aged <18), 47 patients aged 4-10 years, 5 aged 11-14 years, 4 aged 15-17 years and 39 >18 years from 12 geographical regions (Table 1).

[Table 1 here]

***Visual Impairment (VI) Support***

Seventy seven of the 137 (56%) of patients with nystagmus were certificate of visual impairment (CVI) registered (registered sight impaired). Of those registered, 55/77 (71%) received a form of VI support (Portage, specialist equipment). Of those receiving specialist VI teacher support, the most common frequency for support was 2-4 times per year. The median reported ‘benefit of support’ on a 0-5 scale (5= extremely helpful) was 4/5 (range 3-5).

***Charities and Support groups***

Eighty five of the 137 (62%) of respondents were aware of nystagmus charities and/or support groups. Of those aware, 65/85 (76%) had contact with a charity or support group. Helpfulness of charities and/or support groups to the person affected by nystagmus was rated at a median of 3.5 (range 1-5). Helpfulness of charities and/or support groups to carers was rated at a median of 4.5 (range 1-5). Notably, only 32/137 (23%) of respondents had been informed of charities/support groups by a medical professional. Overall those who engaged with a charity rated this as useful, and support the need for these services to be available.

***Preferred route of contact***

Participants identified social media and internet groups as their preferred route of contact for nystagmus support. Participants also identified social media as providing the most useful information about nystagmus. Sixty five of the 137 (47%) respondents rated popular social media sites, charity run websites and affiliated social media streams as providing the most useful information about nystagmus, compared with just 12/137(9%) rating face-to-face support from medical professionals as the best source of information.

***Medical Professionals***

Forty three of the 87 (49%) of carers and 17/49 (35%) participants aged 11+ reported that medical professionals provided them with enough clear information about nystagmus. Only 10/137 (7%) participants aged 11+ and carers rated medical professionals as their best source of information about nystagmus. Additional information desired by participants is shown in Table 2. Overwhelmingly, both carers and participants rated current internet and social media resources as their most useful source of information. Participant feedback of their experience of receiving information about nystagmus varied and is demonstrated in Figure 1.

[Table 2 here]

[Figure 1 here]

***Employment***

All participants in the 11-14 years questionnaire group had thought about what job they would like to do in the future, but none had received advice about future jobs with regards to nystagmus. Those answering the questionnaire for 15-17 year olds, wanted updated information as a young adult, as information had previously been given to their parents. 16/39 (41%) of >18 year respondents are employed full time.

***Geographical variation in responses***

Patterns of clinical practice and patient experience, reported through multiple questions, revealed a theme of geographical variation which was similar to that seen for the awareness of support groups (Figure 2).

[Figure 2 here]

**Discussion**

This study demonstrates that the experience of people with nystagmus and their carers in the UK varies with regards to information and support. Awareness of support groups and charities was lower than expected given the reported benefit of those receiving it and seems to be due, in some cases, to lack of signposting by medical teams. Few patients were recommended a charity or support group by their doctor and instead conducted their own research.

Overall, the perceived quality of information received from medical professionals varied, and many participants desired more information, particularly at the point of diagnosis. A large proportion of participants rated social media and internet resources as their preferred method of information, as well as the method which has provided them with the most useful information. This could reflect the increasing role of social media and other internet resources in patient information and support.

The majority of participants receiving visual support found it useful, but many reported having never been offered it. However, this could be due to limited data collected from these areas. A further study with a larger number of participants could strengthen or dispute this finding and would be needed to fully explore the impact of geographical location and clinical experience.

**Conclusion**

This study highlights the variation of support received by people in the UK affected by nystagmus. It identifies key areas which need to be improved, including receiving more information from professionals about nystagmus, charities and support groups and other sources of support. The study has shown a large variation in practice regards all aspects of support and information. It suggests that more robust guidelines or clinical care pathways may be required and that social media and other internet resources are likely to be instrumental in improving and standardizing this important aspect of clinical care.

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***Declaration if interests***

None of the authors have any financial interest in the work completed in this study.