2.1 Objectives

This study of patient information-seeking behavior prior to referral from primary to secondary care sought to answer the following simple, pragmatic, questions:

- How many patients searched the Internet for medical information prior to referral?
- How many patients called the NHS Direct telephone helpline prior to referral?

The frequency of Internet access (denominator) and use (numerator), and of NHS Direct awareness (denominator) and use (numerator), may be used to gauge the use of these modalities of health information provision.

The main study setting was general neurology outpatient clinics based in two district general hospitals in north west England. Other, similar, studies were also undertaken in a specialist clinic for cognitive, principally memory, disorders. The studies were conducted over the 10-year period of 2001–2010. Some publications relating to these studies and to the author’s interest in telemedicine have already appeared (Larner 2002a, b, c, d, e, f, 2003a, b, 2004a, b, 2005a, b, 2006a, b, c, d, e, f, g, 2007a, 2009a, 2010, 2011a, b, c; Doran and Larner 2010).

Medical information available on the Internet and from the NHS Direct telephone helpline may be conceptualized as technologically based modalities of care which transcend professional clinical boundaries. As such, the data reported may be of interest not only to neurologists but also to clinicians in all specialties who will inevitably encounter patients who have made similar self-directed searches for medical information prior to the clinical encounter. In other words, though the data are specific to one medical specialty during one 10-year time frame, they may be generalizable to apply to other clinical disciplines and may perhaps be used to predict future use of these services. Moreover, these data will be of interest beyond the realm of purely clinical disciplines, since they are of relevance to health services research, to those planning the future configuration of health-related services, and possibly also to sociologists, social and political scientists with an interest in questions of health care provision.
2.2 Methods

The methodology used to examine patient use of the Internet and of NHS Direct was simple and pragmatic, namely asking consecutive patients referred to general or specialist neurology outpatient clinics whether they were aware of these services, and if so whether they had used them. The frequency with which information about Internet and NHS Direct use was volunteered by patients, prior to specific questioning, was also noted.

For service users, the information and advice received was discussed as per patient preference, particularly to gauge whether this had resulted in patient harm or increased risk. All questions were posed during the course of the clinical consultation, not separate from it, usually at the end of history taking (anamnesis) and before neurological examination, since this information finding process was conceived of as being an integral part of clinical history taking. Hence, this was a pragmatic, ecological study, rooted in the context of day-to-day clinical consultation.

This approach was evidently subjective, dependent as it was on patient recall and hence open to recall bias, and moreover was not amenable to external validation, for example by checking through NHS Direct records of logged calls. Nonetheless, it conformed to the idiom of clinical neurological practice: clinicians cannot validate patient reports of, for example, headache or subjective sensory symptoms, but merely take patient report on trust. The data may therefore be taken to provide quantitative and qualitative information about the impact of the Internet and NHS Direct in the context of neurology outpatient clinic consultations. Hence, the approach chosen may be said to have face validity.

Questions were asked of all new patients seen in the author’s general neurology outpatient clinics undertaken at two district general hospitals in the north-west of England. For purposes of convenience, the study was undertaken between the months of January and March inclusive for each of the years 2001–2010 inclusive, thus permitting inter-year comparisons to be made. Study was also undertaken in the period July–September 2007 to permit an intra-year comparison with the January–March 2007 cohort to be made, to examine the (unlikely) possibility of variation in Internet and NHS Direct use with time of year. Some of the analyses reported pertain to all 11 groups thus studied, and referred to as the whole cohort (N=2,395), but most refer to the 10 annual groups, referred to as the annual cohort (AN=2,171) (Table 2.1).

2.3 Analysis

Data were analyzed by overall frequency of service use over time (2001–2010) and also by patient gender and age. Analysis by gender was chosen because of the traditional roles of women in delivering informal medical care and medical self-help and the relative reluctance of men to attend to self-health issues. Analysis by
age was chosen because of the tendency of older people to eschew the use of new technologies for health care (see Sect. 1.3). There were no analyses by patient ethnicity or socioeconomic class, since these data were not routinely collected. Empirically, the vast majority of patients seen in these clinics were of Caucasian ethnicity, consistent with the populations served by the hospitals wherein the studies were based.

