A healthy option? The provision, access and use of health information by academics, professionals and consumers in the UK

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A HEALTHY OPTION?

THE PROVISION, ACCESS AND USE OF HEALTH INFORMATION BY ACADEMICS, PROFESSIONALS AND CONSUMERS IN THE UK

by

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Published work submitted in partial fulfilment of the requirements for the award of Doctor of Philosophy degree of Loughborough University.

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Abstract

This thesis explores the statement that the health information needs and behaviour of the general public, namely health information consumers are comparable with those of academics, health and social care professionals.

The research has been conducted in the broad Interpretist tradition, seeking to understand rather than merely explain human behaviour.

A model depicting the health information and knowledge environment has been developed to show the how the information behaviour of the various populations in the research are interpreted and where they are placed.

The provision, access and use of health information by consumers is the focus of the inner core of the model and is the first theme of the thesis. Several discrete groups of the information poor are investigated to explore their information needs and behaviour.

The middle layer of the model depicts the second theme of this thesis focusing on the attitudes of academics, health and social care professionals in their use and access of health information and IT in everyday practice.

The information behaviour of the health information and library professional is the focus of the third theme of the thesis and is represented by the outer layer of the model. This theme explores the detail and the contribution of the role to the clinical team, the use of Evidence Based Medicine and Clinical Governance.

Conclusions support the opening statement that the health information needs and behaviour of the general public, namely health information consumers are comparable with those of academics, health and social care professionals.

Recommendations are made to promote better and more frequent use of health information and health information professionals in the everyday practice of health and social care; to improve the access and provision of health information for consumers.
Keywords

Clinical Librarian
Consumer Health Information
Evidence Based Medicine

Health Information
Health Policy
NHS
Dedication

“They can’t take it away from you”

To my father and mother, Gerald and Maureen Mollart for their unwavering support of me throughout my educational journey, from Dursley to Loughborough; primary school to PhD.

To my husband Derick for his never ending patience, help and understanding.

To my son, James for always playing the piano whenever I needed to hear something relaxing.

To my sister Sandra who always has the time to talk and listen to me.

My love and thanks to you all.
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To Pam De Chazal, Sally Sargeant, Sahmuel Nikoi, Claire Honeybourne, Linda Ward and Ruth Lewis, I enjoyed uncovering the facts behind Library and Information Services and the prevailing professional attitudes with you, and, oh yes, all the laughs along the way!

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Co authored publications - a note

In accordance with the University requirements to stipulate the involvement and responsibility for co-authored works Janet Harrison (the author Janet Harrison was previously known as Janet Rolinson) contributions to works which are co-authored are indicated in percentage figures in brackets below.

Theme One: Consumer health information needs (Papers 1 – 8)


(33%) contribution. The author was co-investigator for this research project.


(100%) contribution. The author conceived the research project idea and formulated the paper.


(50%) contribution. The author conceived the research project idea and was Principal Investigator. This paper represents the literature review for the research.


(100%) contribution. The author conceived the research project idea and was Principal Investigator.


(50%) contribution. The author conceived and directed this research. The second author did the initial analysis.


(33%) contribution. The author initiated this research and was co-investigator.

(33%) contribution. I jointly initiated this research and was co-investigator.


(40%) contribution. The author jointly initiated this research and was co-investigator.

Theme Two - Part One: The information needs and behaviour of academics, health and social care professionals - Traditional use of information in the research environment. (Papers 9 - 10)


(60%) contribution. The author was the research associate for this research project.


(60%) contribution. The author was the research associate for this research project.

Theme Two - Part Two: The information needs and behaviour of academics, health and social care professionals - Use of information in the health and social care setting. (Papers 11 – 13)


(33%) contribution. The author formulated the idea for and directed this research project.


(70%) contribution. The author was Principal Investigator for this research project.

(70%) contribution. The author was Principal Investigator for this research project.

**Theme Three: The information behaviour of health information specialists (Papers 14 – 17)**


100% contribution. The author conceived the idea and formulated the paper.


(33%) contribution. The author instigated the paper.


(50%) contribution. The author conceived and directed this research. Second author did the initial analysis.


(50%) contribution. The author conceived and directed this research. Second author did the initial analysis.
PART ONE

OVERVIEW OF THE THESIS
A HEALTHY OPTION?

THE PROVISION, ACCESS AND USE OF HEALTH INFORMATION BY ACADEMICS, PROFESSIONALS AND CONSUMERS IN THE UK

0 Introduction
The research contained within this thesis is an exploration of the health information needs and behaviour of consumers, health information professionals, academics, health and social care professionals in the UK. It is assumed by the researcher that the transfer and dissemination of health information is complex and works on many different levels.

0.1 Focus of Thesis
The research is driven by a desire to gain an understanding of the continuum of information needs and behaviour of the individuals within these population groups, their environments and the interactivity between them.

In the title of this thesis, “A Healthy Option? The provision, access and use of health information by academics, professionals and consumers in the UK”, the use of the question mark is deliberate, implying whether or not all of the groups in the title have the same provision, access and indeed use health information in the same way as each other. The question mark also serves to imply that the group and individual social reality and interpretations of the social reality to be found in the research contained in this thesis indicates inequitable provision, access and use across the spectrum of these population and that there is not a “healthy, well balanced option” for all.

The research also highlights the particular context and viewpoints of each of the populations studied. The broad conclusion of the interpretations from the research is that all groups want the right information at the right time in the right format and that their needs are not always adequately met by existing provision.
0.2 Structure of the Thesis

The thesis is divided into two parts. Part One provides a commentary of the research undertaken and places it in the wider context. Part Two contains the associated published research papers.

1 The Commentary

The commentary in Part One describes the information needs and information behaviour of consumers, professionals and academics within health and social care in the UK. An information need as described by Case (2002, p.5) is a recognition that your knowledge is inadequate to satisfy a goal that you have. According to Wilson, cited by Case (2002, pp.75-76) information behaviour is defined as the totality of human behaviour in relation to sources and channels of information, including both passive information seeking, and information use. This also includes face to face communication with others as well as the passive reception of information as in for example watching television advertisements without any intention to act on the information given.

1.1 The Health Information and Knowledge Environment

The commentary places the published research in the wider context and also presents the methodological perspective used. Three themes are identified in the commentary, those of consumer health information needs, the information needs and behaviour of academics, health and social care professionals and the information behaviour of the health information specialist. To represent the focus of the research, Model (1), the health information and knowledge environment, has been developed. The commentary explains how each of the published research papers contributes to the three themes within Model (1). The various populations explored in the research and their information behaviours are interpreted and placed within the health information and knowledge environment.
Model (1)
The Health Information and Knowledge Environment
1.1.1 Theme One: Consumer health information needs
Represented by the inner core of Model (1), considers whether or not the need for health information by the healthcare consumer is met by the available media and the provision by the professionals in the health and social services.

1.1.2 Theme Two: The information needs and behaviour of academics, health and social care professionals
Represented by the middle layer of Model (1), considers the needs and activities of academics, researchers, health and social services professionals in their access and use of health information.

1.1.3 Theme Three: The information behaviour of health information specialists
Represented by the outer layer of Model (1), complements the research in the middle layer and inner core by reviewing the role and information behaviour of the information professional in the healthcare setting and their interactions with the health and allied health professionals in the pursuit, use and provision of health information in patient care management.

2 The Published Papers
Part Two provides the published research papers authored by the researcher to give support, clarification and interpretation of the commentary for Model (1) as described in Part One. The published work in Part Two is therefore grouped into the three specific themes established in Part One, that of consumer health information needs, the information needs and behaviour of academics, health and social care professionals and the information behaviour of health information specialists.

2.1 Research Approach
This section presents the overarching theoretical approach used in the research papers contained in Part Two of this thesis.

Within social sciences there exists a long standing debate and competing views about how "social reality" ought or should be studied. What are described as "Objectivism – Positivist or Constructionism – "Interpretism" have come to represent these two traditions. Depending upon the research questions a study that seeks to answer one or
other of the approaches is deemed more appropriate. Objectivism is the epistemology that states things exist as meaningful entities and that scientific research can obtain objective truth. “This underpins Positivism and is the cornerstone of the quantitative paradigm. Alternatively, Interpretism drawn from Constructionism is based on the interpretation of interactions and the social meaning people assign to their interactions”. (Nagy, Hess-Biber and Leavy 2006, pp.13-14). As Bryman says, this clash of ideas “represents a division between an emphasis on the explanation of human behaviour that is the chief ingredient of the positive approach to the social sciences and the understanding of human behaviour. The latter is concerned with the emphatic understanding of human action rather than the forces that are deemed to act on it”. (Bryman 2001, p.13)

From an epistemological standpoint therefore the published work contained in this thesis in Part Two, has been heavily influenced by the Interpretivist research tradition seeking to understand rather than merely explain the human behaviour studied. The main distinguishing features of the Interpretive/Qualitative paradigm are provided by Gorman and Clayton (2001, pp. 24-26) and Bryman (2001, pp.272-281) as follows:

1. **Seeing through the eyes:** This means viewing events and the social world of the people being studied

2. **Emphasis on context:** This is observing and recording data in the natural setting where events occur i.e.: recording people’s behaviour in context. The researcher can gain rich insight into the situation by being on site. Behaviour that may seem odd or irrational can make perfect sense when the context in which it takes place is understood.

3. **Description:** This refers to the description of the occurrences and what they mean for the participants usually using verbal narratives from the participants themselves, to ensure “the flavour of events” is included in the research; many details of the situation are recorded.

4. **Emphasis on Process:** This is to understand the events and patterns that unfold over time; to grasp the natural history of events essential to the research process.

5. **Induction:** This means using a bottom up approach, sometimes referred to as grounded theory, providing an explanation of the observed events rather than imposing a framework.
6. Flexibility and a lack of structure. What this implies is rather than deciding in advance what ought to be investigated; Qualitative/Interpretivist research favours an open strategy, with the possibility of coming across the unexpected. Rejecting pre-formulated theoretical frameworks in advance of fieldwork.

A broad Interpretivist approach is demonstrated by the research in the papers in Part Two, with an emphasis towards Phenomenology and Social Constructionism.

Phenomenology, according to the work of Schutz (1899-1959) as cited by Bryman (2001, p.13) is concerned with how the individual makes sense of the world around. It is not only a Philosophy but a research method for capturing the lived experiences. (Nagy, Hess-Biber and Leavy (2006, p.37). Phenomenologists insist on careful description of ordinary conscious experiences of everyday life (the life-world) a description of “things”. (Schwandt 2001, p.191)

Social Constructionism has an emphasis on the communal basis of knowledge as shared intelligently and processes of interpretation. The process of interpreting within Social Constructionism is aimed at a gaining understanding of social practices. (Schwandt 2001, pp.30-33). The key features of this perspective are: for any given situation there are an unlimited possible number of explanations and descriptions, in principal not practice one is not superior to any other. Secondly, within Social Construction, modes of description are derived from a relationship which gains meaning through language. Thirdly, that the relationships are bound within the broader patterns of practice and traditions. Finally, sustaining traditions and also challenging such traditions of understanding gives rise to reflection to suspend the obvious and listen to alternative framing of reality thus allowing for development of dialogue for the future. (Gergen 1985, pp. 4-7)

In Theme One, consumer health information needs, several papers 1,3,5,6,7 and 8, give evidence of Social Construction and Phenomenology.

In papers 6, 7 and 8 the Paradigm originated by Dervin cited by Case (2002, p.146) for Sense Making is drawn on and used. Specifically the Micro-Moment Time Line
approach is adopted for face to face interviews to explore the world of Informal Carers and People with Multiple Sclerosis.

In Theme Two, the information needs and behaviour of academics, health and social care professionals gives evidence of Social Constructionism in papers 12 and 13.

In Theme Three, the information behaviour of health information specialists, the research detailed in papers 16 and 17 exploring the experiences of Clinical Librarians, also provides evidence of Social Constructionism.

2.2 Research Methods

Whist it is acknowledged that the Interpretist tradition uses qualitative research methods to investigate information needs and behaviour, the use of the quantitative methods is evident in many of the research papers in Part Two of this thesis. These methods serve to gather background data or baseline data to inform a particular theme. The use of questionnaires in the research was designed to gain in-depth opinion from the participants, principally to understand their viewpoint, following the in the Interpretist tradition “seeing through the eyes”, by allowing free text commentary to be included in the data gathering instrument. The methods used in papers in Theme One, 4,5,6,7 all of the Papers in Theme Two 9,10,11,12,13 and papers 15,16,17 in Theme Three, all demonstrate this.

Several of these papers also employ the multi-strategy approach and quantitative methods for data collection principally to ensure Triangulation, (H1). This refers to the use of quantitative research to corroborate qualitative research findings or vice versa.; Facilitation (H2), this approach arises when one research strategy is employed in order to aid research using the other research strategy; and Complementarily (H3), this approach occurs when the two research strategies are employed in order that different aspects of an investigation can be dovetailed, Hammersely cited by Bryman (2001, p. 447).

The mixed methods approach is also defended in the literature by Wang (1999, p.57) by the term “Methodological – Pluralism”, a means of taking advantage of the
benefits that both quantitative and qualitative methods offer, allowing them to complement each other.

In all three themes of the thesis the use of Methodological – Pluralism and (H1) is employed; in Theme One, consumer health information needs this is evidenced in papers 3 and 6 by the use of a questionnaire and semi structured one-to-one interviews and in papers 7 and 8 by the use of a questionnaire and focus groups; in Theme Two, the information needs and behaviour of academics, health and social care professionals, paper 13 uses a questionnaire and focus group; in Theme Three, the information behaviour of health information specialists, paper 16 uses content analysis and a questionnaire.

Each paper presented in this thesis in Part Two explains the rationale and suitability for choice of the particular quantitative and qualitative method or methods used in that particular research setting.

In conclusion all of the papers presented in Part Two are describing and analysing research within the broad Interpretist tradition.
The Commentary Theme One

Consumer health information needs (Papers 1-8)

3.1 Introduction: Why the need for health information?
Theme One of this thesis is depicted by the inner core of the Model (1) and focuses on:

- The information needs of patients and their families, the general public, otherwise known as the consumers;
- The accessibility of health information sources for convenience and their use.

Health information consumers can be succinctly described as members of the general public who want to find more about their body and their health (Wellcome Trust 2005). According to Baggott, Allsop and Jones (2005, p.5) Williamson states that the “health consumer” can be seen as an interest rather than a commercial entity, with health consumer groups seeking to promote and represent a broad constituency of patients, users and carers”.

The World Health Organisation (WHO) defines health as “a state of complete physical, mental and social well being and not merely the absence of disease or infirmity.” WHO also state that to sustain and maintain the “physical mental and social well being” of a person then information about their own health status is required (World Health Organisation [n.d]).

3.2 Research Questions
The following questions were developed to inform Theme One and build the inner core of Model (1).

- How do the consumers identify and access health information?
- Where do they access information?
- What do they access?
- Is the Internet the preferred source of information?
- Had print and practitioners been abandoned in favour of the new technology?
- What type of information and library services are available for them to use?
- What type of provision is available in the NHS/Social care organisations?
• What type of provision is available in the voluntary sector?
• Is there equitable provision of information sources and services for the general public throughout the UK?

3.3 Traditional communication of health information

The inception of the NHS in the UK in 1948, (Beveridge 1942) is acknowledged as the first government service in the world to provide health care for its citizens from Cradle to Grave (Rivett 1997). Information needs of the citizens were not considered to be a high priority of this service. At the beginning of this research in the mid 1990’s health consumers were still principally called patients, and their information needs were still not considered a high priority by the NHS. It is acknowledged that the paternalistic provision of healthcare begun in 1948 in the UK still prevailed in the 1990’s (Rivett 1997). This paternal approach was also reflected in the information giving and communication with the patient.

The Parsons model (Parsons 1951) and its accompanying description of the relationship between doctor and patient is one that best describes the traditional roles adopted by both doctors and patients in the UK. In its simplest form (Fig.1), it represents the dissemination of information between the major players and shows the traditional power relationship between the healthcare professional and the patient/consumer.
3.3.1 The developing information needs and behaviour of healthcare consumers

The healthcare consumer has been slow to emerge in the UK. The gestation period can be traced via government legislation. A suitable beginning could be acknowledged as The Data Protection Act 1984 (Great Britain 1984) repealed in 1998, by the new wide ranging Act (Great Britain 1998) which made provision for
patients to view certain parts of their medical records. In practice this was not routinely taken up by the public. The public were acknowledged in their own right as information users. Whilst the NHS viewed this as a significant policy and practical move the public obviously did not grasp the significance. The Internal Market, detailed in Working for Patients (Department of Health 1989) signalled a definite shift in the provision and delivery of health care specifically separating the customer and provider role. Baggott, Allsop and Jones (2005, p.2) observed "that since the early 1990's, governments have introduced policies that have, at least symbolically championed the patient".

This evidence of more positive moves from the government towards consumerism and choice in healthcare was cemented by the introduction of The Patients Charter in 1992 (Department of Health 1991). The Patients Charter gave eight healthcare "rights" to patients, including rights 5 and 8 which deal with the right to information. However, the "rights," were as ever in a country without a written constitution, given without a supporting legal framework. According to Gann "information may not automatically lead to health, but without information consumers cannot take their first step." (Gann 1991, p.305).

The Information Management and Technology Strategy of 1992 (Department of Health 1992) also acknowledged the existence of a general public with information needs and the introduction of NHS Regional Health Information Service in 1993 (Rolinson, Maggs and Brittain 1993) was yet another signal to the general public that health information was beginning to appear on the national agenda as a recognised entity. It was apparent from these policy moves that there was shift in focus of both the NHS and Department of Health at this time.

Thus, the drivers for Theme One of the research were identified. Against this background of increasing awareness and recognition by the government of the existence of the health information needs of the public, the NHS gradually began to move towards meeting these needs. The NHS is by definition a national service, but local circumstances, available finance and resources almost always dictate local provision. Unfortunately for the healthcare consumer the implementation of a Department of Health policy can be very different in different areas of the country.
Against this background of a paternalistic information exchange between patient and doctor, together with the emergence of recognition of the information provision for the healthcare consumer, the author was interested to know if health information consumer needs were being identified and met by existing provision.

**Consumer health information provision in the Trent Region (Paper 1)**

In the light of this apparent shift in focus by the NHS, Theme One of the research was developed in 1996, to investigate how healthcare consumers wanted to access and use health information. The research began with a review of health information services for the general public rather than a specific health condition group. The research did not extend to seek the opinion of the general public about the services. The focus of the research was the implementation of Department of Health information policy in a particular NHS region. The findings may, or may not have been indicative of the rest of the country, therefore, should not be generalised. However it can also be argued that "often information behaviour defies generalisation". (Case 2002, p.5).

This research broadly contributed to the inner core of the Model (1), providing detail of how the general public use health services, but it does not specifically answer the question why they use these services.

However, this research does seem to resonate with the government policy of the time, the consumer was not completely at the forefront of Department of Health policy as another information management and technology strategy superseded the 1992 version in 1998 (Department of Health 1998a). Once again this was primarily internal looking, but nods towards the information needs of the public were discernable.

The arrival of NHS Direct service in 1998 (Department of Health 1998b) in Information for health and the White Paper, An information strategy for the modern NHS (Department of Health 1998c) both served the public well in consumer terms. The launch of NHS Direct in 1998 (Department of Health 1998b) could be viewed as the most significant move by the government to acknowledge the health information consumer. However, this nurse-led service, NHS Direct was principally designed to
alleviate the pressures on GP and Accident and Emergency services, providing 24/7 access for the public with the primary role of encouraging the correct use of NHS, providing health information was not designed as the primary focus.

3.3.2 The provision of consumer health information on the Internet
In contrast to accessing and using services provided by the NHS or social services and the voluntary agencies, the Internet has no third party intervention. Access can be gained anywhere at any time. The general development of the Internet and adoption by the general public is far from being for the exclusive use of the “information rich” professionals, as demonstrated by Castells in The rise of the network society (Castells 1996). He also stated that the separation between the consumers and professionals is clearly defined in a global context. It was clearly apparent that the consumers were “information poor and the professionals information rich” (Mazur 1993; Quinnon 1999). This digital divide concerning access is discussed at length by Katz and Rice and had noticeably shrunk in all dimensions: gender, age household income education, race and ethnicity, between 1995 and 2000 in the USA. (Katz and Rice 2002). The development of the Internet gave the public the opportunity to access whole swathes of health information including academic abstracts from the scientific community that were not previously available to them. The public’s thirst for health information via the Internet could be regarded as a beginning of their empowerment in consumer health terms. A discussion paper addressing the relevant issues resulted in Paper 2.

Consumer health information on the Internet – help or hindrance? (Paper 2)
It should be noted that paper 2 was written in 1998, a date considered to be at the relative infancy of the Internet, as indeed was the debate about the use of the Internet by the general public. This paper is exploratory and opinion-based, not empirically-based, never the less it raises the question of the availability of health information to the consumers via the Internet and questions the validity of that health information posted on the medium.

In summary it is suggested in Paper 2 that the general public would require good information retrieval and analysis skills if they were to interpret and use health information from the Internet correctly. Conclusions made were that insufficient
guidelines existed at this time to assist the health information consumer in information analysis. This opinion served to inform the inner core of Model (1) and shape the research in this theme.

Testing the research questions with different sections of the general public was the next step in the research process, especially to further inform the model about the use of the Internet by the general public as a health information provider/source. An interest in the provision of health information for disadvantaged / information poor sections of society was also key to building the inner core of Model (1).

3.3.3 The use of the Internet by health information consumers
One such section of society that the researcher wanted to investigate was adolescents. This group of the population is acknowledged as IT literate; both being taught with and growing up with the medium and yet could be considered to be information poor. Interestingly there has been a question in the Family Expenditure Survey/Expenditure and Food Survey since April 1998 (National Statistics 2003) asking about IT access in the home. The researcher wanted to know if the adolescents' extensive use of IT and the Internet for recreation was replicated in their need for and use of information about sex. The researcher was keen to discover if this age group had adopted the Internet as their major source of information provision. This research is documented in paper 3 and paper 4.

In the name of innocence: adolescents and information about sex.  (Paper 3)
Paper 3, gives an overview of the literature surrounding the provision of sexual health information for adolescents.

Health information for the teenage years: what do they want to know?  (Paper 4)
In this paper the questions surrounding adolescents' health information needs are explored, specifically those needs that are related to sex and sexual health. The project methods, results and conclusions are given in full.

This sensitive subject was addressed with 600 adolescents aged between 11-16 years in Leicestershire and Nottinghamshire, using schools to access the population. Twelve schools were chosen for participation in the project. This large sample size can be
regarded as reflective of the adolescent population in England and generalisation from the data can be drawn.

Surprisingly, the Internet was not identified as the preferred medium of communication by the adolescents in 1997. It would seem that the professional/consumer divide was still in evidence at this time. This research directly informed the inner core of Model (1) and adds to the literature.

The expanding role of the health information consumer was encouraged by the following legislation and cemented the government plans to involve the public in health care; The NHS Plan: a plan for investment a plan for reform in 2000 (Cm 4818, Department of Health 2000). Yet, the digital divide remained at this time as was acknowledged by Castells (2001). More signals for the changing role for the general public, the consumers and health professionals in managing healthcare in the UK were provided by the moves to involve the public and patients in health care by the Department of Health (2003) and the Wanless Report (Wanless 2004).

Subsequently the Internet has proved to be phenomenal success with the general public as exemplified by Nielsen’s Net Ratings (Nielsen/NetRatings, 2006). This medium is a boon to anyone and everyone who wishes to express an opinion without having to substantiate that claim with research findings (Willinsky 2006, pp.111-112). The scale of Internet access is now calculated at some 29 million adults in the UK (National Statistics 2006). Encouraged by these policy moves and the development of technology, the research to inform the inner core of Model (1) in this thesis continued with other groups of the public and specific health groups.

Use of message boards to help patients manage their own health: a case study of mouth cancer (Paper 5)
This paper explores the use and impact of the Internet for a specific patient group via an Internet message board by mouth cancer patients. This was a relatively small sample of patients however, the message board attracted world wide participants and is truly user focussed.
This work, some ten years after the research with adolescents, demonstrates the now easy acceptance of the Internet as a source of health information by the general public. Moreover the use of the Internet by this condition group is way beyond that of the passive user and evidence of patients advising one another rather than receiving advice solely from the professionals is clearly in evidence; thus challenging the Parsons Model (Parsons 1951) and changing the way health information can be communicated. This research clearly informed the inner core of Model (1) expanding the understanding of the health information consumer.

3.3.4 The use of health information by groups of the “information poor”

The inner core of Model (1) was directly informed by research with another group of the population that can be regarded as “information poor”; informal carers. It was found that informal carers numbered some 6 million people in the 1980’s (Green 1988). When this research was undertaken in 2000 it was estimated that approximately 9% of the population of the UK were acting as informal carers (National Statistics 2002). Yet this group were largely unknown and relatively silent in professional health and social care circles. The information needs of informal carers were then not well charted or acknowledged which promoted the researcher’s interest in identifying their information needs.

The information needs of informal carers: An analysis of the use of the micro-moment time line interview (Paper 6)

An Interpretist view was taken in this research, successful access was gained via questionnaire to over 2,000 informal carers. The data from this exercise was used as the basis for conducting interviews with over 60 carers using the Micro Moment Time Line Interview developed by Dervin (1998). Outcomes of the research revealed that different types and amounts of information are required by individuals at different times, (Rector 2001). Conclusions were that information needs of informal carers can be grouped along a time line continuum. Two distinct types of health consumer information behaviour emerged from this research “active and enquiring” and “passive and uninterested”. This was confirmed in the literature by Baker (1994) as “Monitors and Blunters”, the former being “Monitors” and the latter “Blunters”. This research informed the understanding of carers information needs and adds to the inner core of Model (1). The broad Interpretist approach used gives the research relevance
in the wider context and contributes to the literature. Carers are still very much a part of the health consumer landscape; in 2006 the first Director General of Social Care, David Benham said that 1.7 million patients rely on 5 million carers.

An opportunity to expand the research to investigate the information needs of another group of “information poor” consumers resulted in a research project funded by The MS Trust in 2002. (The MS Trust 2005). An investigation to identify the information needs of people with Multiple Sclerosis (MS) was the focus of the work. This provided an ideal opportunity to investigate the needs of consumers with chronic conditions and complemented the earlier research with informal carers who had been found to principally be looking after people with chronic conditions.

It is acknowledged that the majority of people require health information for a variety of reasons, including helping them to cope, to enable them to make informed choices about medical conditions and to gain information about specific conditions. (Booth and Walton 2000). Typically for people with MS, acute clinical episodes can be years apart; therefore the need for information by people with MS could be argued to follow the same pattern as the pattern of disease.

Papers 7 and 8 describe the research into the information needs of people with MS giving research methods, results, analysis, conclusions and recommendations.

**Information needs of people with Multiple Sclerosis and the implications for information provision based on a national UK survey (Paper 7)**

**A survey of information needs of people with Multiple Sclerosis** (Paper 8)

Prior to this research, little was known about the information needs of people with MS. This work adds to the body of knowledge in the literature. Access to people with MS was gained via a database held by the MS Trust. Some 4,000 questionnaires were mailed, resulting in a response of 2,500. This was the largest survey in the UK of this population. The results, not surprisingly, revealed a paucity of information provision for people with MS and a certain amount of mistrust of the medical profession’s willingness to provide information. The Micro Moment Time Line Interview methodology was again used (Dervin 1998); however this time it was in a focus group setting. Results showed, as for the informal carers, two distinct types of information
behaviour "active and enquiring" and "passive and uninterested" (Baker 1994) could be identified. Another type of consumer was also identified in the results, the "expert patient". The expert patient was identified as someone who is so well informed about their own condition that he/she probably has an equal and sometimes superior knowledge to that of the doctor. This information developed the inner core of Model (1). The existence of an "expert patient" results in changing the information provision process occurring between the professional and the patient and shifting of the balance of power between the patient and the doctor.

3.4 Theme One: Conclusions

The findings from the papers in Theme One can be shown to have a significant impact on the amended figure of communication of health information within the community (Fig. 2) and the development of the inner core of Model (1). The research shows that the "healthcare information consumer" is a complex animal with many different attributes. There is certainly more than one dimension to this consumer. The information required from the health and/or social care professionals is demanded in different media, both print and electronic. Moreover, information from other people with the same condition or symptom is also a vital element of information provision for the consumer. Face-to-face contact remains a favourite, preferred method of communication for many of the consumers, "I want to talk it over with someone" echoed throughout the research with the adolescents, the informal carers and the people with MS and indeed was strongly manifested in the mouth cancer study by talking on-line. In the NHS today, perhaps NHS Direct can be acknowledged to have met a certain need from a professional standpoint in providing a phone line with 24 hours cover, with a real person at the other end of the telephone. However, it is still considered that NHS Direct should be further developed (Webster and Williams 2005).

As evidenced by the research in Theme One, two distinct types of information behaviour by consumers emerge and are identifiable within the associated papers in Part Two of the thesis "active and enquiring" and "passive and uninterested" (Baker 1994). At one end of the continuum of health information consumers, lies the expert patient, who will challenge and or add to the professionals' knowledge (Nicholas and Huntington 2003). "The idea of an expert patient suggests a partnership relationship
with health professionals” (Baggott, Allsop and Jones 2005, p.287). At the other extreme of the continuum lies the traditional patient (Parsons 1951) who is quite happy in their role within the model of patriarchal mechanical medicine i.e. to be told what the doctor or other health or social care professional wants them to know. This type of development, of the health care consumer in a partnership role in the doctor/patient relationship found in this research, is acknowledged and critically discussed by (Scambler and Britten 2001, pp.25-45).

As confirmed by Baggott, Allsop and Jones (2005, p.286) “over the past decade a health consumer movement has emerged. There is evidence of a shared discourse, shared values and perceptions; there are networks of interaction and collaboration.” Time will tell if the Freedom of Information Act 2000 (Great Britain 2000) which was fully implemented in January 2005 will encourage the health care information consumers to gain greater confidence in accessing and using their own health data.

Slowly the healthcare information consumer has emerged in the UK with NHS Direct at the vanguard of government policy, the explosion of the Internet and an unrelenting diet of health information via print and other media. The research demonstrated by the papers in Theme One testifies to this development and adds to the literature.

The exploration of the journey of the healthcare information consumer only pauses here, more populations beckon the researcher. The following figure (Fig.2) reflects the findings of these papers in Theme One and highlights the inner core of Model (1):
Inner Core of Model (1)
Communication of Health Information within the Community

Continuum of Health Information Consumers

Active → → → → Passive

Listens / Receives / Uses / Gives Information
Expert Patient
Health / Social Care Professionals

Does Not Listen / Receive / Use / Want / Expect Information
Traditional Patient
Information Professionals
4 The Commentary Theme Two

The information needs and behaviour of academics, health and social care professionals (Papers 9-13)

4.1 Introduction
This theme focuses on the information behaviour from within the broad framework of academics, health and social care professionals. Despite the wide range of academics and professionals included in this theme, several research questions were identified as generic for all of the specific population groups:

4.2 The Research Questions
- How do the professionals/academics identify and access health information?
- Where do they access information?
- What do they access?
- What type of information and library services are available for them to use?
- What type of provision is available in the NHS/social care organisations?
- Is there an equitable provision of information sources and services throughout the UK?
- Do the various populations have atypical or typical information behaviour?

The overall population is divided into two groups, academic researchers and practitioners. The academic researchers contribute to original research thus ultimately feeding the information and knowledge base by the production of scholarly output. Their use of the information and knowledge base is in the accepted, traditional scholarly pattern (Meadows 2003). The academic role spans the university sector, the NHS and other government organisations, and also includes researchers working in the private and voluntary sectors.

4.3 Theme Two - Part One: Traditional use of information in the research environment
The first strand of Theme Two begins with an investigation of traditional use of information by academics in a research environment, namely biologists. This population group is acknowledged as directly contributing to the medical information
and knowledge base, which underpins the Model (1). Therefore, understanding and knowledge of their information behaviour can be viewed as an essential component of the middle layer of the Model (1).

**Use of information technology by biological researchers** *(Paper 9)*

**Information usage by biological researchers** *(Paper 10)*

Following an earlier study of academic scientific information behaviour detailed in the Royal Society Report (Royal Society 1993), the study reported in papers 9 and 10 was designed to discover if biologists acted in the same way as other scientists in their use of information and ICT. The research was funded by the British Library and designed to complement the Royal Society study.

Findings were consistent with the previous research in the Royal Society study (Royal Society 1993). There was a definite correlation between publication status and seniority, i.e. the more senior the personnel the greater their publication rate. Attitudes to the use of IT were similar in all grades of staff; an element of confidence ran through the results. In all four institutions the output of the biologists was positively contributing to the creation of the body of research materials for use by the academic, scientific, health and pharmaceutical communities. This grouping of researchers identified their information needs and showed them embracing IT as a suitable tool to extend and improve their own skills. The research successfully informed the middle layer of Model (1).

4.4 **Theme Two - Part Two: Use of information by professionals in the NHS and social care settings**

The practitioner role explored and studied is expanded beyond that of the medical practitioner to include those working in nursing, the allied health professionals and social care. The expansion of this population to include social workers is deliberate and is in line with the thrust of government policy to manage health and social care under one umbrella, as detailed in the Health and Social Care Act (Department of Health 2001). The health and social care professional is often regarded and acknowledged by the consumer as the “expert” providing information to the consumer at many different levels and times of illness and condition as confirmed by papers in Theme One of this thesis. The second part of Theme Two relates to the attitudes and
behaviour of those “experts” or in the words of Alford cited by Baggott, Allsop and Jones (2005, p.8) the “professional monopolisers” Twenty years later in 1995, according to Baggott, Allsop and Jones (2005, p.9) North argued that professionals and in particular the medical profession constituted a dominate interest. The widespread acceptance by society, in government and within the healthcare system, of their status and knowledge, and the supremacy and indeterminacy of biomedical knowledge has shaped the understanding of others.

The medical profession has traditionally used the scholarly information and knowledge base to identify and confirm successful practice and research, subsequently feeding into consumer understanding via the traditional model of doctor/patient relationship. However, Archie Cochrane’s pioneering work highlights an important information gap. Cochrane noted that “it is surely a great criticism of our profession that we have not organised a critical summary by speciality or subspecialty, adapted periodically, of all relevant randomised controlled trials” (Brice and Hill, in Booth and Brice 2004, p.15). Cochrane thus interpreted the actual use of information by the medical profession as neither rational nor systematic. Brice and Hill cited by (Booth and Brice 2004, pp.17-20) identify the political and social context that created the right environment for the development of Evidence Based Medicine, (EBM) and Evidence Based Practice, (EBP) in England in the late 1990’s. The recognised definition and understanding of EBM used by the government agencies stemmed from the original work by David Sackett (1996). The Department of Health and the NHS subsequently sought to rationalise and systematise the use of information by medical, nursing and allied health practitioners via the introduction of Clinical Governance, the new NHS: modern, dependable (Department of Health 1997) and Continuing Professional Development (CPD). Thus, encouragement for the use of EBM in the NHS was established.

Research papers in Theme Two-Part Two, explore the information behaviour and needs of several different populations of academics, health and social care professionals. This broad mix of professionals and practitioners thus acknowledges the scope of individuals that may be interacting at any given time with the healthcare information consumers, as identified in papers in Theme One.

25
Health professionals' attitudes towards evidence based medicine and the role of the information professional in exploitation of the research evidence (Paper 11)

This background and these drivers led to the commencement of research into this section of this theme in 1998. It is worth noting that the attitudes found in the research with Biologists in papers 9 and 10 are echoed in paper 11. A certain reluctance and some hostility towards the use of EBM was discovered amongst the health professionals. This research informed and contributed to the breadth of understanding in the middle layer of Model (1) and led to further understanding of the inner core of Model (1).

"New tricks for old dogs" providing an electronic acute current awareness service for clinical staff within the hospital setting within the UK (Paper 12)

A request in 2004 to the author from the Medical Librarian at the Greenfield Library, Queen's Medical Centre Nottingham, to evaluate their electronic acute current awareness service (ASCAS) for clinical staff was the impetus to continue this element of the research. This was identified as an opportunity "to move the librarian to centre stage in the policy arena, to bring the user focus to the forefront of all policy areas and, of course, to transfer skills and approaches to their own setting" (Brice and Hill in Booth and Brice 2004, p.21). However, the findings suggests that librarians still appear to unaware of the skills and needs of the user populations that inhabit the healthcare landscape, actual users of ASCAS were few. Both librarians and users may be heading in the same direction but along parallel not interconnecting tracks. This research served to inform the middle layer of the Model (1) and also provided insight into further understanding the outer layer of Model (1).

NHS/Social care interface: a study of social workers' library and information needs (Paper 13)

To further the research in Theme Two-Part Two, a study of the information needs of social workers was undertaken. It was assumed that social workers would reveal similar information needs and attitudes in using evidence in practice to that of medical or nursing staff and allied health professionals as identified in Paper 11. There were implications by association that hospital social workers were using information in a similar way their medical and nursing counterparts as part of the recognised multi-
disciplinary team. Surprisingly, some of the research findings resonated with findings from the information needs of informal carers project in Theme One rather than the medical staff in Theme Two. Often, informal carers did not want to be active and identified in the research as they feared repercussions from exactly the same source as the social workers, i.e. the local authority. This research also served to inform the middle layer of Model (1) revealing a contrasting range of information behaviours to the health professionals discovered in paper II and highlighting the broad range of differing attitudes and skills that exist within this spectrum of professionals and practitioners. Paper 13 reports the research in full.

4.5 Theme Two: Conclusions
The research in this theme has shown that academics, medical, nursing and allied health professionals have some similarities in their needs for, and attitudes to, using and accessing information sources. Within NHS professional and academics groupings, there is a certain amount of confidence displayed in using IT and information needs which can be associated with the existence of an accepted knowledge base. There are, however, differences between these groups and those professionals working in social services. The social services personnel did not display a great deal of confidence in using either IT or information. Therefore, creating information services and sources for both health and social workers that meet all needs is a challenge for the NHS and local authorities. It will need careful negotiation and appropriate service level agreements to be formulated if the challenge is to be successfully met. Similarly the inequality of provision and access to IT and information services observed between the higher education sector and the NHS will also need the same careful negotiation and thought process applied if a successful outcome is to be achieved.

Given that the NHS is not a corporate company and is frequently used in the political aspirations of the government to woo voters and that local authorities also have a political dimension, securing the use of evidence based practice in health and social services in everyday activities will be a difficult and time consuming task to achieve. What did emerge from the research was that there was a growing acknowledgment and acceptance of use of the knowledge base. "The changing attitude of society to the role and status of professional, allied to the increase inaccessible information, has
changed the relationship between patient and practitioner, and forced practitioners to examine more closely their abilities and skills in managing the knowledge so crucial to their performance and professionalism (Booth and Brice 2004, p.4). However, professionals may be better served by the Royal Colleges and professional associations who wish to encourage and lead professional development by use of evidence in practice rather than the NHS or Department of Health.

The middle layer of Model (1) is informed by a rich continuum of academics and practitioners information behaviour. It is proposed that sufficient data has been identified within this thesis to contribute to the construction of the model. It is however acknowledged that further research is required to gain a fuller understanding of this theme and development of the middle layer of Model (1).
The Commentary Theme Three

The information behaviour of health information specialists
(Papers 14-17)

5.1 Introduction
Who and what the health information professionals are in the NHS is the focus of Theme Three. The theme begins with a general perspective of the skills and education considered to be required for the health information specialist, and moves specifically to the role and information behaviour of the Clinical Librarian (CL) working within the NHS. Theme Three is represented by the outer layer of Model (1).

5.2 The Research Questions
The research questions developed to explore this theme and inform the outer layer of the model were:

- What are the skills and education required to undertake a professional health information/library role in the NHS?
- What are the roles and duties of the health information professional?
- Are these roles the consistent across the UK?
- How do the health information professionals interact with clinicians and public?
- Can information behaviour patterns be determined within the health information professional group?

5.3 The information behaviour of information specialists in health services

Growing hybrids: training and education for healthcare information management specialists (Paper 14)
The first opportunity to explore this theme came in 1993. The author obtained funding from the NHS to investigate the profile and behaviour of information staff employed
in the NHS Regional Health Information Services. On investigation of the NHS regional information services in 1993 in England (Rolinson, Maggs and Brittain 1993) it was found that they were often run by county librarians employed by the local authority. The location of the services was usually within a hospital. The purpose of the services was to provide health information for the public. However, as was to be expected, major differences in provision of the type and scale of service were found throughout the country. Differences were also found to exist between the staff employed in different services in respect of qualifications and skills. It was obvious to the researcher from the initial survey that the NHS needed to specifically cultivate, encourage and train information professionals within the organisation for the organisation to achieve a parity of service across the country. Subsequently the author organised and provided training for NHS regional information service professionals. These services were eventually subsumed into NHS Direct.

Paper 14 is a reflective paper by the author presenting a view of the education and skills required for the NHS information specialist. This informs the outer layer of Model (1).

**5.3.1 The information behaviour of Clinical Librarians**

In order to understand the work of the specialist Librarian in the NHS and further develop this strand of the research, a project was undertaken in conjunction with NHS library personnel. The roots for the Clinical Librarian (CL) are firmly based in the early work by Goodall (1954), Farmer (1977) and Lamb (1982). The CL can be identified as the information professional that trains, directs and assists the clinicians in understanding the evidence base. Therefore, it was considered essential to understand the information behaviour of CLs to successful inform and develop Model (1). In 2000 the Leicester General Hospital Trust funded a pilot scheme for a CL. Evidence to support this funding was provided from earlier work in this thesis (Paper 11, 1998). Therefore it seemed appropriate and timely to review the work of the CL in 2002 in an acute NHS setting.
A Clinical Librarian can support Clinical Governance (Paper 15)

This paper focuses on what can be achieved by a CL and the contributions that can be made to the clinical decision process. It also highlights some of the barriers encountered by the CL. It reports that the trial was considered successful and the NHS Trust subsequently funded a CL for two years. The paper concludes that the employment of a CL can assist Clinical Governance. Funding continues to be received for this post and the clinical library service has been subsequently enhanced. The research findings from this work contributed to the decision to continue the funding. This service can be considered to be the vanguard of the CL role in the UK. The research directly contributes to the literature base and best practice; the first UK Evidence based Librarianship conference was held in 2001 at Leicester General Hospital and “is viewed as a major landmark in the progress of the movement”, (Booth and Brice 2004, p.279). This research resulting from paper 15 successfully informed the outer layer of Model (1).

