



“If you talk to somebody that is sighted
they don’t understand”:
the experiences of adults with visual
impairment and sight loss
of NHS Outpatient Eye Care Services
within Shropshire.

EXECUTIVE SUMMARY

July 2015



Shropshire Rural Community Council



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Background: Shropshire Rural Community Council (RCC) was funded by a Healthwatch Shropshire Research Grant to explore patient experiences of NHS hospital eye care services in Shropshire. Shropshire RCC provides information and support for adults with sight loss in Shropshire, and through this work has gathered anecdotal evidence of difficulties for patients of NHS outpatient eye care services in Shropshire.

Nationally, there are almost two million people living with sight loss (1). This figure is set to increase dramatically and it is predicted that by 2020, the number of people with sight loss will rise to over 2,250,000. Furthermore, by 2050 that number will have risen to nearly four million, as a result of both an ageing population and a growing incidence of key health problems, such as obesity and diabetes which can cause sight loss. (2). One in five people aged 75 will have some sight loss and this rises to one in two aged 90 and over (1). Within Shropshire there are an estimated 10,940 people living with sight loss and of this total 1,330 are living with severe sight loss. This is an estimated prevalence of 3.6% which is above the national average of 2.95%. In Telford & Wrekin, it is estimated that 4,240 people have sight loss, with 480 having severe sight loss.

People with visual impairments or sight loss can often experience a rapid loss of independence and become socially isolated, often suffering depression (11). Consequently social withdrawal makes them a hard-to-reach group, until they come into contact with professionals who help with their rehabilitation. Shropshire RCC provides a service to adults with visual and/or hearing impairment or loss by running support groups across the county. The charity targets the growing numbers of older people who are experiencing age related sight loss, to enable them to remain as active and independent as possible, and to avoid social withdrawal, loss of independence and rapid decline in health and well-being which can often result from loss of vision.

Aims: Anecdotal evidence gathered through Shropshire RCC's contact with visually impaired adults within Shropshire suggests that they have some difficulties in their experiences of hospital outpatient eye care services.

The project aims to provide an insight into the barriers and challenges that visually impaired people face in accessing services. It aims to inform the ways in which the patient experience could be improved by demonstrating in which ways patients feel both disadvantaged and disabled by current practices. Finally, it makes recommendations on how the issues raised may be addressed.

Method: In line with the NHS goal of patient-centred care, it was felt that a small scale qualitative research project would best identify the users' views, and give them the opportunity to share their experiences.

The project was devised in two stages: in the first stage, participants took part in individual interviews, discussing outpatient services in order to identify areas of concern as well as good practice. Interpretative Phenomenological Analysis (20) was used to explore the participants' lived experiences and their interpretation of those experiences, and to identify themes across the dataset.

The second stage then considered in more detail themes that arose in Stage 1. A focus group considered areas of concern and asked participants for suggestions on how services might be improved. Thematic Analysis (32) was employed to answer the question in what ways people felt disabled and disadvantaged by their experiences.

In total there were 12 participants, three men, nine women, who had a variety of eye conditions and were widely distributed across the county. They were recruited through personal contacts and support groups.

Results:

Stage 1 highlighted the general nature of the everyday problems people with sight loss encounter, including the nature of sight loss as a hidden disability. With reference to hospital services, themes around the timing of appointments, the physical environment and communication highlighted the way people struggled. Consultants were generally held in high esteem. There was an additional theme around support and the various sources of support, such as official, unofficial and family. The everyday experiences of this group are in line with published literature and highlighted the limitations that sight loss imposes on an individual.

Stage 2 considered the themes from Stage 1, particularly: sight loss as a hidden disability, the physical environment, communication with the hospital and accessing support. It was found that there were two areas where people felt disadvantaged – communication and the environment. Whilst the environment theme concentrated on particular situations that were problematic, communication was a wider theme, encompassing appointment letters, access to information about certification and registration, links between the NHS and support groups.

Discussion:

The Environment: At RSH the corridor on Clinic 10, where patients have to wait for their appointments, was of particular concern for service users. It raised the question of the suitability for purpose and also the emotional impact the environment has on the patients. Being visually impaired in a restricted space frequented by both staff and other patients made the participants feel physically vulnerable and disadvantaged, particularly when there were hygiene concerns. The environment at PRH and Wrekin Community Clinic (35) were considered more favourably, because there was more space which alleviated the feelings of physical vulnerability. Particularly, at Wrekin Community Clinic, the walk-in patients are separated from the patients who are there for injections or cataract operations, which made participants feel as though their condition mattered. The reference to Clinic 10 being a “*cattlemarket*” reflects not just the numbers of patients, but that those patients feel devalued and that care feels impersonal.

The issue which was raised in respect of the Princess Royal Hospital was the signage. It was acknowledged by participants that it is difficult to find ‘a one solution fits all’, due to the variety of eye conditions and the differing levels of sight. Given the problems that signs present to the visually impaired, alternatives such as guides, trained volunteers or audio guides and colour coding, were suggested.

The everyday problems of getting around affected how people travelled to the hospital, although there was evidence that even those with the most sight loss retained some independence, because hospital visits were part of their routine. More broadly, travelling to any hospital presented a variety of challenges for the visually impaired, in terms of transport, whether that was by train (Hereford), bus, hospital transport, car or even on foot. This is particularly true in rural communities within Shropshire, where in some rural areas, buses are infrequent and taxis may be prohibitively expensive.