As these studies were largely descriptive, statistical analyses have been kept to a minimum. Null hypothesis significance testing was used since this remains a standard inferential tool. Standard statistical methods ($\chi^2$ test) were used to examine null hypotheses that proportions were the same in the cohorts being compared (equivalence hypothesis), with $p < 0.05$ considered significant for rejection of the null hypothesis (Bourke et al. 1985).

Cumulative sum (cusum), a method used to identify trends in serial data, including clinical data (Wohl 1977; Kinsey et al. 1989), was applied to the annual cohorts. The method used was that outlined by Kinsey et al. (1989), namely, selection of a reference point (first year data gathered; = 2001 for IT, 2002 for NHS Direct); subtraction of this reference point from successive recordings and the remainder added to the previous sum, with this cumulative sum plotted against time. Using this approach, if successive datapoints are the same as the reference point, the cusum plot remains at zero, if the successive datapoints rise or fall the cusum plot likewise.

One way to represent the “impact” of the Internet and NHS Direct use on neurology outpatient clinics has been to adapt the “number needed to treat” (NNT) rubric, familiar from the description of clinical trial data (Cook and Sackett 1995), to calculate a new parameter, the “number needed to see” (NNS). Just as the NNT is the number of patients a clinician needs to treat with a particular therapy for one patient to benefit or avoid harm (hence, the reciprocal of absolute risk reduction), mutatis mutandi the NNS is the number of patients a clinician needs to see in order to encounter one patient who is aware of or has used the Internet or NHS Direct (hence the reciprocal of the proportion either aware of or using the service). This rubric, which like NNT immediately indicates clinical significance, was initially used to

<table>
<thead>
<tr>
<th>Year</th>
<th>January–March</th>
<th>July–September</th>
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<tbody>
<tr>
<td>2001</td>
<td>198</td>
<td>–</td>
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<tr>
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<td>2009</td>
<td>203</td>
<td>–</td>
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<tr>
<td>2010</td>
<td>267</td>
<td>–</td>
</tr>
<tr>
<td>Annual cohort (AN)</td>
<td>2,171</td>
<td></td>
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<tr>
<td>Whole cohort (N)</td>
<td>2,395</td>
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assess the impact of Internet use in patients attending neurology outpatient clinics (Larner 2005a), and was subsequently also applied to NHS Direct use (Larner 2005b, 2009a).

Analysis of these data by specific clinical diagnosis has been undertaken only for headache (Larner 2003b, 2004b) since this is the most common disorder seen in neurological practice, accounting for between 20% and 25% of patients seen in these general neurology clinics (Larner 2008a), a frequency commensurate with reports from other centers (Carson et al. 2000). A wide variety of headache types may be categorized, specific diagnostic criteria for which (Headache Classification Committee of the International Headache Society 1988; Headache Classification Subcommittee of the International Headache Society 2004) were used in these studies.

Separate studies of Internet and NHS Direct use have also been undertaken in the author’s specialist interest Cognitive Function Clinic (Larner 2008b) based at the regional neuroscience center, to assess service use by patients with cognitive disorders (dementia, mild cognitive impairment, and subjective cognitive complaints) and their carers (Larner 2002e, 2003a, 2007a), who are requested to attend these consultations to provide collateral history (Larner 2009b). Standard, widely accepted, diagnostic criteria for Alzheimer’s disease (McKhann et al. 1984) and other forms of dementia were used.

Monogenic Mendelian disorders, i.e., those inherited as a consequence of a single gene mutation, with autosomal dominant, autosomal recessive, or X-linked patterns of inheritance, are rare in general neurological clinics (Larner 2008c) and in specialist cognitive clinics (Doran and Larner 2009), likewise chromosomal disorders (Adab and Larner 2006) of which Down syndrome is the most commonly encountered (Larner 2007b, 2011d), but because of the wide ramifications of these diagnoses, both at the personal and familial level, the few cases encountered have also been examined. With a family history of disease, it might be anticipated that information seeking behavior would be more common, focused, and persistent.

References

References


Teleneurology by Internet and Telephone
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