However, it has to be acknowledged, that one successful case study does not change a profession. The findings in paper 15 and the successful acceptance of the CL role by an acute NHS Trust motivated the researcher to explore the role of the CL nationally. Papers 16 and 17 provide focus of the CL role nationally.

Clinical Librarianship in the UK: Temporary trend or permanent profession? Part I: A review of the role of the Clinical Librarian (Paper 16)

Clinical Librarianship in the UK: Temporary trend or permanent profession? Part II: Present challenges and future opportunities (Paper 17)

One of the major research aims in this research theme was to discover whether core roles for the CL could be defined in the UK. In the exploration of the role certain areas of similarity were identified; however as usual in the NHS local circumstances dictated what could be achieved, what was allowed and what was funded. Therefore it was concluded that the role and responsibilities of the CL varied throughout the NHS. The research, however, did also identify that the role of the CL was regarded by some users as invaluable to the process of clinical management. In conclusion, the research points to a direct link to the success of the individual CL and to the ability of that individual to market their role and attract enthusiastic medical supporters. If this is
achieved the CL will enjoy a full and participative role in the multi-disciplinary team within the NHS. This work directly informed the outer layer of Model (1). Fig 2 shows the detail of the outer layer of Model (1) as informed by this research and the literature.

Fig. 3 Amendend model of communication of health information within the community

![Diagram](image-url)
5.4 Theme Three: Conclusions

The development of the role of the information professional within the NHS is delicate. Full acceptance of the role of CL has not yet happened in the NHS. The findings of this research confirm this. It is clear that the library and information profession must assist this process if information professionals are to become full members of the multi-disciplinary team. Successful information use may be the cornerstone of Evidence Based Medicine (EBM) but this fact has yet to reach the inner minds and hearts of the medical, nursing and other professions allied to health in spite of government guidelines. The NHS information professional for the most part remains on the outside of the multi-disciplinary team. Movements to change the shape of the NHS librarian are occurring, as is evident in Future Proofing the Profession report by the Health Executive Advisory Group, of the Executive Board of CILIP (2004). Palmer said that Health is an exemplar for the profession as whole (CILIP 2004, p.27). Certainly evidence based information practice is developing, (Booth and Brice 2004, pp.280-291). Clearly, the research in this thesis shows that much more action and research is required to assess this process and create acceptance of the information professional as an equal in the multi-disciplinary team. The outer layer of Model (1) has been informed by the research in this theme and contributes to the literature.

6 Limitations of the Thesis

6.1 Limitations: Theme One - Consumer health information needs

This theme addresses both the information needs of the general public and those of patients with specific conditions. Paper 1 has a regional focus and generalisation to the broader population could be seen as a problem. However, “information behaviour often defies generalisation” (Case 2002, p.5) and given the Interpretist standpoint adopted in the work for this thesis the paper should be considered as a valid contribution to the literature. Paper 2 is opinion-based, not empirically-based, and serves as a starting point for research into the use and provision of health information in society embracing the digital dimension. The research in this theme is not evenly divided between the two groups, that of the general public and the patients with specific conditions, five of the eight papers address the general public information needs, three address specific consumer groups. Paper 5, (Use of the Message Board...
by Mouth Cancer Patients) is the only paper in this theme that addresses the information needs of the acute patient. However, it is considered that the research papers did successfully inform the inner core of Model (1). More research is required to investigate the information needs of patients with acute conditions to inform and develop the inner core of Model (1). This is an area the author wishes to address in the future; mindful of the ethical and sensitive issues surrounding such research.

6.2 Limitations: Theme Two - The information needs and behaviour of academics, health and social care professionals
It is acknowledged that there is certainly more work to be done to understand the information behaviour of the various populations detailed in this theme to develop the middle layer of the Model (1). The theme begins with the research conducted with Biologists designed to show the scientific scholarly and traditional use of information by professionals aligned to healthcare. This could be seen as tangential to the main theme; however there are sufficient matches of the subject matter in papers 9 and 10 to health, to demonstrate a credible link, plus the work is nationally representative.

Papers 12 and 13 in the second part of this theme focus on health and social care professionals and are East Midlands centred and therefore could be seen as regionally biased. The relatively small number of participants reported on in papers 12 (n=45) and 13 (n=35) is also acknowledged as a limitation of the work, which would suggest that as in Theme One generalisation to the broader population is a problem. However, the same argument is presented to justify the findings “often information behaviour defies generalisation” (Case 2002, p.5).

The author acknowledges that more qualitative work is required with healthcare professionals to inform and develop the Model (1) further; the difficulty faced is that most healthcare professionals have capacity issues, namely time.

6.3 Limitations: Theme Three – The information behaviour of health information specialists
This theme represented by the outer layer of the Model (1) begins with a very early paper from 1993, which may seem dated. However, this is included in the thesis as it beginning of the research presented in this thesis into the education and role of the
information professional in the health care environment and is the basis for the later work in this section.

Papers 15, 16, and 17 focus on the role of the Clinical Librarian. Paper 15, does again focus on the East Midlands and highlights the question of generalisation and applicability to the wider population. Papers 16 and 17 continue this theme and do investigate the population nationally. It is however acknowledged that the numbers of these professionals were few in number; this is confirmed in the research, in 2002 only 14 practising Clinical Librarians were employed in the UK. The research presented did serve to inform the outer layer of the model and given the small number of professionals it is reasonable to accord papers 16 and 17 as nationally representative and valid contributions to the literature. It is acknowledged that the role of the information professional in the health care environment is developing as the recent special edition of the Health Information and Libraries Journal (Harrison and Prior 2006, pp.1-2) indicates. It is acknowledged that more research is required to inform and develop the outer layer of Model (1).

7 Further research

Further research has been undertaken by the author designed to give greater depth and understanding to all three themes identified in Model (1) given in this thesis.

7.1 Further research: Theme One - Consumer health information needs

Research in this theme continued during 2005 and 2006 with the North East Museums Libraries and Archives organisation (NEMLAC 2007), investigating the provision of health information and services available for the public in the NHS, Social Services and Public Libraries. The findings from this project informed both the inner core and the outer layer of Model (1).

A new strand of this research theme began in 2007 via the Public Library Partnership funded by Health - Link (2007). The purpose of the research is to evaluate the use of the public library by members of the public engaged in the NHS Choose and Book scheme,(designed to assist the public to choose a healthcare provider for secondary care), (National Health Service 2007). This is a national pilot scheme involving 9 Local Authorities, 9 Primary Care Trusts, 9 Health Libraries and 30 Public Libraries.
The research is planned for 10 months. It is anticipated that findings from this research will primarily inform the inner core of Model (1) and ultimately all three layers of the Model (1).

7.2 Further research: Theme Two - The information needs and behaviour of academics, health and social care professionals
In 2006 a Ph'D student under the supervision of the author began to research the use of information by clinicians in the UK across both the Primary and Secondary sectors. It is anticipated that this research will contribute to the development of the inner core of the Model (1).

7.3 Further research: Theme Three - The information behaviour of health information specialists
In 2006 the author led the Department of Information Science, Loughborough University research team in the evaluation of the National Service Framework (NSF) for the NHS National Library for Health in England 2006. This research involved consultation of key players within the health information field. The research will serve to inform government policy and will contribute directly to the development of the outer layer of Model (1). The author also edited the special edition of Health Information and Libraries Journal (Harrison and Prior 2006, pp.1-2) the research highlighted in this publication will also contribute to the development of the outer layer of Model (1).
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PART TWO

THE PUBLISHED PAPERS
The Published Papers

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To guarantee authenticity, a copy of the first page of the original article precedes each of the reformatted publications.

Janet Harrrison
March 2007
Theme One

Consumer Health Information Needs

Papers 1 - 8
Paper 1

Consumer health information provision in the Trent region

Caroline A. Stevens, Anne Morris and Janet Rolinson, 1996.

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Consumer health information provision in the Trent region

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Abstract: This paper reports the findings of a part of a larger study investigating the sources of consumer health information (CHI) available to the public, with particular emphasis on the use of electronic sources of health information. During the investigation discussions were held with managers and information officers of CHI services to examine provision. Detailed here are the services provided by the Trent region. In consideration of the emphasis on the use of electronic sources of health information, the availability of electronic public access community information systems as sources of health information within the Trent region of the UK is discussed, and the implications for such local government-run systems are reviewed.

Introduction

In recent years a variety of services have developed. In the light of these developments, a study has been carried out to investigate the sources of consumer health information available to the public, with particular emphasis on the use of electronic sources of health information. Part of this research has entailed an investigation into consumer health information services, the findings of which are reported in this paper. To achieve this latter aim, personal visits were made to several RHIS to discuss with the managers the service they provide, the sources of information they use and how they see the service developing in the future. A more in-depth case study of the Trent region was then undertaken. This involved having discussions with project managers and information officers of various CHI services within the region, including a town-based and a hospital-based service, to identify provision. The opinions and ideas recounted in this paper reflect the views expressed by the staff. Part of the wider research project has entailed an investigation of electronic public access community information systems as alternative sources of health information. Several such systems are operational within the Trent region and are explored using the data gathered from a mail questionnaire sent to all systems operational in the UK.

2. Consumer health information provision

The provision of consumer health information (CHI) is increasingly seen as being vitally important in enabling the public to take responsibility for maintaining and improving their health care. Providing health information gives the public the opportunity to choose healthier lifestyles, to assess the risks and benefits of alternative treatments, and to participate in self-care, possibly through the membership of a self-help group (Gann 1991). Informing consumers who are receiving health care has been shown to have positive benefits; increased patient understanding leads to greater compliance with treatment and a reduction in stress, thus aiding recovery (Boore 1977, Hayward 1976).

There is an assortment of health information sources available to the general public. The primary source is undoubtedly the GP (Buckland 1995; Griffin 1994) with the media — that is, newspapers, magazines, television and radio — representing the second most important source (Griffin 1994). GP surgeries and health centres provide leaflets on coping with illness and health promotion while telephone helplines such as the AIDS and national drugs helpline exist to provide information on specific health problems (Kempson 1987). A variety of CHI services have developed over the
Consumer health information provision in the
Trent region

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Abstract:

"This paper reports the findings of a part of a larger study investigating the sources of consumer health information (CHI) available to the public, with particular emphasis on the use of electronic sources of health information. During the investigation discussions were held with managers and information officers of CHI services to examine provision. Detailed here are examples of the services provided by the Trent region. In consideration of the study's emphasis: on the use of electronic sources of health information, the availability of electronic public access community information systems as sources of health information within the Trent region of the UK is discussed, and examples, of such local government-run systems are reviewed.

1. Introduction

In 1991 the government published the Patient's Charter (Department of Health 1991) which acknowledged the value of providing consumer health information (CHI) to the general public, giving them two 'rights'. The first gives patients the right to have risks and alternatives clearly explained to them before having treatment, and the second is the right to receive detailed information on local health services, including information on the standards of service you can expect, waiting times and local GP (general practitioner) services. Subsequently, in 1992, the government directed the Regional Health Authorities (RHA) to set up Regional Health Information Services (RHIS) with the aim of providing information to the public to empower them to become more active in relation to their own health care (Department of Health 1992).
In recent years a variety of services have developed. In the light of these developments, a study has been carried out to investigate the sources of consumer health information available to the public, with particular emphasis on the use of electronic sources of health information. Part of this research has entailed an investigation into consumer health information services, the findings of which are reported in this paper. To achieve this latter aim, personal visits were made to several RHIS to discuss with the managers the service they provide, the sources of information they use and how they see the service developing in the future. A more in-depth case study of the Trent region was then undertaken. This involved having discussions with project managers and information officers of various CHI services within the region, including a town-based and a hospital-based service, to identify provision. The opinions and ideas recounted in this paper reflect the views expressed by the staff. Part of the wider research project has entailed an investigation of electronic public access community information systems as alternative sources of health information. Several such systems are operational within the Trent region and are explored using the data gathered from a mail questionnaire sent to all systems operational in the UK.

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2.1. Consumer health information services

The first CHI services were developed in the UK in the late 1970s (Gann 1991). They remained few in number until the late 1980s, since when the array of services available has steadily increased. The impetus for the development of CHI services has come from two directions. Firstly, there has been an increasing demand for health information from the general public, illustrated by the growing number of health enquiries received by women's magazines and the increasing number of health-related radio programmes (Kempson, 1984). The growth of consumerism with the publication of hospital waiting times and the schools' league tables has increased the belief of members of the general public that they have a right to demand information giving them consumer choice. Secondly, government health policies have demanded that the services provided by health authorities must be more responsive to the needs of the public they serve (Department of Health 1990, 1991). These require that the public have access to health information to allow them to make more informed choices about their health care, and they resulted in the setting up of the RHIS (Department of Health 1991). Thus, the importance of the provision of health information to the general public had been acknowledged politically. This raised the profile of those services already operating and stimulated the development of new services.
2.1.1. Regional health information services. An explanation of the aim and role of the RHIS is provided by the Health Service Guidelines HSG(92)21 from the National Health Service (NHS) Management Executive entitled 'Implementation of the health information services' (Department of Health 1992). The aim of the services is 'to provide information to the public to empower them to become more active in relation to their own health and the development of health care policies and services.' The services are to provide 'accessible, comprehensive, accurate and reliable information which is relevant to users' needs and wants.' In order to achieve these aims, the regions were directed to establish an information centre, or centres, to collect, organise and update information, and liaise with other providers of health information including District Health Authorities, Family Health Services Authorities (FHSA), Community Health Councils (CHC) and Citizens Advice Bureaux (CAB).

The Health Service Guidelines (Department of Health 1992) specified the categories of information to which the public should have access as follows:

- charter standards;
- services the Health Authority has arranged;
- waiting times;
- common disease, conditions and treatments;
- how to complain about NHS services;
- maintaining and improving health.

The health authorities were required initially to provide access to the information service via a freephone telephone number. However, the regions were to consider further access by accepting written enquiries or providing a drop-in service for personal callers. Thus, Trent Healthline, the RHIS of the Trent RHA, was established (see Section 3.1).

2.1.2. Local town-based health information services. Local town-based health information services provide another source of information for the
general public. However, these services are independent of the RHIS and have generally developed on an ad hoc basis. Within the Trent region there exist several such services. In its 1994 annual report (Trent Healthline 1994), Trent Healthline lists 10 such local health information centres, namely:

- Sheffield Healthline;
- Rotherham Health Advice Centre;
- Long Eaton Health Information Service;
- Derbyshire Health Information Service;
- Nottingham Health Information Service;
- Nottingham Self-Help Team;
- Lincolnshire Health Information Service;
- Leicestershire Health Information Network;
- Loughborough Health Information Centre;
- Doncaster Health Shop.

The service provided by one of these services, Rotherham Health Advice Centre, is described in this paper (Section 3.2).

2.1.3. Local hospital-based health information services. Recent years have seen the development of health information services provided within hospitals. Again these are independent of the RHIS. One such example is HealthFacts, available at the Queen's Medical Centre (QMC) in Nottingham (see Section 3.3).

2.2. Electronic, public access, community information systems

The CHI services mentioned above rely on personal interaction for the communication of health information. An alternative method of supplying health information is the use of electronic public access information systems that are, in theory, able to provide health information anonymously, at a wide variety of locations and 24 hours a day. These public access systems may supply health information either alone or as one component of a larger community information package. Two examples of the former systems currently in use in the UK are PIPs, developed in 1993 by Sue Jones (Jones 1994), formerly Manager of Open Health, the South Western RHIS; and
Healthpoint, devised in 1988 by Ray Jones at the University of Glasgow (Jones 1993). These systems provide detailed health information on conditions, treatments, self-help groups and relevant literature. However, these systems are available in only a limited number of regions of the UK.

Electronic public access information systems which provide community information are usually managed by local authorities (for example Merlin (was called Themis) (Baker 1988), Gloucestershire's Viewdata system and HARVIE (Forster 1991), Harlow's Viewdata). They frequently provide health information as just one category of a wide variety of local community information, including council information, clubs and societies, and places of worship. However, the health information available on these systems is often limited, focusing mainly on contact names and addresses for health related organisations. There are a number of public access information systems available in the Trent region, including INFOLINX run by Leicestershire County Council and LINNET run by Lincolnshire County Council. The health information available on three examples of these systems within the Region is reviewed.

3. Consumer health information services within the Trent region

As indicated previously, three CHI services within the Trent region are reviewed, namely:

- Trent Healthline, the Trent RHIS
- Rotherham Health Advice Centre, a town based health information service
- Health Facts, a hospital-based service within the Queen’s Medical Centre, Nottingham

3.1 Trent Healthline

Trent Healthline caters for the geographical area of Barnsley, Derbyshire, Doncaster, Leicestershire, Lincolnshire, Nottingham, Nottinghamshire, Rotherham and Sheffield. The service is located in a Health Centre in Nottingham city centre, close to a large shopping centre. Prior to the
establishment of Trent Healthline, Health Promotion Officers were available on-site to provide health information and this site was, therefore, already associated with health information provision when Trent Healthline was established in 1992.

According to the NHS Management Executive requirements, Trent Healthline provides access for the public via the national freephone number or to those who write or call in personally for information. The service receives an average of 1800 telephone calls per month and 150 personal visits. Eighty-two percent of the calls are from the general public with 18% from professionals. As the service is situated within a Health Centre it is easily and ideally accessible to people visiting the GP within that local area and using other Health Centre services, such as the nurse. Furthermore, it is a location where the public may sensibly expect to find health information and be comfortable in pursuing health information enquiries.

3.1.1. Information provided and sources used.

The information provided by Trent, Healthline is, as specified by the Department of Health, on conditions, diseases and treatment; local NHS and related services; self-help groups; waiting times for hospital treatment; maintaining and improving health; patients' rights; complaints procedures; and charter standards.

Trent Healthline uses a variety of sources for the health information it provides, including reference books and electronic sources such as databases and CDROMs, as detailed below.

(1) Helpbox is a database produced by the Help for Health Trust (Gann 1991) and consists of five files:

- a national file which contains information on national organisations;
- a local file containing information specific to the local community.
including complementary health sources; a books file which contains
details of consumer medical health books;

- a leaflets file;
- a file of audiovisual aids.

The database has the facility to allow the input of local data. Local health
advice centres in Rotherham, Sheffield and Leicester have access to this
database. These centres send in their local information to Trent Healthline
and in return they are able to use the books and leaflets files. There are a
number of other sites subscribing to the data, such as the Queen's Medical
Centre and the City Hospital in Nottingham.

(2) NHS A-Z is another database developed by the Help for Health Trust,
which is a guide to the NHS. It provides details on how to complain, what
services are available and how to access them, and how the NHS is funded. It
also provides information such as under what circumstances abortion is
available and discusses the relevant Acts.

(3) WaitLine, also developed by the Help for Health Trust, provides waiting
times data on hospitals and surgeons.

(4) MDX Health Digest displays consumer health information and scans
journals for articles.

(5) PatientWise is aimed at GPs and provides information on conditions such
as: what it is, why it occurs, treatment, what to watch for, self-help groups,
and how the family is affected.

(6) MEDLINE, on CDROM, provides health professionals with abstracts from
medical journals.

(7) Mayo Clinic Family Health Disc, available on CDROM, gives detailed
health information using multimedia with both sound and moving video
pictures. Unfortunately it is produced in America and, therefore, the
information is provided with an American accent and uses American
terminology.

Another source of health information available at Trent Healthline is provided
by staff of the local Health Promotion Unit (HPU) (part of the Public Health
department of the Health Authority), who attend the clinic and are qualified to
take blood pressures, and can talk knowledgeably on subjects such as diet.

Trent Healthline has a number of plans for ensuring that the information it provides is as up-to-date as possible. In the near future, Trent Healthline is hoping to get online access to the database produced by the NHS Centre for Reviews and Dissemination. This database provides the NHS with information on the effectiveness of treatments, and the delivery and organisation of health care in order to promote research-based practice in the NHS. Information on treatment outcomes is already seen as being very useful to purchasers, but there is an increasingly recognised need that this information also needs to be given to the public. The public needs up-to-date information on recent research in order to make informed choices, and from April 1996 the RHIS will be required to make this information available to all enquirers.

Trent Healthline is also hoping to get access to the Cochrane database, provided by the UK Cochrane Centre. The Centre forms part of an international network called the Cochrane Collaboration which is committed to preparing, maintaining and disseminating systematic reviews of research on the effects of health outcomes. It provides, on CDROM, the most up-to-date information on existing and developing medical technologies.

3.1.2. Advertising of the service.

Trent Healthline employs a Publicity Officer who organises press releases on various conditions, treatments and diseases from time to time. Trent Healthline provides leaflets in libraries, CABs and community centres, advertising its service. It also gets involved with national campaigns such as Condom Week, where free condoms were provided in local public houses. The service advertises its telephone number in a local paper which does a weekly health page, and staff give talks in hospitals.

Trent Healthline staff would like more national advertising of the RHIS. When the freephone service was first launched nationally the RHIS received a great response. The telephone number was available as a credit card-sized leaflet
which could be torn out of the *Radio Times* and kept for future reference. However, there is now no money for national advertising.

3. 1. 3. Assessing the service
To assess the service it provides, Trent Healthline encloses questionnaires with the information packs it sends out to enquirers. Also, members of the local CHC anonymously telephoned into the service requesting health information, and subsequently completed a questionnaire evaluating the service they had received. The staff reported the findings of an independent study of the RHIS carried out by a consumer magazine, in which Trent Healthline was evaluated highly. It was found to give accurate information, was courteous and used the most appropriate sources for its information.

3. 1. 4. Future developments of the service.
Staff at Trent Healthline are concerned with a number of future developments in the service. Major changes in the provision of RHIS are expected in the near future. At present RHIS are financed by RHA. However, April 1996 saw the abolition of the RHA, to be replaced by Executive Regional Offices directly responsible to the Department of Health. Since 1992, the source of funding for the Trent RHIS has been the Trent RHA. However, the abolition of the RHA and the associated contract for services has created a natural anxiety within the RHIS, and fears for its future.

From April 1996 the RHIS, or its successors, have been directed by the government to provide treatment effectiveness and outcomes information to the general public such as that available from the Cochrane Centre. Evidence-based research results are to be used to provide the most accurate and established treatment information to the public, thus enabling them to make choices concerning the best treatment available for their condition. To meet these future demands, Trent Healthline has already produced one booklet detailing the treatment outcomes for various types of depression.

There is much emphasis at present on patient empowerment, a demand which the RHIS is attempting to meet. However, Trent Healthline believes that
the CHC will play an increasingly important role in meeting this aim. One difficult aspect to achieving the aim of patient empowerment is allowing access to health information to those people who do not use the service, such as ethnic minorities, travellers and the general public in social classes 4 and 5. Trent Healthline stresses that it is important that people know their rights and have access to services. Giving information to the consumer assists empowerment and can ultimately lead to redirection of services. Self-help groups act as very good channels for information and for providing empowerment: for example, the National Childbirth Trust publishes latest research results. Trent Healthline feels that at present the RHIS acts as gatekeeper because it decides what information to pass onto callers, and it is important for this situation to change in favour of the consumer.

Trent Healthline feels that electronic public access information systems could be used to provide health information to the general public. There is a great deal of readily accessible information which could be added to a multimedia system, and be available in GP surgeries and health centres, but Trent Healthline has no plans for developing this route as an information source. It feels that local government, which frequently manages these systems, is keen to give information to the general public because it is more answerable to the public than the NHS, which has always remained rather distant.

As regards the Internet, the staff at Trent Healthline recognises that there is much information available from this source, but at present have no clear plans as to how the World Wide Web or the NHS-wide network will be of use to them.

3. 1. 5. Summary.

In summary, Trent Healthline offers a health information service that local people are likely to find accessible. The staff have available a range of health information sources, and plan to keep abreast of new information sources such as the NHS Centre for Reviews and Dissemination, and the Cochrane database. They are preparing themselves for future service demands by producing documents on research-based treatment outcomes. As may be
expected, much uncertainty surrounds RHIS at present with the abolition of the RHA in 1996. Several questions remain unanswered:

- where will Trent RHIS obtain its income from in the future?
- will local or other commissioners negotiate contracts with Trent RHIS of equal value to those of previous RHA contracts?
- will the Trent RHIS be able to maintain the same level of service in the future as in 1994/95?

Thus it would appear that the future of the Trent RHIS is unclear.

3.2. Rotherham Health Advice Centre

The Health Advice Centre (HAC) at Rotherham was set up in 1990, funded by the FHSA, to provide town centre-based offices for promoting the services of the FHSA. The Centre is based in shop premises in Rotherham's town centre. It initially started by providing information to the general public on doctors and chemists, and staff were able to dispense medical cards and prescription exemption certificates. Rotherham Healthline, the telephone health enquiry service, started at the end of 1992. The Centre aims to provide a free, confidential, information and advice service for the public, health care staff and other professionals.

The majority of enquiries are received from the general public. These enquiries are mainly from personal callers to the advice centre, but some request information by telephone and occasionally by letter. In the year April 1994/95 the Centre received 9737 enquiries, representing an increase of nearly 20% on the previous year. The most frequent enquiries were concerned with family health services, that is:

- patient data services such as medical cards;
- information on the four contractor professions: GPs, dentists, pharmacists and opticians;
- health promotional areas including aural care treatment, healthy eating and travellers' health.

During the past year, Rotherham Healthline has received 1138 telephone
enquiries which equates to 12% of total enquiries received at the HAC. Whenever possible, written information is provided to the caller for future reference. Written information on specific diseases and conditions in non-medical language is available.

3.2.1. Information provided and the sources.
The HAC supplies a range of health information as listed below:

- the location of family doctors, dentists, opticians and pharmacists, and the services they provide;
- how to change your family doctor or register with a new one, and how to register with a doctor;
- local health services such as hospitals, clinics and community services;
- diseases and conditions in non-medical language;
- details of self-help groups both nationally and locally;
- how to complain about health services;
- local waiting times for out-patient appointments, and in-patient and day case operations;
- how to maintain and improve your health;
- help with NHS costs such as prescriptions, dental treatment or sight tests;
- local health care Charter Standards.

For their information sources, the HAC tends to use rather more hard copies than does Trent Healthline. Rotherham HAC uses hard copies such as reference books and leaflets to provide information on medical conditions, but it also has the database, PatientWise, available. It also uses hard copy to supply information on hospital waiting times. The HAC supplies Trent Healthline with local Rotherham information in order for it to add this information to its Helpbox files, and in return the HAC receives a full copy of the Helpbox database. The Centre provides Rotherview, Rotherham MBC's electronic public access community information system, with a directory of dentists and doctors, but not with data on self-help groups as Rotherview uses its own hard copies of this information.
Rotherham HAC personnel were keen to stress the point that they are not medically qualified, and so can only give health information as regards to conditions and treatment once a person has been given a diagnosis.

3.2.2. Services provided.
The HAC provides the general public with a variety of practical services, namely:

- processing of prescription pre-payment certificates;
- dates of previous cervical smear tests;
- dates for breast screening appointments;
- replacement medical cards.

The Centre also organises specialist advice sessions run by professional advisors on a regular basis. These sessions include:

- an ear care nurse who will do hearing tests;
- a dietician who can give general dietary and nutritional advice and information;
- an organiser from the volunteer bureau to answer enquiries relating to volunteering;
- an ethnic link worker who is available to interpret and translate for Rotherham's ethnic minority citizens;
- an officer from the Community Health Council who is able to give independent help and advice about health services, and can assist with complaints;
- a benefits officer who provides advice on welfare rights and benefits information.

During the last year the Centre has increased its services to the public by becoming involved in a number of projects. Firstly, in an effort to reduce the number of teenage pregnancies, the Centre is able to provide free condoms to those young people who ask for contraceptive advice on Saturday afternoons. Secondly, a daily poster displays the air quality in Rotherham each day and the pollen count in summer. Thirdly, a 'Weigh In' service allows
members of the public to call in regularly and keep a check on their weight. Lastly, a Health Promotion Officer attends the clinic on a sessional basis to offer help and support in giving up smoking.

3.2.3. Advertising the service.
In order to publicise the service, the Centre produces a bi-monthly news sheet which is circulated to many sites including all Rotherham District General Hospital Trust patient waiting areas, clinics, health centres, GP surgeries, libraries, churches and statutory agencies which deal with the general public. Copies are also sent to local media contacts. Recently the Centre received funding for the production of a new leaflet advertising its service which was delivered to most Rotherham households using the local free press. Copies of this leaflet were also produced in large print, Braille and Urdu. Further advertising has come from staff holding a stand at the Rotherham Show, and by giving talks about the Centre to organisations and groups. Staff also mount various health promotional window displays at the Centre including 'enjoy fruit and vegetables', 'national condom week' and 'alcohol advisory service display'.

3.2.4. Future developments of the service.
Staff from the Centre visit other similar services which give them ideas as to how to develop the service they provide: for example, the 'Weigh In' service. Furthermore, the increasing variety of enquiries received at the Centre increases the knowledge of the staff, which adds value to the service they are able to offer the people of Rotherham.

3.2.5. Summary.
The Rotherham Health Advice Centre offers a service that the local people of Rotherham are likely to find highly accessible. Moreover, besides providing information and advice, the Centre is also able to provide practical help such as supplying medical cards, while trained professionals provide specialist services. The fact that the number of enquiries the service has received in the last year has increased by 20% on the previous year, despite the existence of Trent Healthline, demonstrates that it is fulfilling a need.
3.3. HealthFacts

HealthFacts is a hospital-based health information service available in the Queen's Medical Centre (QMC), one of the major city hospitals in Nottingham. The service originated from a proposal put forward by a hospital librarian who was receiving many health enquiries. In August 1993 the service was initiated with the appointment of a Project Manager on a one-year temporary part-time contract, but the success of the project resulted in a permanent full-time contract. The Project Manager stresses that she is neither a librarian nor medically trained, but as she used to working on the information desk at the city library, she feels she is ideally experienced in dealing with enquiries for information from the general public. The service presently comes under the auspices of the Chief Executive's Office within the subsection of Quality and Consumer Relations. However, bearing in mind possible changes to the service in the future, responsibility for the service may transfer to the Information Management and Technology section.

3.3.1. Information provided and sources used.

The remit of the service is to provide information to patients and their visitors, and to health professionals asking on behalf of patients. HealthFacts provides information on conditions and diseases, healthy lifestyle, self-help groups and waiting times. The service at present uses the Cardbox database, received from Trent Healthline, but the service is shortly to transfer to Helpbox. The majority of enquiries concerning waiting times relate to the QMC. For national waiting times, the small number of enquirers are referred to Trent Healthline. HealthFacts receives a number of enquiries for information on healthy lifestyles, such as healthy eating habits, but the number of enquiries is less than when the service first started. The information on local and national self-help groups is provided by Nottingham Community Health Care Trust. The manager also has at her disposal the book stock available in the hospital library.

HealthFacts is able to supply enquirers with loose leaflets, fact sheets, and magazine and journal articles. The Project Manager finds that the supplies of information she has available are building up as the number of enquiries.
increases. Much of the information the service has collected stems from enquiries requiring further manual information searches by the Manager.

HealthFacts liaises with all the local health information services. The Manager attends a Health Information Forum for services within the Nottingham area, which meets quarterly and includes staff from information services at the City Hospital, the Children’s Centre at the City Hospital and county libraries. From discussions at the Health Information Forum, it is clear that each health information service has a different set of users and thus, rather than duplicating services, the local health information services complement each other.

3.3.2. Future developments in the service.

At present the HealthFacts service is located at one site within the hospital. As a means of increasing the value of the service, the staff are considering locating information points around the hospital in order to develop a network of health information services within one hospital. Out-patients’ clinics are thought to be an obvious target for information services as people have just come out from a consultation, are eager for more information and yet do not know where to seek further information. At present there is no information at the point of clinical contact. The information would be provided using Helpbox, the database developed by the Help for Health Trust. Local computer access points would resolve the problem of hospital clients having to make their way to just one information point within the hospital. This development was discussed with the Quality and Customer Relations Manager, whose department is responsible for the HealthFacts service.

The Manager stated that, using the results of a questionnaire, the HealthFacts service was able to establish that it was delivering benefits. However, it was a limited facility because as it was in a fixed place, it was accessible only to a limited number of people. The management realised they were able to offer significant access to information for ambulant patients who came to the office, to their relatives and to health professionals, but not to in-
patients who were unable to visit the office. This led them to look at other entities within the hospital that had similar aims and used similar systems and facilities, and they decided to try to incorporate some of these services together. This took two approaches. Firstly, it was decided to have one overall Project Manager for these services, and secondly to develop a peripatetic, 'roving' information service such as that employed by the hospital library service. It is envisaged that the service will start by providing health information leaflets, but it is hoped eventually to have a portable computer system. The manager said that they had been considering the use of touch screen information systems but unfortunately, with the abolition of the RHA, this scheme has had to be deferred for the time being. At present, the service does not have sufficient funding in order to establish local access information points; the budget is too small to consider buying IT equipment. However, as the service is delivering benefits and must develop in order to remain of value, it is felt that maybe the service should be transferred to the control of the Information Management and Technology section, which would be able to fund the necessary IT developments.

With regards to the use of electronic information systems for providing health information, the Manager of HealthFacts feels that Healthpoint, the electronic health information system developed by Ray Jones, might be satisfactory as a health promotion tool but would be inadequate for many of the enquiries received at HealthFacts. Frequently people are seeking a great deal more information at more depth, and are seeking guides to further reading which the manager feels cannot be supplied by Healthpoint.

The Project Manager believes the general public are taking more interest in their health and are becoming more assertive, which she feels is due to the Patient's Charter. The public feel more confident in interacting with consultants and asking for particular treatments. This is especially true of younger people; older people are still curbed in their actions by the traditional doctor/patient relationship.

A further example of the value of the hospital-based information services is
illustrated by the fact that the QMC is currently setting up a new health information service designed especially for the children's wards.

Thus, there are planned changes for both the HealthFacts service offered to hospital clients and for the management of the service.

3.3.3. Summary.
HealthFacts is able to provide health information at a time when it may be expected that people are most in need of it. Staff have found that the HealthFacts service is of benefit to users (Patterson 1994). The service is seen as being important by hospital managers, illustrated by their desire to establish local service points which will make it more accessible to a greater number of people within the hospital.

4. Electronic public access community information systems
Four examples of electronic public access community information systems operating within the area covered by Trent RHA are Leicestershire's INFOLIX, Lincolnshire's LINNET, Rotherham's MBC Rotherview and Nottinghamshire's County Contacts. The range of health information available on these systems was identified using the data gathered from a mail questionnaire sent to all systems operational in the UK.

Leicestershire's INFOLIX provides information on selfhelp groups only, but has plans to extend the amount of health information available. The system has been in operation for more than three years and is available in 19 sites including libraries, council buildings, leisure centres and village halls.

Lincolnshire's LINNET provides a wider range of health information such as lists of doctors and dentists, self-help group contacts, and healthy lifestyle information. There are no plans to extend the range of health information provided as there is a local health information service operational. The system has been in operation less than one year and is available in three libraries.
Rotherham's Rotherview provides a comprehensive range of health information. This includes health service information, self-help group contacts, information on conditions and diseases, healthy lifestyle information, performance data such as hospital waiting times, and health information services - that is, services offering health information to the public such as Trent Healthline. Rotherview has been in operation for approximately seven years and is available in 28 sites, including libraries, leisure centres, advice and job centres, and benefits offices.

Nottinghamshire's County Contact had only been in operation in its present form for a matter of weeks at the time of the research. At that time there was no health information at all on the system but contact had recently been made with the local Health Authority to discuss the possibility of putting health information onto the system. At the time of the research, the system provided information such as benefits and education information, leisure services, and council departments, and was available in 12 sites in town halls, shopping centres and libraries. It is recognised that the system needs to be available in places other than libraries because a large section of the community does not go to the library. The Project Manager stressed that he was keen to add information such as health and public utilities information in order to make the system more public-information oriented, because he felt it centred too much at present on county information, in particular council information. Discussions had recently commenced with the local cable TV company so that the information provided by the system would be available in a Ceefax form for the public on their own TVs, thus making the information available to an even wider audience.

The amount of health information provided by these examples of electronic public access information systems operating within the Trent region varies enormously, but it is important to recognise that these systems provide an alternative source of information for some categories of health information. The systems represent a source of information that is available at more than one site, and are free to access. Furthermore, as there is no personal
interaction needed at all for the communication of information, any feelings of embarrassment are avoided. Thus, these systems are an important alternative source of health information.

5. Conclusions

The publication of the government paper, the Patient's Charter (Department of Health 1991), made the provision of health information to the general public not only desirable but obligatory, and since then an array of services has developed. This research investigated the provision by a number of services within one region. It is clear from this investigation that there exists a network of services providing consumer health information in the Trent region which offers the local people a selection of health information sources. All of the Trent services reviewed in this paper have developed since 1991, the year of publication of the Patient's Charter (Department of Health 1991). The impressions gained are that the health information services are receiving greater numbers of enquiries and are planning to develop the services they offer, either in terms of the range of information available or in terms of the accessibility of the service to a larger audience. This demonstrates the growing demand for health information, and the recognition by health services managers of the importance of providing accessible health information.

The picture drawn from this review is one of a hierarchy of complementary services: Trent Healthline, the RHIS, provides a service to the whole of the Trent region, with more local services providing possibly more accessible and practical advice to smaller portions of the Trent population. Trent Healthline provides access to its services mainly via the national freephone telephone number. The drawback to this is that the majority of potential clients are required to have access to a telephone in order to use the service, and therefore this service does not reach those who do not have easy access to a telephone, such as travellers or homeless people, or people who are not confident speaking over the telephone, such as elderly people or those whose first language is not English.
Rotherham Health Advice Centre is likely to be especially accessible to the general public, being situated in shop premises in the town centre and offering a wide range of practical services. Providing practical services may be one way of reaching a wider audience because people coming in for one reason may then decide to ask for information on other aspects of health.

The HealthFacts information service of the Queen's Medical Centre, Nottingham is making information available at the time when it may be most required, and when questions relating to health care are uppermost in people's minds. It is at this point that the public wants information on how to convalesce following an operation or illness, how to cope with a long term illness (perhaps with the support of self-help groups), and how to avoid further illness or deterioration. Hospital-based services may be expected to provide the most accurate information concerning questions relating to the hospital in which the service is situated.

The electronic public access community information systems operational within the Trent region frequently provide less detailed health information, but they are available in a wider range of sites, most frequently in libraries - a traditional source of information. These systems are free to access and people can browse pages of interest at their own leisure, and in complete anonymity. However, in general the use of electronic information systems as a means of providing health information to consumers is seen as only an alternative source of providing limited information.

Following visits to other RHIS as part of this research, it is acknowledged that the offices of Trent Healthline may be comparably more accessible as a drop-in facility and so overcome some of the difficulties associated with access to a telephone. Generally, the services offered by the RHIS visited were judged to be very similar with each appearing to have particular interests. Staff at Trent Healthline, for example, were concerned primarily with gaining access to, and providing, information on treatment effectiveness and outcomes, and secondly with producing policy documents on providing service excellence. Midlands Health Point staff in the West Midlands, on the other hand, were very involved
with running their own local health campaigns, some of which are of specific interest to the local community, while staff at Health Info Line in Milton Keynes had an interest in relevant research such as the impact of CHI on people's behaviour.

This illustration of CHI provision in the Trent region, albeit far from a complete description of the services available, illustrates the various forms that health information services and sources may take and how, far from duplicating services, they complement each other. By providing health information in a variety of forms, accessible by a range of methods and available at different locations, a comprehensive health information service will be provided to the general public which is more likely to reach a wider audience. As the demand for health information grows, the number of such services provided and their accessibility may be expected to increase. In this way, the aims of the Patient's Charter (Department of Health 1991)-the provision of health information to the general public -will be met. Thus empowered, health consumers can choose to take an active role and make a significant contribution in the management of their own healthcare. Also, the wide variety of health information sources can provide evidence based on medicine for the many pressure groups within the healthcare field.

The effects of the increasingly empowered consumer on NHS policy have not yet been fully realised nor comprehensively measured.

References


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Paper 2

Consumer health information on the Internet - help or hindrance?


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Harrogate, March 1998, British Computer Society, pp. 207 - 13
Consumer health information on the Internet — help or hindrance?

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Keywords: INTERNET, CONSUMER HEALTH, HEALTH INFORMATION, MEDLINE

Summary
The Internet contains vast amounts of uncensored data. It is growing by the second, completely unrestricted by policy, company procedure, or regulation. Thus the healthcare consumer when searching for information is faced with an array of data in unspecified order, of unspecified quality, and authoriation. It is truly a web, a myriad of data, waiting to ensnare the naıve user.

This can be seen as a great extension of medical knowledge for the healthcare consumer. In the UK setting it is in complete accordance with the Patients' Charter, giving 'rights' to health information.

The alternative view is that the information published is unauthorised and can be misinterpreted by consumers. Examples of the various types of sites are given.

The conclusions drawn are that the effects on the health policy and health professional practice of the empowered healthcare consumer have not yet been successfully analysed. However, it is suggested that the newly informed and empowered consumer may force a paradigm shift in the traditional doctor-patient relationship.

