Shropshire Rural Communities' Charity

Making Shropshire a great place for everyone to live no matter what challenges they face

- Registered independent Charity
- Established in 1961
- Subsidiary charity “Healthwatch Shropshire”
- 30 Staff
- Over 150 volunteers
- Board of 10 Trustees
- Main offices on Shrewsbury Business Park
- Active throughout Shropshire, Telford & Wrekin

A little about us……

Local People *finding* Local Solutions *through* Local Projects

Strengthening communities & improving quality of life



- 600+ Voluntary & Community groups
- 4500 individual family carers
- Developing & delivering projects & services for wide cross-section of Shropshire's residents

Local People *finding* Local Solutions *through* Local Projects

Tackling isolation and vulnerability

Support and social activities for people with sight or hearing loss

Sight and Hearing Loss Support

Adults living with sensory loss in Shropshire Telford & Wrekin

Information and advice – Emotional Support – Practical Assistance

Emphasis on living full and active lives, independence where sensory loss doesn't hold you back!

Hearing Loss Support

- Help people adjust to hearing aids – home visits and clinic
- Work closely with Audiology across the hospitals and around the whole county
- Effective Hearing Programmes
- Partner with other organisations
- Support See Hear Van
- See Hear Exhibition

SLOG's!

- Information and Opportunity
- Increasing confidence/independence
- Fun activities, speakers, outings
- Varied & interesting programme
- Meet Monthly: Shrewsbury, Oswestry, Ludlow + Cycling!

Responding to people's concerns

- We are:
- A point of contact for people with sensory loss
- A source of information and help
- Independent and impartial
- Close to the ground- strong relationships with service users and families
- Able to help these groups have their voices heard

METHODOLOGY

Project Outline

Stage One

- To explore general experiences around sight loss and patient experiences of hospital outpatient eye care within Shropshire
- Individual interviews with a small group of participants
- Interpretative Phenomenological Analysis

Stage Two

- To explore the themes generated by Stage One, and consider recommendations
- Focus group
- Thematic Analysis

Qualitative v Quantitative Methodology

Quantitative: strength in numbers

e.g. cohorts drug trials

Statistical accuracy, errors and outliers

Qualitative: Sheds light on

individual experiences

reflect universal experiences

Allows participant to

tell their own story

Stage 1 - Interpretative Phenomenological Analysis

- Popular health psychology method
- Based on the phenomenological philosophy of Husserl and Heidegger, and explores the lived experience of the participants in the here and now, and their interpretation of those experiences.
- Procedure laid out by Smith, Flowers & Larkin (2009)
- Small number of participants (five)
- Semi-structured one-to-one interviews, with a schedule of open ended questions
- Transcripts analysed for themes within each interview and common themes across the data set.

Participant profile (patients' conditions have been generalised to protect anonymity)

Participant (pseudonym)	Gender and Age	Registered blind	Level of sight/ condition
Roco	Male, 67	Yes, within last 12 months	Blind in one eye, since childhood; corneal graft and poor vision in other eye
Dilys	Female, 75	Yes, circa 7 years ago	Blind in one eye, very limited sight in other eye. Glaucoma
Judith	Female, 55	Yes, circa 15 years ago	Blind in one eye, very limited sight in other eye. Glaucoma
Vera	Female, 88	Yes, within last two years	Blind in one eye, very limited sight in other eye. AMD
Imogen	Female, 67	No	Limited vision in one eye. Glaucoma/ Macular Degeneration

Stage 2 – Thematic Analysis

- Flexible qualitative method also used widely in health psychology
- According to terms laid out by Braun & Clarke (2006)
- "Essentialist" approach – reports experiences, meaning and reality of participants
- "Theoretical" approach- researcher driven looking for answers to specific questions
- "Semantic" approach – themes identified with the explicit or surface meaning of the data
- Focus group discussion (7 participants, 2 facilitators) around four specific questions generated from Stage 1
- Themes identified through notes, looking for patterned response

Participant profile

Name	Gender	Registered blind	Age	Level of sight/ condition
P1	Male	Yes	67	Severely visually impaired – No light sensitivity Glaucoma and complications of surgery
P2	Female	No	76	Partially visually impaired – wet AMD in both eyes, still able to drive
P3	Male	Yes	72	Severely visually impaired – Detached retinas in youth led to partial sight loss; more recently, AMD
P4	Female,	No	68	Partially visually impaired – diabetic retinopathy and diabetic oedema
P5	Female,	Yes	64	Severely visually impaired – Coreo retinal and macular degeneration
P6	Female,	Yes	n/a	Severely visually impaired – Diabetes retinopathy, macular oedema, macular degeneration
P7	Female	No - carer	69	No visual impairment