Communication:

Stage 1 participants discussed that the format of appointment information and requests for patient information was often inappropriate, being sent out in letters in regular font sizes, and therefore illegible for those with visual impairments. There was limited evidence of more user friendly formats, such as text-messaging being used. However, it is understood that this issue of notification format is being addressed now by the NHS central appointment system within Shropshire, and, during the time this research was undertaken, systems were undergoing change. The issue of third

parties, such as family members, being able to be informed of appointments is particularly important for this service user group, who may struggle regardless of the alternatives offered, or for those with memory loss. It is important that the preferred format, and the existence of a third party, is noted on health records, so that there is consistency of approach. However, the preferred format should be reviewed as needs change. (23)

The discussion around preferred formats drew attention to the access to appointments, particularly in terms of waiting times. Whilst the issue of waiting times is beyond the scope of this report in terms of making recommendations, it is nonetheless a matter of huge concern to patients, since they experienced delays and cancellations which meant the preferred intervals between appointments were not being adhered to. For those with age-related macular degeneration, these delays were of particular concern, as they believed their Lucentis injections were not being administered within the timeframe suggested by NICE guidelines. Patients believed these delays were due to the pressure of numbers within the ophthalmic clinics.

The participants also felt that there was a lack of joined up services, with poor communication between those services they accessed. For example GPs were seen as stepping stones to consultants, and as such were portals to care, but they were considered to be ill-informed about the roles of specific consultants and the certification and registration processes at times.

Secondly, the participants felt there was inadequate provision of information relating to support available post diagnosis. Although individuals were happy with the communication with the consultant when they saw him or her in person, and also with the support groups they accessed, the lack of joined-up services impacted on them and others they came into contact with. It was acknowledged that the consultant's time was precious, and that was spent explaining their condition rather than sign posting to further support.

The role of an ECLO (Eye Clinic Liaison Officer) was discussed: the importance of an ECLO's role is that it is patient focussed and looks beyond the disability per se to offer support to the individual. The impact of the support an ECLO can offer positively affects quality of life, by providing emotional support, signposting the patient to groups or helping with certification and registration processes. Whilst it was acknowledged that a previous trial of employing an ECLO at RSH was unsuccessful, it was also highlighted that that ECLO was not well supported in their role, having no allocated space to work in. This study also acknowledged that two members of the nursing team in the

Ophthalmology Department have undergone ECLo training, which was applauded by the participants. A study, published in 2013, has demonstrated that an ECLo provides a cost-effective alternative to nursing staff or consultants meeting the additional support needs of the visually impaired (38).

Participants were not always dealt with appropriately within the hospital setting and sight loss awareness training is considered to be vital. The 'My Guide' programme, from the Guide Dogs for the Blind, is being introduced into Princess Royal Hospital, and needs to be rolled out across Shropshire. In particular, patients need to be made aware if sighted guides are available, and that they may request them on arrival at the hospital; thus patients may avoid the indignity of being put in a wheelchair when they are capable of walking.

Throughout the accounts there is an acceptance of how things are, and there is little mention of complaints. However, patients do have a right to express their concerns and should know how to complain if they feel that is appropriate. Finally, Healthwatch Shropshire should continue contact with sight loss groups in order to fully understand these issues and to ensure the rights of those with sight loss and visual impairment are championed.

Recommendations:

ENVIRONMENT

1. The emotional impact of the environment needs to be understood and acknowledged by hospital staff and commissioners.
2. Royal Shrewsbury Hospital Clinic 10 corridor needs to be addressed by either
 - a. Improving the environment , i.e. moving the clinic to a new location
 - b. Allowing people to sit in the main waiting area, and improving communication to call them in to see the consultant (by intercoms, nurses, or volunteer staff)
3. Access around Princess Royal hospital needs to be addressed – by methods other than signage – audio, internet, or even by volunteer sighted guides.
4. Comparison with other eye hospitals may bring forward some suggestions for good practice, such as locally at Wrekin Community Clinic, and further afield, such as Manchester.

COMMUNICATION

1. All staff should be trained how to address the patients appropriately, from the moment they enter the hospital, not just within the eye clinics.
The My Guide programme should be rolled out further in PRH, and within RSH.
2. The visual awareness training should be extended to those working in GP surgeries, including GPs, who also need to be aware of up-to-date information about consultants and their specific roles, and made aware of the certification and registration processes, and wider community based support.
3. Formats for communication between hospital and patients should be discussed at the first appointment, and recorded on notes. The format of communication should also be reassessed according to changing needs.
4. Information links between hospital and support groups need to be built and maintained.
5. Information provided by support groups needs to be disseminated in an effective and timely manner. Information should be available when a patient needs it, not just when a volunteer group is available to hand it out.
6. The timely distribution of information and support may be facilitated by the employment of an Eye Clinic Liaison Officer (ECLO).
7. Patients need to understand the pathway their care is taking, and should be informed of both health and social care processes involved if appropriate.
8. Patients should be informed of their rights, and processes by which they could complain if they wish to.

KEY RECOMMENDATION:

Many of the issues raised here are covered in the RNIB's Low Vision Services Assessment Framework. It is therefore recommended that an audit according to that tool would enable services to be evaluated and reviewed, and identify potential gaps (see Appendix 4).