Introduction
A well informed public is one of the major facets of the recent White Paper, A service with ambitions. Careful planning by health authorities is required if this is to be achieved in an effective way, with recourse to relevant audiences targeted correctly and budgets matched appropriately. Meeting the needs of the ever demanding consumer health public is not an easy task.
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Introduction
A well informed public is one of the major facets of the recent White Paper, *A service with ambitions*. Careful planning by health authorities is required if this is to be achieved in an effective way, with recourse to relevant audiences targeted correctly and budgets matched appropriately. Meeting the needs of the ever demanding consumer health public is not an easy task.

The healthcare consumer
Why do consumers seek health information? Several reasons arise from the paternal attitudes adopted by some clinicians in the consultation with patients. The doctor's authority is defined by Osmond as:
- **sapiental** - doctors must know or appear to know more about medicine than their patients;
- **moral** - the right to control and direct with concern for the good of the patient; and
- **charismatic** - which comes close to magical powers in that patients often do not understand what the treatment is doing to them, only that they are hopefully being healed.

Doctors who sit behind their desks, making them a barrier in the consulting room, are maintaining authority; a simple test of seeing where doctors sit in their rooms shows the understanding patient immediately what the relationship is likely to be. The doctor creating barriers does not make a situation conducive to asking for, or receiving, information. However, there is an opposite and beneficial effect of a doctor's non-verbal behaviour. The patient who experiences the doctor using the power of touch can establish trust and a mutual sharing of care, which in turn stimulates information sharing at both a practical and emotional level.

There may be another totally different set of reasons causing a patient to deliberately seek health information away from the clinical setting. Some of these reasons could be due to:
- an inability to retain, or a denial of, what was told in the surgery;
• an attempt at self diagnosis, and/or prognosis;
• a desire to seek complementary medicine or self help;
• the avoidance of communication with their doctor because of shyness, reticence or apprehension;
• the seeking of knowledge from information providers seen as peers, rather than doctors who may be seen as superior;
• the opportunity to manipulate or to fake illness;
• the search for an answer to a medical problem where one does not yet exist; and
• a possibility of the formation of the basis for legal redress when operative techniques or treatments have failed. 

Consumer health information and the Internet
Are the health professionals and authorities failing to recognise and harness the great benefits of the Internet to inform the public about health to assist them in meeting the dictates of A service with ambitions?

The Internet is "a massive network of computer networks. It is a super network, which covers most of the globe and connects tens of millions of users on millions of computers attached to thousands of networks. It is the fastest growing communications system in the world and over the last few years has been doubling every few months."

In 1996 it was estimated that there were about five million documents already available. There are enormous amounts of health information available on the Internet including, but not exclusively, sites devoted to: medicine, alternative therapy, pharmacy, nursing, physiotherapy, health economics and radiography.

In consumer health information terms these spin out into different types of sites that group together in the following way:
• reference: resource lists, indexes, book lists, charity newsletters;
• medical: treatment, drug use, therapy, alternative therapy, spiritual healing,
pharmaceutical, commercial products;
• personal: self help groups, news groups, mailing lists, emotional support;
  and
• professional: advice agencies, e.g. the Samaritans.

**Medical database - Medline**
The releasing of Medline to the American public as launched by VicePresident Gore on 26 June 1997 via the Internet at [http://www.nlm.nih.gov](http://www.nlm.nih.gov) is undoubtedly a boon to the healthcare consumer, and demonstrates the American commitment to giving health information to their citizens. Medline is perhaps the most widely used, and easily accessed, quality database. The information found here is not exclusively designed for the consumer; it is designed to inform the enquirer in medical terms about precise medical conditions and precise medical treatments. Therefore, vague feelings, terms, or conditions, cannot be entered. This dictates a rigorous articulate method of searching to achieve results i.e. information. Casual browsing or serendipity will not achieve the same results. It has previously been used exclusively by the medical and pharmaceutical industry. However, this extension of franchise of information, by the very nature of the Internet gives access on a worldwide scale.

"From a computer in the comfort of their own home or from one in their neighbourhood library, Americans will be able to access timely and accurate medical information," the Vice- President said. "Better and more up-to-date information in the hands of consumers means we can treat diseases more quickly and maybe prevent some of them in the first place."

Health and Human Services Secretary Donna Shalala said, in a statement released at the press conference, "American citizens now have at their fingertips both the scientific information gathered by the National Library of Medicine, as represented in Medline, and the extensive consumer health information in Healthfinder, the service for the public that we announced in
April. We are committed to using the new technology, including the World Wide Web and the Internet, to provide health information to the public."

Self-help/consumer
One example of the true healthcare consumer becoming an expert in the field of medical information and using the Internet to give an understanding of a medical condition is demonstrated by Linda Newall. The new site for hysterectomy has been developed by Linda following a hysterectomy at the age of 32. Prior to the operation, she had to make the very difficult decision concerning the proposed surgery with little or no relevant information available nationally or internationally. This prompted her to make the development and dissemination of information about hysterectomy for young women i.e. under 45 years, the focus of her MSc dissertation. This was undertaken in the Department of Information and Library Studies at Loughborough University. The resulting Web site, containing copious information about hysterectomy, can be found at http://web.ukonline.co.uk/Linda.Newall/index.htm. It has been accepted by various search engines - Yahoo, Altavista, Lycos and also submitted to Excite. This is an excellent example of the personal self-help type of site.

Thus the different types of sites provide a differing profile of information. New sites can literally appear at any time of the day or night, such is the international and interactive nature of the phenomena. The general principles for using the Internet for consumer health information remain applicable to the user. However, the sensitive and personal nature of health information set this subject area apart from others for several reasons.

The expert
The lay setting of the Internet without the need for recourse to a third party, professional or other, allows the emergence of the 'expert' giving definitive, uncompromising advice; and secondly the 'evangelist' giving advice one step ahead of the expert with the benefit of religious fervour. The expert can appear in any guise, often disguised as a medic. However, the one common thread in all of these experts is the definite positive results for curing the illness that they provide. A convincing example is the site
The `evangelist'

The evangelist type is probably the most dangerous and alarming individual to emerge from the labyrinth of the Internet. Their views are given with uncompromising fervour. This is amply demonstrated on many sites. However, an example of this at its best as a genre is the following URL http://wwwengre.isu.edu/-murimort/dep.html (Web crawler). The words seem to appear as a part of a religious text: "Verily, verily I say unto you, whatsoever ye shall ask the Father in my name, he will give it to you. Rockville, MD 20852 (301) 231-9350 National Depressive and Manic Depressive Association, 720 N Franklin St, XXX 501." It's natural to feel worried and sad. The words are designed to empathise and sympathise with the depressed searcher appealing to their vulnerability.

The association with religious phraseology may cause great offence to those who hold religious beliefs. However, this use of religious phraseology associated with treating illnesses is not a new idea. It is a well rehearsed and often practised modus operandi often achieving cult following, and can be charted through the ages from witchcraft to the more modern cult, the Moonies. Both of these information providers can of course lead to the exploitation of the enquirer. At best, they mislead the enquirer or give false hope for a seeker of a cure or treatment for an illness.

However, the opportunity the Internet provides for communication across international boundaries is undeniably one of its great strengths. The emotional support available for sufferers, relatives, friends and carers for those with chronic, terminal illness, or rare conditions, cannot be measured by audit alone. This best use of health information on the Internet can therefore be viewed as a balance against the expert and evangelist. Therefore the plethora of health information that exists and is constantly and rapidly changing.
emerging on the Internet is there for consumption by the consumer.

**Information to empower consumer choice**

Two questions emerge: is this information overwhelming or necessary for choice for a healthy lifestyle? Certainly the mantra of the consumer health information movement taken from *Health for all by the year 2000*, the declaration of Alma Alta, which states that "The people have a right and duty to participate individually and collectively in the planning and implementation of their healthcare"\(^6\) echoes this necessity for healthy lifestyle choice. This would suggest an unpinning of information provision to be able to participate in the planning and implementation of healthcare.

"Information is the first step to every healthy choice. Improvements in our health depend on us taking control over, and responsibility for, health as an important component of our everyday lives. This active participation requires full and continuing access to information: information about our bodies, their workings in health and illness, and the services available to us in treatment and care, support and cooperation."\(^7\)

This theme is again echoed in the Patient’s Charter with rights \(^5,8\) dedicated to the provision of information, you are entitled to:

- have any proposed treatment, including any risks involved in that treatment and any alternatives, clearly explained to you before you decide whether to agree to it;
- receive detailed information on local health services. This includes information on the standards of service you can expect, waiting times and on local GP services.\(^8\)

The thrust of evidence-based medicine within the Health Service is also demonstrating the need for information to underpin practice. Arguably this is aimed at the professional rather than the public. However, in managing care does not the consumer need to be as well informed as the professional? Evidence-based medicine is defined as an approach to healthcare that promotes the collection, interpretation, and investigation of valid, important
and applicable patient-reported, clinician-observed, and research-derived evidence. The best available evidence, moderated by patient circumstances and preferences, is applied to improve the quality of clinical judgements. 

Guidelines for the Use of the Internet by the consumer

If the consumer is to make best use of the plethora of health information on the Internet then surely guidelines are required:

- browsing - it is OK to browse! - for conversational use, casual/ passive use;

Questions to ask when searching for consumer health information:

- is the information up-to-date?
- check dates/currency of information;
- is source identified;
- is there a reference you can use?
- what is the agenda of the site?
- who is the anticipated audience? and
- relevance - is there a US bias, is it relevant for the UK?

Actions

- If the site meets your needs, bookmark it so that you can return easily;
- note the URL; and
- remember, if recommending a URL, these can change daily.

Conclusion

By using a series of guidelines the consumer can decide if health information on the Internet is a help or a hindrance. The effects of the increasingly empowered consumer on NHS policy have not yet been fully realised nor comprehensively measured. "Seeking consumer health information via the Internet will undoubtedly inform and empower the consumer in a way that may force a paradigm shift in the traditional doctor-patient relationship.

References


Paper 3

In the name of innocence: adolescents and information about sex

Evelyn Kerslake and Janet Rolinson, 1996.

The New Review of Children's Literature and Librarianship, 2, 57-73
In the name of innocence: adolescents and information about sex

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It is clear that, in relation to sexual issues, the costs of adolescents remaining in a state of information poverty may be immense. What is rather less clear, however, is how this deficit should be redressed - how and by whom information about sex should be provided and what information is regarded as necessary by the adolescent consumers of that information. These considerations are the focus of a study currently being conducted at Loughborough University in the Department of Information and Library Studies.

This paper explores issues surrounding sex information for adolescents within the existing literature. It describes the role of sex information within the context of the growing consumer interest in general health information. Secondly, it identifies the issues commonly included in sex information and outlines both 'official' sources of information about sex, eg. school sex education courses, and 'unofficial' sources of information, eg. via peer groups. Finally, those sexual issues which are rarely, or never, discussed by any information sources are briefly considered. A broadly social constructionist approach is used to explore the complex positioning of adolescent information users.

'The value of information is not intrinsic, but lies in the uses to which it can be put. From these uses, advantages can be derived which are beneficial to the 'owner' of the information and which would not have been attainable without it. If access to information is controlled, whether economically or in any other way, the potential benefits of possessing it will be lost by those to whom it is denied. These propositions underpin the concepts of 'information wealth' and 'information poverty'...

The starting point for this study is to consider the value of information, here outlined by Feather, in the particular context of adolescents and information about sex. The second class status of adolescents, along with other groups in UK society, has been recently demonstrated by the Government's decision to deny certain benefit entitlements to those aged between 16 and 25 years. This move is echoed by adolescents' only partial access to information which is more completely available to most adults. For example, adolescents may only join a public library with the permission of a parent or guardian, may only see certain films with an adult, and are
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deny certain benefit entitlements to those aged between 16 and 25 years. This move is echoed by adolescents' only partial access to information which is more completely available to most adults. For example, adolescents may only join a public library with the permission of a parent or guardian, may only see certain films with an adult, and are often denied information about institutions (such as schools) in which they are directly involved. The unsuccessful attempt in 1996 to pass legislation curbing the content of magazines aimed at adolescent girls, on the grounds that the content was too sexually explicit for this audience, is a recent example of an attempt to censor the availability of information about sex to adolescents. Censorship of some types of 'adult' information, then, is constructed as legitimate before that information is deemed suitable for consumption by adolescents. The rationale for such censorship is that the innocence of children and adolescents must be protected and maintained, even if the price this extracts is their continuation in a state of ignorance. Adolescents, therefore, are denied some information and, in contrast to most adults, are in a state of relative information poverty.

A central focus of the construction of childhood innocence is sexual innocence and it is this which adults aim to 'protect' by denying children and adolescents access to information about sex. Here, the 'innocence is ignorance' equation is writ large. Against a broad backdrop of increasing sexual activity at an earlier age the cost, borne by the adolescent, of this lack of information is ignorance. This may lead to sexual behaviour which puts the adolescent at risk of sexually transmitted diseases and unwanted teenage pregnancy. Further, sexual ignorance is no defence against sexual abuse and exploitation. The costs of information poverty in this particular area are, then, potentially immense.

Distinguishing between 'information' and 'knowledge'

Although a great deal has been written on acquiring sexual knowledge, for example through school-based sex education, rather less work has been done investigating where adolescents obtain information about sexual issues. The following distinction between information and knowledge is made here:
...most would accept a definition of information that saw it as data ordered in a meaningful fashion. If it is to be meaningful, then there must have been human intervention of some sort in its creation. But the information, so created, can be stored, in print, or in a computer, independently of human beings. Knowledge refers to a subsequent stage, in which the information is absorbed and understood by new users. 12

Information is seen as providing an incomplete description of the world, which has to be incorporated into a socially constructed frame of reference and sense-making model 13. Dervin and Nilan argue that all information needs occur within a 'gap' of the available knowledge, which the individual seeks to remedy 14. Conflation of the terms knowledge and information is unhelpful to information-poor adolescents attempting to bridge gaps in the sex information available to them. In mainstream healthcare, health information gaps are bridged more readily since the recent establishment of health information services. In 1991 Regional Health Information Services were established in the UK, in all of the then 14 Regions. Since the reduction of the number of Regional Health Authorities to eight, and further subsequent removal of the regional tier, Regional Health Information Services are now firmly placed in the healthcare market as independent players, without 'top sliced' funding. Naturally some may not survive the market forces. However, well established, services, eg. Help for Health Trust and the Lister Hospital continue to thrive and adequately meet the needs of consumers. The distribution of health information throughout the UK is, as with all health care provision, inequitable which will inevitably contribute to the lack of information about sex available to adolescents. Regrettably, unlike McDonald’s, a health information service is not in every town centre.

**Health information and sex information**

Information about sexual issues should be seen in the more general context of expanding health information for healthcare patients or consumers 15. Gann describes the rationale for this move as based on both a desire to maintain improvements in health and, simultaneously, to decrease national expenditure on health provision:
Improvements in our health depend on us taking control over, and responsibility for, health as an important component of our everyday lives. This active participation requires full and continuing access to information: information about our bodies, their workings in health and illness, and the services available to us in treatment and care, support and cooperation.¹⁶

Gann also describes a tension in health information created by two competing ideologies:

"On the Left, it [self-help health information] is seen as a vehicle for increased control of the individual's own life, a seizure of power from the state; on the Right, the call is for a dismantling of services such as the National health Service on the grounds that a bureaucratic state has encroached on the freedom of the individual; self-help here means helping oneself and letting others fend for themselves as best they can ... ¹⁷

This tension is compounded by the divergent approaches adopted by two Government departments¹⁸: the Department of Health, who promote dissemination of health, and sex, information, and the Department of Education, who have discouraged teachers from engaging in some types of sex education. A result of this is that there has been a failure to introduce a systematic approach to the provision of sex information to adolescents, at either national or local levels. Although health information is now more generally accepted as one of the 'patient's rights' in the light of the 1991 Patients' Charter, the rights of adolescents to sex information are mediated by the roles of schools and parents. Between these two mediators the voice of the adolescent information consumer is muted, if indeed it is not entirely absent. The continuing use of existing methods of sex information is therefore justified by the exclusion of this voice, which various studies involving adolescents have demonstrated would bring a highly critical evaluation to the debate ¹⁹,²⁰,²¹

Sex information: subjects included
The existing literature identifies the following subjects as ones generally covered by 'official' sources of sex information ²²,¹¹,²⁴,²⁵,²⁶:

- growth and development
- human reproduction
- physiology
• family life
• menstruation
• sexual relationships
• contraception
• sexually transmitted diseases, including HIV/AIDS

Issues rarely included in 'official' communications about sex information, and only infrequently in 'unofficial' sources include27-33

• masturbation;
• sexual orientation;
• sexual abuse;
• pregnancy options (abortion, adoption, keeping the baby);
• obtaining advice about contraception and sexually transmitted diseases;
and,
• sexual response.

As indicated above, there are two major divisions between the sources of information about sexual issues used by adolescents. These have been referred to in the existing literature as 'official' as opposed to unofficial sources of information34; or, as 'scientific' as opposed to 'realistic' or 'practical' sources of information35. The 'official' sources include school, parents and family planning clinics - and could include public libraries if recommendations in the Investing in children report by the Library and Information Services Commission for England are acted upon36 - and the 'unofficial' sources include friends, television, magazines and books. The 'official' and 'unofficial' sources are subsequently discussed.

'Official' sources of information about sexual issues

There are a number of sources of information about sexual issues which may be considered as 'official' or legitimate mouthpieces and these include, primarily, school sex education, parents, GPs and family planning clinics.
These are identified here as legitimate sources mainly because of the power relations involved between the adolescent information consumer (who is positioned as, at least, doubly powerless by both lacking information and being a non-adult) and the information provider. The power relations are compounded further by the interconnecting effects of race, class, disability, sexual orientation and so on. While similar power relations impact upon information provision by `unofficial' sources, these contain more opportunity for the adolescent consumer to negotiate a response or resistance simply because they are `unofficial'. For example, teenage magazines are a frequently used source of information about sex, produced in the political economic context of the white, heterosexual, capitalist, patriarchal publishing industry. However, magazines are not formally imposed on adolescents (although they may well be informally imposed by peer expectations) and it is here that opportunity for increased negotiation lies. The `official' sources of information about sex for adolescents are briefly explored.

**School sex education**

School sex education begins at primary school level and is acknowledged by many commentators to be an important source of information about sexual issues. However, the provision of information about sex in the social context of school is fraught with difficulties, prompting Thompson and Scott to comment that while school offers the potential for `a public shared knowledge', it is not the `ideal context'. This ideal of public knowledge, is, in any case, limited as school sex education is only available to those children within the school system who are permitted to participate in sex education lessons and who are in school on the days in question. Sex education is the only part of the National Curriculum from which parents have the right to remove their child.

The context of current school sex education is primarily influenced by two interconnected relationships: that of the Government, education authorities and schools; and that of parents and children. The Government made its stand on sex education in the 1993 Education Act, which unambiguously stated that the primary responsibility for sex education should lie with parents.
and not schools:

*The prime responsibility for bringing up children rests with parents. School should therefore recognise that parents are key figures in ... preparing [their children] for the challenges and responsibilities which sexual maturity brings. The teaching offered by schools should be complementary and supportive to the role of the parents.*

If parents should be the primary source of information about sex for their children then the message for schools is clear: they are in a secondary 'supportive' position. Although this reflects the stated preferences of both parents and children in various survey reports, the same surveys simultaneously point to a gulf between this preference and what actually happens. Allen writes in her survey:

... over a fifth of the mothers and nearly 40 per cent of the fathers said that they had never talked about any of the [sexual] subjects to their children ... it is quite clear that it would be utterly wrong to assume that parents will automatically give their children any information, let alone discuss these matters which are so much part of life.

In practice, parental determination to inform their children about sex often gives way to parental embarrassment, perhaps caused by fear that the child may know more about sex than the parent, which in turn may hinge on the parents' own poor sex education". There is some indication that there are gender differences here, as the menarche may provide an opportunity for girls to discuss sexual issues with their mothers, although this is not so for all girls. Similarly, Farrell and Kissling note that there are class differences in the extent to which parents participated in informing their children about sex, with middle class parents more likely to do so than working class parents. The outcome from this situation is that:

- parents would like to inform their children about sex, *but don't*;
- children would like to learn about sex from their parents, *but don't*; and,
- Governmental legislation pressures schools to take only a "supportive" rather than a leading role in sex education.

From this perspective, then, school sex education would seem to do a minimal
amount towards redressing the state of information poverty which many adolescents find themselves in with regard to information about sex. Evidence from US and UK studies indicates that this situation is compounded by the particular dynamics of classroom teaching.

In the classroom

Trudell's illuminating study of the classroom context of US school sex education offers a detailed analysis of the dynamics and power relations impacting on these lessons. She emphasises the need to see the teacher's actions in the lesson in a particular context where the teacher has to 'get through' the material for that class and keeps to non-controversial topics to maintain discipline in the class. From the students' perspective, Trudell describes them variously as actively engaging with the subject by:

- offering 'ambiguous acquiescence' which is described as 'neutral conformity to classroom procedures and information' possibly in order to obtain good grades in a required course. Some students said this despite already claiming to know much of the information presented in the class. This was also a strategy for avoiding embarrassment in a peer group.
- contesting the school's 'official' version of sexual knowledge. Trudell particularly notes this of the 'female dirts' and black students', who opposed the school's 'official' knowledge with their experientially based knowledge. This included challenging the 'official' language used to describe sexual issues - which Thompson and Scott's interviewees described as "clinical", "factual", "distant", "biological", "mechanistic" and "removed" - with slang and obscene terms.

Trudell, like other researchers demonstrates that while school was seen as an important and reliable source of information about sex, it was limited because:

*by far the most common criticism of sex education at school was that it had little or no relationship to the real choices and pressures around sexuality* ...

Criticisms 'consistently' noted by the young women interviewed by Thompson and Scott included the school's failure to take account of the context in which sexual behaviour takes place and its personal and social consequences.
GPs and Family Planning Clinics

Both GPs and Family Planning Clinics occasionally feature in the literature as sources of reliable information about sexual issues which are used by adolescents. However, adolescents perceive various disincentives to using these facilities. One study found that adolescents saw family planning clinics as places where they would be asked personal questions by disapproving older staff. Being below the legal age of heterosexual consent is a particular barrier for girls who fear that family planning clinics may be unwilling to help them, or may punish them by informing their parents that they have tried to obtain contraception, thus further demonstrating adolescents' lack of empowerment. A response to this by health authorities has been to set up young people's drop-in advice centres in secondary schools. The Trent Young People's Survey reported that 20 per cent of girls and 12 per cent of boys would use such a centre for professional advice on contraception.

The Trent Young People's Survey found that although many of the adolescents interviewed said that advice from their doctor was 'easy to understand' and accessible, they also said that they were afraid to use this information source because they feared their parents might be informed, were anxious about what was going to happen to them at the surgery and were concerned that they would be seen attending. The importance of confidentiality is emphasised by Allen who reported that, for adolescents attending Family Planning Clinics, this was seen as more important than accuracy, in seeking information and advice. Allen also notes that some adolescents did not see sexual issues as 'important' enough to consult a doctor about, and consequently feared being reprimanded for wasting the GP's time.

Summary: problems and benefits

There are two main concerns about the 'official' sources of information about sex seen in the literature. First, these sources are seen by adolescents as too distant and removed from the actual experience of sexual issues. Second, those providing this information may well be part of a potentially punitive legislative bureaucracy which curtails the amount of information they are
permitted to provide. This suggests that those seeking the information and possibly those providing it too, may be punished if they are found to have contravened particular laws. However, 'official' sources - with the exception of parents - are frequently seen as providing 'reliable' information. So, while there are significant drawbacks to the 'official' sources of information about sex which mean that adolescents may remain 'information poor', for those adolescents who are able to negotiate contact with those sources, they may be a reliable source of practical information.

'Unofficial' sources of information about sexual issues

Various studies have found that adolescents use a variety of 'unofficial' sources of information about sex, for example, friends, magazines and television programmes. Many of these sources are gendered, with, for example, girls using teenage magazines more than boys. The extensive use of 'unofficial' sources of information contributes to providing a discussion of the experiential aspects of sexual issues, which is almost entirely missing from the 'official' sources. Thompson and Scott comment that the young women in their study said that:

... sex education at school is 'a waste of time' and the really important information is to be found in the playground and the girls' toilets.

Traditional prejudices would appear to be confirmed. The importance of peers as sources of information about sex is emphasised in writing on 'unofficial' sources: one study found that a third of adolescents thought their friends were the most important source of information about sex. A Schools Health Education Unit survey found that peers were the main source of information about sex for over a third of 15-16 year olds. Allen provides a number of reasons why the adolescents in her study preferred to consult their peers about sexual issues rather than any of the 'official' sources:

- familiarity means that the issue could be discussed 'naturally' in the course of conversation and without embarrassment;
- the assumption by adolescents that their peers are in a similar position to themselves; and,
adolescents 'tried their problems or questions out on their friends before seeking a second opinion'.

This last point indicates that adolescents assess peer group information critically, and in Allen's study only 4 per cent of respondents thought that friends were a reliable source of information on sex. The distrust of peer information seen across several studies is sometimes accompanied by anxiety about personal ignorance of sexual knowledge and experience in comparison with others in the peer group. However, such distrust of the validity of peer information has to be weighed against the scarce opportunity provided by peers to offer sources of experiential sexual knowledge and information, and opportunities to learn about managing the lived experience. Lack of experiential knowledge offered in official sources of information about sex is cited by adolescents in many studies as a major failing.

Thompson and Scott discuss ways that the young women in their study attempted to 'bypass the 'Chinese whisper' approach' to sex information by finding out the information for themselves, but without recourse to the 'official' sources of information:

*We found that young women would frequently search for sexual references in any available sources such as popular sex manuals, 'Jackie Collins' books, and most commonly in magazines aimed at young women. Problem pages were frequently cited as sources of sexual information.*

Other sources include: medical encyclopedias; pornographic magazines and films; newspapers; television programmes, especially soap operas; and videos. Research by the Family Planning Association found that boys aged 13-17 used The Sun as their main source of information about sex, and other work suggests that, while there is no boys' equivalent to the magazines for adolescent girls, boys covertly read those magazines, and this is implicitly recognised by the presence of agony uncles, as well as agony aunts, on the problem pages.

However, as with peer information, these other sources of information are also subjected to a critical evaluation by adolescents. The emphasis on an active, critical reception of this information negates a construction of 'information poor'
adolescents as 'cultural dupes'. In the face of the apparent distrust of these sources of information, Jackson offers an insight into the reason why they remain popular:

Part of the appeal of these magazines is that they speak to those who are still classed as children, still lack the rights of adulthood but who aspire to the maturity and status that young womanhood seems to offer ... [they] want the right to know about [sex].

As the 'official' sources of information about sex fail to meet this 'right to know', adolescents turn to these 'other' sources to redress this paucity.

**Summary: Problems and benefits**

The main problem associated with the 'unofficial' sources of information about sex is that they are unreliable, perhaps providing misinformation or being unable to provide any information whatsoever, merely rumour and speculation. They also will not provide the information consumer with any type of counselling, although the problem pages in teenage girls' and women's magazines usually carry advertisements for Brook advisory clinics, family planning clinics and other 'help lines' where counselling may be obtained. The three main benefits of 'unofficial sources' are that they are easy to locate and, unlike many of the 'official' sources, are not embarrassing to refer to. Finally, and most importantly, 'unofficial' sources offer experiential information about sex, which is not provided by the official sources.

**Developments in information provision: peer education**

Peer education has recently been added to the strategies which have been the more traditional ways of providing information about sexual issues to adolescents. A Sex Education Forum report says that peer education starts from the often repeated finding that friends are an important source of information about sex, and enables 'friends to do a better job' by selecting, from volunteers, adolescents who are then trained to lead sessions with other, slightly younger, adolescents. The aim is that:

The peer educators are seen as role models, and as acceptable sources of information about this type of behaviour, as they are perceived as being more likely to know what they are talking about. They also have greater empathy for the struggles of young people to come to terms with their own sexual feelings, and the sexual pressures around them.

The rationale for peer educators is that they combine the ability to overcome
barriers of distrust and fear about confidentiality associated with 'official' sources of information, with the ability to offer reliable information. A similar rationale is used to back the use of theatre in sex education\textsuperscript{96}. The use of peer educators has been hailed as 'one of the more effective approaches\textsuperscript{97} to providing information and education about sexual issues to adolescents. However, Milburn brings a cautionary note to the discussion of peer education saying that:

- peer education is expensive because it depends on thoroughly trained and supported staff;
- little research exists demonstrating the validity of peer education and its effect on information consumers;
- class, race and gender differences in receptivity to peer education have not been thoroughly investigated.\textsuperscript{98}

Even taking these concerns into account, the opportunity offered by peer education to bridge the gap between the information about sex provided by 'official' and 'unofficial' sources appears to be valuable.

**Conclusion**

The literature outlined here emphasises the need for a major shift in the provision of sex information for adolescents. The discrepancy between the sex information needs of adolescents and that information provided is partly due to the lack of a systematic approach to sex information and sex education in the widest sense. There is however a need for systematic outcomes, imposed at Government level. An example appears in the *Health of the Nation*, where one of the preventative targets is given:

... to reduce by at least 50\% the rate of conceptions amongst the under sixteens by the year 2000.\textsuperscript{99}

Beyond the need to meet Government imposed targets, there is a further more pressing need for addressing this issue, which can be seen by focusing on the value of sex information. In some information domains, the cost/value
calculation is difficult to evaluate because:

... such a calculation has to deal with a negative, the thorny problem of the loss which may be incurred by the absence of information.\textsuperscript{100}

Where the 'absence of information' significantly contributes to the continuation of sexual ignorance, the value of such information may be seen in its ability to promote informed sexual behaviour, which decreases (but, of course, does not eliminate) the level of risk involved in sexual activity.

Identifying the nature of information and the sources of information which are important to the adolescent information consumer necessitates an empirical research method which can address these issues within the social context of information seeking. This is reinforced by comments in a circular from the Department for Education which advises schools that they should:

... consider feedback from pupils on their learning needs using questionnaires, discussions etc which will help to identify pupils' current concerns and their existing skills and knowledge,\textsuperscript{101}

Therefore, this study will continue with focus group discussions about sex information with adolescents (see Kerslake and Goulding\textsuperscript{102} for a discussion of focus groups providing a data collection method against a naturalistic social context). This approach will not only help to 'iron out' problems with current provision, as Ray and Went\textsuperscript{103} suggest. It will also help ensure that the information offered, whilst constructed from a privileged adult position, addresses the information needed by adolescents and begins to alleviate the state of information poverty currently imposed on this group, thus moving adolescents towards an information rich position.

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Health information for the teenage years: what do they want to know?


*Information Research, 3(3), 1-9*
Health Information for the Teenage Years: What do they want to know?

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Loughborough University, UK

Abstract: What are the health Information needs of adolescents? What do they want to know? Sex 'n drugs 'n rock and roll? Reviewed are the information needs of adolescents within the educational setting, analyses of previous use and sources of Health Information and also the anticipated needs and preferred sources for the future. The changing need for Health Information from medical information to information relating to image and sexuality is reported. The restrictions of the educational system and the National Curriculum in teaching Health Information are identified, as are the differences in roles and responsibilities of the teachers who have a designated interest teaching Health Information.

Introduction

In July 1992, the Government launched The Health of the Nation, (1992). Within the document five key areas of public health were identified as focal points for government policy and action: coronary heart disease and stroke, cancers, mental illness, accidents and HIV/AIDS and sexual health. Within each key area, national targets were set.

The production of The Health of the Nation, was a definite shift in philosophy from the treatment of the illness in an individual to the development of a healthy nation of individuals. Prevention rather than cure had emerged as the way forward for public health. While some targets were vaguely determined, others were clearly stated, e.g.

"... to reduce by at least 50% the rate of conceptions amongst the under sixteen's by the year 2000."

Therefore the spotlight here is directly focused upon the adolescent and their behaviour, and ultimately their use and recourse to health information in this specific area.

Together with the Children Act 1993, and Children First, A Study of Hospital Services, 1993, the need for good personal and written information for children is emphasised. It is highlighted in the Children First report, that 90% of all health care for children is provided by the primary sector, therefore it is imperative that health information for adolescents is available across the whole spectrum of the subject; not merely sexual behaviour and the use of drugs. Within schools, awareness of health information for adolescents is provided within the context of Personal and Social Education (PSE). However, recourse to adolescent needs is limited. "Censorship of some types of "adult" information, then, is constructed as legitimate before that information is deemed suitable for consumption by adolescents. The rationale for such censorship is that the innocence of children and adolescents must be protected and maintained, even if the price this extracts is their continuation in a state of ignorance. Adolescents, therefore, are denied some information and, in contrast to most adults, are in a state of relative information poverty." (Kerslake & Rolinson, 1996:58). A short regional study in the Department of Information and Library Studies at Loughborough University, funded by the School of Humanities, (now the Faculty of Science) aimed to investigate this under-researched area.

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http://www.shef.ac.uk/~is/publications/infres/paper42.html
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It is acknowledged that health information messages are thrown at adolescents from many directions, organisations and people:- the Department of Education and the Department of Health, NHS, Health Promotion, Family Planning clinics, pharmaceutical companies, doctors, school nurses, social
workers and friends, youth organisations such as Scouts and Guides and of course, the mass media in various forms - teenage magazines, newspapers, television and the cinema. The focus of the study was seen as a starting point to investigate these conflicting messages. Trying to measure what health information is needed, and where and how it should be delivered is strewn with difficulties because of the vast scope of the remit.

What is health information?

Health information may be defined as information on a continuum between health education and health promotion. Therefore access to health information may contribute to health education and promote healthy lifestyle choices.

"Information is the first step to every healthy choice. Improvements in our health depend on us taking control over, and responsibility for, health as an important component of our everyday lives. This active participation requires full and continuing access to information: information about our bodies, their workings in health and illness, and the services available to us in treatment and care, support and co-operation" (Gann, 1986)

A literature search has revealed little or no evidence of the expressed needs of adolescents addressed in the provision of health information within the community setting.

Aims and objectives of the study

The aim of the study was to investigate the needs for health information of a sample set of Leicestershire and Nottinghamshire adolescents between the ages of 13 - 16 years. The study spanned both the private and the state sectors.

The objectives were to:
• ascertain what the sample set of adolescents consider to be their priorities for health information needs, if any.
• identify the various sources of information e.g. public library, GP surgery, school.
• investigate the various media used for the communication of health information to adolescents
• identify best practice in the provision of health information
• identify the adolescents’ preferred source and media for the provision of health information
• consider if the adolescents’ expressed needs are reflected in recent government health legislation

Study protocol

The sensitive nature of personal health information, combined with seeking the views of adolescents dictated that the study investigated the various communications media used in the provision of health information for adolescents rather than the observation or monitoring of oral communication of such information on a one-to-one basis.

Focus of the study

The focus of the study was adolescents within the community. To achieve a sample population across the whole spectrum of society, it was decided to target a sample population within the educational setting including both the state and private sector.

24 schools were short listed within Leicestershire and Nottinghamshire. Of these, 12 were selected, sufficient to give an insight into local practices yet yield enough information for discussion in the wider context. The study population was a sample of 635 students aged 13 - 16 years who were attending years 9, 10 and 11 in 12 schools in Leicestershire and Nottinghamshire. The gender split was approximately 50% boys and 50% girls.
The schools were selected to represent the different types of communities within the two counties. Including schools representing the city area, a suburban area, a market town, a mining villages and a rural village, these were roughly matched across the two counties, although comparing the responses between the two counties was not part of the research protocol. Two Independent Schools, a girl’s school in Nottinghamshire and a boy’s school in Leicestershire, also formed part of the study.

Initial telephone calls were made to the schools to the Principle, Vice Principle or Head Teacher to establish protocols and ethical approval for the study. These initial telephone calls identified the member of staff who was responsible for teaching health information and who would be the contact for the study within the school. Also the purpose and methodologies were also fully explained. All details of the study were confirmed in writing to the schools.

Data were collected using a questionnaire which sought information about the health information needs of the students. They were completed in class time, with assistance and supervision from the teaching staff. The use of postal questionnaires was rejected as not being suitable because of the known low response rate to this methodology. Completion under supervision in the class room was considered essential in order to avoid the joint completion of the questionnaires by groups of students within the school or elsewhere, and also non completion. Thus a high response rate of over 98% was achieved. One-to-one interviews were also conducted with school staff responsible for, or involved in, delivering health information education.

Both quantitative and qualitative data were sought in the study. The questionnaire was designed to determine the adolescents understanding of health information and its importance in their lifestyles. It sought to find out if they had ever needed health information, and if so where they had obtained it. Their views were recorded on the quality of the information in terms of needs met and if it was written in terms that could be understood, or was it too technical. Finally the questionnaire asked for information on the sources that adolescents would prefer to use to obtain health information.
Adolescent Views of Health Information

In response to the question "What is Health Information ", overall, and encouragingly, most respondents, regardless of gender, said that health information imparted advice and guidance, rather than facts and figures or warnings.

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<tr>
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<th>Boys</th>
<th>Girls</th>
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<tr>
<td>Advice / Guidance</td>
<td>232</td>
<td>234</td>
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<tr>
<td>Facts / Figures</td>
<td>40</td>
<td>40</td>
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<tr>
<td>Warnings</td>
<td>50</td>
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<td>Total</td>
<td>n = 322</td>
<td>n = 298</td>
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Table 1: What is Health Information?

Most rated health information either 'very important' (40%) or 'quite important' (54%), rather than 'not important' (6%).

In response to the question "have you ever needed health information?" of 632 adolescents who answered, two thirds of them stated that they had needed health information at some time in the past.

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<td>208</td>
</tr>
</tbody>
</table>

Table 2: Have you ever needed Health Information?

Over half the boys (59%) and three quarters of the girls (76%) said they had previously needed health information.
Previous use of Health Information Sources

The study population had used a variety of sources to meet their information needs. The sources were grouped into four 'macro' areas - places, written sources, people and multi-media - and four groups were then divided into a total of 23 sub categories.

<table>
<thead>
<tr>
<th></th>
<th>All Boys</th>
<th>All Girls</th>
<th>All Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Places</td>
<td>57%</td>
<td>72%</td>
<td>63%</td>
</tr>
<tr>
<td>Written Sources</td>
<td>40%</td>
<td>65%</td>
<td>51%</td>
</tr>
<tr>
<td>People</td>
<td>55%</td>
<td>72%</td>
<td>62%</td>
</tr>
<tr>
<td>Multi-media</td>
<td>32%</td>
<td>52%</td>
<td>41%</td>
</tr>
</tbody>
</table>

Table 3: Sources used by Adolescents to meet Health Information needs

Although the percentages by gender show some differences, the sources are still ranked in closely the same order so that the top ranking macro information sources, for all respondents, were places and people. Within each of these groups, the top three selections were:

- in the places grouping: GP's surgery, dentists and opticians;
- in the written sources: leaflets, booklets and magazines;
- in the people grouping: doctors, parents and friends; and,
- in the multi-media grouping: television, video and films.

The absence from this listing of school nurses in the people grouping is unsurprising given the unequal provision of school nursing services in the two counties. Some schools had a full time nurse on the premises, others had a part time nurse, and some only had a contact name.

Internet resources are also noticeable by their absence from the top three multi-media information sources. They were used by merely 3% of respondents. This is surprising given the apparent IT and Internet awareness of adolescents and the encouraged and extended use of IT equipment in
schools, homes and public libraries. The evidence of the study shows that the availability of the Internet facilities within schools was limited and not widely used.

The use of a telephone help line as a source of health information was also recorded as surprisingly small, only 3% of respondents preferred this method of obtaining information. The success of "Help for Health", "Health Information First" and the Trent Help Line do not appear to have penetrated the adolescent market. This is surprising given the availability and easy access to telephones within our society, and also the confidential and professional nature of the services provided. Yet the runaway success of the charity Childline, shows that a telephone service can be successful for children / adolescents. Therefore the study shows that the majority of adolescents prefer to talk to a professional face-to-face to obtain health information.

The previous use of health information above was contrasted in two ways with anticipated future use. First, one question aimed to gauge which sources adolescents were prepared to use to find health information. Responses showed that young people were happy to visit places (where the most frequently selected category was 'GP's surgery'), use written sources (where the most frequently selected category was 'leaflets'), to talk to people (where the most frequently selected category was 'parent') or to use multi-media (where the most frequently selected category was 'television') to get health information. Approximately two-thirds of the total respondents selected each of these categories.

Preferred Sources of Health Information

Respondents were asked for their preferred method of receiving health information across all macro groupings. Here responses were fairly evenly balanced between the places (27%), people (24%) and written sources (32%) macro groupings. The much-hyped multi-media sources were the preferred source of health information for merely 9% of respondents. As this rejection is by young people who may well be the most computer literature section of society, this should indicate a warning on the appropriateness of channelling
substantial amounts of health information via this source. Within the 23 sub-
groupings, the overall preference was to go to a GP’s surgery (selected by
16% of respondents) and the second preference was to talk to a doctor (selected by 11%). The difference in these two responses is that at a GP’s surgery it may be possible to speak to another health professional other than the doctor i.e. the practice nurse or health visitor.

Future use of Health Sources

The survey also examined the type of health information which respondents said they had previously needed and that which they anticipated needing in the future.