Ethical issues

- British Psychological Society's code of ethics.
- Participants were informed of what participation would entail; their right to withdraw during and after the interview; opportunity to ask questions.
- Timescale was agreed for withdrawing data, anonymity was assured and discussed with relation to pseudonyms and withholding identifying data.
- Whilst written consent was obtained, because of the difficulties this participant group have in reading, all forms were read to them.
- The researcher also gave careful consideration to sensitivity and vulnerability during the interview process. Where appropriate, the participant was pointed to sources of further information, such as support groups.

Key Themes

- **Personal responses to sight loss**
  social and emotional impact on the individual
  'It's the worst thing not being able to see people… cos you can't make friends the same'
- **Access and barriers to care and treatment**
  access, communication, timing of appointments
  'I said to my husband… "given that it's a sight clinic you'd have thought they would have had a big change of date"'
- **Support for people with sight loss**
  services, peer support, family members
  'Reception staff say "Go and take a seat" they don't sort of say to you where to take a seat'

Patient Experiences

Impact on the Individual

- Increased difficulty with everyday tasks
- Increased dependence on others- family
- Social isolation
- Loss of confidence
- Depression
- Helplessness, resignation, embarrassment, frustration and anger

'I'm careful every day out and about… it's the self-confidence that I did have I don't have when it comes to crossing roads and I don't like crowded places cos I bump into people and things…'

Access & barriers to care

'people that go to these places are very anxious I mean it's just for a pressure check for me but I still don't like going you feel a big het up about it'

Three key areas of concern…

1. **Communication with the hospital:**

- between hospital staff and patients

- from the hospital for appointments

'*from the psychological point of view it's sensitivity I feel that I now have to <u>indicate</u> sometimes in a polite and definite way that I can't see certain things*'

2. The timing of appointments

- cancellations and waiting times

'When I phoned up the Lucentis coordinator she would say "there is no chance you'll get an appointment in two weeks, you'll be lucky to get one in 4-6 weeks"'

3. The physical environment

- location, waiting area and signage

'when you're looking at a brick wall sort of thing it's just horrible and people coming through… with zimmer frames and guidedogs and everything you know we're doing this sort of thing almost putting your feet up on your chair that is.. that really is terrible'

Sources of Support

- Information and advice:

'clinicians and other professionals sometimes do not know what support is available or where to go for it'

'I just got a town guide and looked through organisations'

- Emotional support
- Rehabilitation and re learning
- Social and peer support
- Family members as carers: *'but you need a... sighted person to find out what, where and when'*

Key Recommendations

Environment

1. The emotional impact of the environment on patients needs to be acknowledged by staff and commissioners.
2. Royal Shrewsbury Hospital Clinic 10 corridor needs to be improved either by
   a) moving the clinic to a new location
   b) Allowing people to sit in the main waiting area, calling them in to see the consultant by intercom, nurses, or volunteer guides

Environment cont'd..

3. Access around Princess Royal hospital would be improved by methods other than signage – audio, internet, or even by volunteer sighted guides.

4. Drawing on best practice examples with other eye hospitals to inform improvement for good practice, such as locally at Wrekin Community Clinic, and further afield, such as Manchester.

Communication and Support

1. All staff should be trained how to address the visually impaired patients appropriately. The My Guide programme should be rolled out further in PRH, and within RSH.

2. Visual awareness training should be extended to GPs and staff in GP surgeries who also need up-to-date information about consultants roles, the certification and registration processes, and other support.

Communication and Support cont'd..

3. Formats for communication with patients should be discussed and recorded at the first appointment and reassessed as needs change.

4. Information links between hospital and support groups need to be built and maintained.

5. Information should be available when a patient needs it from local groups.

Communication and Support cont'd..

6. Access to information and support could be improved by having an Eye Clinic Liaison Officer (ECLO).

7. Patients need to understand their care pathway through health and social care processes.

8. Patients should be informed of their rights, and how to make a complaint.

Key Recommendations

Many of the issues raised here are covered in the RNIB's Low Vision Services Assessment Framework. An audit using this tool would enable services to be evaluated and reviewed, and identify areas for improvement.
(see Appendix 4 of the Report or copy of the Report available separately).

Questions & responses

Next steps:

where do we go from here…

Shropshire Rural Communities Charity

Tackling disadvantage in Rural Shropshire