

MINOPS Response to FDA

B. Information About the Use of Prescription Medication Information By People Who Are Blind or Visually-Impaired

1. How do people who are blind and visually-impaired currently get their prescription drug information?

MINOPS response:

Medicines Information Needs of Older People with Sight Loss (MINOPS) is a project conducted at the School of Healthcare Studies, University of Leeds, and receives funding from the Royal National Institute of the Blind (RNIB) and the National Lottery Research Grants fund, both funders are UK organisations. The research aims to find out what medicines information that older people with sight loss need, describe whether there are any gaps in current provision and how the situation can be improved. The study is qualitative in design and involves depth interviews with older people with sight loss, their carers and health care professionals.

Currently, we have collected half of our data and our preliminary findings suggest that in the UK, blind and visually-impaired people receive information about their prescribed medicines in the same standardised way that normally sighted patients do, that is in small print, on thin, folded paper and written in a highly technical style. In other words, very few provisions are made for the difficulties in reading that visual impairment brings about. As a consequence, few people with sight loss are able to access medicines information in a format of their own choice, such as Braille, large print or audio formats.

As a result, people with sight loss often have to resort to alternative strategies, such as remembering spoken information or asking another person to read information to them, or to ignore the information all together. Such strategies are imperfect, which leads to negative consequences which further disadvantage older people with sight loss:

- ?? There is a loss of privacy due to other people reading otherwise confidential information relating to healthcare.
- ?? Older people with sight loss do not become fully informed about treatments and services.
- ?? Older people with sight loss are less able to participate in decisions about treatment.
- ?? Most importantly, they run the risk of gaining less benefit from their medicines.

2 What aspects of visual impairment are important to addressing the issue of access to prescription drug information? What other factors might be important to addressing this issue?

Preliminary themes in our data point to a desire on the part of older people with sight loss, as well as those involved in their care, to have prescription drug information provided in a format of the individual's choice. This may be large print, in cassette form or, to a certain extent, in Braille. There does not appear to be a single solution that would suit all; rather, a variety is important. People with sight loss form a heterogeneous group and their

information needs and preferences vary. Therefore, it may be important to have medicines information in a variety of formats in order to cater for differing needs.

Furthermore, altering the format is not the only issue in the provision of information for people with sight loss. Layout and content are equally as important. Numerous studies (Raynor and Yerassamou 1997) have shown that medicines information is frequently written in a style of language which can be considered highly technical and will be difficult for most lay people to understand. In addition, the content of the medicines information must be relevant to the patient. Preliminary analysis of the data taken from the MINOPS project suggests that including exhaustive lists of potentially rare side effects can be off putting and this may have an impact upon people's decision to comply with their prescribed medication regimens.

3 How can essential drug information be effectively communicated to people who are blind or visually impaired?

As well as providing information in an accessible format and whose content is relevant to the patient, the data elicited so far in the MINOPS project highlights a desire for health care professionals to become more involved in the communication of essential drug information. For example, General Practitioners (family doctors), community pharmacists and nurses are cited by patients as having a potentially important role to play in the provision of medicines information. In the UK, General Practitioners prescribe the medication and may carry out periodic reviews in the case of repeat prescribing. Such reviews may offer the opportunity for information provision. In some cases, nurses are becoming more involved in medicines management, particularly for older people and pharmacists dispense medications.

The policy surrounding medicines information provision should recognise that sight loss is predominately an older people's concern, as a high proportion of people registered blind or partially sighted in the UK are aged over 65 years. People in this age group are by far the biggest users of prescribed medicines.

Early findings from the MINOPS project suggest that both GPs and pharmacists could equally play a role in the provision of medicines information. Pharmacists, in particular, could become a central resource for providing information in different formats (large print, cassette) and minority ethnic languages, available upon request. For example, standard written information provided by a pharmaceutical company could be stored on a computer or accessed online at the relevant company's website and the pharmacist could manipulate font size and perhaps layout to suit the user's requirements. Similarly, the pharmacist could have a member of staff record relevant and personalised information onto cassette tape upon request.

Alternatively, pharmaceutical companies could provide medicines information online, including text that can be enlarged, as well as sound bytes, which would be directly accessible by the user with sight loss. However, there are issues of how accessible this information could be, particularly to a generation of people unfamiliar with computers, and perhaps a health care professional could act as information 'broker' or 'infomediary' to the patient to help the patient find the information that he or she wants to know.

C. Information About Existing and Emerging Technologies (Including Internet-based Information Services)

7. What are the barriers to using these assistive technologies?

A PhD, which is currently being undertaken as part of the MINOPS project, concentrates on older people with sight loss and their perceptions of technology. In the UK, there is heavy investment in introducing technology in healthcare services and this includes the potential of the public using technology to access healthcare services. This is explained in further depth in the Department of Health document 'Electronic Health Horizons' (University of Newcastle, 2000).

Although work carried out for PhD is still quite immature, preliminary data collected thus far indicates that, while low-tech assistive technology such as magnifying glasses are in relatively common use, many older people with sight loss perceive themselves to be excluded from using technology. This could be on the level of using a computer to access healthcare services online, or using assistive technology, such as recordable medicine bottles. It is also interesting to note that by the term 'technology', all of the older people interviewed understand this as 'computers'. Moreover, the data suggests that reasons for feeling excluded from using technology fall in to a number of themes or categories. Firstly, older people with sight loss perceive a 'skills gap' which they see as disabling them from accessing applications such as the Internet. This may also have to do with perceptions of age and how they believe younger people are more able intellectually to learn how to use technology.

Secondly, sight loss itself is frequently mentioned as a barrier to using technology. For example, the older people interviewed in this study believe that because they cannot see the equipment, that is, primarily the screen and the keyboard, then computers are not designed or 'intended' for them. There appears to be little awareness of how computers can be modified, in the form of larger keyboards, talking software, text on-screen that can be manipulated to larger characters, websites that can be accessible to people with sight loss.

Another preliminary theme occurring in the data for this study is that of inclination. A number of participants interviewed claim that they are simply not interested in computers, partly due to the perceived skills gaps discussed above and because some older people see technology as something new, which is of little relevance to their lives, and has played little part in their past working lives and is simply 'not for them'.

Finally, the cost of technology is a recurring theme in the data as a perceived barrier to the uptake of technology. In the UK, Internet-enabled technology is relatively expensive for older people with sight loss who may have little income.

Naturally, the above comments come from data collected as part of a PhD which is less than a year old. Therefore, the emerging themes coming from the data and discussed above are still in a preliminary state. However, while there is top-level, government-sponsored encouragement of technology uptake in UK healthcare, the PhD aims to ask questions of a more fundamental, grass-roots level of how technology is perceived by people who are potentially excluded from this discourse, namely older people with sight loss.

References

Raynor DK, Yerassimou N. Medicine information: leaving blind people behind? *BMJ* 1997; 315: 268

Purves I, Wilson R, Gibson M. *Electronic Health Horizons*, University of Newcastle, 2000.

Royal National Institute of the Blind [www.nib.org.uk] (last accessed 15th June 2004)