<table>
<thead>
<tr>
<th>Description</th>
<th>Previous needs</th>
<th>Anticipated needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dental care</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Diagnosed medical condition</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Eye care</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Sports/Exercise</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>Diet/Food</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Allergies</td>
<td>6</td>
<td>11</td>
</tr>
<tr>
<td>Skin care</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td>Sexual issues</td>
<td>8</td>
<td>3</td>
</tr>
<tr>
<td>Drugs</td>
<td>9</td>
<td>7</td>
</tr>
<tr>
<td>Smoking</td>
<td>10</td>
<td>9</td>
</tr>
<tr>
<td>Alcohol</td>
<td>11</td>
<td>8</td>
</tr>
<tr>
<td>Safety in the home</td>
<td>12</td>
<td>12</td>
</tr>
</tbody>
</table>

Table 4: Previous and future health information needs (ranked by frequency of response)

These responses demonstrate a shift in concern, which is particularly noticeable in the top three ranking anticipated needs, away from health information for dental care, medical care, and eye care, towards health
information relating to sports / exercise, diet and sexual issues, i.e. body image and sexuality. As these are prime sites for socially constructed 'norms' of sexual attractiveness, it is unsurprising that the third ranked future need is explicitly on sexual issues. Looking at the percentages of respondents involved, the percentage saying they anticipated needing information on sexual issues was 35%, almost treble the figure who said they had already sought information in this area (13%).

Teaching staff responsible for health information education in schools

The study revealed an array of different titles and rank of the members of staff nominated as responsible for health information education in each school. This indicates the diverse and non comparable approach to the subject by both counties and the schools within them. It does not suggest a systematic approach to the teaching of the subject. This is reflected in policy and practice.

<table>
<thead>
<tr>
<th>Type of School</th>
<th>Nottinghamshire</th>
<th>Leicestershire</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inner City</td>
<td>Assistant Deputy Head</td>
<td>Head of Modern Languages</td>
</tr>
<tr>
<td>Suburb</td>
<td>Head of Food and Textiles - Co-ordinator for Health Education</td>
<td>Assistant Principal</td>
</tr>
<tr>
<td>Mining Village</td>
<td>Deputy Head</td>
<td>Principal</td>
</tr>
<tr>
<td>Market Town</td>
<td>Acting Deputy Head</td>
<td>Head of Student Welfare</td>
</tr>
<tr>
<td>Rural Village</td>
<td>Head</td>
<td>Head of Personal &amp; Social Education</td>
</tr>
<tr>
<td>Independent</td>
<td>Deputy Head</td>
<td>Chaplain</td>
</tr>
</tbody>
</table>

Table 5: Teaching Staff Responsible for Health Information Education within Schools.

The responsibility for teaching for health information education was not easily apparent and identified to one specialist or individual within the 12 schools. Only one school within the study identified a co-ordinator for Health Education. PSE was usually taught in year tutor groups by the form teacher.
Obviously the differing ability of individuals to provide education for a range of subjects including sex, contraception, drug use/misuse and emotional adolescent changes was vast and not unlike the curate’s egg, good in parts. However the study also shows that the teaching of sex education is often provided after a proportion of students have become sexually active i.e. in year 11.

Training for individuals within schools also differed. The training of teachers in this particular field was reduced drastically in 1993 in that the Department of Education announced the cessation of 7 year part funding of health education units providing in-service training to teachers in sex and drugs education.

**National Curriculum**

This lack of comparability of identification of teaching staff for health information education, together with the different years in which different aspects of the subject are taught throughout the various schools indicates different interpretations of the National Curriculum - key stages 3 and 4.

The National Curriculum, Key Stage 3, section 2 - Humans as Organisms, *(Department for Education, 1995: 17, 18)* details the following subjects: nutrition, circulation, movement, reproduction, breathing, respiration and health. Health had the following three specific points:

- that the abuse of alcohol, solvents and other drugs affects health;
- that bacteria and viruses can affect health;
- that the body’s natural defences may be enhanced by immunisations and medicines.

Reproduction has the following specific point about:

- the physical and emotional changes that take place during adolescence.

The issues surrounding these physical and emotional changes are, by their very nature, complex and difficult to explain in a group situation. They often
require, therefore, one-to-one teaching and/or counselling, thus impinging on the all too little precious time available within the National Curriculum for Science. The depth of teaching required to fulfil the implications of the National Curriculum statement on the emotional changes that take place during adolescence really demands a separate timetable slot other than the meagre allowance within science. In the study, it was observed that this level of information provision was not successfully achieved within the PSE allocation. It would appear that emphasis within schools in science teaching remains predominantly in the factorial not the pastoral. Indeed, reminiscent of Mr. Gradgrind in Dicken’s "Hard Times":

"Now, what I want is, Facts. Teach these boys and girls nothing but Facts. Facts alone are wanted in life. Plant nothing else, and root out everything else. You can only form the minds of reasoning animals on Facts: nothing else will ever be of any service to them. This is the principle on which I bring up my own children, and this is the principle on which I bring up these Children. Stick to Facts, sir!" (Dickens, 1974: 1)

Despite the differing standards in health information education observed in the study, and the declared anticipated needs of the adolescents for information surrounding sexual issues, "Section 241 of the Education Act 1993 gives parents the right to withdraw their children from any of all parts of a school’s programme of sex education, other than those elements which are required by the National Curriculum Science Order" (Allen, 1987: 20)

Once again this emphasises the state of relative information poverty the adolescents can find themselves in if the parental right is exercised. However there is no evidence within the study to suggest that parents were exercising their right to withdraw children.
Health Promotion Events

To increase general awareness of all health information issues, several schools had taken the initiative to hold special events and open sessions for health professionals to bring the health information message to the school and students. The types of professionals invited to these events span the whole spectrum of health care - school nurses, dieticians, beauty therapists, ophthalmologists and also the police specialist drug and rape teams. The most favoured times for these events was either immediately after school or lunch times. However on both occasions attendances by students and parents had been very poor. On a rudimentary note the timing of the events, either lunch time or immediately after school closes are not conducive to the majority of working parents' hours or for parents who look after family at home. Also given that these events were aimed at adolescents both parents and the adolescents may assume that the parental accompanying role was unwelcome.

Conscious effort has to be made by the adolescent to go to the event either during lunch time effectively whilst still at school or after school outside official hours. The objectives of these events were to bring health information professionals and adolescents together in a non threatening environment, to remove all difficulties of finding the right type of information and greatly improve access.

However to attend this sort of event demands that the adolescent conforms in an information behavioural role, and is seen to conform to this model by others. Effectively an adolescent may have a passive interest in health information. However by attending a special event dedicated to the subject demands a paradigm shift from passive behaviour to active behaviour. This is obviously not a shift easily undertaken by the majority of adolescents in the study. It may not be considered "cool" to be seen seeking health information.

Conclusions

Three major conclusions have arisen from this research:
the shift of emphasis of the adolescent's need for information about medical conditions to information relating to body image and sexuality;

the emphasis of schools' health information education on the mechanics of sex education, in accordance with key stages 3 and 4 of the National Curriculum, thus leaving little time for discussion of the emotional changes surrounding these issues; and,

the apparent lack of a systematic approach to health information education in either county or sector.

The evidence would suggest that health information needs of adolescents are not being fully met within the community setting.

As the second phase of this research, the conclusions have been explored with focus groups of adolescents from the schools which participated in the study reported here, to achieve a greater understanding of their health information needs.

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- Rolinson, J. (1998) "Health information for the teenage years: what do they want to know?" *Information Research, 3*(2)
Paper 5

Use of Message boards to help patients manage their own health: a case study of mouth cancer

Janet Harrison and Clare Jones, 2006.

Library and Information Research, 2006, 30(94), 20-29
Refereed papers

Use of Message boards to help patients manage their own health: a case study of mouth cancer

Janet Harrison and Clare Jones

Authors
Janet Harrison is a Senior Lecturer in Information Science at Loughborough University. Her research spans the continuum of consumer health information needs and provision. Currently she is involved in the evaluation of the National Service Framework for the National Library for Health (England).
Clare Jones is an Information Skills Trainer for Swansea NHS Trust. She graduated in 2005 with a First Class honours degree in Information Management and Business Studies from the Department of Information Science, Loughborough University.
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Abstract
The growth of consumer health information, the rise of e-health and the recognition of the benefits of health self-support groups have inspired the continual development of health related message boards. This study investigates the use of a message board provided by the Mouth Cancer Foundation, specifically, the role that the message board played in providing members with the information they need. Phenomenological thematic analysis of the content of a sample number of messages was employed to identify key themes. It was found that the role of the community and anonymity provide an ideal foundation for emotional and physical information needs to be delivered to patients, giving a specific focus on radiotherapy. Conclusions identify that the Mouth Cancer Foundation Message Board is a successful consumer health information source for patients. Recommendations include a multi agency and voluntary sector co-ordinated approach for the provision of information for Mouth Cancer patients.

Introduction - Why E-Health?
A significantly high number of researchers have reported the increasing use of the Internet as a vital source of health information including (Pereira et al, 2000) and (Satterlaund et al, 2003). Health services and information delivered through the Internet are referred to as E-Health (Lea et al, 2004) and it has also been suggested that

One of the most promising aspects of the rise of E-Health is the widespread availability of electronic peer to peer community venues, where people with common interests gather virtually to share experiences, ask questions, or provide emotional support and self help.

(Eschenbach et al 2004,1166-1167)

Earlier Eschenbach had written that material obtained from the Internet can be a rich source for researchers interested in understanding the experiences and views of people and patients.” (Eschenbach and Till 2001,1103). Clearly the Internet has been established as a relevant source of health information for the health information consumer.

The Mouth Cancer Foundation - impetus for the research
Acknowledging the literature and the growing use of the Internet in everyday life, the focus of this research was driven by an interest in the provision of health information for the health information consumer via the Internet. Cancer was initially chosen as a condition for the research project as it is known to affect a large proportion of the population. It is estimated that 1 in 3 people in the UK will be affected by cancer, (Cancer Research UK, 2006) in their lives. This epidemiological spread of the condition has spawned massive amounts of consumer health information about cancer in all types of media. However, this topic was considered far too wide and unsuitable to be used as the focus of the proposed research project. Therefore, the proposal was refined to a specific type of cancer - mouth cancer.

Research was undertaken to discover what type of information and or websites were available for patients with mouth cancer. The Mouth Cancer Foundation was subsequently identified as a provider of such information.
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Acknowledgment

The authors would like to thank Dr. Vinod Joshi, Consultant in Restorative Dentistry, St Luke’s Hospital Bradford and Pinderfields Hospital, Wakefield,
UK, for his help in providing background material for this research and for his permission to analyse content from the message board.

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refined to a specific type of cancer; mouth cancer. Research was undertaken to discover what type of information and or websites were available for patients with mouth cancer. The Mouth Cancer Foundation was subsequently identified as a provider of such information.

**The Mouth Cancer Foundation – information provision**

The Mouth Cancer Foundation is a registered charity and provides information for mouth cancer patients about treatment and prevention via a website. It is not part of the NHS provision. The Mouth Cancer Foundation website can be seen as an example of the use of information and communications technology, to support the information needs of the general public, diagnosed patients with mouth cancers and their carers, friends, family and health professionals. The website was originally created by Dr V.K. Joshi (Consultant in Restorative Dentistry, St Luke's Hospital and Bradford and Pinderfields Hospital, Wakefield of the Oncology Clinic Restorative Dental Service), who is a leading clinician in the treatment of mouth cancer. His reason for creating the website portal was to assist information provision for mouth cancer patients, as he had discovered that,

*There was no UK web site that focused on mouth cancer awareness, early detection and the information and support needs of patients with these cancers.*

(Joshi, 2004, 4)

The website went live on 7th January 2002 and provides links to various sources of free information relevant to mouth cancer. On January 7th 2003, a year after the website was launched, a message board was added in order to try and “explain the intricacies of care and treatment from a personal angle.”

(Joshi, 2004, 5)

*It allows communication between individuals with oral cancer and their family members who seek information and help from survivors and other carers.*

(Joshi 2004, 6)
Personal stories are the only way a newly diagnosed patient can find out what the journey is like from people with first hand experience.

(Joshi, 2004, 4).

It was observed that the Mouth Cancer Message Board had attracted good numbers of users since its launch in 2003 (526 registered members at the time of the research, currently 940 registered members. “In September 2005, the site received a record number of 48,564 visits in that month alone, coming from over 25,973 distinct Internet addresses. 150,508 pages were viewed generating 1,136,159 hits in the month of September 2005” (Mouth Cancer Foundation, 2005).

The Mouth Cancer Foundation Message Board - the focus of the research

The researchers considered the Mouth Cancer Foundation message board to be ideal for the purposes of investigating how, why and what cancer patients communicate between themselves. The researchers acknowledge that the use of message board data has complex, sensitive and ethical implications and the data is considered private and personal. It can also be argued that data on message boards is in the public domain, as highlighted in the literature (Eysenback and Till, 2001). The research was conducted mindful of all of these issues. Therefore, it was considered essential to negotiate with Dr. Joshi creator of the website and message board to gain a mutual understanding for use of the data. An understanding was gained by the researchers to proceed with the research. The following were developed as the aim and objectives of research:

Aim:

To investigate the role of the Mouth Cancer Foundation message board in providing mouth cancer patients with the information they need.

Objectives:
To investigate the use of the message board;
To analyse how information is being communicated by patients using the message board;
To analyse what information is being communicated via the message board.

This paper reports the investigation of the role of the Mouth Cancer Foundation Message Board in providing members with the information they need to manage their own health.

Selection of Messages for the Research

A qualitative approach was considered to be most appropriate method to investigate the content of the messages being posted and to identify the most prevalent themes. To get a true picture of the role that the message board plays in delivering information to members, a passive content analysis of the messages was therefore chosen to be the most reliable method. (Eysenbach and Till, 2001) Although this approach would be time consuming due to the complexity of analysing unstructured data it was felt that the results obtained would reflect actual behaviour and reasoning of the users as opposed to a quantitative approach which would identify frequency of use.

It was recognised that resource constraints meant that not every message could be analysed and therefore a sample would need to be taken. The two fields identified for sampling purposes were considered to be all registered members and all messages. As a full list of members was available to the researchers, it was decided that using this list was the most appropriate way to select a sample. The sample was obtained by the random sampling method; every tenth person recorded in the list of members was selected until 20 members had been selected. Each member was assigned a unique number from 1 – 20 to provide anonymity. Again using the random sampling method 35 messages were identified for the study. The random selection
ensured that the messages chosen for the study could have been posted at any time, by anyone and in any of the message boards' on-line forum.

<table>
<thead>
<tr>
<th>First Stage</th>
<th>Pre-Reading of all Messages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Second Stage</td>
<td>Messages read again to identify categories to form a matrix.</td>
</tr>
<tr>
<td>Third Stage</td>
<td>Messages re-examined and quotes cut and pasted from the message into the matrix under the relevant category.</td>
</tr>
<tr>
<td>Fourth Stage</td>
<td>Messages re-examined to satisfy that no important quotes had been left out or put in the wrong field</td>
</tr>
</tbody>
</table>

**Table 1: Stages of Message Selection**

The content analysis followed Sullivan's phenomenological thematic analysis (Sullivan, 2003) of two online support groups.

The sample messages were evaluated to identify content and a matrix structure was created to accommodate the different categories. An iterative process was carried out whereby each message was analysed and evaluated four times as demonstrated in Table 1.

The process began with a pre-reading of all the messages. Each message was read again and categories identified for the matrix. Quotes were then extracted from the messages and subsequently added into the matrix. The messages were then re-examined to ensure that nothing of interest had been omitted or put into an incorrect category. Once the messages had been analysed and put into the matrix structure it became apparent that the analysis of 35 messages would be too ambitious for the time available for the duration of the research project.
Therefore, it was decided that the focus of analysis would be reduced to the first 20 messages. Open coding (Robson, 2002) was completed, the matrixes were reviewed and categories were either merged together, deleted completely and/or sub categories identified to ratify the data.

**Focus of Interest on the Message Board**

The overall tone of the message board can be described as friendly and inviting. When members join the message board they are often welcomed by active members. When members are anxious or scared they are often supported and reassured by other members. A strong sense of community was identified within the message board and it was clear that some members have made considerably stronger bonds regardless of location. There seems to be few boundaries in terms of content, as the message board is an environment in which members are free to discuss their fears and anxieties without restriction.

Discussion amongst the members using the message board were analysed thematically and the following categories emerged as the most popular.

- Initial Concern
- Side Effects - Radiation
- Feelings
- Anxiety
- Advice/Information
- Community

Investigation of these categories indicated that some of the categories fell under information needs (i.e. initial concerns, side effects of radiation), whilst others described the role of the message board (i.e. expressing anxiety, seeking advice and or information).

**Central Role of the Mouth Cancer Message Board**
It was identified that two central roles appeared to be fundamental to the use of the message board, which were essential in meeting information needs. They are the role of the community and the role of anonymity.

Central Role of the Mouth Cancer Message Board - Role of Community

Responses of advice and information sharing, empathy, support, admiration, normalisation, expression of feelings and anxiety are “characteristics of close relationships within a community” (Miller and Gergen, 1998, 190). These types of exchanges were all identified in this research, indicating that a community among members of the message board had been formed, allowing for informal and very personal discussion amongst them. Friendships between those members who are actively involved in posting messages are certainly evident despite Wright's comment in 2000 who suggested that topic specific discussions within the cancer community allowed people to avoid more general irrelevant information about cancer and to obtain support for specific concerns without the expectations associated with long term relationships (Wright, 2000).

Central Role of the Mouth Cancer Message Board - Role of Anonymity

Previous research has highlighted that participants of health related online support groups benefit from the anonymity of such groups and communication. (Wright,2000). To remain anonymous also allows members

To voice their complaints, test out bizarre ideas and identities, ask questions that might reveal their stupidity, or engage in behaviour they prefer others not to know about.

(Wallace, 1999, 240)

It is noted that “low risk discussions about high risk topics can be explored in a virtual environment”. (Adelman et al, 1987,137).
This role was considered in context of mouth cancer patients and the exchanges taking place and it is hypothesised that for mouth cancer patients' anonymity has several other benefits in a virtual world.

Firstly, treatment can often leave patients with visible scars and facial disfigurements and other physical disabilities, including speech and eating problems. Bernadette Castle, a counselling psychologist from the charity Changing Faces recently commented that

*Negative reactions can reinforce any negative feelings that person with a disfigurement might have about themselves. They can feel like they are on duty all the time, lacking the anonymity, others take for granted.*

(Myers, 2005)

Secondly, several researchers have paid attention to the social implications for individuals facing health conditions. One of these social implications is the stigma that is often attached to an illness or condition. Due to the misconceptions about causes of cancer there is stigma of being a cancer patient. The Internet therefore can "play an important role for people who need support from others due to afflictions society stigmatises," (Wright and Bell, 2003, 43) offering a forum for people who feel stigmatised by being a cancer patient, and to disclose personal information with a sense of safety.

Therefore, the ability to remain anonymous within a virtual community plays a significant role for the mouth cancer patient who, maybe too afraid, embarrassed or uncomfortable to seek information about their illness in the "face to face" world.

**Information Needs of Message Board Users**

**Radiotherapy**

The highest volume of quotes taken from the 20 messages referred to radiotherapy which highlights that this is an area of concern for members. Therefore the subsequent discussion will focus upon the physical and emotional information needs regarding radiation and will discuss the various
roles of the message board in delivering members with information in this area.

Radiotherapy - Physical Information Needs

Physical information needs identified in the content analysis included advice and information concerning:

- What foods to eat and what foods to avoid
- Timescales of recovery
- Treatment advice that could ease pain and help with eating
- Dealing with weight lose
- Role of Advice and Information

Members who participated in exchanges concerning radiotherapy were generally mouth cancer patients not carers or friends of patients. The posters of messages were often from mouth cancer patients who had recently finished radiotherapy treatment and were seeking advice. The respondents were often mouth cancer patients who had completed radiotherapy (sometimes years ago).

It was evident from the messages analysed that members often disclosed a very personal narrative of their problems and did not directly correspond with a question seeking advice or suggestions. Sending a narrative “into the air, so to speak” was a common online information seeking strategy, and one that has a more successful response rate than messages which directly ask for a response. (Galagher et al, 1998) Respondents would offer information and advice by sharing their personal experience of what foods they avoided and those that they could eat and how they dealt with pain, infections and weight lose often accompanied by timescales of recovery.

Question from Patient - Poster of message

“I am a non-smoker, non-drinking, male 49, never ill, tumour on roof of mouth discovered May 2004, treatment stated July 5, ended 17 August. Radiation 36 times (15 minute sessions) chemo 2 weeks, no surgery."
Burn damage to the mouth is so severe I cannot eat, and barely drink. Foods are limited to soft eggs, oatmeal, clear soups – all warm only. It seems like zero improvement since the last day of radiation (8/17/04).

Response from another Patient

“This eating business is a long slow job but slowly comes. I couldn’t eat any foods that were really acidic for over a year. Real fresh tomatoes with lemon juice on pancakes which is strange. Eating is very difficult for at least 6 months possibly up to a year I think. The improvements tend to be fortnightly rather than daily. Try going with strong flavoured foods like smoked salmon which slithers down compared to cooked food.”

Exchanges between patients, involving personal advice and information sharing, appeared to be more common than, scientific exchanges, involving health experts. This was also found by Preece, (Preece, 1999) who recognised that discussion was mainly between people who were in the same situation rather than between health experts. However, the contributions of Dr. Joshi cannot be ignored as it was observed that his medical knowledge often played an important role in providing advice and information concerning radiotherapy treatment and side effects, as evidenced here.

Response from Doctor

“Hope the side effects of the radiotherapy aren’t bothering you too much. You can find out more about the side effects of her treatment here: Several of my patients have found Gelclair helpful in dealing with the mouth ulcers and sore mouth caused by the radiotherapy and Biotene useful for coping with a dry mouth”

However, as Preece suggested,

Physicians can provide the facts but other patients can tell you what it really feels like and what to expect next, in a way that only someone with personal experience can. (Preece, 1999, 63)

It is also suggested that patients,
Go in search of people who will listen to them and who will address everyday issues and fears that healthcare providers may either not realise or have time to address.

(Wright and Bell, 2003, 44)

Based upon the findings from this research it can be argued that the Mouth Cancer Foundation Message Board became a pivotal role for some patient’s management of radiotherapy side effects and their information needs and as Walther and Boyd (Walther and Boyd, 2002) identified, due to the asynchronous communication of computer mediated communication, there is a high quality of information exchanged as this communication allows time to write a good request or a good response.

Radiotherapy - Emotional Information Needs

Emotional information needs, included empathy, support of others through agreement, congratulations (boosting of self esteem), gratitude for something said and normalisation of a stated problem.

Empathy and Support

Eley suggested “emotional bonds can be very strong between members of discussion groups” (Eley, 2003) and this was certainly evident between members of the Mouth Cancer Foundation Message Board. These emotional bonds create a very empathetic and supportive environment. Eley was building upon earlier research including Preece and Ghozati (Preece and Ghozati, 1998) who suggested that empathy has a very important role in online support groups that are concerned with health matters. It was noticed that when referring to radiation, Mouth Cancer Foundation message board members were often quick to offer empathy and support to one another. Researchers have identified 3 different types of empathic messages in support groups on the internet. (Preece and Ghozati, 1998)

- Empathising with another’s situation and suggesting ways to cope;
• Empathising about life style;
• Indirectly requesting empathy of telling ones story as a means of inviting others to respond.

All three types of empathetic messages were evident in discussions between members of the Mouth Cancer Foundation Message Board. The following quote demonstrates the third type of empathetic message. This type of online information seeking strategy where, it was common for members to send a narrative “into the air so to speak.” has also been identified by Galagher. (Galagher et al., 1998).

Patient statement “into the air, so to speak.”

The examination concluded that I can not gain the protein I need through eating alone, (at the rate I am eating and ability to eat), and I need to be feed through a tube in my stomach. From the beginning I hated this idea, and didn’t oppose it, but asked if I really needed that. I was told months ago that my weight would be watched. I never heard anything more about the tube, even when complaining and loosing weight. The Doctor phoned my chief Doctor and they agreed, I need the tube now. Now that is 105 days after my admittance to the hospital. I think they made an error a long time ago in the lack of installation of this tube. I actually thought my body was stronger, but I was wrong. I cringe to think about this new routine, but I want to get on with the painfully slow recovery. I am told that radiation bums in the mouth can take months to heal, and slowly they will heal. The radiation is a powerful toxin that stays in the systems after it has damaged what it can. So this week I’ll add another chapter to this book, dealing with this tube that I thought I could bypass.”

This message indirectly evoked the following response where the respondent “empathised with the member’s lifestyle.
Response 1

"I am so sorry that this has happened to you. It is a horrible disease at best. The aftermath is just as horrible as the surgery."

Later the discussion turns to a respondent who shows appreciation of members who express the first type of empathetic message “suggesting ways to cope.”

Response 2

"the number of tips one can pick up on the site concerning our various queries. Particularly those from yourself with, regrettably, your long experience with coping."

The relationship between members and the wish to help other members cope better, has been reported in the literature as to often derive the greatest benefit to those offering the support and empathy.

This may be defined as altruism, which is an important coping strategy for some patients who find emotional balance in helping others.

(Weis 2003, 767)

Support and empathy were often found to be interchangeable as the following quote displays:

Response 3

"at least try to stay focused. I know this is the hardest part of the radation.....We are here trust me.....just hang in there.....these will be some of the darkest days for you, just remember that they do go away."

The quote identifies elements of suggesting ways to cope “stay focused”, empathising with someone else’s situation “I know this is the hardest part”, support “we are here trust me ” and reassurance that “they do go away”
Role of Normalisation

Festinger’s social comparison theory hypothesised that “individuals seek to have and maintain a sense of normalcy and accuracy about their world. (Festinger, 1954). In time of uncertainty, Festinger predicted that affiliative behaviours would increase as people sought others’ opinions about how they should be thinking or feeling” (Davison et al, 2000, 205). Analysis of the Mouth Cancer Foundation network identified that as Festinger’s theory states members were seeking “a sense of normalcy and accuracy about their world” and that they were seeking “other’s opinions about how they should be thinking or feeling.” (Festinger, 1954) It was found that members were seeking to normalise both the physical side effects of their treatment and their emotional feelings.

Question

“Any ideas on the radiation burns of the inner mouth and how it goes, how long it goes and why wont this heal?!”

Statement

“Let me tell this to someone who understands, who will not flinch and turn away from my suffering”

Statement

“You can ask anything, even if you think the topic in question only happens to you, and I bet someone will have experienced the same”

Similar to the role of advice and information it was evident that most members often disclosed a very personal narrative of their problems, therefore not directly seeking normalisation but expecting it due to the norms and culture of the community.

The following quote illustrates how a comment by a member, provided a fellow member with a feeling of normalisation. In this case the member was
Not seeking normalisation nor was the previous member offering normalisation; instead the effect of normalisation occurred accidentally.

**Statement**

**Member 1**

“For some reason my tastebuds differ all the time don’t know why. But you may be lucky and not have this problem.”

**Member 2**

“You don’t know how good that made me feel to read that to know someone else still has up and down taste. We think our taste is back and wham a week of indifferent taste sensations. One thing I have learnt about all this is that we all have different taste changes so all we can do is say what we eat and find acceptable even if another find it disgusting.”

Members who participated in normalisation exchanges were generally mouth cancer patients. The posters of such messages were often the patients who had recently finished radiotherapy treatment and were seeking to find normalisation. The respondents were often patients who had completed radiotherapy (sometimes years ago).

**Lurking**

Discussion has centred on the information needs and roles played by members who post messages however statistical analysis showed that on 30th January 2005, 40.9% of the members of the Mouth Cancer Foundation message board had not posted any messages. One assumption that could be made is that these members are happy to observe the content of the message board and that their information needs are satisfied by doing this. The role of the message board in this instance is Lurking. Lurking refers to reading messages posted by others on electronic spaces, without postings ones own message. Some estimations place the number of lurkers to active posters as a hefty majority of users who frequent a particular group. (Walther & Boyd, 2002) With a high percentage of 40.9% this was most certainly
evident with members of the Mouth Cancer Foundation Message Board, indicating that Lurking is a significant role in information seeking strategy when using the Mouth Cancer Foundation Message Board as a health information source.

**Negative Exchanges**

This project identified the roles that the Mouth Cancer Foundation Message Board plays in meeting information needs, the positive effect in delivering information have been considered. Conversely, the roles that have a negative effect on meeting information needs must also be considered.

Five categories of discourse in computer mediated conversation, includes punitive interchange which includes doubt regarding the genuineness of participant’s accounts and critique of actions. (Miller and Gergen, 1998) Punitive interchanges were not evident within the Mouth Cancer Foundation Message Board as the culture of the message board is very trusting but awareness that the anonymity of such communication allows members to be someone they are not must be recognised. Of the 20 messages analysed there were no comments questioning the validity of a member or description in fact the following comment was made:

**Statement**

*The sincerity of everyone here compared with some of the other cancer sites I have visited is just unbelievable.*

However, the following statement written by a member of the message board, does include comments that criticise people’s actions of participating in this message board. The member expressed the following concern:

**Statement**

*I realize some people have to harp on their own misery and misfortune but it has no added value to read this stuff – if it promotes doubt and worry.*
This member is suggesting that by reading other people's experience with mouth cancer increases the anxiety and fear that a patient may feel, thus having a negative impact on the information he/she receives. However, comments such as this were rare echoing the work by Egdorf and Rahoi (Egdorf and Rahoi, 1994) in their online community study who stated that very little communication was coded as negative.

Conclusions

- The fundamental role of the Mouth Cancer Association Message Board was that it has two key roles for Mouth Cancer Patients: Community, the support of a network of people if and when required and Anonymity, the right to remain anonymous within the community if and when desired.

- Roles such as seeking and giving advice and information, empathy and support, and seeking and offering normalisation all deliver relevant information needs, to the patient, in order to help him cope with their care.

- "Lurking" on the message board is normal and acceptable behaviour. It was found that a high percentage of members do not post messages; they observe and lurk in the background, it would seem that the role of "Lurking" is a pivotal activity for mouth cancer patients.

Recommendations

It is recommended that:

- Information about the effects of Radiotherapy and the side effects it can cause should be provided more fully to Mouth Cancer Patients. Radiotherapy is often used in the treatment of mouth cancer. However, the side effects of radiotherapy for patients are often upsetting and distressing and this is the information that is not routinely and appropriately given to patients. The message board revealed many
exchanges concerning radiotherapy between Mouth Cancer patients for both physical and emotional information needs.

- Information is required by patients in remission. As many patients who contributed to the message board exchanges had finished their treatment it seems apparent that once the patient has finished treatment, and is in remission, the available information sources are limited. Once out of the formal healthcare system patients and/or health information consumers turn to alternative sources to seek answers.

- It is recommended that all information provision concerning mouth cancer and treatment should be improved. Leaflets, websites, books and other sources of information should be developed by consumers, patients and health and information professionals. A co-ordinated approach to this would be ideal in order to provide the best possible information for patients.

Summary

This work highlights an honest, grounded and reflective insight into the information needs of patients and their choice of the Internet as the medium to express and meet those needs. This research identifies the depth of knowledge of the “expert patient” and their willingness to share this information with others. It is incumbent upon information professionals to harness this knowledge and work together with the “expert patient” to develop knowledge management systems for health information provision.

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Paper 6

The information needs of informal carers: An analysis of the use of the Micro-Moment Time Line Interview


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The information needs of informal carers: An analysis of the use of the Micro-Moment Time Line Interview

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Abstract
Informal carers and the contribution that they make in caring for people in the community is now recognised by government. The publication of the National Strategy for Carers attests to this. This paper presents the findings of a study into informal carers in Leicestershire, commissioned by Leicestershire Social Services Department. Specifically, the paper focuses on the use of the Sense-Making approach to study the informal carers’ information needs. Sense-Making theory is explained and a discussion of the development and administration of the micro-timeline interview is given. Sample data derived from the interviews are reviewed followed by a discussion of the acceptability and appropriateness of the Sense-Making method in the context of understanding informal carers’ information needs. The paper concludes that the Sense-making methodology is an appropriate technique to use with this population.

Introduction
This study, commissioned by Leicestershire Social Services Department, was a study of informal carers in Leicestershire excluding Leicester City and Rutland. The objectives of the study were:

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Department. Specifically, the paper focuses on the use of the Sense-Making approach to study the informal carers' information needs. Sense-Making theory is explained and a discussion of the development and administration of the micro-timeline interview is given. Sample data derived from the interviews are reviewed followed by a discussion of the acceptability and appropriateness of the Sense-Making method in the context of understanding informal carers' information needs. The paper concludes that the Sense making methodology is an appropriate technique to use with this population.

Introduction

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1. To provide an accurate picture of the demographic distribution of informal carers in the county of Leicestershire (excluding Leicester City and Rutland). This was to include their age, gender, ethnicity, their relationship with the cared for person, the condition of the cared for person and the time spent caring.

2. To provide an understanding of the carers' information needs.

This paper focuses on the second objective of the study; namely, understanding the information needs of informal carers. Specifically, the paper focuses on the use of Dervin's Sense-Making approach [1] to study informal carers' information needs. Sense-Making was used to ensure that the study findings reflect the informal carers' experience from the perspective of the informal carer rather than from the service providers' point of view, thus providing a rich picture of the informal carers' situation. The paper reports on the methodological challenge of applying Sense-Making to a study of informal carers and discusses the development of the interview protocol, its acceptability to the carers and evaluates the appropriateness of Sense-Making in the context of informal carers.
The Impetus for the Research
In recent years, changing patterns of health and social care have placed greater emphasis on care in the community, which has become an important part of the health care system. As a result of this emphasis, the majority of care for people who are unable to care for themselves is through informal carers [2].

Since 1997, The UK government has made carers and issues surrounding care in the community a priority. It is suggested that one reason for this is that it is cheaper for the State if care is provided informally without pay. It is in the State's interest therefore to promote informal care and provide support so that relatives can continue to care. A second reason is the realisation by government of the enormous demands made of carers that have for too long gone unacknowledged [3]. Third, it has been recognised that being cared for in one's home is for many people, preferable to being in a care home or hospital, and that being at home enhances the cared for person's sense of well-being [4].

The government's focus on carers culminated in the publication of the National Strategy for Carers published in February 1999 [3]. The National Strategy identified for particular attention, carers of working age, carers of people with dementia and young carers, and was the driver for Leicestershire Social Services commissioning a survey of informal carers.

Informal Carers
It is estimated that there are six million informal carers in the UK of whom 855,000 are providing care for more than 50 hours a week [5]. Generally speaking, both men and women care, although most family carers are women and men are far less likely to become carers. However, once they have become carers, men and women report similar experiences of caring. The majority of carers are spouses or partners followed by adults caring for elderly parents. Caring is found in all social classes, but like in many other spheres of life, those with more financial resources and greater advocacy
skills, fare better [6]. About 75% of the total time devoted to caring comes from carers that live in the same household as the cared for person. It has also been found that because the physical demands of caring are often far greater than the physical demands made of adults in their normal daily lives, carers are more likely than non-carers to have a longstanding physical disability or illness [2]. Moreover, most informal carers receive very little help from statutory agencies and they are often unaware of their entitlements.

Carers often have a wide range of information needs that require to be met and therefore, information is a vital part of support for informal carers [7]. The importance of timely, accurate and accessible information for carers is illustrated by the inclusion of an entire section on 'information for carers' in the National Strategy for Carers [3]. One area in which carers have a need for information is about the illness of the person cared for. Uncertainty about the course, treatment and prognosis of a disease is difficult for a carer to live with, especially when it is a close relation with the illness [7]. From the carer's perspective, diagnosis, prognosis and information about the disease helps in understanding the symptoms, thus allowing the carer to avoid blaming the cared for person, for something that he or she cannot control. For example, a carer would be less likely to interpret behavioural problems as misbehaviour when they have adequate information on the symptoms of Alzheimer's or dementia generally.

Most carers talk of the great satisfaction that they receive from looking after and nurturing a relative. For many, caring proves to be a very rewarding and positive experience. However, together with the feeling of satisfaction, there often are feelings of resentment and anger at the cared for person for changes in the carer's social life among other things. This is often accompanied by a sense of guilt on the part of the carer. In summary, though rewarding, caring can quickly become physically and economically costly. Thus the ability of informal carers to care for someone at home depends on the material, social and professional support available.

The Leicestershire informal carers study involved a questionnaire survey of
2000 informal carers in Leicestershire followed by an interview study consisting of a subsample of 60 of the 2000 informal carers. The results of the questionnaire survey showed that 71% of the carers who responded [N= 174], were aged between 40 and 69, and 68% were women a finding similar to other studies [5]. Despite many carers stating that their own health was good (73%), in a separate question carers reported suffering with back trouble (45%), depression (48%), exhaustion (54%), sleep problems (60%) and stress (76%). Seventy five per cent (75%) of the carers were unemployed and among those that were employed, the majority (63%), were employed part-time, a finding replicated in other studies [5]. Eighty eight per cent (88%) of the carers lived with the cared for person. The carers' relationship with the cared for person was as follows: 47% were either a spouse or partner, 29% looked after a child and 20% looked after elderly parents.

The cared for person was commonly above 75 years old and with a relatively even distribution between females and males (46% female, 54% male). Their medical condition was varied and often the cared for person had a number of medical complaints. However, by far the most predominant condition was stroke and confusion joint first, followed by Alzheimer's.

**Methodology**

**Background to Sense-Making**

Dervin's Sense-Making method has been built over a number of years since 1972 [8]. The aim of the method is to provide a way to understand information in specific contexts and also to understand how information needs come about and how they are resolved [1]. It has been described as a model by commentators but in Dervin's own writing, she says of Sense-Making that it is "a set of assumptions, a theoretic perspective, a methodological approach, a set of research methods and a practice" [9]. Dervin defines "Sense-Making" as a label for a coherent set of concepts and methods used to study how people construct sense of their worlds.

Philosophically, Sense-Making does not fall in either of the two main
paradigmatic traditions: the positivist, neo-positivist tradition (giving rise to quantitative methods) or the constructivist, critical theory tradition (giving rise to qualitative methods). Rather, Sense-Making displays attributes of both traditions.

Sense-Making is predicated on a number of assumptions. The first and core assumption of Sense-Making is that reality is never unbroken but rather has gaps or discontinuities. It further assumes that because reality is constantly changing, the concept of gap is generalisable [1, 10].

The second assumption of Sense-Making is that information is not an objective entity existing independently of human beings. On the contrary, information is seen as a direct artefact of human observing which in turn is constrained by the following four factors:

1. Human Physiology: Human beings are unable to make some observations that other species can.
2. Present time-space. Because we are bound in time-space, our observing at any given time is limited by where we are.
3. Past time-space. We are descended from different histories and our histories in part, influence our observations today.
4. Future time-space. Our observations today rest partly upon our focus for the future. Further, following from the discontinuity assumption, our observing today cannot be valid for tomorrow.

These constraining factors on human observing imply that information is a subjective entity.

Dervin illustrates her method using what she calls the "Sense-Making metaphor" [10]. The metaphor has three elements to it: situation, gap and use. She argues that all information needs arise from a discontinuity or 'gap' in one's knowledge. Dervin's 'gap' is synonymous with what is usually referred to as information needs in other models. The gap develops out of a situation in time and space, which defines the context in which the information need arises. Finally, the gap is bridged by employing what she calls uses or helps.
It is important to recognise that the Sense-Making metaphor is operationalised using the Micro-Moment Time-Line Interview method. This method was chosen as the most suitable way to understand and gain information from the Informal Carer population and the scenarios they experience. The method entails asking the interviewee to talk through what happened in a given situation, step by step. For each of these steps, the interviewee describes what questions, or confusions he or she had and what needed to be made sense of. For the method to work well, the interviewer should ensure that at least two elements of the three-element situation-gap-use model are discussed and that data for each element is linked to a micro-moment.

Applying the Methodology
The interview protocol used for this study was developed with the aim of uncovering specific situations informal carers encounter and their associated information behaviours. Dervin's writings were used to inform the development of the protocol [1, 9]. The protocol was divided into three sections each focusing on the situations, gaps and uses elements of the model. In the first section, situations, interviewees were asked to think back over their time as a carer and name three events (bad or good), that stood out in their minds. This was intended to reveal the situations thereby defining the context of information need. After three events had been identified, for each event, the following questions were asked: The first question was to describe what had happened in these events, and what questions or confusions the interviewees had. These included what was not known and what difficulties or problems they had. The aim here was to clarify the 'situation'. These two questions formed the nucleus around which the rest of the interview was built.

The second section was a discussion of the nature of the 'gap'. What was it that was preventing the interviewees from moving forward? It also included questions about their knowledge of the 'gap'. Had they [interviewees], been in a similar 'gap' before? There was also a question on the importance to the interviewees of having the 'gap' bridged. This was followed with a question on how the 'gap' was bridged in the situation under discussion? Where did they
go to find relevant answers, and how did they know where to go? What helped move them along?

There then followed a question about their success in moving through the 'gap'. Were they satisfied that they had resolved the discontinuity or 'gap'? Further, did they consider that they got a full answer? They were also asked what if anything acted as a barrier or constraint in finding an answer to close the 'gap'? That is, what hindered /stopped them, what was difficult, what obstacles did they face? This latter question was counterbalanced with a question about what they saw in particular as helping. This section on the nature of the 'gap' was closed with a general question about how they felt about the situation.

The last section of the interview protocol was on the uses made of the help /answers that had been obtained. The first question was whether the interviewees had an expectation that the answer would help once it was found. This was followed by a question to ascertain whether the answer helped in ways that were expected or in other ways. To counterbalance this question, they were asked another question about whether they expected that the answer would present problems? And if so, were these expected to be new or old problems?

The next question asked how having the answer helped. Did it resolve the situation? This was again counterbalanced with a question did the answer hinder progress in any way or cause problems? These two questions were asked because Sense-Making focuses on how humans construct sense and therefore does not assume an automatic association between information [the answer] and use. The final question asked what, with hindsight, would have helped in finding the answer?

The initial interview protocol was piloted for unambiguity and comprehension using six informal carers who met the study criteria but were not used in the final analysis. As a result of the pilot, minor changes in the wording of some question were made. Following these changes, the content of the interview
Recruitment of Carer Interviewees

The first phase of the study consisted of a questionnaire survey. In order to recruit carers for the interview study, the 2000 informal carers in the questionnaire survey were asked to indicate when returning their questionnaires, their willingness or otherwise to participate in an interview study. Those who were interested were contacted by phone and a suitable time arranged for the interviews to take place. Interviews took place in the carers' homes [because they can seldom find time to be away from home due to the demands of the caring role] and were tape-recorded with the carers' permission. The researchers were mindful of the vulnerability of the interviewees and the potential sensitivity of the information to be captured. Therefore, at the outset of the interview, assurances were made as to confidentiality, and the interviewee's right to withdraw from the study at any time without giving a reason was emphasised. The average interview lasted about ninety minutes and a further thirty-minute post-interview winding down period was allowed for. All interviews were transcribed in full. The interviews were analysed using Atlas.ti which is a qualitative data analysis software.

Data derived using sense-making

Using Sense-Making it was possible to collect rich information which was carer-centred rather than system centred. An example of two interview transcriptions will be used to illustrate the type of data that it was possible to obtain using Sense-Making and thus to establish the carers' information needs and seeking. The first example used is that of an interview with a woman carer whose husband had recently been taken ill and was confined to a wheel-chair. This first example reflects the sort of situation that most people would expect carers to be in. The second example used is slightly different. It relates to a woman whose 14 year old daughter has epilepsy and exhibits challenging behaviour. She has always had behavioural problems but it is only with the onset of adolescence that her behavioural problem has become a cause for concern. Excerpts from the two interviews are given in sequence.
Interviewee 1

Identifying Critical Situations
The aim of the first part of the interview protocol was to identify in what type of situations carers need information. When asked to think of any three events that stood out in her mind, this is what interviewee 1 said:

A. - The main thing is when I first started being a carer finding out all the information.
Q. - Yes
A. - Benefits and things like that

She could only identify the one situation described above. The interview proceeded with a discussion of this situation but later came back to identify two more situations which were also discussed. The focus here is on the 'situation' involving benefits.

Her husband had stopped work suddenly after a fall left him part-paralysed, and as a result, they were on a reduced income. The situation therefore was trying to sort out their financial matters.

Identifying the Nature of 'gap'
What was the 'gap'? What confusions, muddles did she have in her mind with regard to their situation? She said:

A - I didn't know what benefits Rob was on, what he was entitled to or anything or what I was entitled to.

Clearly, she was not sure at all about benefits entitlement. All that she knew was that her husband would be entitled to some benefit and perhaps she herself. Apart from this, she was uninformed. She knew that she had to do something about benefits but didn't really know what.

Thus far we have established what her situation was and what needs she
had. What her 'gap' was. The interview then moved on to a discussion of the nature of her 'gap'.

She was asked how much did she know about benefits at the time:

- So how much did you know about benefits and the rest.
A - A little bit because I used to work in the Post Office but not a great deal.
- You used to work at the Post Office?
A - Yes
- So you had some idea of the sort of benefits you might be entitled to?
A - Yes, might be, but until you read up about them or ask about them you don't really know which ones apply and which don't, and if I got something whether he would get less or anything like that, it was very complicated.

Though she had worked in a Post Office and thought she had some knowledge of benefits, it was only when she was in the situation of having to arrange benefits for herself that she realised how incomplete and inadequate her knowledge was for the task at hand. She also mentions how complicated the benefits system is - difficult to make sense of. However, one advantage she had was that she knew how and where to get the information she required as the following excerpt illustrates.

A - It was just a matter of looking it up and going to the local office and talking to people there, getting all the details.

Her choice of words suggests that it was an easy matter to find the answer she was looking for. She went on to say that having an answer was important to her because she needed to sort out their financial situation:

A - No I think I needed to know.
When asked if she thought she had got a complete answer concerning benefits she said:

A - I think so,

A tentative rather than emphatic answer. And what did she see as a barrier or hindrance when looking for an answer?

A - Only the complicated way things are done that's all, that was the biggest barrier, trying to find out all the details, it was all so complicated and confusing. The tax and benefits and things like that you know, it was just so confusing, you try to find some information for yourself and its just confusing, so you have got to go somewhere and talk to somebody about it or ring up and get an explanation.

She again mentions the word 'complicated' once and 'confusing' three times. It is clear at this point that what from the foregoing narrative at first seems a straightforward information seeking activity, is not. Rather, it was a confusing and complicated affair. She goes on to say that she would have liked to have been able to find out for herself all that she needed to know. In the event, she was forced into "talking to someone" about it; something she did not want to do.

So, in this situation, what was helpful in moving her along?

A - Yes the local benefits office, the person there was quite helpful and I also got hold of a copy of the Age Concern book, which gives details of all that about it, sort of thing. Mostly geared towards different kinds of benefits, there is quite a lot of useful information in there, well set out, easy to understand.

This answer shows that information seeking is not a linear activity in that she now mentions that she also had a copy of the Age Concern book which
she relied upon but had not mentioned previously. She obviously found it useful because she says so and adds that it is well set out and easy to understand. When asked how she got hold of the Age Concern book she said:

A - Good question, I think his dad [Father in Law], mentioned that they did a book and he had seen it and it had got all the benefits in it.

Again this indicates that the information seeking process was not linear and pre-defined. She was talking to people about her situation in an effort to obtain an answer and was picking useful ideas along the way. She could not even remember straight away how she had come to hear about the Age Concern book. However, when she was asked how long it took to resolve the benefits situation this is what she said:

A - It took a little while to sort it out if I remember because I had to get all the details of that and then finding information and filling in the forms and everything, about an hour I should think.

When asked how she felt about the situation she said:

A - Slightly frustrated probably

Information Use

Turning to information uses she said that she expected the answer she got would resolve the problem and it helped in the way expected.

A - Yes, well we got the answers we needed in the end, all the information

She said that she did not expect that the information would present any problems and neither did it. She was then asked the following question:
Q - And so you did not encounter any problems as a result of what you are saying, like for instance, anything like, I thought I could do this or I could do that and then you subsequently learn that no I can't, that sort of thing ....

A - Oh, right. I think that would be part of working through the process of ending up with the final answer of what we were looking for.

This is a reference to the complicated and confusing nature of the benefits system.

How did having the answer help?

A - Well I suppose if we hadn't have got the answers we wouldn't have ended up with the correct benefits we were entitled to, we did need those answers and they helped us to get through to the right benefits.

How did the answer hinder? Having the answer did not hinder in any way. Finally, when asked what with hindsight, would have helped, she said:

A - I think all the information was not easy to understand, everything is all so tied up with everything else and it affects everything else, one thing affects something else and that affects something else, you know you just don't know. You can't find information that easy you have got to go and dig it out from somewhere. I am not really used to read information and filling forms and that sort of thing, its all so complicated, if they could make that easier then I know they have got to have certain restraints to make sure everything is right, its just so complicated and all so tied up together, all the different benefits.
are all affecting each other and it doesn't make life easy at all. When you are looking for certain benefits, the Age Concern book is very good in some ways but it just shows you how there are all types of benefits, it refers to all the different things you can do this, you can't do that, if you get this somebody else might not get that, so complicated. If they could make - (sigh) - (laughter) - you'd expect them to make it complicated in the first place haven't they? A - I think they could simplify things definitely, I don't see why there are so many different allowances that do the same job, I mean it depends where you are living, what age you are, whether you are working whether you are not, whether you can work or whether you can't work, you know, this doesn't make sense.

She obviously had a hard time in finding an answer though she was able to make-sense of the minefield in the end.

**Interviewee 2**

*Identifying Critical Situations*

Interviewee 2 had this to say about her situation:

The focus here is her daughter's challenging behaviour and how to manage the situation.

A - Well it's very difficult because I have been saying for a very long time. I have been saying for 10 years that she has challenging behaviour, but it's also she is quite petite and like I have always been able to control her. She doesn't listen to you, you can't... reason with her. She knows she is doing wrong one minute, but it doesn't stop her doing it the next minute.

When asked what questions, muddles and confusions she had, she said:
A - Her behaviour hasn't really changed, but she has just grown. So the behaviour becomes more of a problem, but she has actually picked up various unsociable language at the moment as well, and she has very good language, speaking language but she has little comprehension, of the spoken word and so sometimes she doesn't understand what she's saying, and that it is bad to say it. So she can say these things out in public and you get severe reactions from it. Things like that are quite difficult and I am actually finding that quite difficult to come to terms with.

Her daughter has always had challenging behaviour. The difference now is that her daughter has grown and is much more difficult to restrain physically and mentally. She has learnt unsociable language and uses it freely. As a result, this woman is constantly being embarrassed by her daughter's behaviour and consequently has a number of unanswered questions.

When asked what previous knowledge she had of managing and coping with challenging behaviour she said that she did not know anything at all and added:

A- No, no one actually tells you what to do about behaviour, they will say right we will just sit her down and occupy her and keep her calm and that or just hold her hand and things like that and hold her wrist's and that. The most they actually said was this is how you should deal with that, and we have been to behaviour psychologists and they haven't told us how to manage this at all.

Identifying the Nature of 'gap'
After identifying her 'situation' and discussing the questions she had, the interview turned to a discussion of the nature of her 'gap' and specifically, what information seeking strategies she used in order to find
out what she required to know.

A - Well she went to a hospital in Oxford for her epilepsy which also had a behaviour management centre there as well and they just told me she should go to residential school for badly behaved children, which I think was totally inappropriate, because she would just copy the bad behaviour and wouldn't learn anything from it. That was four years ago we were told that. And I personally think that epilepsy and her behaviour go hand in hand, not in all cases but the children to have to deal with their own difficulties epilepsy and actually be able to run around and talk... I think behaviour goes hand in hand. It's very difficult to get a place and there are very few and a long distance away. Saying that, we are going to visit two... in the next three weeks. I just find it really difficult in that there are a lot of people out there who offer to help you I don't feel that you do get... you don't actually get told what to do about it.

She has been to doctors but in common with the findings of other interviews, there was a perception that no one was listening to her. Worse, the answer she was getting she considered 'inappropriate' and complains that no one could give her a straight answer. When asked whether in her opinion she obtained a full or partial answer she said that she only got partial information. This bearing in mind that she has been seeking an answer for ten years. She also said it was important that she find an answer.

A - Well I think it is important. I think she needs to behave socially, she needs to be socially acceptable, and at the moment the way we are going she in not going to be socially acceptable and I find that very difficult so I think it is really important that we have this information.

What did she see as an obstacle to her finding an answer:
A - Well there are very long waiting lists to get an appointment with a behaviour psychologist. I think when you are having a very bad time, it's something you need to see straight away, you know, they tend to have really bad behaviour and it can go on for weeks and weeks and you can't get to see anybody or discuss it with anybody. And then they go into decline and sort of be really good for a bit, and then you don't press for your appointment because you are like going through a good patch, then you hit another bad patch and still your appointment hasn't come through you know, and it's very difficult. And there are times when you really think I ought to get somebody on the phone to speak to at this particular moment in time, but you are really struggling and nothing can be done about it, you know.

How did she feel about this?

A - Not very satisfactory really. I think there should be some guidelines out there to tell you this is likely to happen, I think that's probably a let down really. But you don't know in most of these cases, and it may be because obviously progress in health... but there aren't many of these children who have grown into adulthood, and we don't know what happens because not all of the children are alike. They vary tremendously and if it wasn't for antibiotics she would have died when she was eight months old.

Turning to information use, she said that having some information helped but that it did not help in the way expected.

A - Did it help in the way you expected or different ways?

A - Well I didn't expect to be experiencing now what I have, so I obviously didn't get that information, it's difficult to say really.
With respect to what would have helped with hindsight, she said:

A- Well I don't know, that's the other thing. I don't know what the answer is. I think personally she needs to go to an epilepsy school, where they can try and sort out her epilepsy as best they can. I think she needs 24 hour observation for a time and I think perhaps a couple of terms in a epileptic school with a medical facility on site, these schools do have hospitals on site and doctors and nurses and that. And I think that would be a good idea and then also look at her behaviour as well. I think that at this moment in time, that would be best thing. I think that all children with difficult epilepsy should have the opportunity to go to an epileptic school to try and get the epilepsy sorted.

When she was asked what her main information sources are she said:

A - Well when I want information I quite often go to the Family Support Centre and they have done a great deal for families to make you aware of, it links with the British Red Cross Family Support Centre and the manager there has... She is a mine of information and I mean at the moment Kate is going through this transitional process in the education when as soon as I mention transitional, with you all this information comes up and we get somebody who know about that and to talk to everybody on this and to be able to go to this place and to ask questions and if they don't know the answers they will try and find out for you. And they know all about the volunteers etc in the City and the County and they know all the places... And so mainly that's why I go, it's not until recently that I realised because Kate's so very very difficult, I had to go to the Social Worker and it's not until recently that I realised that they have access to everything.
Discussion

Acceptability of the Interview Protocol

Many carers undergo severe emotional stress in the course of their caring role. Mindful of this the researchers were apprehensive that the interview questions may prove to be too intrusive especially where emotional and sensitive situations were being discussed. In fact, this was not a problem. Quite the reverse, carers were keen to talk about their lives and experiences, almost finding a voice for their frustration. In only two interviews, carers broke down emotionally but the remainder were able to cope very well considering that the method entails the interviewee reliving the situations. In this respect therefore, the interview protocol was acceptable to the informal carers and shows the wide applicability of the Sense-Making method in uncovering the lived experience of people in different contexts.

Appropriateness of the Sense-Making Method

The method was successful in teasing out situations that were important in the carers' daily lives. In the case of the first carer, state benefits was the first situation she thought of. This was true for many other carers too. Sense-Making is particularly effective because as with using the 'critical incident technique', the interviewee is not prompted in any way about the topic of the interview. Therefore any situations identified are those that are significant for the interviewee or the carer in this case. It was also possible to quickly establish what her need was and what type of information she required. Her mental state was also revealed in that she continually mentioned being confused and finding the whole process complicated.

For this particular carer, her knowledge of benefit entitlements, having worked in a Post Office, was insufficient to help her in finding an answer. This was because what she really needed to have was information on specific benefit entitlements and the interrelationships between different benefits, information which was not available in the booklets she had read and which she had not gleaned in her years paying out benefits. This is an important finding because it has a bearing on the development of relevant information.
Also revealed is the curious way in which almost the natural instinct for people is to describe situations as a neat package. An example of this is when the present carer says of finding the information she needed:

A- "it was just a matter of looking it up and going to the local office and talking to people there, getting all the details."

However, it was not as simple or clear cut as this, as she clearly reveals further into the interview. The Sense-Making focus on barriers and hindrances, is therefore a valuable tool for teasing out the difficulties experienced by the interviewees which they edit out of their account of what happened and which represent their true experiences.

The question on how important it was to have the information is relevant because it is a measure of the amount of effort that will be expended in finding an answer. The present carer needed to have the information because it was directly related to her means of livelihood. It was therefore important that the `gap' be bridged as she herself said:

A- "No, I think I needed to know."

This meant that she talked to people and was forced to "go and dig it out", something she might perhaps not have done had it not been as important to have an answer.

The Sense-Making method was also useful in revealing her information seeking strategies. First, she went to the benefits office; something most people would have done. However, she could not have found a full answer because she was also relying upon interpersonal contacts. We know this because she said her father-in-law mentioned the Age Concern book, said he had seen it and recommended it. So she went and obtained a copy of it. It can be argued that she used the path of least resistance for her information
seeking because she chose methods that would involve speaking to people and not reading leaflets/booklets or using the Internet (they were connected to the Internet at home). The reason for this could be because (as she reveals at the end of the interview), she is not good at reading information and filling in forms. Admittedly she used the Age Concern book, (because it was recommended) but in her answer to what would have helped in hindsight, there is a sense that the book though useful, complicated the issue for her in a way. This might have had something to do with the fact that she had to read the book but perhaps also has and it did not relate to her situation but gave a generic overview of the benefit system. This has implications for the packaging and presentation of information in a way that relates to the need of the user. Information provision needs to relate to the situation of the user simplifying and synthesising the information variables.

By choosing this information seeking strategy, this carer did not use many information sources. Rather, she used one document and interpersonal contacts to obtain the answer that she wanted. Why did she use these sources? She confirmed that she does not like to have to read information of this kind and would much rather talk to someone one-to-one. It can be presumed she uses this method because it gives an opportunity for clarification to be made, muddles sorted out and importantly, the filtering of information so that relevant answers are found.

Eventually a satisfactory outcome was found as she was able to make sense of the benefits minefield through talking and some reading and was thus able to apply for and get the benefits that both her husband and herself were entitled to.

Conclusions
This article was about the use of the Sense-Making method in identifying the information needs of informal carers in a way that is anchored in their experience. A researcher can choose from a large number of research techniques, however, Sense-Making was well suited to the task and it was possible to uncover a variety of problematic ‘situations’ that the carers
experienced. Even more valuable was that it was possible to identify types of 'situations' that carers experienced and have problems with. These situations were clustered under broad headings:

- severe emotional stress;
- lack of information;
- financial difficulty;
- contact with services (General Practice, nursing services, the benefits agency, social services and voluntary organisations).

**Recommendations**

These were organised to provide a lead for change for the service provider i.e. Social Services, Health and the Benefits Agency.

Key strands to the recommendations were:

- The need for co-ordination between Social Service departments and other agencies;
- Improved access to information and the wider dissemination of information about support available;
- Improved information provision for service provider staff;
- Improved information provision for informal carers.

At a more detailed level, proposals for the content and delivery of specific information solutions that related to carers in general, specific types of carer and solutions that related to problematic situations experienced by informal carers were suggested. The need for a co-ordinated service for informal carers, that cut across service provider boundaries, was also highlighted. On the basis of this report and bearing in mind the recommendations Leicestershire Social Services were able to review their current initiatives and identify those that would help to address these recommendations. In addition new initiatives were instigated.
Summary
In summary, using the Sense-Making method, it was possible to identify informal carers' perceptions of critical situations associated with being an informal carer. It was also possible to isolate the factors that made the 'situations' problematic. As a result information solutions were proposed. On the basis of these findings and recommendations Leicestershire Social Services were able to evaluate their current service provision and make plans for further support of informal carers in Leicestershire. In this case, therefore, the sense-making approach and the micro-timeline technique proved useful for gathering relevant data and enriched the quantitative data derived from the questionnaire survey.

References


Paper 7

Information needs of people with multiple sclerosis and the implications for information provision based on a national UK survey

Mark Hepworth, Janet Harrison and Nicole James

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Introduction

This research took place between January and October 2002. It was commissioned and funded by the MS Trust. Research into the information needs and information provision for people with Multiple Sclerosis (MS) was driven by a belief, supported by previous research, that information provision was inadequate (Robinson et al., 1996; Baker, 1997) — also that information and knowledge are beneficial to the wellbeing, in terms of feelings of control, depression and reduced dependence on the health service, of people with MS (Somerset et al., 2003).

The aims of this study were to:

• provide systematically a comprehensive understanding of the information needs of people with MS;
• determine what information needs were most important to people with MS;
• determine what information was currently most difficult to find;
• specify what information should be made available to people with MS; and
• recommend how information should be made available to people with MS.

The results of the research were expected to help determine the information policy of the MS Trust and also provide guidance, in terms of information provision, for service providers in the health and social services as well as other voluntary organisations and public information providers. This paper focuses on the information needs that were identified, explaining the subject-matter and why this information is important, the form in which it is required and the way it should be provided.

Overview of multiple sclerosis

There are approximately 85,000 people with MS in the UK. MS affects more women than men (approximately two women for every one man) and is generally diagnosed between the ages of 20 and 40. In parts of Scotland it is estimated that one in 500 will have MS; for the rest of the UK it is approximately one in every 1,000.

In MS the myelin sheath around the nerve cells is attacked, the nerves become demyelinated and may not function as they should. MS can affect any part of the central nervous system and can potentially alter movement and muscle activity at several different sites, giving rise to a variety of
Information needs of people with multiple sclerosis and the implications for information provision based on a national UK survey

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Abstract

Qualitative and quantitative methods were used to study the information needs of people with multiple sclerosis (MS) in the UK. Categories of information need were identified; their importance and difficulty in obtaining them quantified. The research highlighted how there were significant differences in terms of people's desire for the information, the topics in which they were interested and how they wanted that information. Information provision to people with MS was found to have improved dramatically over the last seven years, but was found to be inconsistent in terms of subjects covered. However, it should be borne in mind that it may be difficult for people to take on board information for a variety of reasons. Furthermore, different individual needs mean that information provision is a complex task. Many intervening factors can make it fail. The research made it clear how access to relevant information, provided in an appropriate way, could significantly improve the quality of life of the person with MS and that there is considerable scope for improving provision of information to people with MS.
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estimated that one in 500 will have MS; for the rest of the UK it is approximately one in every 1,000.

In MS the myelin sheath around the nerve cells is attacked, the nerves become demyelinated and may not function as they should. MS can affect any part of the central nervous system and can potentially alter movement and muscle activity at several different sites, giving rise to a variety of physical and psychological symptoms. Although it was first identified in the 1860s, the cause(s) of MS remain in dispute and a cure is elusive.

MS is a particularly challenging disease in that it is highly unpredictable, and can result in a wide range of psychological and physical challenges that can vary from year to year and day to day - which can lead to a high degree of uncertainty and a need for information (Wilson et al., 2002).

Previous research

Little specific research has previously been conducted on the information needs of people with MS. Earlier research tends to be general and does not attempt to identify comprehensively and categorise the information needs of people with MS. It has been recognised, however, that people with MS need to make long-term, information-based decisions about their condition (Wollin et al., 2000).

In 1996, in the UK, Robinson et al. (1996) conducted a qualitative study of the needs of people with MS. Part of this study concerned information. They found that appropriate information was hard to find and use and that it was not available when and where they wished to access it. The information needs that were identified included:

- information on the condition itself;
- symptoms and managing symptoms;
- current research;
- benefits and entitlements;
- insurance and mortgage advice;
- transport for the disabled;
suitable holiday venues;
respite care;
medical and complementary therapies;
social and support groups;
voluntary organisations;
employment and statutory rights advice; and
home adaptations and aids.

The report highlighted that individuals might have different information needs at any particular time due to different circumstances. The report concluded that a centralised source of information would be useful.

In 1977 Matson and Brooks in the USA studied people with MS to determine how they had adjusted to the condition since diagnosis. They concluded that most adjustment takes place in the first ten years after diagnosis. Based on their findings they proposed a four-stage model of adjustment to MS, in which information plays a role. Newly diagnosed patients entered stage 1 (denial) immediately. Here they sought information through different medical channels in an attempt to dispute the diagnosis. In stage 2 (resistance) it was shown that people acknowledged the possibility of having MS and anxiously sought information about the condition and a cure. Patients also turned to others with the same condition and participated in groups or classes to garner any information that might be helpful. Stage 3 involved telling other people about MS. Stage 4 began when a person had fully accepted the condition.

Matson and Brooks (1977) stated that information given by the consultant was seen as inadequate, perhaps because patients desired life-encompassing direction, which might be beyond the knowledge of the individual consultant. Most people with MS wanted practical information that would help them live with their condition. To find this information they used a variety of sources, with varying degrees of success.

Stewart and Sullivan (1982), in the USA, found that information-seeking activity starts in the pre-diagnosis period and continues until a diagnosis of MS is confirmed. They also found that, because symptoms could be fleeting
and might vary from one exacerbation (attack) to another, people engaged in "physician shopping" until they found a doctor who could diagnose their condition. People also sought information from popular literature and medical texts, as well as from health professionals, family and friends. Matson and Brooks (1977) noted that, in the post-diagnostic period, people with MS wanted practical information to help them live with their condition and sought information from other people with MS.

Baker (1997) in the USA undertook a study of people who had recently undergone an acute exacerbation of MS. This study involved a questionnaire survey of 260 women. The results helped to identify categories of information need and contributed to the questionnaire design in the current study. Categories of information need included:

- **physiological** (general information about MS, nutritional literature, fatigue, bowel and bladder disturbances etc.);
- **psychological** (dealing with a hidden disability, emotional behaviour, spiritual material etc.);
- **social** (education, support for family members, branches for women etc.); and
- **economic** (insurance, employer relations etc.).

Baker revealed gaps in people's knowledge about physical symptoms which people with MS were experiencing, emotions they felt, and drugs that could be used. Various sources of, and barriers to, obtaining information were identified. The results also suggested that health professionals needed to be aware of the continuing need for relevant, current and specific information to help people with MS retain their independence and to enable them to make informed decisions.

Baker (1994) also found that people tended to fall into the category of either "monitors" or "blunters", that is, people "either want information to handle an uncontrollable event or turn away from it because information is perceived to increase their level of anxiety".
A New Zealand-based study by Gregory et al. (1996) discovered that people with MS found generic information regarding MS readily available, but that practical information at a local level was frequently difficult to obtain.

In a review of health-care preferences of people with MS in the UK, Somerset et al. (2001) found that three-quarters of the people surveyed reported lacking advice about at least one MS-related issue and 17 per cent lacked advice in five areas. The most frequently consulted health professional was the GP, followed by the hospital consultant. The professional that most people said they would have liked to see was an MS specialist nurse. The study concluded that people with MS displayed a wide variation in their unmet needs, and that information about MS management (both conventional and unconventional), relevant tailored advice and access to appropriately skilled professionals should be components of high quality care.

The literature does, therefore, provide some insight into the information needs of people with MS, their information-seeking behaviour and information provision. The needs can be seen to be broad and people with MS might not be successful in satisfying them. There were insufficient detailed empirical data to enable a comprehensive definition of the information needs of people with MS.

The research, discussed here, aimed to build on the previous research and to provide a more comprehensive view of the information needs of the MS population in the UK both at the time of diagnosis and thereafter.

Methodology

Qualitative and quantitative methods were used. A total of 11 focus groups involving 103 people with MS of differing severity took part. These were held in England, Wales and Scotland in MS therapy centres. People were recruited through the centres, via local MS Society support groups and newsletters of the MS Trust and the MS Society. The population was therefore self-selected. However, each focus group session recruited people from one of three groups: people who needed no walking aids (59 per cent), wheelchair users
(20 per cent), and those who used a walking-stick or walker (21 per cent). This breakdown corresponds to national figures on mobility for the MS population (Compston, 1998). At the start of the sessions respondents were asked to identify significant situations during their time with MS. Three to four of the most common situations were discussed by each group. Dervin’s (1999) sense-making methodology was used to structure the discussion. The information needs associated with situations were identified as well as barriers to access. This qualitative approach helped to understand the experience of people with MS and ensured that the categories of information need were grounded in the reality of the people with MS.

These data, along with the published literature and input from stakeholders and the MS Trust, were used to inform the development of a questionnaire. The questionnaire was distributed to 4,100 people with MS through the MS Trust, MS Society, therapy and respite centres, newspapers and the Internet. To aid completion by the MS community, the questionnaires used large print and tick boxes; 2,030 questionnaires (49.5 per cent) were returned. No follow-up was instigated, partly because a 49.5 per cent response rate was felt to be good and also because of the time scale of the project. Again this was not a random sample; people chose to be respondents. Of the respondents 1,509 were female, 512 were male and nine did not disclose gender (a ratio of 3:1, which compares with the national norm of 2:1). Respondents were aged between 16 and 75. The earliest diagnosis was 1937 and the most recent 2001; 553 people with MS were diagnosed within the last five years. Data gleaned from the returned questionnaires helped to quantify the demand for and value of categories of information, the difficulty in finding information and what was required generally and specifically at diagnosis. The survey also determined how information provision has varied over time.

In addition audio-diarying was used to capture data on the day-to-day experience of a person with MS. Audio-diarying was undertaken by only five people, all who had severe symptoms of MS. Each person was given a small, easy to manipulate micro-cassette recorder and tapes and was instructed to record events, situations in their daily life where they needed to know
something or wanted to find out something or had a problem that they needed to resolve. Any time a situation like this occurred they were asked to record what they were trying to resolve, why and whether or not it was resolved and, if it was, how. This technique of data collection was done primarily to see what kind of data would be generated rather than as a primary survey tool. This method did prove effective in providing detailed data on the situations the respondents confronted and their thoughts at the time - and generated greater detail than that generated by the other two methods. The audio data made apparent, for example, the range of symptoms that a person with MS could experience over a short period of time and also the importance, in terms of general wellbeing and quality of life, of taking an active role in life. Owing to the small sample the audio data were given little weight in terms of the overall findings.

Findings

**Qualitative data**

Focus group sessions were all tape-recorded and later transcribed and then coded. A total of 132 generally problematic topics were identified by focus group respondents. Topics were categorised under the following headings:

- A lack of knowledge when dealing with new situations associated with having MS, particularly at the time of diagnosis, but also subsequent situations such as finding out about state entitlements. This topic included discussion of how information is and should be provided. For professionals who are involved with MS it is hard to remember what it is like for a person who knows nothing about the condition or how to cope with a condition like MS.
- General symptom management including finding out about symptoms and possible actions they could take that could help.
- The difficulty of communicating with family, friends and colleagues and the need for appropriate information to help.
- The problems associated with disabled access and transport and the lack of supporting information.
• The need to make contact with and talk to other people with MS for both emotional and informative support.

Discussion of these topics helped to identify information needs and also provided an insight into how information should be made accessible.

**Quantitative data**

The questionnaire design was informed by the data gathered from the focus group sessions, the published literature and discussion with the stakeholders and the MS Trust. The questionnaire focused on:

- information provision and information needs at diagnosis;
- determining the importance of categories of information and the difficulty in obtaining them; and
- the best format (paper, face-to-face, Internet etc.) for access and delivery.

The aggregated data for all respondents were analysed. In addition the data from people who had been diagnosed in the last five years (553 respondents) were analysed separately to see whether the picture had changed over the last five years. It was found that information needs remained consistent and that information provision was still inconsistent in terms of topics covered and at provision. However, the number of people who said they received information at diagnosis has increased dramatically over the last 20 years (in 1980 only 20 per cent of respondents received information, whereas in 2000/2001 70 per cent received information). In the last five years more information was provided on two areas: drugs and MS nurses. This reflects the introduction of disease-modifying drug therapies and the increase in the number of MS nurses.

At diagnosis over 50 per cent of the respondents wanted information on managing symptoms, drug treatments, disease course, physical symptoms, exercise, diet and information for the family. A distinction was found between the information needs at diagnosis and long-term information needs. This is discussed later. When respondents were asked whether or not they wanted to
know about the different categories of information, they generally welcomed this information. However, not all people with MS wanted the same information or wanted to be informed at all. This may be because the severity of the condition can vary dramatically and people can experience very different symptoms. It may also be related to the information-seeking behaviour of the individual and intervening variables such as self-efficacy or coping strategies (Wilson, 1999) and Baker's (1994) conception of "monitors" and "blunters". These individual differences may influence how people react to situations, whether people seek information, what information they require and how it should be provided.

Discussion of information needs and implications for information provision: the need for a holistic approach

**The whole community**

Information provision needs to be targeted at three communities. These are people with MS, the general public (including the family, friends and colleagues), and state and voluntary service providers. As far as the authors are aware, with regard to MS, little has been done to tailor the provision of information about MS specifically to the different "communities" that are involved with MS. Each of these communities requires similar information but they require it in a different form and depth. Emphasis will also need to be placed on different types of information for different communities.

**The public**

The public need a basic understanding of MS. Even people who currently have no direct contact with a person with MS need to be informed about MS. Some of the problems experienced by people are due to the ignorance exhibited by the general public. For example, in the workplace, a person with MS who experiences severe fatigue in several cases was considered lazy. A lack of knowledge about MS could also influence employment practice. In the domestic situation the lack of understanding shown by the family also led to difficulty. In extreme cases this led to partners leaving due to misconceptions
about MS. Again, through ignorance, some family members were concerned with whether MS was contagious.

Information needs to be made available to the general public about MS through the national and local media. This would need to relate to the information needs of the employer, colleague, friend or acquaintance. In addition, probably a more effective way in the long term would be to incorporate in secondary schooling, probably under the heading of "citizenship", information about MS. Ideally other conditions, particularly those that lead to care in the home, would be covered, since there is similar ignorance about other conditions and the help available (Hepworth et al., 2000).

Information also needs to be designed that is appropriate for the family. Some headway has been made in this direction, for example, a book entitled My Dad's Got MS (Hetherington and Young, 2001). This approach needs to be more comprehensive, so that similar information (although with differing content) would be developed that was designed for other family members.

Access to this community information would need to be provided that was relatively simple, for example, not laden with medical terminology, clearly presented, and in a factual and positive manner (Ward and Cavanagh, 1997). This would include an overview of what MS is, the possible effects, medical support, social services support and voluntary groups. Information that helped people deal with specific situations would have to be provided separately and when appropriate. Geographical personalization, so that people are informed about local support groups and services, should be practised.

If the person with MS is helped by someone who acts as an informal carer, then the information needs of the carer are going to be significant, particularly if the condition of the person with MS is severe. The informal carers would require far more information than other members of the public. They would also have a need for different types of information over time, as the condition of the person with MS changed. Ideally, the situation of the carer as well as the person with MS would be monitored and appropriate information and
support provided as necessary. This may sound ambitious from the perspective of service providers. However, the cost of enabling a person with a critical medical condition to stay at home, through information- and need-related services, is far cheaper than maintaining that person in state care. According to Walker and Dewar (2001), informal carers save the UK Government £57.4 million per year.

**Service providers**

Similarly, service providers would need general information about MS, the help and information that are available. The latter would help them to direct people with MS to informational and practical support. For example, a recent study of the information needs of hospital social workers, who work with adults leaving hospital, confirmed that they required overviews of medical conditions, medication and possible side-effects as well as information about legislation, policy guidelines and other relevant agencies (Harrison et al., 2002). This would help them to assess the kind of support the person would need and what can be provided.

Service providers, including health- and social-care professionals and support groups, would benefit from training in the information needs of people with MS and how these might be satisfied. This would help them to understand what questions people with MS may have and hence what information was needed, when this may be required and how it should be provided. Service providers need to be aware of the variability of the condition and how the nature of MS may change over time. This implies that needs should be monitored over time and that health and social records need to be maintained, so that people do not need to instigate help from scratch when it is needed in the future. A better knowledge of the condition could also place service providers in a position to recommend services of which the person with MS may not have been aware or which they found difficult to request. For example, it took people with MS who had bladder problems a long time to find out about catheters, partly because they were embarrassed to discuss such personal problems and because information about bladder disturbances and catheters had not been found or given to them. Once they did know about these areas,
and were able to take advantage of this equipment, it was easier to travel from the home. This had a big impact on their lives.

In the focus group sessions diagnosis was the most common topic discussed. Where unsatisfactory experiences were described (49 per cent of people attending the focus groups) these were associated with "a lack of support", "poor attitude" and "providing no information". However, it should be noted that being diagnosed is in itself a negative experience and is likely to colour a person's judgement of the situation. Furthermore, the majority of people who did attend focus groups had been diagnosed more than ten years before, since when the situation has improved. Nevertheless from the questionnaire it was seen that 29 per cent of those diagnosed in the last five years felt they received no information at diagnosis. This indicates that information provision by health care professionals is not always successful and could be improved. Understanding what information is likely to be needed and knowing how to provide that information are not easy, bearing in mind that there are individual differences in terms of what is relevant to a person and what they actually want and also how they want it. Health professionals involved in diagnosis would therefore probably benefit from training in the information needs of people with MS and also how to provide information at diagnosis in a supportive and sensitive fashion.

**The person with MS**

Someone with MS should be seen as a person, and not only as a person with MS, who is likely to want to take an active role in life. Information should be provided that helps achieve this goal. Enabling people to participate actively in life as a result of access to information, and becoming better informed and more knowledgeable, whether in the home, workplace or elsewhere, has a positive impact on their self-esteem and general wellbeing. This may seem self-evident. It is, however, easy for service and information providers to focus on the condition and information specific to that condition rather than see the person with MS in the broader light and understand the impact access to information can have. As a result they may underestimate the importance of information provision and fail to provide information that helps the person with
MS really engage and participate in life. The audio tapes, for example, provided a good illustration of where an individual had become informed and had found out about adapting his car and sources of finance to do so, which meant he could take his daughter to graduation. This meant a great deal to the person with MS, including increasing his mobility, independence and, importantly in this case, being able to fulfil his parental role.

Failing to take into account that the person with MS is, like any other person, fulfilling numerous roles, such as parent, wife, wage earner etc. and is having to deal with situations associated with these leads to simplistic and inaccessible information provision. First, without an understanding of the significance of information it is hard to prioritise what information to offer. Second, organisations that do not take this on board tend to provide information that only relates to the function of the organisation rather than the wider needs of the person. Third, research has shown that information seeking tends to take place when people have to resolve specific situations and tend not to seek information on topics that do not immediately concern them (Osiobe, 1998). When browsing for information people recognise useful information, partly because it obviously relates to their current situation (Bates, 1989). The success of frequently asked questions is largely to do with this. The user does not have to wade through an A-Z of functions that they may or may not understand; in other words, they recognise the task and then the solution. A booklet called *Tips for Living with MS* (MS Trust, 2002), about how to deal with common situations experienced by people with MS, was popular, for similar reasons, among people with MS. These tips were collected from people with MS by the Department of Information Science at Loughborough University and collated, synthesised and published by the MS Trust. Therefore one way of providing information for people with MS is to identify common situations with which people have to deal, such as driving a car or dealing with an employer, and provide the necessary information. Information that enables someone to drive a car who has a physical disability would include, for example, information about mobility schemes, car adaptations, possibly the usefulness of a catheter, disability access and so on. This “package” of relevant information, related to solving a particular life
problem, would be easily recognised by the person with MS, when needed, and the fact that the information was integrated would mean that the person would not have to locate and interrogate numerous sources. However, as well as providing information in a way that relates to specific situations, information also needs to be provided in a discreet way, so that people can find out about a specific topic quickly.

The information that people with MS stated they wanted at diagnosis is shown in Table I. What is evident from Table I is that, although there was a significant demand for most of these categories of information, there was a significant proportion of people who did not want that information. This highlights the complexity of information provision and raises questions, such as whether offering the information in a particular way would change the percentage of people who wanted it.

After diagnosis, drawing on both the qualitative and the quantitative findings, it was determined that the following categories of information would help to satisfy the information needs of people with MS. These categories fall under two headings:

(1) Information about MS.
(2) Information that helps the person with MS interact with the world around them. This distinction may seem misdirected in that it could reinforce the mistaken perception of seeing the person with MS primarily in terms of their condition rather than as a person. As mentioned earlier, it would be good design practice to provide information through life situations as well as through a "directory" of topics.

Information about MS

In general people with MS should be provided with information about:

- MS, a general explanation. This would include an explanation of what MS is and how the body is affected. Diagrams can be very effective at communicating this kind of information.
• **MS research trials.** This was one of the areas about which respondents found it either difficult or very difficult to find out (45.8 per cent). Owing to there not being a cure for MS, at present, people with MS are keen to find out about new clinical trials, for example, the findings of the cannabis trials. People with MS were also interested in getting involved in trials but did not know how.

• **Drug treatment.** For similar reasons people wanted to know about drug treatments and whether new drugs were becoming available to people with MS and the regulations and costs associated with them; 44 per cent found this difficult or very difficult to find out.

• **Symptoms.** MS can result in many symptoms, such as loss of balance and mobility in general, sight problems, pain, severe fatigue and stress. Symptoms about which people highlighted it as being difficult to find out were balance problems, emotional changes and memory problems. People with MS can experience new symptoms. Each time this occurs they need an explanation of what is happening, how serious it is and what can be done. Support groups proved particularly popular, because people could ask others about a symptom and someone else who had experienced it would inform them. Respondents did indicate that one could not always rely on the views of other people with MS. Another route for discussing symptoms (and other topics), that the MS Trust have offered, was via electronic chat sessions where people can exchange information. An expert was also present who could give a professional view and act as a moderator. Treatment and management of symptoms were highlighted as a separate topic. There is a distinction between knowing what something is and how to treat or cope with it. This kind of information can be provided in a factual way. However, where coping is more relevant than treatment, through the use of drugs, physiotherapy etc., information provision would need to be broader and require thoughtful design in that it should be motivating and include coping strategies. Information on the full range of symptoms experienced by people with MS and their treatment or management is therefore required.
• *Prognosis*. Providing information on this area requires sensitivity. Some health professionals, in conversation, say that people do not want to know how the condition could develop either at diagnosis or at any other time. This was borne out to some extent from our findings (47 per cent did not want information). It is also an area of uncertainty due to the unpredictable nature of the disease. However, 53 per cent of the respondents who had been diagnosed within the last five years wanted, at diagnosis, an indication of the disease's course. It is likely that this response would depend, to some extent, on the condition of the person and also on how they are dealing with the situation emotionally. Prognosis can help people to plan and take control assuming a suitable state of mind.

• *Physiotherapy*. A total of 80 per cent of all respondents thought it important or very important to know about physiotherapy. It was thought generally less difficult to find out about than other topics.

• *Complementary therapy*. A total of 68 per cent of respondents thought it was important to know about complementary medicine. This includes hyperbolic oxygen as well as other complementary approaches such as massage, acupuncture and complementary medicines. One concern expressed by respondents and the MS Trust was that there is little quality control in this area and now, through the World Wide Web, people can become aware of and use "alternative" approaches that are harmful.

• *Nutritional advice*. There is evidence that diet can have an effect on MS symptoms and that certain foods exacerbate the negative symptoms of MS. As a result (and also because drug treatments may not be effective) there was a lot of interest in diet.

• *Health and fitness*. Similarly, maintaining health and fitness is thought to be beneficial. People with MS wanted information about what exercise could help and how to take part in appropriate exercise. Aquatics, for example, is felt to be particularly appropriate, because the water provides support for the weakened body and also reduces body heat, which has an adverse effect on people with MS (National Multiple Sclerosis Society, 2003).
Emotional changes. This was a topic about which people with MS found it difficult to find out. As well as suffering from depression and mood changes people with MS can also experience severe fatigue that can have a negative impact on people's state of mind. Being aware of the likely emotional changes that can take place and also ways that can help to ameliorate them is therefore important.

Information that helps the person with MS interact with the world around them

Information that helps the person with MS interact with the world around them is not directly concerned with the medical condition. This includes information about the following:

- **Service providers.** Health service, social service, benefits agency, non-government and voluntary organisations, and the services they provide. Previous research with informal carers (Hepworth et al., 2000) and recent work with people with Alzheimer's disease (Pritchard, 2003) highlight the difficulties people have with dealing with the various bodies that can provide help for the person with MS. The lack of knowledge people have about state and non-government organisations means that when people have a need they find it very difficult to understand exactly what organisations do, the responsibility of different roles, such as a community nurse, and how to instigate services (including how to fill forms appropriately). Organisational charts need to be made available to help people contact the right people. In addition advice on how to complete application forms needs to be provided. Increasingly we are seeing attempts to provide more "joined-up" services. This will be helpful in that organisational boundaries will be less likely to get in the way of information provision.

- **Support groups.** These groups played a key role for many people with MS. It should be noted that some people were not keen on joining groups. This was partly because they did not want to see people in a worse condition, as this indicated what the future might bring, or they did not want to be constantly reminded of their condition. Other people
found support groups extremely useful for exchanging information, learning about their condition, identifying additional support and providing emotional support. Generally the atmosphere in therapy centres, for example, was extremely supportive and helped people maintain a positive state of mind.

- **Aids and appliances.** This was a category of information that related to people who had more severe MS and had, for example, problems with mobility. Again finding out about aids and appliances and their relative merits as well as potential sources of funding was not easy. In fact once one knows where to look there is a wealth of information on this area and Disability Living Centres, that show a wide range of aids and appliances, are found in most large towns.

- **Facilities for the disabled.** Similar to the above, this category is not specific to MS. However, severe MS does tend to be associated with problems that require access to facilities for the disabled. Finding out sufficient detail about disabled access is not easy and in the UK disabled access is poor. This situation is primarily due to ignorance about disability among the general public and presumably weak legislation enforcing good design. A conversation with people with MS about a building that was supposed to be "disabled-friendly" indicated that it was not. They thought that disabled people should be involved in the planning and design. Poorly designed buildings provide a severe barrier for people with disabling MS who want to take an active part in life. Hence information needs to be made more readily available on disabled access and facilities in public buildings. In addition, people with MS with problems with mobility also needed to find out about making their own home "accessible" and possible sources of finances to do this.

- **MS and work and the issues associated with giving up work.** Being able to work and bring in an income is, of course, of fundamental importance to most people. It was, therefore, not surprising that people with MS wanted information about work, their rights, employer obligations, dealing with their employer and also what would happen and what they could do, if they had to give up full-time employment.
• **Communicating about MS with family, friends, colleagues and the public.** As mentioned earlier, information for the family, friends, colleagues and the public is very important. It was difficult for people with MS to communicate with others about their condition. People with MS need information that they can give to such people. Material specifically designed for this purpose would therefore be useful.

• **Leisure activities including, when necessary, provision for the disabled.** Information about leisure was not the most important type of information that people wanted. A total of 31 per cent of people with MS did state that they found it difficult or very difficult to find out about appropriate leisure activities and holidays. It was important for people with MS to know what was possible, rather than assume that it would be impossible to take holidays and enjoy leisure activities, especially if disability was an issue.

These categories of information are similar to those generally recognised as being required by people with an illness (Duman, 2003). The categories listed here cover a wider range of topics and include information not directly related to the condition but are important for the person's well-being and ability to participate in life.

**How should information be made accessible?**

From the authors' experience of conducting studies of people's information needs and information-seeking behaviour it is felt that there is still considerable scope for understanding how information should be provided and what factors influence whether information is taken on board and has an impact on the consumer of the information. As can be seen from the data provided here within a community, such as people with MS, the demand for different types of information is varied, as is how people want information. Generally, with regard to people with MS in this study, a number of information characteristics were important for successful information provision.
Information should be provided:

- **In a positive manner.** People with MS stated that the majority of information they received emphasised the probable negative outcomes rather than stating what can be done. Publications that talked about how people coped with their MS, and specific conditions, were very popular. Information can be provided about a particular condition. If the information is combined with positive instruction and "tips" and reassurance about the things that can still be achieved, then the information is more likely to be absorbed and a more positive frame of mind maintained. This can help a person take a proactive and positive approach to managing their condition.

- **In a way that helps and motivates people to take action.** This is similar to the last point; however, more thought is required into what kind of information is going to enable people to take action. On the one hand, as noted above, information can be phrased in a positive way and practical instruction given that will help people cope. It may also be the case that, at different points in time and depending on the frame of mind of the individual, information should be provided in different ways. In counselling, for example, the theory behind motivational interviewing techniques (Miller and Rollnick, 2002) states that people go through a cycle of stages when they are trying to change their behaviour. These stages are contemplation, determination, action, maintenance and relapse. During these stages they are open to certain types of information: factual, positive, supportive etc. They argue that helpful information will correspond to these stages or states of mind. It is possible that similar or identifiable states of mind are associated with dealing with a condition such as MS and a greater understanding of how changes in people's state of mind affect their need for information would be beneficial.

- **That corresponds to the physical, psychological and social situation of the person with MS.** People tend to want information that relates to their specific situation. This needs to be taken into account when providing information. In other words, people need to be able to identify
information that relates to their situation and receive information that is relevant or takes into account their situation. Technological approaches to doing this will be discussed later.

- **In a way that is sensitive to the desire for information and its possible impact on the individual.** As noted, not all people demand all categories of information or any at all. This has to be taken into account by the information provider and catered for accordingly rather than that one should assume, for example, one message for all. As discussed earlier, this requires the information provider to be sensitive to the needs of the individual, whether in face-to-face situations or when interaction is through a machine.

- **Using the most effective means of communication.** This will vary depending on the nature of the information and the cognitive and physical ability of the person with MS. For example, face-to-face communication was found to be more appropriate for sensitive or complex issues, such as balance problems, bowel and bladder disturbances, drug treatments, emotional problems etc. Leaflets and booklets were thought to be more appropriate for topics such as access and transport, aids and appliances, benefits and entitlements, working and MS etc. Newsletters were felt to be most appropriate for information about research in general and specific research trials. Discussion groups helped answer questions and enabled people to share experiences. Different types of information resources have different characteristics that may or may not be attractive to different users. For this reason access should be provided to different sources of information that satisfy different needs, for example, academic and professional articles, popular press, experts and other people with MS. Each of these sources has different characteristics in terms of the depth, detail and style of presentation that will be more or less appropriate depending on the information need of the person with MS and their preference for how information is presented. For example, other people with MS are valued for their insight into specific situations and their ability to provide relevant information in a way to which others can relate. Academic articles are popular with independent learners.
who want detailed information about research, that has gone through a peer review process, and have the ability to understand the terminology used and feel unthreatened by the academic style of presentation. People should therefore be given a choice as to what type of material they can access.

- **Using different presentation techniques to cater for individual conditions that a person with MS may experience.** Overall 60 per cent of respondents stated that MS affected their information seeking and finding. For example, severe fatigue was cited by 47 per cent of respondents as affecting their information seeking. This was followed by mobility (45 per cent). Problems with concentration also affected access to information. The design of information provision needs to take this into account in both paper-based and electronic domains. People with high fatigue and low concentration levels are going to require information in a succinct form with emphasis on a graphical rather than textual presentation of information. Mates (1995) has shown that good design, for example, using large print and contrasting colours, makes information easier to interpret. The quality of design of information for people with MS is very varied. Different organisations provide different as well as the same information that is aimed at different audiences, such as health professionals or people with MS. Some follow good design standards, others do not. Greater cognisance of good practice by information providers is necessary. For example, notice needs to be taken of the work of the Centre for Health Information Quality (2003). The latter have developed criteria for checking the quality of public information. The Welcome to Plain English Campaign (2003), as well as the King's Fund book (Duman, 2003) on producing health information, also provide guidance. In addition Web designers need to conform with good practice. In particular, the World Wide Web Consortium's Web Accessibility Initiative should be taken into account (WAI, 2003). The NHS have also sponsored the Discern project (Discern, 2003), which provides a tool to help to evaluate Web sites. Currently, much information available via the World Wide Web is difficult to access by people with physical
disabilities such as poor sight due to poor design of Web sites and their inability to be read by screen readers (Scherer and Galvin, 1996; Oppenheim and Selby, 1999). In addition, small font and a lack of contrasting colours inhibit access. Hence information provision needs to be designed, so that people can access it despite their disability and can take advantage of adaptive/"assistive" technologies. Legislation, concerning electronic access to information, will come into force in 2004 (RNIB, 2002) that should help to improve the current situation.

Further research

Further work is required into the effect of individual differences (psychological and physiological) on the desire to learn and to be informed and the use of information. Research is also needed into how technology can help to provide personalised information.

A number of technological approaches have been taken to offer personalised Web pages. Bental et al. (1999) summarised a number of projects in this area. At the University of Brighton the ICONOCLAST project (ICONOCLAST, 2003) investigated how appropriate style and layout of documents can be determined through interaction between the author and the system. Patient leaflets were analysed to understand effective layout. At Loughborough we are currently investigating how Extensible Mark-up Language (XML) can be used to provide personalised information delivery based on the user's situation.

XML is a sub-set of Standard Generalised Mark-up Language (SGML). XML is designed to describe data and what data are. It is not a replacement for Hypertext Mark-up Language (HTML). HTML is designed to display data and to focus on how data look using pre-defined tags. In XML the publisher defines the tags. For example, <prognosis> could be a tag that is then used to identify material about prognosis. A browser does not know how to display an XML document. Therefore there must be something in addition to the XML document that describes how the document should be displayed. This is the role of XSL. XSL consists of three parts: XSLT (a language for transforming
XML documents); XPath (a language for defining parts of an XML document); and XSL Formatting Objects (a vocabulary for formatting XML documents) (W3C, 2003b).

XSL is a language that can transform XML into XHTML, filter and sort XML data, define parts of an XML document, format XML data based on the data value (like displaying negative numbers in red), can output XML data to different devices, like screen, paper or voice (W3C, 2003a).

A screen was designed that allowed the user to make choices and indicate their situation, condition and information needs. For example, they could request large font and specify that they suffered from severe fatigue and that they had recently been diagnosed. This generated XSL scripts that then worked on the XML document. For example, having selected large font, the following XSL code was generated: (see equation 1) where the number five signifies large font. Other characteristics of documents such as subject-matter, level of depth, text density, relevance to stage of MS, would have to be defined and a taxonomy would need to be developed that describes documents and their content, so that appropriate content can be generated when required.

If a portion of text in the XML document was tagged <start stage="a" den="ab">, this meant that, when the XSLT code was generated that stated the person with MS was at stage "a", i.e. recently diagnosed and wanted information in brief "ab", then a positive motivational piece of brief text was displayed from the XML document. XML and XSLT therefore work in conjunction, where XSLT is the programming language that develops the logic using standard conditional statements that act on the XML document. Using this approach, one highly structured document can be presented in very different ways to the reader.

Conclusion

This paper has described the information needs of people with MS. Possible solutions were also discussed. The need for people with MS to have access
to information about MS as well as to information that helps them interact with the world around them was highlighted. To improve the situation of people with MS, information and training should also be made available about MS, and the information needs of people with MS, to the general public and service providers.

The information needs of people with MS were seen to be complex because:

- the needs change over time;
- the range of topics they may or may not need to know about;
- variations in the desire for information; and
- there are differences in how information is needed due to the physical and psychological state of the person with MS.

To achieve the level of personalisation required to effectively provide information to these communities, evolving technology can be exploited as well as standard methods of information provision and exchange. Our current understanding of exactly how the state of the individual affects their need for information and what this means for the design and delivery of personalised solutions is still relatively crude and requires further investigation. For example, what is the most appropriate taxonomy to describe different types of information held in XML documents? What is the most appropriate way of communicating different types of information about MS to a person experiencing severe fatigue or lack of concentration? Can information be presented in such a way that a "blunter" becomes a "monitor"? How would it be best to package information for the public and family? How can information be packaged in such a way that people with MS can easily recognise the situations with which they are dealing with and then find all the appropriate information that will help? For many of these questions we can envisage possible answers. However, to achieve a better understanding, individual differences need to be studied in more detail; an appropriate methodology for storing information needs to be developed; and access to this information through a range of techniques needs to be enabled. Having done this, these solutions need to be evaluated in terms of their impact on the MS community and the other target communities. The lessons learned through this kind of
exercise would enable the full-scale implementation of relevant and personalised information solutions to people with MS. This work would also be relevant to other information providers who want to provide similar information services on different topics.

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<th>Table I What information would you have liked or not liked at diagnosis?</th>
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<td>Possible drug treatments</td>
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<td>Indication of disease course</td>
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<td>Possible physical symptoms</td>
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<td>Information on exercise</td>
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<td>Information on diet</td>
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<td>Occupational therapy</td>
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<td>Other</td>
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(See equation 1)
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Keywords
focus groups, information provision, multiple sclerosis, questionnaire survey

Introduction

Research into the information needs of and information provision for people with MS (PWMS) was driven by a belief, supported by previous research [1, 2], that information provision was inadequate. In addition, there is evidence that information and knowledge are beneficial to the wellbeing of PWMS in terms of increased personal control and reduced dependence on the health service [3].
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Introduction

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This research took place between January and October 2002. It was conducted by the Department of Information Science at Loughborough
University and was commissioned and funded by the MS Trust. The aims of the study were to:

- systematically provide a comprehensive understanding of the information needs of PWMS
- determine what information needs were most important to PWMS
- determine what information was currently most difficult to find
- specify what data, information and knowledge should be made available to PWMS
- recommend how data, information and knowledge should be made available to people with MS.

The results of the research were expected to help determine the information policy of the MS Trust and also provide guidance, in terms of information provision, for service providers in the health and social services as well as other voluntary organizations and public information providers.

**Overview of multiple sclerosis**

There are approximately 85,000 PWMS in the UK. MS affects more women than men (approximately two women for every one man) and is generally diagnosed between the ages of 20 and 40. In parts of Scotland it is estimated that 1 in 500 will have MS; for the rest of the UK it is approximately 1 in every 1000.

In MS the myelin sheath around the nerve cells is attacked; the nerves become demyelinated and may not function as they should. MS can affect any part of the central nervous system and can potentially alter movement and muscle activity at several different sites, giving rise to a variety of physical and psychological symptoms. Although it was first identified in the 1860s, the cause(s) of MS remain in dispute and a cure is elusive.

MS is a particularly challenging disease in that it is highly unpredictable. It can result in a wide range of psychological and physical challenges that can vary
from year to year and day to day - which in itself can lead to a high degree of uncertainty.

Previous research

Little research has previously been conducted specifically on the information needs of people with MS. Earlier research tends to be general and does not attempt to identify comprehensively and categorize the information needs of PWMS. It has been recognized, however, that PWMS need to make long-term, information-based decisions about their condition [4].

In 1996, in the UK, Robinson et al. conducted a qualitative study of the needs of PWMS [1]. Part of this study concerned information. They found that appropriate information was hard to find and use, and that it was not available when and where they wished to access it. The information needs that were identified included:

- information on the condition itself
- symptoms and managing symptoms
- current research
- benefits and entitlements
- insurance and mortgage advice
- transport for the disabled
- suitable holiday venues
- respite care
- medical and complementary therapies
- social and support groups
- voluntary organizations
- employment and statutory rights advice
- home adaptations and aids.

The report highlighted that individuals might have different information needs at any particular time owing to different circumstances. The report concluded that a centralized source of information would be useful.
In 1977, Matson and Brooks in the USA studied PWMS to determine how they had adjusted to the condition since diagnosis [5]. They concluded that most adjustment takes place in the first 10 years after diagnosis. Based on their findings they proposed a fourstage model of adjustment to MS, in which information plays a role. Newly diagnosed patients entered stage one (denial) immediately. Here they sought information through different medical channels in an attempt to dispute the diagnosis. In stage two (resistance) it was shown that people acknowledged the possibility of having MS and anxiously sought information about the condition and a cure. Patients also turned to others with the same condition and participated in groups or classes to garner any information that might be helpful. Stage three involved telling other people about MS. Stage four began when a person had fully accepted the condition.

Matson and Brooks stated that information given by the consultant was seen as inadequate, perhaps because patients desired life-encompassing direction, which might be beyond the knowledge of the individual consultant. Most PWMS wanted practical information that would help them live with their condition. To find this information they used a variety of sources, with varying degrees of success.

Stewart and Sullivan [6], in the USA, found that information seeking activity starts in the pre-diagnosis period and continues until a diagnosis of MS is confirmed. They also found that, because symptoms could be fleeting and might vary from one exacerbation (attack) to another, people engaged in 'physician shopping' until they found a doctor who could diagnose their condition. People also sought information from popular literature and medical texts, as well as from health professionals, family and friends. Matson and Brooks [5] noted that in the post-diagnostic period, people with MS wanted practical information to help them live with their condition and sought information from other people with MS.

Baker [2] in the USA undertook a study of people who had recently undergone an acute exacerbation of MS. This study involved a questionnaire survey of
260 women. The results helped to identify categories of information need and contributed to the questionnaire design in the current study. Categories of information need included:

- physiological (general information about MS, nutritional literature, fatigue, bowel and bladder disturbances, etc.)
- psychological (dealing with a hidden disability, emotional behaviour, spiritual material, etc.)
- social (education, support for family members, branches for women, etc.)
- economic (insurance, employer relations, etc.).

Baker revealed gaps in people’s knowledge about the physical symptoms PWMS were experiencing, the emotions they felt, and the drugs that could be used. Various sources of and barriers to obtaining information were identified. The results also suggested that health professionals need to be aware of the continuing need for relevant, current and specific information to help PWMS retain their independence and to enable them to make informed decisions.

Baker [7] also found that people tended to fall into the category of either ‘monitors’ or ‘blunters’, that is, people ‘either want information to handle an uncontrollable event or turn away from it because information is perceived to increase their level of anxiety’.

A New Zealand based study by Gregory et al. [8] discovered that people with MS found generic information regarding MS readily available, but that practical information at a local level was frequently difficult to obtain.

In a review of health care preferences of people with MS in the UK, Somerset et al. [9] found that three-quarters of the people surveyed reported lacking advice about at least one MS related issue and 17 per cent lacked advice in five areas. The most frequently consulted health professional was the GP followed by the hospital consultant. The professional that most people said they would have liked to have seen, however, was a MS specialist nurse. The
study concluded that people with MS displayed a wide variation in their unmet needs, and that information about MS management (both conventional and unconventional), relevant tailored advice and access to appropriately skilled professionals should be components of high quality care.

The literature does, therefore, provide some insight into the information needs of PWMS, their information seeking behaviour and information provision. The needs can be seen to be broad and PWMS might not be successful in satisfying them. There is currently, however, insufficient detailed empirical data to enable a comprehensive definition of the information needs of PWMS.

The study reported here aimed to build on the previous research and to provide a more comprehensive view of the information needs of the MS population in the UK both at the time of diagnosis and thereafter.

Methodology
Qualitative and quantitative methods were used. Eleven focus groups involving 103 people with MS of differing severity took part. These were held in England, Wales and Scotland in MS therapy centres. People were recruited through the centres, via local MS Society support groups and newsletters of the MS Trust and the MS Society. The population was therefore self-selected. However each focus group session recruited people from one of three groups: people who needed no walking aids (59%), wheelchair users (20%) and people who used a walking stick or walker (21%). This breakdown corresponds to national figures on mobility for the MS population [10]. At the start of the sessions respondents were asked to identify significant situations during their time with MS. Three to four of the most common situations were discussed by each group. Dervin's sense-making methodology was used to structure the discussion [11]. The information needs associated with situations were identified as well as barriers to access. This qualitative approach helped us to understand the experience of PWMS and ensured that the categories of information need were grounded in the reality of the PWMS.
These data, along with the published literature and input from stakeholders and the MS Trust, was used to inform the development of a questionnaire (see Appendix). The questionnaire was distributed to 4100 people with MS through the MS Trust, the MS Society, therapy and respite centres, newspapers and the Internet. To aid completion by the MS community, the questionnaires used large print and tick boxes. A total of 2030 questionnaires (49.5%) were returned. No follow-up was instigated, partly because the response rate was felt to be good and partly because of the timescale of the project. Again this was not a random sample; people chose to be respondents. Of these respondents, 1509 were female, 512 were male and nine did not disclose gender (a female: male ratio of 3:1 which compares with the national norm of 2:1). Respondents were aged between 16 and 75. The earliest diagnosis was 1937, the most recent 2001; 553 of the respondents were diagnosed within the last five years. Data gleaned from the returned questionnaires helped to quantify the demand for and value of categories of information, the difficulty in finding information and what was required generally and specifically at diagnosis. The survey also determined how information provision has varied over time.

In addition, audio diarying was used to capture data on the day-to-day experience of a person with MS. Audio diarying was undertaken by only five people, all of whom had severe symptoms of MS. Each person was given a small, easy to manipulate micro-cassette recorder and tapes, and was instructed to record events, that is situations in daily life where they needed to know something, wanted to find out something or had a problem that they needed to resolve. Any time a situation like this occurred, they were asked to record what they were trying to resolve, why, whether or not it was resolved, and if it was resolved, how. This technique of data collection was done primarily to see what kind of data would be generated rather than as a primary survey tool. This method did prove effective in providing detailed data on the situations the respondents confronted and their thoughts at the time – and generated greater detail than that generated by the other two methods. The audio data made apparent, for example, the range of symptoms that a PWMS could experience over a short period and also the importance, in terms of
general wellbeing and quality of life, of taking an active role in life. However, owing to the small sample the audio data were given little weight in terms of the overall findings.

Qualitative findings
The focus group sessions were all tape recorded and later transcribed and then coded. This led to the identification of key themes discussed later and helped to identify categories of information need that were included in the questionnaire survey. A total of 132 generally problematic topics were identified by focus group respondents. Topics were categorized under the following headings; the quotations given stem from the focus group sessions.

Diagnosis
The most common problematic situation was the diagnostic process itself. This was responsible for the greatest number of negative experiences amongst the people involved in the focus groups. Of the people attending the focus groups, 49 per cent mentioned the negative experience they had when they were given their diagnosis. Only eight people were happy with the way they were given their diagnosis. Consultants and GPs were criticized in a number of ways, including a lack of knowledge (among GPs) about MS, a lack of support, poor attitude, and no provision of information. One comment sums up this view:

I was told I had MS and that it was incurable . . . I was lying there thinking I was going to die, he did not explain anything to me.

It should be borne in mind, however, that being diagnosed as having MS is in itself a negative experience and is likely to influence a person's view of the situation and the people involved. It should also be noted that the questionnaire data showed that more often than not information had been provided at diagnosis, and the situation has improved dramatically over the last seven years.
General symptom management
A key concern was dealing with specific symptoms, particularly balance problems and bowel and bladder disturbances, but also symptoms such as fatigue, memory problems and pain. These were identified as areas where information was needed.

General information provision
Respondents highlighted the lack of information, poor provision of information by health professionals and general ignorance about the disease among both health and care professionals as well as the general public.

They also drew attention to their own ignorance of the various help and support services, as well as about MS, particularly at the time of diagnosis. For example, finding out about benefits and entitlements as well as how best to instigate services (form filling etc.) was mentioned in all focus groups.

I knew nothing of MS, I knew nothing.
How much do you know about benefits and all that stuff?
A lot now.
And before?
Nothing.

The PWMS' lack of knowledge and difficulty in communicating their situation plus the ignorance of colleagues also had a negative impact in the workplace. MS and the workplace was identified as an area that PWMS were concerned about.

Communicating with family, friends and colleagues
The lack of knowledge about MS among the wider community was problematic in the sense that the behaviour of the PWMS could be misinterpreted, for example, fatigue was interpreted as laziness. Owing to lack of readily available information for the family etc. about MS, emphasis was placed on the PWMS to explain their condition, which was both intellectually and emotionally difficult.
Support from the family was not guaranteed and misunderstandings occurred, as the following quotation shows:

The lack of faith from other members of my family was quite hard, often I was accused of malingering.

**Access and transport**

This topic is not specific to the MS community but more generally to anyone experiencing physical disability. Nevertheless, PWMS in the focus groups who experienced difficulty with mobility found a lack of facilities and also found it difficult to find out about the facilities available away from the home.

She said oh we have disabled toilets . . . they were up a spiral staircase.

Getting equipment that improved mobility was felt to be difficult in terms of finding out what was available, where it could be obtained and sources of funding.

**Talking to other PWMS**

Positive circumstances that were discussed tended to involve contact with sympathetic people who provided constructive help and information. These included talking to other PWMS, who proved to be a source of emotional support and also information. The comment of one respondent encapsulates this view:

It's saying – my little finger's been twitching like mad – and someone says – oh I've had that – and you think oh, I'm normal.

Support groups, including therapy centres, were therefore popular for this reason but also because a number of services were available in one place.
Quantitative findings
As noted, the questionnaire design was informed by the data gathered from the focus group sessions, the published literature and discussion with the stakeholders and the MS Trust. The questionnaire focused on:

- information provision and information needs at diagnosis
- determining the importance of categories of information and the difficulty in obtaining them
- the best information format (paper, face-to-face, Internet etc.) for access and delivery.

The aggregated data for all respondents were analysed. In addition, data from people who had been diagnosed in the last five years (553 respondents) were analysed separately to see whether the picture had changed over the last five years. It was found that information needs remained consistent and that information provision was still inconsistent in terms of topics covered and at provision. However, the number of people who said they received information at diagnosis has increased dramatically over the last 20 years (in 1980 only 20% of respondents received information, whereas in 2000–1 70% received information). In the last five years more information was provided on two areas, drugs and MS nurses. This reflects the introduction of disease modifying drug therapies and the increase in the number of MS nurses.

At diagnosis over 50 per cent of the respondents wanted information on managing symptoms, drug treatments, disease course, physical symptoms, exercise, diet and information for the family. A distinction, however, was found between the information needs at diagnosis and long term information needs. This is discussed in the conclusions. When respondents were asked whether or not they wanted to know about the different categories of information they generally welcomed this information. However, it can be seen from Table 1 that not all people with MS wanted the same information or wanted to be informed at all. Exactly why this is the case is unclear. It may be because the severity of the condition can vary dramatically and people can experience very different symptoms. It may also be related to the information seeking
behaviour of the individual and intervening variables such as self-efficacy and coping strategies [12] and Baker’s conception of ‘monitors’ and ‘blunters’ [7].

Table 1 Information that respondents would have liked at diagnosis (all respondents)

<table>
<thead>
<tr>
<th>What information would you have liked?</th>
<th>Liked</th>
<th>% liked</th>
<th>Not liked</th>
<th>% not liked</th>
</tr>
</thead>
<tbody>
<tr>
<td>Managing symptoms</td>
<td>1334</td>
<td>65.7</td>
<td>685</td>
<td>33.7</td>
</tr>
<tr>
<td>Possible drug treatments</td>
<td>1232</td>
<td>60.7</td>
<td>787</td>
<td>38.8</td>
</tr>
<tr>
<td>Indication of disease course</td>
<td>1121</td>
<td>55.2</td>
<td>901</td>
<td>44.4</td>
</tr>
<tr>
<td>Possible physical symptoms</td>
<td>1118</td>
<td>55.1</td>
<td>901</td>
<td>44.4</td>
</tr>
<tr>
<td>Information on exercise</td>
<td>1093</td>
<td>53.8</td>
<td>926</td>
<td>45.6</td>
</tr>
<tr>
<td>MS specialist nurse</td>
<td>1089</td>
<td>53.6</td>
<td>929</td>
<td>45.8</td>
</tr>
<tr>
<td>Information for family</td>
<td>1072</td>
<td>52.8</td>
<td>947</td>
<td>46.7</td>
</tr>
<tr>
<td>Information on diet</td>
<td>1017</td>
<td>50.1</td>
<td>1002</td>
<td>49.4</td>
</tr>
<tr>
<td>Benefits and entitlements</td>
<td>995</td>
<td>49.0</td>
<td>1024</td>
<td>50.4</td>
</tr>
<tr>
<td>Physiotherapy</td>
<td>986</td>
<td>48.6</td>
<td>1031</td>
<td>50.8</td>
</tr>
<tr>
<td>Contact for group of newly diagnosed</td>
<td>948</td>
<td>46.7</td>
<td>1071</td>
<td>52.8</td>
</tr>
<tr>
<td>Alternative therapies</td>
<td>939</td>
<td>46.3</td>
<td>1080</td>
<td>53.2</td>
</tr>
<tr>
<td>Organisation addresses</td>
<td>913</td>
<td>45.0</td>
<td>1106</td>
<td>54.5</td>
</tr>
<tr>
<td>Possible psychological symptoms</td>
<td>885</td>
<td>43.6</td>
<td>1133</td>
<td>55.8</td>
</tr>
<tr>
<td>Counselling</td>
<td>804</td>
<td>39.6</td>
<td>1215</td>
<td>59.9</td>
</tr>
<tr>
<td>Work related information</td>
<td>714</td>
<td>35.2</td>
<td>1305</td>
<td>64.3</td>
</tr>
<tr>
<td>Driving</td>
<td>637</td>
<td>31.4</td>
<td>1380</td>
<td>68.0</td>
</tr>
<tr>
<td>Occupational therapy</td>
<td>570</td>
<td>28.1</td>
<td>1449</td>
<td>71.4</td>
</tr>
<tr>
<td>Other</td>
<td>115</td>
<td>5.7</td>
<td>1906</td>
<td>93.9</td>
</tr>
</tbody>
</table>

When asked in general about their information needs, over 40 per cent of respondents felt that it was very important to have information on balance, walking problems, bowel and bladder disturbances, drug treatments and research (see Table 2).

Table 2 Importance of information (all respondents)

<table>
<thead>
<tr>
<th>Topic</th>
<th>Unimportant %</th>
<th>Not very important %</th>
<th>Important %</th>
<th>Very important %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access &amp; transport</td>
<td>18.4</td>
<td>25.4</td>
<td>30.8</td>
<td>21.9</td>
</tr>
<tr>
<td>Access to MS research trial</td>
<td>3.4</td>
<td>14.7</td>
<td>42.3</td>
<td>36.8</td>
</tr>
<tr>
<td>Aids &amp; appliances</td>
<td>9.9</td>
<td>19.8</td>
<td>41.1</td>
<td>25.3</td>
</tr>
<tr>
<td>Balance, problems walking</td>
<td>4.0</td>
<td>7.3</td>
<td>37.6</td>
<td>47.6</td>
</tr>
<tr>
<td>Benefits &amp; entitlements</td>
<td>5.8</td>
<td>8.7</td>
<td>38.5</td>
<td>44.1</td>
</tr>
<tr>
<td>Bowel &amp; bladder disturbances</td>
<td>5.6</td>
<td>10.5</td>
<td>37.7</td>
<td>43.3</td>
</tr>
<tr>
<td>Complementary therapies</td>
<td>6.0</td>
<td>22.5</td>
<td>43.2</td>
<td>24.8</td>
</tr>
<tr>
<td>Drug treatments</td>
<td>1.9</td>
<td>8.3</td>
<td>36.5</td>
<td>50.6</td>
</tr>
<tr>
<td>Emotional changes</td>
<td>5.0</td>
<td>17.0</td>
<td>41.9</td>
<td>32.3</td>
</tr>
</tbody>
</table>
Generally PWMS (65 per cent of the respondents) found it difficult to find out about drug treatments, research trials, balance problems, emotional changes, stress, new and unusual symptoms, and state benefits and entitlements. These data indicate areas where it is particularly important to improve information provision. See Table 3 for further details.

Table 3 Difficulty of finding information

<table>
<thead>
<tr>
<th>Topic</th>
<th>Very difficult</th>
<th>Difficult</th>
<th>Slightly difficult</th>
<th>Not at all difficult</th>
<th>Not needed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access &amp; transport</td>
<td>9.0</td>
<td>19.2</td>
<td>21.2</td>
<td>13.3</td>
<td>32.7</td>
</tr>
<tr>
<td>Access to MS research trial</td>
<td>24.2</td>
<td>21.6</td>
<td>19.8</td>
<td>17.7</td>
<td>11.3</td>
</tr>
<tr>
<td>Aids &amp; appliances</td>
<td>4.8</td>
<td>15.9</td>
<td>24.5</td>
<td>29.4</td>
<td>21.0</td>
</tr>
<tr>
<td>Balance, problems walking</td>
<td>10.6</td>
<td>15.6</td>
<td>21.2</td>
<td>32.2</td>
<td>13.5</td>
</tr>
<tr>
<td>Benefits &amp; entitlements</td>
<td>16.5</td>
<td>24.7</td>
<td>26.2</td>
<td>20.4</td>
<td>21.4</td>
</tr>
<tr>
<td>Bowel &amp; bladder disturbances</td>
<td>14.7</td>
<td>23.6</td>
<td>25.1</td>
<td>21.6</td>
<td>10.5</td>
</tr>
<tr>
<td>Complementary therapies</td>
<td>11.2</td>
<td>20.5</td>
<td>27.4</td>
<td>22.1</td>
<td>15.2</td>
</tr>
<tr>
<td>Drug treatments</td>
<td>20.0</td>
<td>24.2</td>
<td>21.0</td>
<td>21.3</td>
<td>8.3</td>
</tr>
<tr>
<td>Emotional changes</td>
<td>18.8</td>
<td>24.7</td>
<td>20.8</td>
<td>11.2</td>
<td>18.0</td>
</tr>
<tr>
<td>General information about MS</td>
<td>5.1</td>
<td>11.7</td>
<td>25.6</td>
<td>52.2</td>
<td>2.0</td>
</tr>
<tr>
<td>General symptom management</td>
<td>9.9</td>
<td>21.8</td>
<td>32.9</td>
<td>24.4</td>
<td>5.1</td>
</tr>
<tr>
<td>Home modifications</td>
<td>10.9</td>
<td>16.9</td>
<td>20.0</td>
<td>18.3</td>
<td>29.7</td>
</tr>
<tr>
<td>Information for families/friends</td>
<td>8.5</td>
<td>15.4</td>
<td>22.9</td>
<td>29.6</td>
<td>17.6</td>
</tr>
<tr>
<td>Leisure activities &amp; holidays</td>
<td>15.0</td>
<td>16.5</td>
<td>18.7</td>
<td>13.7</td>
<td>31.4</td>
</tr>
<tr>
<td>Memory problems</td>
<td>14.1</td>
<td>23.3</td>
<td>21.6</td>
<td>11.8</td>
<td>24.7</td>
</tr>
<tr>
<td>New and unusual symptoms</td>
<td>15.0</td>
<td>26.7</td>
<td>27.4</td>
<td>13.1</td>
<td>11.8</td>
</tr>
<tr>
<td>Nutritional advice</td>
<td>9.6</td>
<td>16.8</td>
<td>23.7</td>
<td>32.7</td>
<td>12.6</td>
</tr>
<tr>
<td>Occupational therapy</td>
<td>8.9</td>
<td>15.0</td>
<td>19.7</td>
<td>24.7</td>
<td>25.8</td>
</tr>
<tr>
<td>Organisational addresses</td>
<td>3.3</td>
<td>6.9</td>
<td>21.3</td>
<td>55.2</td>
<td>7.6</td>
</tr>
<tr>
<td>Physiotherapy</td>
<td>10.0</td>
<td>14.1</td>
<td>21.5</td>
<td>40.4</td>
<td>10.3</td>
</tr>
<tr>
<td>Research</td>
<td>11.2</td>
<td>17.2</td>
<td>26.2</td>
<td>33.4</td>
<td>6.0</td>
</tr>
<tr>
<td>Stress</td>
<td>13.8</td>
<td>22.9</td>
<td>25.4</td>
<td>16.3</td>
<td>15.7</td>
</tr>
<tr>
<td>Visual problems</td>
<td>9.5</td>
<td>17.1</td>
<td>24.6</td>
<td>23.0</td>
<td>21.0</td>
</tr>
<tr>
<td>Working with MS</td>
<td>14.2</td>
<td>16.5</td>
<td>16.1</td>
<td>12.3</td>
<td>34.6</td>
</tr>
</tbody>
</table>
Respondents were asked about their preferred medium of delivery for the various categories of information. Leaflets, face-to-face contact, newsletters and magazines were the preferred media. The Internet scored comparatively low, i.e. generally no more than 5 per cent of respondents chose the Internet for any one category. The only exceptions were general information on MS (6.3%), leisure activities (6.7%), organization addresses (8.3%) and research (8.7%). This low response for the Internet may reflect the age range of the respondents, the majority being between 40 and 60 years of age, who may be less comfortable with the Internet than younger respondents. Generally face-to-face contact was preferred for sensitive and complex issues such as new and unusual symptoms (42.8%), emotional changes (42.8%), balance (41.8%), and bowel and bladder disturbances (39.9%). On the other hand, leaflets were preferred for topics such as access and transport (41.5%), information for the family (38.7%) and benefits and entitlements (36.4%).

The questionnaire data (as well as the focus group data and the audio diary data) made it evident that the cognitive and physical ability of the person with MS affected their information behaviour. For example, fatigue and loss of concentration are likely to affect the effort required and the ability to find and use information. Limited mobility, impaired sight and a lack of manual dexterity can all have a negative impact on information access. These are areas that need further exploration to see how information can be provided in a way that is accessible for people who experience these kinds of problems.

**Conclusion and recommendations**

Someone with MS should be seen as a person, and not just as a person with MS, who is likely to want to take an active role in life. Information should be provided to help achieve this goal. Enabling people to participate actively in life (as a result of access to information and knowledge), whether in the home, workplace or elsewhere, has a positive impact on their self-esteem and general wellbeing. This may seem self-evident. It is, however, easy for service and information providers to focus on the condition and the information specific to that condition rather than seeing the PWMS in the broader light. As
a result they may underestimate the importance of information provision and fail to provide information that helps the PWMS really engage and participate in life. The audio tapes, for example, provided a good illustration of where an individual had become informed and had found out about adapting his car and sources of finance to do so, which meant he could take his daughter to her graduation. This meant a great deal to the PWMS and their state of mind in obvious ways, such as mobility and control, but perhaps more importantly in being able to fulfil their parental role.

Information provision needs to be targeted at three communities. These are people with MS, the general public (including the family, friends and colleagues) and state and voluntary service providers. The public need general information about MS and living with MS and the support available. This would help them to understand the condition and provide necessary support. The information would need to be written in a way that was easily understood and encouraged a positive supportive manner. Similarly service providers would need general information about MS, and the help and information that are available. The latter would help them to direct PWMS to informational and practical support.

Service providers, including health and social care professionals and support groups, would probably benefit from training in the information needs of people with MS and how these might be satisfied. Service providers need to be aware of the variability of the condition and how the nature of MS may change over time, and that informed support is required over an extended period. Health professionals involved in diagnosis also need training in how to provide information at diagnosis in a supportive and sensitive fashion. This is particularly important because it was clear that people varied dramatically in their desire to have information. Also PWMS were particularly responsive to information that was provided in a positive manner, such as tips which helped people to take action. Information should therefore be provided:

- in a positive manner
• in a way that helps and motivates people to take action
• corresponding to the condition of the person with MS
• in a way that is sensitive to the desire for information and its possible impact on the individual
• using the most effective means of communication. This will vary depending on the nature of the information and the cognitive and physical ability of the person with MS. For example, face-to-face communication will be more appropriate for sensitive or complex issues. Leaflets, booklets, newsletters, e-mail, World Wide Web, video conferencing and chat rooms, however, could all play a role in information provision and exchange
• using different formats to cater to the individual needs of the person with MS. For example, fatigue and problems with concentration would demand that information is provided in a succinct manner. Visual problems would also have an impact on information provision
• enabling access to different types and sources of information, for example: professional articles, popular press, experts and other people with MS to satisfy the information seeking behaviour of the person with MS. Enabling access to other people with MS should be seen as a key role for any information provider.

Relevant content would need to be created or gleaned from existing sources (however, second-hand resources will probably not correspond to the needs described above). The following categories of information should be provided to the person with MS (bearing in mind the need for the provider to take into account the situation of the individual).

**Information at diagnosis**

At diagnosis people with MS should have access to information on:

• general information about MS
• managing symptoms
• drug treatments
• the possible course of the condition
• physical symptoms
• information on exercise
• information for the family
• information on diet.

Thereafter categories of information need to fall under two headings: information about MS, and information that helps PWMS to interact with the world around them.

Information about MS
People with MS should be provided with information about:
• a general explanation of MS
• MS research trials
• drug treatments
• symptoms
• prognosis
• treatment and management of symptoms
• physiotherapy
• complementary therapy
• nutritional advice
• health and fitness
• emotional changes.

Information that helps PWMS interact with the world
This would include information about:
• service providers (health services, social services, benefits agency, voluntary organizations)
• the services that providers give
• support groups
• aids and appliances
• facilities for the disabled
• MS and work, and the issues associated with giving up work
• communicating about MS with family, friends, colleagues and the public
leisure activities including, when necessary, provision for the disabled.

These categories of information are similar to those generally recognized as required by people with an illness [13]. However, the categories listed here cover a wider range of topics and include information which is not directly related to the condition but is important for the person's wellbeing and ability to participate in life.

Positive accounts by other PWMS about how they cope with the disease were popular, because the information came from an insider, was contextually relevant and was couched in a positive manner. Public information providers should ensure that this kind of material is made available.

Further work is required into the effect of individual differences (psychological and physiological) on the desire to learn and to be informed and the use of information. Research is also needed into how technology can help to provide personalized information. At Loughborough University we are currently investigating how Extensible Markup Language (XML) can be used to provide personalized information delivery based on the user's situation. Other technologies such as advances taking place in wireless technology (Wi-Fi) and the increased availability of broadband access in the future should enable information providers to provide 'real-time' personalization and the use of the most appropriate medium, such as voice, video or text, for the individual. Exploration of these areas should lead to information solutions that relate to the specific needs of PWMS, enabling them to inform themselves and become knowledgeable. Knowledge generated from this work could be applied to other communities whose learning is hindered by current information provision and non-provision.

In the meantime, although health and related information provision has improved greatly, there is still a need to make this kind of information more accessible and consistently available in the UK through a broad range of existing channels.
Appendix: questionnaire

Please note the original questionnaire was printed in 14 point type to aid legibility. Owing to the change in font the format of the questionnaire is slightly different from the one sent out. Nevertheless the reader can get an understanding of the questions asked.

Tick boxes were chosen to make it possible to ask many questions without tiring the respondent.

The Information Needs of People with Multiple Sclerosis

Please tick the appropriate boxes.
All information will be treated in the strictest confidence.

Please tick if someone filled this questionnaire in on your behalf _

Section 1. Personal Information

1.1 Are you: Male _ Female _ 1.2
Postcode:.................................

1.3 What is your age? 16 or under _ 17-19 _ 20-29 _ 30-39 _
40-49 _ 50-59 _ 0-64 _ 5-69 _ 70-74 _ 75+ _

1.4 Approximate year of first symptoms: ......................

1.5 Approximate year of definite diagnosis of MS: ..............

Please tick if you have not received a definite diagnosis _

1.6 Current employment status:
Full-time _ Seeking work _
Part-time _ Permanently unable to work _
Retired _ Full time education _
Voluntary _
Other: ........................................................................................................
1.7 At any time has your MS affected your employment status?
Yes _
No _

1.8 Please rate YOUR symptoms and disabilities overall using this scale.
Circle the number which would represent your symptoms.
(0 = no symptoms 10 = severe symptoms)

0   1   2   3   4   5   6   7   8   9   10

Section 2. Time of Diagnosis

2.1 WHO did YOU receive your diagnosis from? (Tick one only)
Consultant Neurologist _
Nurse _
Other hospital doctor _
GP _
Relative _
Have not had a diagnosis _
(Please go to Qs. 3.1)
Other: ..........................................................................................

2.2 WHAT information were YOU given at the time of your diagnosis?
(Tick all that apply)
Possible physical symptoms _
Possible psychological symptoms _
Information on diet _
Counselling _
Information on exercise _
MS specialist nurse _
Possible drug treatments _
Driving _
Managing symptoms _
Organization addresses _
Indication of disease course _
Contact for group of newly diagnosed _
Physiotherapy _
Benefits and entitlements _
Alternative therapies _
Work related information _
Occupational therapy _
Information for family _
No information was given _
Other: ..........................................................................................

2.3 In what areas would YOU have LIKED to be given information at the time of your diagnosis? (Tick all that apply)
Section 3. Finding Information on MS

3.1 WHO do YOU GO TO for useful information on MS? (Tick all that apply)

Alternative Therapist _ MS Society (Head office) _
Benefits Agency _ MS Society (Local branch) _
Carer _ MS Trust _
Citizens Advice Bureau _ Neurologist _
Dentist _ Other local branch _
Dietician _ Pharmacist _
Family _ Physiotherapist _
Friends _ Other people with MS _
GP _ Social Services _
Library _ MS Therapy Centre _
MS specialist nurse _
Other: ..........................................................................................................

3.2 How DIFFICULT has it been for YOU to find out about the following: (Please tick ONE box per line)

<table>
<thead>
<tr>
<th></th>
<th>Very</th>
<th>Difficult</th>
<th>Slightly</th>
<th>Not at all</th>
<th>Not</th>
</tr>
</thead>
</table>

218
| Access & transport | difficult | difficult | difficult | needed |
| Access to MS research trial |          |          |          |        |
| Aids & appliances |          |          |          |        |
| Complementary and alternative therapies |          |          |          |        |
| Balance, problems walking |          |          |          |        |
| Benefits & entitlements |          |          |          |        |
| Bowel & bladder disturbances |          |          |          |        |
| Drug treatments |          |          |          |        |
| Emotional changes |          |          |          |        |
| General information about MS |          |          |          |        |
| General symptom management |          |          |          |        |
| Home modifications |          |          |          |        |
| Information for families/friends |          |          |          |        |
| Leisure activities & holidays |          |          |          |        |
| Memory problems |          |          |          |        |
| New and unusual symptoms |          |          |          |        |
| Nutritional advice |          |          |          |        |
| Occupational therapy |          |          |          |        |
| Organisational addresses |          |          |          |        |
| Physiotherapy |          |          |          |        |
| Research |          |          |          |        |
| Stress |          |          |          |        |
| Visual problems |          |          |          |        |
| Working with MS |          |          |          |        |

Section 4. Being given Information on MS

4.1 In what WAY would YOU PREFER information on MS to be provided to you? (Please tick ONE box per line)

<p>| Access &amp; transport | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 |
| Access to MS research trial |          |          |          |          |          |          |          |          |          |          |          |
| Aids &amp; appliances |          |          |          |          |          |          |          |          |          |          |          |
| Complementary and alternative therapies |          |          |          |          |          |          |          |          |          |          |          |
| Balance, problems walking |          |          |          |          |          |          |          |          |          |          |          |
| Benefits &amp; entitlements |          |          |          |          |          |          |          |          |          |          |          |
| Bowel &amp; bladder disturbances |          |          |          |          |          |          |          |          |          |          |          |
| Drug treatments |          |          |          |          |          |          |          |          |          |          |          |
| Emotional changes |          |          |          |          |          |          |          |          |          |          |          |
| General information about MS |          |          |          |          |          |          |          |          |          |          |          |
| General symptom management |          |          |          |          |          |          |          |          |          |          |          |</p>
<table>
<thead>
<tr>
<th>Column</th>
<th>Heading</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Leaflet</td>
</tr>
<tr>
<td>2</td>
<td>Book</td>
</tr>
<tr>
<td>3</td>
<td>Video</td>
</tr>
<tr>
<td>4</td>
<td>CD-Rom</td>
</tr>
<tr>
<td>5</td>
<td>Magazine</td>
</tr>
<tr>
<td>6</td>
<td>Newsletter</td>
</tr>
<tr>
<td>7</td>
<td>Audio Cassette</td>
</tr>
<tr>
<td>8</td>
<td>E-Mail</td>
</tr>
<tr>
<td>9</td>
<td>Face-to-Face</td>
</tr>
<tr>
<td>10</td>
<td>Over Telephone</td>
</tr>
</tbody>
</table>

### 4.2 How IMPORTANT is it for YOU to have information on the following:
(Please tick ONE box per line)

<table>
<thead>
<tr>
<th></th>
<th>Unimportant</th>
<th>Not very important</th>
<th>Important</th>
<th>Very important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access &amp; transport</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Access to MS research trial</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aids &amp; appliances</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Complementary and alternative</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>therapies</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Balance, problems walking</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Benefits &amp; entitlements</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bowel &amp; bladder disturbances</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drug treatments</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotional changes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>General information about MS</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>General symptom management</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home modifications</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Information for families/friends</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Leisure activities &amp; holidays</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
4.3 Does your MS affect how you find information? Yes _ No _
If yes, how? (Please tick all that apply)

Sight _ Dexterity _ Memory _
Mobility _ Fatigue _ Concentration _

Other: ...........................................................................................................

Section 5. Information and YOU – (OPTIONAL)

5. Give one example of when you got information that made a positive
difference to your life.

...........................................................................................................
...
...........................................................................................................
...
...........................................................................................................
...
...........................................................................................................
...

OPTIONAL:
If you have any tips to give to someone else with MS please write them below:

...........................................................................................................
...
...........................................................................................................
...
...........................................................................................................
...

OPTIONAL:
I would like to be placed on the MS Trust mailing list _
I am willing to be involved in further research about information for people with MS

Name: ..............................................................................................
Address: ..............................................................................................
..............................................................................................
Postcode: ..............................................................
E-mail: ..............................................................

THANK YOU
PLEASE RETURN IN THE PRE-PAID ENVELOPE PROVIDED

Data Protection:
The Multiple Sclerosis Trust will use information supplied by you to keep you informed about the work of the Trust. If you have any query about the information the Trust holds and the use they make of it please contact the Trust.

The Department of Information Science, Loughborough University will use information supplied by you to help analyse current data and also to conduct future research into the need for and use of information by people with MS. Names and addresses of participants will not be disclosed by either the MS Trust or the Department of Information Science, Loughborough University to other organizations.

Acknowledgements
I would like to thank the people with MS who took part in the study; the MS Trust for funding the project; and Nicole James, Research Associate, for helping to collect the data.

References
1 Robinson I, Hunter M, Neilson S. A Dispatch from the Frontline: The Views of People with Multiple Sclerosis about their Needs. A Qualitative Approach.


7 Baker L. Monitors and blunters: patient health information seeking from a different perspective. *Bibliotheca Medica Canadiana* 1994; 16 (2); 60–3.


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Janet Harrison
Theme Two – Part One

The information needs and behaviour of academics, health and social care professionals – Traditional use of information in the research environment

Papers 9-10
Use of information technology by biological researchers


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Print bound close to the spine
Use of information technology by biological researchers

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Abstract

Recent studies of computer-based information-handling by scientists have tended to look at such activities across all the sciences. This is true, in particular, of the recent Royal Society (RS)/British Library (BL)/Association of Learned and Professional Society Publishers (ALPSP) survey. The present study aims to complement these by concentrating on the biological sciences only. It surveys the usage of information technology and related factors by researchers at four institutions - an agricultural faculty, a university school of biology, a government research establishment and a pharmaceutical laboratory.

It is found that there are differences in usage, depending on the institution and specialism involved. It also appears that senior researchers in biology are typically more information-active than junior researchers, but that senior/junior differences in the use of information technology are relatively minor, and can mostly be explained in terms of the resources on senior staff time.

When compared with the RS/BL/ALPSP survey, some results of the present study agree well (e.g. regarding the average level of online access to information). Others differ (e.g. electronic information usage in the pharmaceutical laboratory is higher than the earlier survey might suggest). Overall, the present study indicates that, though the information-handling activities of biologists may differ on average from other specialisms, their total spread is so great that most approaches can be matched by some group within the biological sciences.

Introduction

There has been a number of recent studies of the use of computers for information-handling by British scientists [e.g. 1, 2, 3, 4]. These have mainly been broad surveys covering several branches of science. There has been less in the way of in-depth studies of computer usage within a single research discipline. It was therefore decided to study communication and computers within one particular scientific field. The results for this can then be compared with broader surveys to see whether both the average level of computer usage and the spread of activity was similar within a single discipline to those found for scientific researchers in general. At the same time, this narrower focus should reveal more detail than was possible with the wider surveys.

Biology was selected as the specific topic for study for a number of reasons. Its subject matter encompasses a wide range of categories of information and types of information-handling. In consequence, information required by biologists can be found in anything from old printed publications to the most sophisticated of modern electronic databases. Biological research is also carried out in a variety of information environments - laboratory v. fieldwork, university v. industry, etc. Biological research has been expanding rapidly in recent years. Studying computer usage in biology may help forward planning during a period of considerable change in biological information-handling.
Use of information technology by biological researchers

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A.J. Meadows
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H. Smith
University of Leicester, UK

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information). Others differ (e.g. electronic information usage in the pharmaceutical laboratory is higher than the earlier survey might suggest). Overall, the present study indicates that, though the information-handling activities of biologists may differ on average from other specialisms, their total spread is so great that most approaches can be matched by some group within the biological sciences.

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Methodology

Four groups of biologists from different information environments were chosen.
for study - a university agricultural faculty, a university school of biology, a
government research establishment and a pharmaceutical laboratory. (These
are labelled W, X, Y and Z, respectively, in subsequent tabulations.) The
agricultural faculty and the government establishment had research interests
oriented more towards classical biology than the school of biology or the
pharmaceutical laboratory. Between them, these groups cover the main
categories of employer and the main biological research fields. The topics
covered by these institutions are listed in Table 1.

Certain constraints were seen as applying to the method of data-gathering to
be employed in this project. Firstly, previous general surveys of computer
usage have been mainly quantitative in approach. To facilitate comparison
with them, it therefore seemed best to concentrate on quantitative data in the
present project. Secondly, some vetting of questions beforehand was
involved, especially with the pharmaceutical laboratory. Finally, previous work
indicated that questions dealing with the use of information technology could
sometimes be sensitive (e.g. when staff or students felt that they ought to be
accessing computers more than they did). These various constraints sug-
gested that the best data-gathering method would be a questionnaire survey
replied to anonymously.

In constructing the questionnaire, an attempt was made to use the same
questions at each institution (a very few were institution-specific). A small pilot
survey was carried out at the school of biology in May/June 1993. The revised
questionnaires were then sent out in sequence to the four selected institutions
over the period May 1993 to January 1994. It was decided to set a minimum
target number of 40 responses from each institution in order to allow
appropriate statistical analysis. The final response rates are shown in Table 2.

Table 1 Coverage of biological topics by institution

<table>
<thead>
<tr>
<th>W</th>
<th>X</th>
<th>Y</th>
<th>Z</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Agricultural</td>
<td>Plant and Ecological Chemistry</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Anatomy</td>
<td>Plant and Ecological Chemistry</td>
</tr>
</tbody>
</table>

229
Agricultural Botany | Biochemistry | Biochemistry and Physiology | Cellular and Molecular Biology
---|---|---|---
Biochemistry and Physiology | Botany | Crop Management | Microbiology
Botany | Genetics | Entomology and Nematology | Pharmacology
Horticulture | Microbiology | Plant Pathology | 
Soil Science | Pharmacology | Soil Science | 
| Physiology | 
| Zoology |

Note: A small number of staff from ancillary subjects, such as statistics, also returned questionnaire forms.

Table 2 Response rate from each institution

<table>
<thead>
<tr>
<th>Institution</th>
<th>No. issued</th>
<th>No. of returns</th>
<th>% Return</th>
</tr>
</thead>
<tbody>
<tr>
<td>W</td>
<td>100</td>
<td>64</td>
<td>40%</td>
</tr>
<tr>
<td>X</td>
<td>200</td>
<td>49</td>
<td>25%</td>
</tr>
<tr>
<td>Y</td>
<td>170</td>
<td>84</td>
<td>49%</td>
</tr>
<tr>
<td>Z</td>
<td>80</td>
<td>57</td>
<td>71%</td>
</tr>
<tr>
<td>Total</td>
<td>610</td>
<td>254</td>
<td>42%</td>
</tr>
</tbody>
</table>

Background variables

It was decided, on the basis of previous surveys, that the personal characteristics of respondents that were most likely to correlate with information-handling were age, highest educational qualification and position. The distributions of these are listed in Tables 3, 4 and 5.

Although the university retirement age is higher (at 65 years) than at the other two institutions, the data suggest the number of over-60s in universities is
small. All four institutions had a clear majority of respondents aged 40 or less. The two institutions with an orientation towards classical biology (W and Y) had an appreciably higher proportion of older staff than those more concerned with modern biochemistry (X and Z). The commonest educational qualification was the PhD. Master's degrees only occur with any frequency in agriculture; otherwise, the next most common highest qualification was the Bachelor's degree.

Table 3 Age distribution

<table>
<thead>
<tr>
<th>Age range</th>
<th>W</th>
<th>X</th>
<th>Y</th>
<th>Z</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 30</td>
<td>42%</td>
<td>51%</td>
<td>38%</td>
<td>34%</td>
</tr>
<tr>
<td>31 – 40</td>
<td>23%</td>
<td>29%</td>
<td>25%</td>
<td>48%</td>
</tr>
<tr>
<td>41 – 50</td>
<td>23%</td>
<td>12%</td>
<td>29%</td>
<td>16%</td>
</tr>
<tr>
<td>51 – 60</td>
<td>3%</td>
<td>6%</td>
<td>7%</td>
<td>2%</td>
</tr>
<tr>
<td>&gt; 60</td>
<td>8%</td>
<td>2%</td>
<td>1%</td>
<td>0%</td>
</tr>
</tbody>
</table>

Table 4 Highest qualification

<table>
<thead>
<tr>
<th>Qualification</th>
<th>W</th>
<th>X</th>
<th>Y</th>
<th>Z</th>
</tr>
</thead>
<tbody>
<tr>
<td>DSc/MD</td>
<td>9%</td>
<td>4%</td>
<td>4%</td>
<td>0%</td>
</tr>
<tr>
<td>PhD</td>
<td>42%</td>
<td>63%</td>
<td>44%</td>
<td>61%</td>
</tr>
<tr>
<td>Master</td>
<td>25%</td>
<td>4%</td>
<td>14%</td>
<td>9%</td>
</tr>
<tr>
<td>BSc/BA</td>
<td>22%</td>
<td>29%</td>
<td>25%</td>
<td>25%</td>
</tr>
<tr>
<td>Other</td>
<td>2%</td>
<td>0%</td>
<td>13%</td>
<td>5%</td>
</tr>
</tbody>
</table>
Table 5 Position held

<table>
<thead>
<tr>
<th>Post</th>
<th>W</th>
<th>X</th>
<th>Post</th>
<th>Y</th>
<th>Post</th>
<th>Z</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research Student</td>
<td>42%</td>
<td>25%</td>
<td>Scientific Officer</td>
<td>29%</td>
<td>Scientist</td>
<td>23%</td>
</tr>
<tr>
<td>Research Assistant</td>
<td>5%</td>
<td>23%</td>
<td>H.S.O.</td>
<td>35%</td>
<td>Senior Scientist</td>
<td>65%</td>
</tr>
<tr>
<td>Research Fellow</td>
<td>27%</td>
<td>23%</td>
<td>S.S.O.</td>
<td>9%</td>
<td>Research Mgr.</td>
<td>7%</td>
</tr>
<tr>
<td>Lecturer</td>
<td>8%</td>
<td>8%</td>
<td>UG7</td>
<td>21%</td>
<td>Head of Dept.</td>
<td>5%</td>
</tr>
<tr>
<td>Senior Lecturer</td>
<td>5%</td>
<td>15%</td>
<td>UG6</td>
<td>2%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reader</td>
<td>2%</td>
<td>4%</td>
<td>UG5</td>
<td>4%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Professor</td>
<td>13%</td>
<td>2%</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The presence of research students and research assistants in universities implies a larger number of lower-level posts there, though there are significantly fewer research assistants in the agricultural faculty than in the school of biology. At the upper end of the scale, some 20% of the staff were in senior management positions (more at the government laboratory and fewer at the pharmaceutical laboratory).

Respondents were asked to assess their own communication activities. Approximately three-quarters of the respondents had produced some kind of publication since 1990 (less at W and Z; more at Y). The relative shortfall in the agricultural faculty appears to be due to the higher proportion of research students there. Besides research, appreciable time was spent on teaching and administration (Table 6).

Table 6 Involvement in teaching and administration

<table>
<thead>
<tr>
<th>Activity</th>
<th>W</th>
<th>X</th>
<th>Y</th>
<th>Z</th>
</tr>
</thead>
<tbody>
<tr>
<td>Teaching</td>
<td>45% (20)</td>
<td>41% (10)</td>
<td>23% (5)</td>
<td>0</td>
</tr>
<tr>
<td>Administration</td>
<td>42% (50)</td>
<td>35% (25)</td>
<td>22% (30)</td>
<td>68% (40)</td>
</tr>
</tbody>
</table>
Teaching was highest in the agricultural faculty (and was higher than expected at the government establishment). The highest involvement in administration was at the pharmaceutical laboratory, but the load was also high in the agricultural faculty. Refereeing of papers or grant applications occupies about one-third of the university respondents for five to ten hours per month. The same is true of 15-20% of the government establishment staff, but no staff at the pharmaceutical laboratory are involved in these activities.

**Communication activities**

Respondents were questioned about the time they expended on reading about their research, or in communicating about research with their colleagues. Table 7 indicates how many spent more than four hours per week on either activity. The most striking difference here is the relatively larger amount of communication that goes on at the pharmaceutical laboratory.

**Table 7**  
**Reading and communicating**

<table>
<thead>
<tr>
<th>Activity</th>
<th>W</th>
<th>X</th>
<th>Y</th>
<th>Z</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reading</td>
<td>50%</td>
<td>39%</td>
<td>45%</td>
<td>46%</td>
</tr>
<tr>
<td>Communicating</td>
<td>33%</td>
<td>39%</td>
<td>43%</td>
<td>68%</td>
</tr>
</tbody>
</table>

As Table 8 indicates, most respondents in all institutions felt that the level of research information provision (via the library, etc) was satisfactory.

**Table 8**  
**Level of satisfaction with the provision of research information**

<table>
<thead>
<tr>
<th>Proportion satisfied</th>
<th>W</th>
<th>X</th>
<th>Y</th>
<th>Z</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>87%</td>
<td>80%</td>
<td>94%</td>
<td>87%</td>
</tr>
</tbody>
</table>
By way of contrast, there was some dissatisfaction with the ability to communicate externally to the institution. This was examined by asking respondents to indicate whether they had been subject to any restrictions in their use of external communication channels. Significant levels of restriction are recorded in Table 9. (This question was not pursued at the pharmaceutical laboratory: restrictions were mainly due to financial pressures, and we were informed this was not a major factor at the laboratory.) The percentages quoted represent the proportion of respondents who reported a high level of 'restriction on the activity during the previous year. (A significant proportion of their colleagues indicated that they had experienced some lesser level of restriction.) Conference attendance is clearly now being affected, even when the participant is due to give a paper. The government establishment is less affected by restrictions on such activities as telephone discussions or photocopying.

Table 9 Restrictions on communications

<table>
<thead>
<tr>
<th>Activity</th>
<th>W</th>
<th>X</th>
<th>Y</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conference travel</td>
<td>29%</td>
<td>16%</td>
<td>30%</td>
</tr>
<tr>
<td>Conference travel and paper</td>
<td>18%</td>
<td>8%</td>
<td>21%</td>
</tr>
<tr>
<td>Long distance telephone</td>
<td>26%</td>
<td>12%</td>
<td>0%</td>
</tr>
<tr>
<td>Photocopying</td>
<td>3%</td>
<td>6%</td>
<td>1%</td>
</tr>
</tbody>
</table>

Use of computers

Most respondents had a microcomputer ('micro') on their desks, though the proportion varied from two thirds in the agricultural faculty to virtually everyone at the pharmaceutical laboratory. Those who did not have one immediately to hand could almost all access one within their own department. All these micros were networked at the pharmaceutical laboratory, whereas only one-third of the respondents in the agricultural faculty could access
networks readily. A comparison of the data in Table 10 shows that the two establishments with a bias towards classical biology were less likely to have micros and, more especially, networked micros available. At the same time, there was no great difference between the institutions in terms of use of computers at home.

Table 10 Availability of computers

<table>
<thead>
<tr>
<th>Availability</th>
<th>W</th>
<th>X</th>
<th>Y</th>
<th>Z</th>
</tr>
</thead>
<tbody>
<tr>
<td>Computer on desk</td>
<td>66%</td>
<td>84%</td>
<td>70%</td>
<td>98%</td>
</tr>
<tr>
<td>Networked computer</td>
<td>33%</td>
<td>73%</td>
<td>48%</td>
<td>98%</td>
</tr>
<tr>
<td>Computer use at home</td>
<td>55%</td>
<td>53%</td>
<td>48%</td>
<td>42%</td>
</tr>
</tbody>
</table>

About one-third of all the respondents use a computer more frequently than once a week to collect data (Table 11). A somewhat smaller proportion use computers for statistical purposes with the same frequency. There is greater variation in the applications of graphical display: relatively few in the agricultural faculty use computers for this purpose, but almost half the respondents at the pharmaceutical laboratory do so. Respondents at the pharmaceutical laboratory not only have more networked micros, they also use network access more often for such activities as electronic mail, or accessing electronic bulletin boards. Easily the most frequent application of computers overall is for word-processing. However, under most headings, there are considerably more respondents who rarely, if ever, use a computer for that purpose, than those who do. In particular, the generally low level of networked activities (including electronic mail), except at the pharmaceutical laboratory, is worth noting.
Table 11  Usage of computers  (all figures are percentages)

<table>
<thead>
<tr>
<th>Computer activity</th>
<th>W</th>
<th>W</th>
<th>X</th>
<th>X</th>
<th>Y</th>
<th>Y</th>
<th>Z</th>
<th>Z</th>
</tr>
</thead>
<tbody>
<tr>
<td>Collection of data</td>
<td>36</td>
<td>38</td>
<td>30</td>
<td>47</td>
<td>29</td>
<td>48</td>
<td>33</td>
<td>44</td>
</tr>
<tr>
<td>Statistical analysis</td>
<td>27</td>
<td>32</td>
<td>32</td>
<td>43</td>
<td>16</td>
<td>44</td>
<td>33</td>
<td>37</td>
</tr>
<tr>
<td>Graphical display</td>
<td>12</td>
<td>31</td>
<td>40</td>
<td>19</td>
<td>31</td>
<td>35</td>
<td>48</td>
<td>18</td>
</tr>
<tr>
<td>Word processing</td>
<td>79</td>
<td>7</td>
<td>80</td>
<td>4</td>
<td>56</td>
<td>10</td>
<td>70</td>
<td>4</td>
</tr>
<tr>
<td>Searching CD-ROMs</td>
<td>2</td>
<td>66</td>
<td>4</td>
<td>75</td>
<td>6</td>
<td>69</td>
<td>20</td>
<td>29</td>
</tr>
<tr>
<td>Electronic mail</td>
<td>26</td>
<td>49</td>
<td>21</td>
<td>58</td>
<td>26</td>
<td>61</td>
<td>98</td>
<td>-</td>
</tr>
<tr>
<td>Electronic file transfer</td>
<td>2</td>
<td>88</td>
<td>2</td>
<td>89</td>
<td>-</td>
<td>87</td>
<td>6</td>
<td>74</td>
</tr>
<tr>
<td>Electronic bulletin boards</td>
<td>9</td>
<td>88</td>
<td>2</td>
<td>94</td>
<td>5</td>
<td>86</td>
<td>27</td>
<td>49</td>
</tr>
<tr>
<td>Online databases</td>
<td>12</td>
<td>68</td>
<td>18</td>
<td>20</td>
<td>9</td>
<td>53</td>
<td>20</td>
<td>34</td>
</tr>
<tr>
<td>Electronic diary</td>
<td>5</td>
<td>93</td>
<td>2</td>
<td>96</td>
<td>1</td>
<td>98</td>
<td>-</td>
<td>100</td>
</tr>
<tr>
<td>Personal bibliography</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personal electronic database</td>
<td>12</td>
<td>68</td>
<td>15</td>
<td>57</td>
<td>14</td>
<td>77</td>
<td>2</td>
<td>89</td>
</tr>
<tr>
<td>Other</td>
<td>7</td>
<td>80</td>
<td>-</td>
<td>100</td>
<td>33</td>
<td>52</td>
<td>30</td>
<td>30</td>
</tr>
</tbody>
</table>

The data in column 1 for each institution indicate the proportion of respondents who are involved in the activity more than once per week. The data in column 2 give the proportion who are rarely or never involved in the activity.

Table 12 explores what activities are included under the category 'Other' in Table 11. As the latter table indicates, the range of such additional activities varies considerably between the different institutions. It is clear from Table 12 that some of these other activities (e.g. manipulating DNA/protein sequences) are related to the type of research that predominates at the institution. However, it is interesting that only the government establishment mentions networked authoring of papers.
Table 12 Other tasks for which computers are used

<table>
<thead>
<tr>
<th>Activity</th>
<th>W</th>
<th>X</th>
<th>Y</th>
<th>Z</th>
</tr>
</thead>
<tbody>
<tr>
<td>Computer simulations</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Courseware preparation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Data reduction modelling</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Developing computer software for other users</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Drawing plans for field experiments</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Games</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Graphics for presentations</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home Office records</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Library catalogue</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Manipulating DNA/protein sequences</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Molecular biology applications</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Programming</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Record keeping</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Searching sequence databases</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Software development</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Storage and data for experiments</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Writing internationally authored papers by email</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Another point from Table 11 is taken up in Table 13. This relates to the use of online databases. The amount of online searching obviously varies widely between institutions. Respondents at the universities were more likely to undertake online searches themselves - a result, apparently, of the greater provision of assistance by information personnel at the other two institutions. A range of reasons was given for not accessing online databases; one significant one being lack of awareness of what is available.

Table 13 Online searching

<table>
<thead>
<tr>
<th>Activity</th>
<th>W</th>
<th>X</th>
<th>Y</th>
<th>Z</th>
</tr>
</thead>
<tbody>
<tr>
<td>Use online searches</td>
<td>52%</td>
<td>84%</td>
<td>63%</td>
<td>79%</td>
</tr>
<tr>
<td>Carry out own searches</td>
<td>68%</td>
<td>85%</td>
<td>49%</td>
<td>42%</td>
</tr>
<tr>
<td>Satisfied with results*</td>
<td>57%</td>
<td>78%</td>
<td>73%</td>
<td>84%</td>
</tr>
</tbody>
</table>
Finally, respondents were asked which online information services they used (other than purely local resources, such as their library online public access catalogue). As Table 14 indicates, the usage of such external services was not high, and was also spread quite widely. The exception was BIDS, the new entrepreneurial provider of online services to the academic world. It is already attracting as much attention at the government establishment as at the universities.

Table 14 Use of online services

<table>
<thead>
<tr>
<th>Name of service</th>
<th>W (N=64)</th>
<th>X (N=49)</th>
<th>Y (N=84)</th>
<th>Z (N+57)</th>
<th>Total (N=254)</th>
</tr>
</thead>
<tbody>
<tr>
<td>BIDS</td>
<td>9</td>
<td>33</td>
<td>24</td>
<td>-</td>
<td>66</td>
</tr>
<tr>
<td>Medline</td>
<td>3</td>
<td>-</td>
<td>-</td>
<td>15</td>
<td>18</td>
</tr>
<tr>
<td>CAB</td>
<td>6</td>
<td>-</td>
<td>7</td>
<td>-</td>
<td>13</td>
</tr>
<tr>
<td>Current contents</td>
<td>-</td>
<td>2</td>
<td>-</td>
<td>8</td>
<td>10</td>
</tr>
<tr>
<td>Dialogue (host only)</td>
<td>-</td>
<td>-</td>
<td>3</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td>Chemical abstracts</td>
<td>-</td>
<td>-</td>
<td>5</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>EMBL database</td>
<td>-</td>
<td>6</td>
<td>-</td>
<td>-</td>
<td>6</td>
</tr>
<tr>
<td>DNA/Protein database</td>
<td>-</td>
<td>2</td>
<td>-</td>
<td>-</td>
<td>2</td>
</tr>
</tbody>
</table>

Publishing activity

It is a commonplace of university research that a high level of intake of information often correlates well with an enhanced level of output. Hence, in looking at computer usage, it seemed appropriate to compare this with publishing activity. Respondents were asked to record the number and type of their own publications since January 1990. Table 15 shows the proportion of respondents who had published at all under each heading during that period. It had been suggested during our pilot study that a distinction is sometimes drawn by biologists between 'journal articles' and 'primary research papers'.
These were therefore put down as different categories in the questionnaire. In the event, it was evident from the returns that many respondents conflated these two entries.

In general, the patterns of publication displayed in Table 15 are fairly similar for all four institutions. Taking all types of publication together, staff at the pharmaceutical laboratory publish least. The two institutions with a classical biology bias particularly emphasize the publication of reports. The production of journal publications at the two universities seems low, but it has to be remembered that a considerable proportion of the respondents were research students or research assistants.

**Table 15 Publishing activity (all figures are percentages)**

<table>
<thead>
<tr>
<th>Category</th>
<th>W</th>
<th>X</th>
<th>Y</th>
<th>Z</th>
</tr>
</thead>
<tbody>
<tr>
<td>Journal articles</td>
<td>37</td>
<td>33</td>
<td>49</td>
<td>33</td>
</tr>
<tr>
<td>Primary research papers</td>
<td>36</td>
<td>43</td>
<td>51</td>
<td>39</td>
</tr>
<tr>
<td>Short communications</td>
<td>22</td>
<td>45</td>
<td>33</td>
<td>25</td>
</tr>
<tr>
<td>Review articles</td>
<td>20</td>
<td>31</td>
<td>27</td>
<td>10</td>
</tr>
<tr>
<td>Reports</td>
<td>30</td>
<td>12</td>
<td>42</td>
<td>-</td>
</tr>
<tr>
<td>Edited works</td>
<td>14</td>
<td>14</td>
<td>26</td>
<td>3</td>
</tr>
<tr>
<td>Authored books</td>
<td>8</td>
<td>2</td>
<td>6</td>
<td>3</td>
</tr>
</tbody>
</table>

The data here record the proportion of respondents who produced at least one publication under each category heading during the period under review.

**Conclusions**

In analysing the foregoing data, respondents have been separated into two groups - junior staff and senior staff. The distinction is made on the basis of their background characteristics: age, position and highest qualification were found to correlate reasonably well at all four institutions. Cut-offs were established for each characteristic (at 40 years old, a senior management position and possession of a PhD) to divide junior from senior.
In these terms, it was found that senior staff were significantly more information-active both as providers and as recipients of information. They published more under most categories of publication, read more, and communicated more with colleagues than junior staff. Hardly surprisingly, they also had fewer financial restrictions placed on their communication activities.

One purpose of the present survey was to compare results for one discipline with results for science as a whole. More especially, the recent Royal Society study [2] provides a basis for comparison of data obtained fairly close in time to the present investigation. The data presented here on electronic information handling agree reasonably well with the Royal Society data where they overlap, both for general activities (e.g. level of online access to information) and for specific points (e.g. the growing importance of BIDS). There is also agreement that lack of awareness of information sources is one of the major obstacles to expanding their use.

However, there are also points of difference. For example, the pharmaceutical laboratory has a much higher level of electronic information usage than would be expected from the Royal Society results. It seems likely that the latter do not fully reflect the importance of computer-based information for research in the area of molecular biology. This point receives some backing from the greater level of concern with electronic information-handling in the school of biology as compared with the more classically-oriented faculty of agriculture and government research establishments. It is clear that commercial enterprises are better able to provide all the facilities required, and that the pressures there ensure that these facilities are used.

The Royal Society survey found that most respondents would like to access their library via a workstation. An earlier survey [1] noted that scientific researchers were tending to try and handle all their computer activities from a single workstation. The present survey extends these conclusions. Respondents clearly wished to carry out as many activities from their own workstations as possible, and this included accessing, either directly or via intermediaries, all the information services they needed.
It has been part of computer mythology that younger people are happier using computers than older people. This might seem to be reflected in the Royal Society survey result that junior staff in higher education are more pro-technology than the average, while senior staff in industry and research institutions are less pro-technology than the average. However, the present study suggests that the situation is more complex than this. Many differences between junior and senior staff are small. In some cases - for example, in the use of personal electronic aids (local files, databases, etc) - senior staff appear to be more committed than junior staff. Even significant differences are explicable in terms other than computer phobia among older people. For example, senior staff are more likely to use stand-alone computers than junior staff. The explanation here seems to be that senior staff find it more difficult to obtain uninterrupted periods at the computer when they are at work than is possible for junior staff; so they work at home, where many computers are not networked in the UK. It is true, too, that many junior staff are more likely to be involved in word-processing than senior staff; but the explanation seems to be that senior staff have greater opportunities to delegate word-processing to support staff. In fact, the main reason for differences between junior and senior staff appears to be the level of information overload on the latter, rather than a lack of acceptance of computer-based handling methods. This hypothesis may be supported by the finding of the present survey: that staff with particularly heavy teaching or administrative loads were somewhat less likely to use computers for information-handling purposes.

Biologists were described in the Royal Society survey as members of the scientific discipline which was least conservative in its approach to information handling. The present survey suggests that, though this may be true, there is a very wide spread in terms of practice. This spread is partly institutional in origin, but there are also clear-cut differences depending on the type of biological research involved. Taking the whole range of the biological sciences, it seems that the differences in computer-based information handling within biology are as wide as anything to be found across the sciences as a whole. In other words, problems of access to information can be as diverse within this single discipline as in a range of disciplines.
Acknowledgements

We are particularly grateful to the British Library Research and Development Department for providing the funding for this project. We are also indebted to the staff at each of the four institutions surveyed who helped with the distribution and collection of the questionnaires. We thank Mr H. Al-Shanbari for his assistance in reducing the data.

References


Paper 10

Information usage by biological researchers


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Print bound close to the spine
Information usage by biological researchers

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Received 2 February 1995

Abstract.
Continuing change in the provision of, and access to, scientific information has stimulated interest in the nature of recent information usage by scientists. Recent studies have looked at this question in terms of science as a whole. The present study complements these by concentrating on the biological sciences only. It surveys research information usage in four institutions - a university agricultural faculty, a university school of biology, a government research establishment and a pharmaceutical laboratory - and complements a study of information technology usage by biological researchers which has already appeared. It is found that biologists have a spread of information needs which parallels that of all the sciences taken together. Changes in information-handling in biology are occurring, but to differing extents, depending on the institution and the biological specialism.

Methodology
Four sets of biologists with different backgrounds and interests were chosen for study: from a university agricultural faculty, a university school of biology, a government research establishment and a pharmaceutical laboratory. (These are referred to in subsequent tabulations as institutions W, X, Y and Z respectively.) The agricultural faculty and the research establishment were rather more oriented towards classical biology in their research interests than the school of biology and the pharmaceutical laboratory. Between them, these groups covered the main categories of employer and the main areas of research in biology.

The previous studies of scientific information usage that we are using for comparison have relied primarily on questionnaire surveys. To facilitate the comparison, especially in statistical terms, a questionnaire approach was therefore used for this project. So far as possible, the same questions were used for all the institutions (a few had to be institution-specific). A small pilot test was carried out with the school of biology in May–June 1993. The revised questionnaires were then sent out in sequence to the four selected institutions over the period May 1993 to January 1994. It was decided to set a target of a minimum number of 40 responses from each institution, to permit acceptable statistical analysis: chasing up would occur as necessary. The final response rates are shown in Table 1. Questionnaires regarding usage of information technology were
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Continuing change in the provision of, and access to, scientific information has stimulated interest in the nature of current information usage by scientists. Recent studies have looked at this question in terms of science as a whole. The present study complements these by concentrating on the biological sciences only. It surveys research information usage in four institutions - a university agricultural faculty, a university school of biology, a government research establishment and a pharmaceutical laboratory - and complements a study of information technology usage by biological researchers which has already appeared. It is found that biologists have a spread of information needs which parallels in its diversity that of all the sciences taken together. Changes in information-handling in biology are occurring, but to differing extents, depending on the institution and the biological specialism.

Introduction

There has been a number of studies of information usage amongst British scientists in recent years [e.g. 1, 2, 3]. These have typically surveyed a range of institutions and several different scientific disciplines, and so have provided an overall view of how scientific information is utilised at present. There have, however, been few recent in-depth studies of information usage within a particular scientific discipline. It was therefore decided to carry out such a study in order to compare information usage within a single discipline with usage across science as a whole. The intention was to see: (i) whether, or not, the level and spread of usage were similar for both and (ii) what additional information on usage could be provided by a
more narrowly focused study. As explained in an earlier publication [4], biology was chosen as the science best suited for such a comparison.

Methodology

Four sets of biologists with different backgrounds and interests were chosen for study: from a university agricultural faculty, a university school of biology, a government research establishment and a pharmaceutical laboratory. (These are referred to in subsequent tabulations as institutions W, X, Y and Z respectively.) The agricultural faculty and the research establishment were rather more oriented towards classical biology in their research interests than the school of biology and the pharmaceutical laboratory. Between them, these groups covered the main categories of employer and the main areas of research in biology.

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Table 1
Response rate from each institution

<table>
<thead>
<tr>
<th>Institution</th>
<th>No. Issued</th>
<th>No of Returns</th>
<th>% Return</th>
</tr>
</thead>
<tbody>
<tr>
<td>W</td>
<td>160</td>
<td>40</td>
<td>25</td>
</tr>
<tr>
<td>X</td>
<td>200</td>
<td>49</td>
<td>25</td>
</tr>
<tr>
<td>Y</td>
<td>170</td>
<td>81</td>
<td>48</td>
</tr>
<tr>
<td>Z</td>
<td>80</td>
<td>53</td>
<td>63</td>
</tr>
<tr>
<td>Total</td>
<td>610</td>
<td>223</td>
<td>36</td>
</tr>
</tbody>
</table>

Background variables

It was decided, on the basis of previous surveys, that the most meaningful parameters in terms of information-handling were likely to be the respondent's age, highest qualification and position. These are analysed in Tables 2-4.

Some differences might be expected at the upper end of the age range, since retirement is at 65 in the universities, but at 60 in the government research establishment and the pharmaceutical laboratory. In fact, the data suggest very few over-60s in the universities. All institutions had a majority of respondents aged 40 or less. The two institutions with an orientation towards classical biology (W and Y) had a higher proportion of older staff than those more concerned with biochemistry (X and Z). In terms of highest qualification, the commonest was the PhD. MAs occurred frequently only in agriculture; otherwise, the next commonest qualification was a Bachelor's degree. The presence of research students in universities equates to a larger number of lower-level posts there. Research assistants appear to be deficient in the agricultural faculty, as compared with the school of biology. At the upper end of the scale, some 10-20% of the staff (more at the research establishment) are in senior management posts.

Respondents were also asked about their basic involvement in communication. Approximately three quarters of the respondents had produced some kind of publication during the period since January 1990 (less at X and Z; more at W and Y). Apart from research, appreciable time was spent in teaching and administration (Table 5). Teaching was highest at the agricultural faculty, but was also surprisingly high at the research
establishment. Respondents at the pharmaceutical company were most involved in administration, but the administrative load in the agriculture faculty was quite high. University respondents who are involved in refereeing spend an appreciable amount of time on this activity. Refereeing, whether of papers or of grant applications, typically averages five to ten hours per month. The maximum times recorded for the various activities (e.g. up to 300 hours a month for research) reflect the fact that many respondents, especially at universities, have a long working day.

Table 2
Age Distribution

<table>
<thead>
<tr>
<th>Age Range</th>
<th>W</th>
<th>X</th>
<th>Y</th>
<th>Z</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;30</td>
<td>23%</td>
<td>63%</td>
<td>32%</td>
<td>28%</td>
</tr>
<tr>
<td>31–40</td>
<td>32%</td>
<td>27%</td>
<td>26%</td>
<td>47%</td>
</tr>
<tr>
<td>41–50</td>
<td>30%</td>
<td>10%</td>
<td>30%</td>
<td>23%</td>
</tr>
<tr>
<td>51–60</td>
<td>13%</td>
<td>0%</td>
<td>12%</td>
<td>2%</td>
</tr>
<tr>
<td>&gt;60</td>
<td>2%</td>
<td>0%</td>
<td>0%</td>
<td>0%</td>
</tr>
</tbody>
</table>

Table 3
Highest Qualification

<table>
<thead>
<tr>
<th>Qualification</th>
<th>W</th>
<th>X</th>
<th>Y</th>
<th>Z</th>
</tr>
</thead>
<tbody>
<tr>
<td>DSc / MD</td>
<td>5%</td>
<td>8%</td>
<td>4%</td>
<td>0%</td>
</tr>
<tr>
<td>PhD</td>
<td>68%</td>
<td>46%</td>
<td>50%</td>
<td>55%</td>
</tr>
<tr>
<td>Master</td>
<td>22%</td>
<td>2%</td>
<td>9%</td>
<td>4%</td>
</tr>
<tr>
<td>BSc / BA</td>
<td>5%</td>
<td>42%</td>
<td>23%</td>
<td>32%</td>
</tr>
<tr>
<td>Other</td>
<td>0%</td>
<td>2%</td>
<td>15%</td>
<td>9%</td>
</tr>
</tbody>
</table>
Table 4

Position held

<table>
<thead>
<tr>
<th>Post</th>
<th>W</th>
<th>X</th>
<th>Y</th>
<th>Post</th>
<th>Z</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research Student</td>
<td>30%</td>
<td>33%</td>
<td></td>
<td>Scientific Officer</td>
<td>25%</td>
</tr>
<tr>
<td>Research Assistant</td>
<td>0%</td>
<td>18%</td>
<td></td>
<td>H.S.O.</td>
<td>30%</td>
</tr>
<tr>
<td>Research Fellow</td>
<td>30%</td>
<td>24%</td>
<td></td>
<td>S.S.O.</td>
<td>14%</td>
</tr>
<tr>
<td>Lecturer</td>
<td>18%</td>
<td>10%</td>
<td></td>
<td>UG7</td>
<td>25%</td>
</tr>
<tr>
<td>Senior Lecturer</td>
<td>10%</td>
<td>8%</td>
<td></td>
<td>UG6</td>
<td>5%</td>
</tr>
<tr>
<td>Reader</td>
<td>5%</td>
<td>2%</td>
<td></td>
<td>UG5</td>
<td></td>
</tr>
<tr>
<td>Professor</td>
<td>7%</td>
<td>4%</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 5

Involvement in teaching and administration

<table>
<thead>
<tr>
<th>Activity</th>
<th>W</th>
<th>X</th>
<th>Y</th>
<th>Z</th>
</tr>
</thead>
<tbody>
<tr>
<td>Teaching</td>
<td>57% (38)</td>
<td>31% (9)</td>
<td>21% (8)</td>
<td>0</td>
</tr>
<tr>
<td>Administration</td>
<td>52% (40)</td>
<td>29% (15)</td>
<td>20% (25)</td>
<td>77% (50)</td>
</tr>
</tbody>
</table>

The data indicate the proportion of respondents involved in the activity followed by, in brackets, the average hours per month that they expend on the activity.

Information usage

Respondents were asked about the amount of time they spent on reading research materials and in communicating with their colleagues. Table 6 records how many read for more than four hours per week, and how many communicated with colleagues for more than that amount of time. In terms of reading, the research establishment differed from the others, in the sense that the amount of reading was less. However, respondents here spent more time than those at universities in communicating with colleagues. This was still considerably less than the communication rate of respondents in the pharmaceutical laboratory.

In connection with their reading, respondents were asked about their use of the institution's library. The results in Table 7 show the proportion of staff who visited the library at least once per week. Library visits appear to be less frequent at the universities than at the government establishment or the
pharmaceutical laboratory. Partly, this is a question of the ease with which the library can be visited (in terms of distance from the laboratory, etc), but it also appears that senior staff in universities acquire research reading material via their research students and research assistants.

Table 6
Reading and communicating

<table>
<thead>
<tr>
<th>Activity</th>
<th>W</th>
<th>X</th>
<th>Y</th>
<th>Z</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reading</td>
<td>55%</td>
<td>50%</td>
<td>35%</td>
<td>50%</td>
</tr>
<tr>
<td>Communicating</td>
<td>39%</td>
<td>35%</td>
<td>48%</td>
<td>67%</td>
</tr>
</tbody>
</table>

Table 7
Frequency of Library Visits

<table>
<thead>
<tr>
<th>% visiting once per week or more often</th>
<th>W</th>
<th>X</th>
<th>Y</th>
<th>Z</th>
</tr>
</thead>
<tbody>
<tr>
<td>% visiting once</td>
<td>39%</td>
<td>37%</td>
<td>48%</td>
<td>70%</td>
</tr>
</tbody>
</table>

Table 8
Level of satisfaction with the provision of research information

<table>
<thead>
<tr>
<th></th>
<th>W</th>
<th>X</th>
<th>Y</th>
<th>Z</th>
</tr>
</thead>
<tbody>
<tr>
<td>80%</td>
<td>65%</td>
<td>94%</td>
<td>83%</td>
<td></td>
</tr>
</tbody>
</table>

The percentages represent the proportion of respondents who indicated that they were satisfied.

When respondents were asked questions concerning their satisfaction with provision of research information via the various channels, most of them seemed happy with what was available (Table 8). The exception was in the school of biology, where it was felt there was some conflict between information provision by the departmental library and the university library.

Informal communication

Respondents were next asked about their informal communication activities. As Table 9 indicates, most attended laboratory meetings (i.e. meetings of their research group) frequently. With the exception of the research establishment,
attendance at departmental seminars was also high. External meetings and conferences were naturally attended less often, but a majority of the respondents had participated in these during the preceding year.

Table 9 suggests that informal communication in biology is good both inside and outside the institution.

Table 9
Attendance at meetings

<table>
<thead>
<tr>
<th>Meeting</th>
<th>W</th>
<th>X</th>
<th>Y</th>
<th>Z</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attend at least once a month:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Laboratory meetings</td>
<td>60%</td>
<td>67%</td>
<td>66%</td>
<td>79%</td>
</tr>
<tr>
<td>Departmental seminars</td>
<td>61%</td>
<td>71%</td>
<td>37%</td>
<td>64%</td>
</tr>
<tr>
<td>Attend, but less than once a month:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Workshops, etc</td>
<td>65%</td>
<td>50%</td>
<td>57%</td>
<td>68%</td>
</tr>
<tr>
<td>Conferences</td>
<td>57%</td>
<td>80%</td>
<td>73%</td>
<td>63%</td>
</tr>
</tbody>
</table>

Table 10
Restrictions on communication

<table>
<thead>
<tr>
<th>Activity</th>
<th>W</th>
<th>X</th>
<th>Y</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conference travel</td>
<td>45%</td>
<td>25%</td>
<td>26%</td>
</tr>
<tr>
<td>Conference travel and paper</td>
<td>26%</td>
<td>8%</td>
<td>16%</td>
</tr>
<tr>
<td>Long-distance telephone</td>
<td>13%</td>
<td>15%</td>
<td>3%</td>
</tr>
<tr>
<td>Photocopying</td>
<td>15%</td>
<td>8%</td>
<td>0%</td>
</tr>
</tbody>
</table>

However, it was decided to cross-check this by asking whether respondents had experienced any restrictions in terms of their use of communication channels. The areas where there was a significant number of affirmative answers are shown in Table 10.
It should be noted that that question was not asked at the pharmaceutical laboratory. (Restrictions were almost always related to finance, and this was specifically stated not to be a relevant factor in the pharmaceutical environment.) The percentages quoted represent the proportion of the respondents who reported a high level of restriction on the activity during the previous year. A significant proportion of their colleagues indicated that they had experienced some lesser level of restriction. It is clear that attendance at conferences is now carefully controlled, primarily for financial reasons. Even when the respondent is intending to offer a paper at the conference, funding may not be forthcoming. Hence, contact via external meetings is less frequent than a significant proportion of the respondents would like.

The next question listed informal communication channels under three headings: internal, external and privileged. (The last covered information gained during editorial or refereeing activities.) Respondents were asked to indicate which of these channels they had used for exchanging research information during the past year. The results in Table 11 indicate, as expected, that discussions with one's immediate colleagues are a major source of research information. Externally, the rise of fax as a means of research communication is noticeable, and it is clearly now being followed by electronic mail. The institutions with a biochemical emphasis (X and Z) show a somewhat greater use of electronic mail, and a somewhat lower use of traditional correspondence for research purposes than those with a greater emphasis on classical biology (W and Y). The editing and refereeing of papers more commonly occur in universities, and, as Table 11 shows, can be a useful source of information for a minority of, usually senior, staff there. Refereeing of grant applications seems to be less useful.
Table 11

Use of informal channels

<table>
<thead>
<tr>
<th>Channel</th>
<th>W</th>
<th>X</th>
<th>Y</th>
<th>Z</th>
</tr>
</thead>
<tbody>
<tr>
<td>Internal:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>discussion</td>
<td>95%</td>
<td>92%</td>
<td>88%</td>
<td>89%</td>
</tr>
<tr>
<td>External:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>correspondence</td>
<td>53%</td>
<td>30%</td>
<td>35%</td>
<td>16%</td>
</tr>
<tr>
<td>fax</td>
<td>43%</td>
<td>38%</td>
<td>35%</td>
<td>34%</td>
</tr>
<tr>
<td>telephone</td>
<td>51%</td>
<td>42%</td>
<td>43%</td>
<td>44%</td>
</tr>
<tr>
<td>e-mail</td>
<td>15%</td>
<td>21%</td>
<td>17%</td>
<td>32%</td>
</tr>
<tr>
<td>conferences</td>
<td>11%</td>
<td>10%</td>
<td>4%</td>
<td>10%</td>
</tr>
<tr>
<td>Privileged:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>papers refereed</td>
<td>14%</td>
<td>15%</td>
<td>8%</td>
<td>8%</td>
</tr>
<tr>
<td>grant applications</td>
<td>3%</td>
<td>10%</td>
<td>1%</td>
<td>0%</td>
</tr>
<tr>
<td>papers edited</td>
<td>11%</td>
<td>5%</td>
<td>5%</td>
<td>2%</td>
</tr>
</tbody>
</table>

Formal communication

The respondents were provided with a list of information sources and asked to indicate which they use (at least once per month. Their answers, in terms of the percentages using the source, are listed in Table 12. Under 'Other', respondents at the pharmaceutical laboratory were asked about their use of two in-house sources: (i) their corporate enquiry service and (ii) their current awareness service. The two figure recorded at the bottom of column 2 in Table 12 represent the proportion of staff using these respective services. It should be added that current awareness services (e.g. Current Contents) are the most significant item for the universities under 'Other'.

There is an overall similarity between the response, from the different institutions, with research journal, figuring, as expected, as the most important source throughout. However, some differential pattern does emerge between these institutions. The agricultural faculty and the research establishment use books, newspapers/magazines, and government publications more and electronic sources less than the school of biology and the pharmaceutical laboratory. These fit in with differences previously noted in the information habit: of W/Y, on the one hand, and X/Z, on the other. Theses are only of much importance at universities (and, indeed, a more detailed analysis shows
that they are mostly used by research students).

Table 12
Use of formal channels

<table>
<thead>
<tr>
<th>Channel</th>
<th>W</th>
<th>X</th>
<th>Y</th>
<th>Z</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research journals</td>
<td>100%</td>
<td>98%</td>
<td>88%</td>
<td>96%</td>
</tr>
<tr>
<td>Review publications</td>
<td>61%</td>
<td>65%</td>
<td>53%</td>
<td>55%</td>
</tr>
<tr>
<td>Books</td>
<td>69%</td>
<td>46%</td>
<td>72%</td>
<td>39%</td>
</tr>
<tr>
<td>Conference proceedings</td>
<td>45%</td>
<td>15%</td>
<td>26%</td>
<td>17%</td>
</tr>
<tr>
<td>Laboratory manuals</td>
<td>30%</td>
<td>40%</td>
<td>29%</td>
<td>19%</td>
</tr>
<tr>
<td>Indexes/Abstracts (print)</td>
<td>30%</td>
<td>15%</td>
<td>29%</td>
<td>28%</td>
</tr>
<tr>
<td>Indexes/Abstracts (electronic)</td>
<td>35%</td>
<td>65%</td>
<td>25%</td>
<td>66%</td>
</tr>
<tr>
<td>Theses</td>
<td>22%</td>
<td>10%</td>
<td>3%</td>
<td>-</td>
</tr>
<tr>
<td>Government publications</td>
<td>11%</td>
<td>-</td>
<td>6%</td>
<td>-</td>
</tr>
<tr>
<td>Newspapers/magazines</td>
<td>28%</td>
<td>10%</td>
<td>28%</td>
<td>9%</td>
</tr>
<tr>
<td>Other</td>
<td>43%</td>
<td>94%</td>
<td>9%</td>
<td>[30/89]*</td>
</tr>
</tbody>
</table>

The data represent the proportion of respondents who use the channel at least once per month.

- Respondents at Z were asked specifically about: (i) their corporate enquiry services and (ii) their current awareness services.

Respondents were then asked to record the number of their own publications since 1990. It had been suggested during our pilot study that a distinction is sometimes drawn by biologists between "journal articles" and "primary research papers". These were therefore put down as distinct categories in the questionnaire. In the event, it appeared that many biologists conflated these activities. Table 13 indicates the proportion of respondents who had published at all under each heading since January 1990. In general, patterns of publication are fairly similar, but respondents from the pharmaceutical laboratory publish appreciably less overall. The writing of reports appears to be more frequent in the agricultural faculty and the research establishment.
Table 13
Proportion publishing since January 1990

<table>
<thead>
<tr>
<th>Category</th>
<th>W</th>
<th>X</th>
<th>Y</th>
<th>Z</th>
</tr>
</thead>
<tbody>
<tr>
<td>Research journals</td>
<td>55%</td>
<td>44%</td>
<td>44%</td>
<td>26%</td>
</tr>
<tr>
<td>Primary research papers</td>
<td>42%</td>
<td>27%</td>
<td>54%</td>
<td>30%</td>
</tr>
<tr>
<td>Short communications</td>
<td>35%</td>
<td>25%</td>
<td>37%</td>
<td>34%</td>
</tr>
<tr>
<td>Review articles</td>
<td>17%</td>
<td>23%</td>
<td>35%</td>
<td>9%</td>
</tr>
<tr>
<td>Reports</td>
<td>25%</td>
<td>15%</td>
<td>39%</td>
<td>-</td>
</tr>
<tr>
<td>Edited works</td>
<td>7%</td>
<td>15%</td>
<td>18%</td>
<td>9%</td>
</tr>
<tr>
<td>Authored books</td>
<td>7%</td>
<td>12%</td>
<td>7%</td>
<td>7%</td>
</tr>
<tr>
<td>Book reviews</td>
<td>15%</td>
<td>12%</td>
<td>17%</td>
<td>2%</td>
</tr>
</tbody>
</table>

The data here record the proportion of respondents who produced at least one publication under each category heading during the period under review.

Table 14 records the proportion of respondents who had published under any heading since the beginning of 1990. It also notes the average number of publications produced over this period. The research establishment ranks highest, and the pharmaceutical laboratory lowest, in both proportion of respondents publishing and the average number of items published per capita. The pharmaceutical company necessarily has to limit its range of publications to maintain commercial secrecy. It is worth noting that the next research-selectivity exercise in the UK will ask for four research publications to be specified over the same sort of time period as has been used here. The fact that the average number of publications recorded for the two universities is four might seem to imply that some members will have difficulty in reaching this target. It has to be remembered, however, that many of the low scoring authors are research students or research assistants, who may not be returned in the UK exercise.

Since journals were evidently the most important source of information at all four institutions, respondents were asked which journals they regarded as most important for their work, and which they therefore read on a regular basis. One immediately obvious point is that few journal titles are common to all the sites. Indeed, Nature is the only title cited by all four institutions, followed by Science which is cited by three. The great majority of the titles are recorded by one respondent only. In terms of spread of titles, the
agricultural faculty and the government establishment have some similarities (e.g. in their citing of soil science journals), whilst the school of biology and the pharmaceutical laboratory are similar in the major emphasis they place on *Nature* and *Science*. More generally, respondents at the first two organisations cited a wide range of relatively low-impact journals, while those at the latter two cited a more restricted list of high-impact journals. If *Nature* and *Science* (which have impact factors of 22 and 21 respectively) are omitted, the spread of impact factors among the journals cited > 5 times is shown in Table 15.

Table 14
Publications record

<table>
<thead>
<tr>
<th>W</th>
<th>X</th>
<th>Y</th>
<th>Z</th>
</tr>
</thead>
<tbody>
<tr>
<td>Proportion publishing</td>
<td>85%</td>
<td>69%</td>
<td>89%</td>
</tr>
<tr>
<td>Average number of publications</td>
<td>4</td>
<td>4</td>
<td>6</td>
</tr>
</tbody>
</table>

Table 15
Spread of journal impact factors

<table>
<thead>
<tr>
<th>W</th>
<th>X</th>
<th>Y</th>
<th>Z</th>
</tr>
</thead>
<tbody>
<tr>
<td>Impact factor range</td>
<td>0.6–1.2</td>
<td>3.3–12.6</td>
<td>0.5–4.1</td>
</tr>
</tbody>
</table>
Membership of scientific societies showed less clear-cut differences than the journals read. Some of the societies covering major biological fields had members distributed across the institutions. Table 16 shows the proportion of respondents who are members of the most commonly joined societies. However, a number of societies had members at only one of the institutions (e.g. the Biophysical Society at the school of biology). The spread of society membership was greatest at the research establishment, followed by the agricultural faculty. This does correspond, to some extent, with the spread in journal readership, as does the differential emphasis on membership of particular societies (see, for example, the Society for General Microbiology in Table 16).

Respondents were finally asked how they would rank different categories of information source in terms of their importance for research. As Table 17 shows, there was general agreement about what the important sources were, but not about the order of priority. (It should be added that 'Information group' in the pharmaceutical laboratory was a particular method employed by the information scientists there to assist researchers in keeping up with information needs.)

Table 16
Membership of scientific societies

<table>
<thead>
<tr>
<th>Society</th>
<th>W</th>
<th>X</th>
<th>Y</th>
<th>Z</th>
</tr>
</thead>
<tbody>
<tr>
<td>Biochemical Society</td>
<td>11%</td>
<td>15%</td>
<td>4%</td>
<td>17%</td>
</tr>
<tr>
<td>Institute of Biology</td>
<td>10%</td>
<td>-</td>
<td>7%</td>
<td>5%</td>
</tr>
<tr>
<td>Society for Experimental Biology</td>
<td>3%</td>
<td>10%</td>
<td>8%</td>
<td>-</td>
</tr>
<tr>
<td>Society of General Microbiology</td>
<td>-</td>
<td>13%</td>
<td>5%</td>
<td>14%</td>
</tr>
</tbody>
</table>

Table 17
Resources for research problem-solving in priority order

<table>
<thead>
<tr>
<th>Resource</th>
<th>W</th>
<th>X</th>
<th>Y</th>
<th>Z</th>
</tr>
</thead>
<tbody>
<tr>
<td>Own files</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Library of institution</td>
<td>2</td>
<td>3</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>Discussion with local colleagues</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Information group</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>3</td>
</tr>
</tbody>
</table>
Conclusions
The data in the foregoing sections have been analysed in terms of the seniority of respondents, since this is known to be a significant factor in research communication. 'Seniority' here involves a mix of characteristics - age, position and highest qualification – which were generally well-correlated with each other in the present survey. It was found that senior staff on this definition were more information-active across the board. They both published more under most categories of publication, and made greater use of information sources. They typically read more than junior staff, and communicated more. They obtained more information via editing and refereeing, and had fewer restrictions placed on their communication activities (e.g. attendance at conferences).

As noted at the beginning, one purpose of this survey was to extend earlier findings, and especially the Royal Society study [3]. Though different questions were asked in the two surveys, some overlap was included to allow for comparison. The greater information activity of senior researchers found here is hinted at, but not fully demonstrated, in the Royal Society data. At the same time, the level of activity is not necessarily identical. Table 18 compares the usage of four different information sources investigated both in the Royal Society survey and in the present survey. Some of the differences can be explained by the different periods covered (six months for the Royal Society survey and one month here). However, not all can be explained in this way. For example, the difference in use of printed abstracts is almost certainly real, indicating a lower usage of such sources by biologists than the average.

Table 18
Usage of information sources

<table>
<thead>
<tr>
<th>Source</th>
<th>100%</th>
<th>88-100%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Journals</td>
<td>100%</td>
<td>88-100%</td>
</tr>
<tr>
<td>Books</td>
<td>99%</td>
<td>39-72%</td>
</tr>
<tr>
<td>Conference proceedings</td>
<td>95%</td>
<td>15-45%</td>
</tr>
<tr>
<td>Printed abstracts</td>
<td>81%</td>
<td>15-30%</td>
</tr>
</tbody>
</table>

There are other points where the two surveys complement each other. For
example, the Royal Society survey found that personal contacts were used for information by 97% of the respondents over the previous six months. The present survey has found that 88-95% of our sample obtained information via internal discussions during the previous month, underlining the fact that most oral information exchange is with colleagues near at hand. Again, the Royal Society finding, that younger scientists, tend to be more critical of library services than older scientists, can perhaps be linked to our finding that senior scientists tend to delegate the acquisition of library based information to others. Both surveys agree that users in industry are likely to be more positive about their library/information services, mainly - according to the present survey - because industrial libraries/information services provide more proactive assistance to their users.

A major finding of the Royal Society survey was that scientists preferred their information sources to be familiar and well-established. Though this is reflected, too, by the present survey, some indications of change are also clearly evident; for example, in the growing use of fax, electronic mail and electronic indexes/abstracts. The real difference, however, comes in the responses from the pharmaceutical laboratory. It is clear that, in this industrial firm, researchers have already moved significantly towards the everyday use of newer, electronically delivered information sources. (It is worth adding that the differences in information handling between senior and junior staff are least in the pharmaceutical laboratory.)

It was noted earlier that the agricultural faculty (W) and the government research establishment (Y) have a greater orientation towards classical biology than the school of biology (X) or the pharmaceutical laboratory (Z). This difference seems to be linked to differences in their information handling. For example, staff at W and Y are interested in a greater spread of journals than those at X and Z, and staff in the former institutions use books as information sources more than those in the latter. These tend to be the communication characteristics of classical biology [5]. One interesting result is that newspapers and magazines are a significant source of information for staff at W and Y. This is a characteristic of applied science: a term which does
describe an appreciable amount of the research going on at each of these institutions. Conversely, staff at X and Z are more concerned with electronic sources of information than their peers at W or Y. This orientation tends to be a distinctive feature of research in the area of molecular biology.

The data in the Royal Society survey cover the whole range of science, analysing the spread of responses in terms of subject, seniority, type of institution, etc. Where that survey and the present survey overlap (e.g. in terms of usage of information sources), it appears that the biological sciences display a spread of characteristics which is little different from that of the sciences as a whole. In other words, providing for the information needs of biologists requires a range of services similar in type to those required to cater for the needs of science as a whole. The same conclusion has also been reached concerning biologists' use of information technology [4]. Hence, in information terms, the biological sciences provide an excellent exemplar of the totality of the sciences.

Acknowledgements

We are particularly grateful to the British Library Research and Development Department for providing the financial assistance which allowed this project to be undertaken. We are also indebted to the staff at each of the four institutions who helped with the distribution and collection of questionnaires.
References


Theme Two – Part Two

The information needs and behaviour of academics, health and social care professionals – Use of information in the health and social care setting

Papers 11-13
Health professionals' attitudes towards evidence-based medicine and the role of the information professional in exploitation of the research evidence


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Print bound close to the spine
Health professionals’ attitudes towards evidence-based medicine and the role of the information professional in exploitation of the research evidence

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Revised 30 May 1998

Abstract
The aim of a survey, undertaken at an English National Health Service (NHS) trust hospital in the summer of 1996, was to examine health professionals’ awareness of evidence-based medicine (EBM), their attitudes towards problems in implementing EBM locally and their views of the role of the library in supporting EBM. A postal questionnaire (response rate 48%; 182/475) provided baseline information for planning. More doctors than nurses or PAMs (professionals allied to medicine) had heard of the term EBM, but most of the health professionals were in agreement with the principles of EBM despite not understanding the term fully. Most of the health professionals wanted access to resources at the workplace, and doctors in particular preferred to do their own searching. Many health professionals doubted whether a librarian could find the relevant research articles, suggesting the need for better promotion of library services in support of EBM, emphasising value-added services.

Introduction
Attitudes towards the use of evidence from properly conducted clinical trials on the efficacy of therapies vary considerably in the health sector. The pharmaceutical industry is information-intensive in its meticulous approach to the collection and collation of research data (required for regulatory purposes). However, practicing doctors, who have traditionally had the clinical freedom over prescribing treatments for patients, have not always had the same access to well-organized information resources, and the same is true for other clinicians (health professionals engaged in clinical care). Pressures for change are coming from those funding health care, who are increasingly looking for evidence of the clinical effectiveness of treatments prescribed, partly in response to the widening gap between health care supply and demand, fed by greater public expectations. Both purchasers and providers of health care in the UK are now more aware of the importance of relevant information about the latest clinical knowledge and research [1, 2], but within the health service there remain problems of ensuring that health professionals have easy and timely access to that evidence base for
Health professionals' attitudes towards evidence-based medicine and the role of the information professional in exploitation of the research evidence

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Evidence-based medicine (EBM) is defined [3] as an approach to health care that promotes the collection, interpretation and investigation of valid, important and applicable patient-reported, clinician-observed and research-derived evidence. The best available evidence, moderated by patient circumstances and preferences, is applied to improve the quality of clinical judgments. Thus, EBM de-emphasises intuition, unsystematic clinical experience and pathophysiological rationale as sufficient grounds for clinical decision-making and stresses the examination of evidence from clinical research [4]. Acting on the evidence should, it is suggested [5], require the integration of individual clinical expertise with the best available external clinical evidence, which means clinically relevant research. The systematic review of randomised trials of therapies is the gold standard for objective guidance on whether a particular therapy is truly effective or not. The work of the Cochrane Collaboration and the NHS Centre for Reviews and Dissemination concerns the collation and synthesis of the research evidence for diagnostic tests and
therapies, and dissemination of that evaluated evidence in the form of systematic reviews collected on the Cochrane Library database [6].

Some delay between the publication of research which demonstrates convincing evidence of the effectiveness (or otherwise) of a particular therapy is almost inevitable, but there are several examples where the time lag between availability of evidence and implementation appears to have been unacceptable. Examples include the slow uptake in use of thrombolytic therapy for myocardial infarction [7] and, equally, the continuation of therapies shown to be ineffective for certain women with menstrual disorders [8]. The time lag may be decreasing now and a survey [9] of members of BAMM (British Association of Medical Managers) and the National Association of Fundholding Practices found that 76% of the respondents among the fundholders and 95% of the responding BAMM group had used or intended to use the EBM process to review clinical practice. Fundholders were willing to change practice on the basis of evidence from randomised trials, but evidence from clinical outcomes studies was equally compelling. On the other hand, around 40% had changed clinical practice on the basis of their own observations and experiences - justifiably possibly, but not evidence-based medicine in the full sense. Interventions to help health professionals to improve their clinical decision-making and practice in line with research findings often seem to require a multifaceted approach to continuing professional education [10]. Health services management and policy also need to support more collaboration between research, policy makers, health professionals and the public [11]; and that might suggest that new organisational models be considered [12].

In theory, the health information professional has an important role in an environment which encourages the dissemination of evaluated information. The inadequacy of the existing organisational model to support evidence-based medicine and clinical effectiveness is indicated in a survey [13] of all trusts and health authorities in England and Wales. Existing library and information services were often inadequate and unable to support evidence-based practice. Only 60% of trust libraries were open outside office hours,
and more than one in five trusts restricted library access to certain clinical groups. However, some National Health Service (NHS) organisations are expanding their library and information services by making the information available to clinicians at, or close to, their workplaces through computer networks. This has resulted in a large increase in the number of MEDLINE searches carried out per week [14]. The role of the librarian should, it was suggested, be as the manager of the local 'evidence centre', acting as an information broker to add value to the information and support the information users.

The support that the health 'information broker' should provide may depend on the type of health professional and their role. Doctors, nurses and PAMs (professions allied to medicine, e.g. radiography) have different information needs for clinical information, and their use of the library and bibliographic databases varies accordingly [15, 16, 17, 18, 19]. The 'value of information' studies [15, 16] suggest that the primary value of information obtained from the library is often for continuing education and that it is unwise to expect to link information 'inputs' directly to outputs in the form of immediate behaviour change in clinical practice. Attitude change and culture change towards an acceptance of the importance of the evidence base of practice is, however, an important first step.

The concept of the health librarian playing a more active role in the clinical team as a clinical librarian was pioneered decades ago in the USA and Canada by Gertrude Lamb at the University of Missouri-Kansas City School of Medicine. A review [20] of the early North American services found that the cost of the outreach programmes often contributed to the discontinuation of such programmes, despite the benefits gained in increased awareness of library services by the health professionals and increased awareness of clinical information needs by the information services. In the UK, the clinical librarian experiment at Guy's Hospital between 1978 and 1980 involved two clinical librarians appointed respectively to the Department of Medicine and Department of Surgery. Evaluation [21] found that medical literature was needed only occasionally to resolve current patient care problems and
information was not usually required urgently. The clinical librarians' involvement in the patient care environment was less advantageous than had been expected, although one difficult factor may have been organisational, in that the Guy's programme had no formal links with the library.

With the increase in 'end-user' searching, there has been a shift in thinking about the role of the health information professional. With the advent of CD-ROM, there was less emphasis on mediated searching and more emphasis on end-user instruction and support [22]. For the health professional, who values clinical experience highly as a part of the clinical knowledge base, the ability of the information professional to identify articles clinically relevant has always been questionable; one study of clinical librarians noted that nearly two-thirds of the physicians had made some attempt to locate the desired information (usually by consulting colleagues or personal resources) before consulting the clinical librarian, although the clinical librarian usually found new information for them [23]. Librarians can recognise and select useful articles as effectively as practising physicians [24] and librarians' searches may be more precise than those of experienced physician end-users [25]. Many health professionals in the UK are not sufficiently familiar with database searching and, even if skills are acquired, they may be insufficiently practiced to keep up a level of competence beyond that of the basic searcher [26, 27].

User education may increasingly focus on the preparation of a search strategy [28] and development of critical appraisal skills [29, 30]. There should be a greater emphasis on the usefulness of the search results for the user and less on the recall and precision of the research results for one particular search which may be a small part of an ongoing quest for information on a topic of concern to a particular clinician. Health information professionals need to ensure that the networking systems installed are convenient and suit the spectrum of needs of the information users in an organisation, and training should provide the ability to improve through practice [31]. The ideal knowledge-based workstation is still a matter of some conjecture, though indications from the Value project [15] are confirmed in a study at Heidelberg [32] that increased availability of access to MEDLINE should result in more
searches being done for direct patient care, though the majority of accesses are still made for research purposes.

**Background of study**

The purpose of the study was to investigate the knowledge of, attitudes to and the use of EBM by health care professionals at a large NHS trust hospital. The project also investigated whether health care professionals viewed the role of the library as the main provider of information to support EBM, as well as studying their preferences for the delivery of EBM information. The research project was initiated by the Advisory Group of the local Health Information Plan, in collaboration with the Department of Information and Library Studies, Loughborough University, and conducted by one of the authors (Ruth Lewis) for a Masters dissertation (as an unfunded project).

The NHS trust hospital concerned is one of the largest teaching hospitals in the UK and is committed to the use of EBM in clinical practice. It had been proposed that the information resources necessary to support the development and practice of EBM at the hospital could be provided by the library, which is run by a university and situated on the hospital site. The library was already a resource provider for the hospital, in terms of computerised bibliographic databases, literature searching expertise, document supply and bibliographic advice. However, in terms of support for the practice of EBM, it was not known which information resources the health care professionals would prefer to use, or whether they would want the information made available at the library or within the clinic. In addition, it was not known if clinical practitioners were sufficiently familiar with using computers to prefer accessing online information to support the use of EBM.

**Methodology**

The measuring instrument used was a postal questionnaire, using the hospital internal mail. Interviews were deemed impractical in view of the time constraints on the project, which required descriptive quantitative baseline
information only. A pilot study was carried out at the Clinical Science Library
prior to the main study in order to test the adequacy of the questionnaire as
well as the clarity of the questioning.

The final questionnaire consisted of 36 questions: a mix of closed, response-
type with some attitudinal questions for which the traditional five-point Likert
type format was used. The questionnaire was divided into five sections, as
follows.

Section A: designed to ascertain what respondents knew about the meaning
of EBM.

Section B: to identify how many health care professionals were either already
using EBM or interested in doing so.

Section C: designed to discover what type of information support health care
professionals would prefer, to enable them to practise EBM.

Section D: to deduce who was already using the library and if they would
prefer the literature searching, necessary to practise EBM, to be
carried out by a librarian.

Section E: used to collect personal information about the respondent, such as
their job title, age category, when they qualified and whether they
had carried out any research (to check that the sample was
approximately representative).

Each questionnaire was given a unique identifiable (ID) number and was
colour coded according to the category of the respondents. Each head of
department (or, in the case of nurses, head of directorates) was sent a letter
asking if they would participate in the survey by distributing the questionnaires
to staff of various grades working within their department. In addition, the
letter explained the background and purpose of the study and assured the
confidentiality of the information received.

Sample
The large number of staff at the trust (over 4,000 in total, including 117 PAMs,
501 doctors and 1,797 nurses) precluded sampling the whole population for
the project. It was thus decided to use a sample of 200 nurses, 200 doctors
and 75 PAMs. A relatively large sample size of 75 was used for the PAMs category, as the total population was only 117, but contained several distinct subgroups. An incidental sampling method was used, which involves selecting the most accessible people. As it was also recognised that there were important subgroups within the population, i.e. staff working within different specialities, an Incidental Quota sampling method [33] was used. However, the various grades of staff working within these groups were only selected incidentally, as the only instructions given to those distributing the questionnaires was that they should be handed out to qualified staff of various grades working within the department. Time constraints precluded the use of a random sampling method, which would have eliminated the possibility of bias inherent in a convenience sample design and would, therefore, have been methodologically superior.

Results

Response
Of the 475 questionnaires distributed, 192 were returned. However, only 182 were deemed usable, as ten had not been completed adequately, with some having been returned with only the first page filled in. This gave a response rate of 40%. The overall sampling distribution for the study was 36 (48%) PAMs, 75 (37%) nurses and 71 (35%) doctors. This meant that the doctors were the category with the poorest response rate, followed by the nurses. However, the number of individual respondents within each category was a similar ratio to that established within the original sampling distribution. Time constraints precluded the use of reminder letters to boost the response rate.

Analysis
The data collected from the questionnaires were analysed using descriptive statistics, in order to describe the results in terms of the most important features of the sample, e.g. averages and range, etc. The characteristics within the three different categories of doctors, nurses and PAMs were compared to identify any differences or trends.
The data were analysed using the computer software package SPSS for Windows, and the results from the questionnaires were entered twice to enable the identification of any errors in data entry. The computer software package Microsoft Excel was used to produce the graphs.

**Awareness of EBM (Section A)**

When asked if they had heard of the term 'evidence-based medicine', over 95% of the doctors said that they had, in comparison to approximately 45% of the PAMs and nurses. In addition, far more doctors claimed that they understood what is meant by the term than did nurses or PAMs (Table 1).

Table 1: Understanding of the term "evidence-based medicine"

<table>
<thead>
<tr>
<th>Category</th>
<th>PAMs</th>
<th>Nurses</th>
<th>Doctors</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>15 (41.7%)</td>
<td>35 (47.3%)</td>
<td>63 (88.7%)</td>
<td>113 (62.4%)</td>
</tr>
<tr>
<td>No</td>
<td>21 (58.3%)</td>
<td>39 (52.7%)</td>
<td>8 (11.3%)</td>
<td>68 (37.6%)</td>
</tr>
<tr>
<td>Total</td>
<td>36</td>
<td>74</td>
<td>71</td>
<td>181</td>
</tr>
</tbody>
</table>

The PAMs apparently had the least understanding of the term. It was, therefore, not surprising that the level of awareness of the commitment of the trust to the practice of EBM is greatest among the doctors and least among the PAMs (Table 2).

Table 2: Awareness of the Trust's commitment to EBM

<table>
<thead>
<tr>
<th>Category</th>
<th>PAMs</th>
<th>Nurses</th>
<th>Doctors</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>True</td>
<td>6 (16.7%)</td>
<td>19 (25.7%)</td>
<td>32 (45.1%)</td>
<td>57 (31.5%)</td>
</tr>
<tr>
<td>False</td>
<td>0 (0.0%)</td>
<td>2 (2.7%)</td>
<td>2 (2.8%)</td>
<td>4 (2.2%)</td>
</tr>
<tr>
<td>Don't know</td>
<td>30 (83.3%)</td>
<td>53 (71.6%)</td>
<td>37 (52.1%)</td>
<td>120 (66.3%)</td>
</tr>
<tr>
<td>Total</td>
<td>36</td>
<td>75</td>
<td>71</td>
<td>181</td>
</tr>
</tbody>
</table>

The level of understanding, awareness and personal commitment to EBM were explored further in the attitudinal questions (Table 3).
Table 3: Attitudes towards EBM

<table>
<thead>
<tr>
<th>Attitudinal statement</th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Undecided</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>Total no. of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>EBM is a new method of making treatment cost effective</td>
<td>1%</td>
<td>26%</td>
<td>37%</td>
<td>30%</td>
<td>6%</td>
<td>175</td>
</tr>
<tr>
<td>Prac: ticing EBM increases the certainty that the proposed treatment is cost effective</td>
<td>16%</td>
<td>57%</td>
<td>23%</td>
<td>3%</td>
<td>1%</td>
<td>176</td>
</tr>
<tr>
<td>EBM complements the evidence gained, from both sound clinical skills and experience</td>
<td>12%</td>
<td>55%</td>
<td>28%</td>
<td>4%</td>
<td>1%</td>
<td>174</td>
</tr>
<tr>
<td>Research using clinical trials is far more reliable than research using observational methods</td>
<td>11%</td>
<td>45%</td>
<td>31%</td>
<td>12%</td>
<td>1%</td>
<td>174</td>
</tr>
<tr>
<td>EBM requires the use of critical appraisal skills to ensure the quality of all the research papers</td>
<td>10%</td>
<td>45%</td>
<td>33%</td>
<td>1%</td>
<td>0%</td>
<td>166</td>
</tr>
<tr>
<td>Effective searching skills and easy access to bibliographic databases are essential to using EBM</td>
<td>24%</td>
<td>47%</td>
<td>27%</td>
<td>3%</td>
<td>0%</td>
<td>174</td>
</tr>
</tbody>
</table>

Most of the sample population (as a whole) thought that the practice of EBM increases the certainty that treatment will be effective, but were unsure how much EBM has to do with cost-effectiveness. In addition, the sample population generally agreed that sound clinical skills and experience are important, with strongest agreement from the doctors. There was strong support for the view that EBM requires access to bibliographic databases and particular searching skills, but it could be queried whether the sample knew exactly what bibliographic databases are. This was arguably rather a leading question, but one of the aims of the project was to increase the awareness of the library's role in EBM, and many library surveys, such as this, do have a promotional element.

Table 4: Use of bibliographic databases

<table>
<thead>
<tr>
<th>Category</th>
<th>PAMs</th>
<th>Nurses</th>
<th>Doctors</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>15 (42.9%)</td>
<td>31 (41.9%)</td>
<td>65 (91.5%)</td>
<td>111 (61.7%)</td>
</tr>
<tr>
<td>No</td>
<td>20 (57.1%)</td>
<td>43 (58.1%)</td>
<td>6 (8.5%)</td>
<td>69 (38.3%)</td>
</tr>
<tr>
<td>Total</td>
<td>35</td>
<td>74</td>
<td>71</td>
<td>180</td>
</tr>
</tbody>
</table>

Use of evidence for EBM (Section B)
This part of the survey explored if, and how, health professionals used the bibliographic databases they might need to help them to practise EBM. Doctors were, by far, the group most likely to have used a bibliographic database, with MEDLINE the database most frequently used.

Table 5: Attitudes towards seeking out research literature

<table>
<thead>
<tr>
<th>Attitudinal statement</th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Undecided</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>Total no. of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Published research findings are useful in finding the most appropriate treatment regime available</td>
<td>10%</td>
<td>71%</td>
<td>15%</td>
<td>4%</td>
<td>0%</td>
<td>175</td>
</tr>
<tr>
<td>Previous work experience is more important than research findings in choosing the best treatment available for a patient</td>
<td>2%</td>
<td>20%</td>
<td>31%</td>
<td>45%</td>
<td>2%</td>
<td>176</td>
</tr>
<tr>
<td>Busy clinicians do not have the time to find and critically appraise the relevant research papers</td>
<td>7%</td>
<td>37%</td>
<td>19%</td>
<td>32%</td>
<td>5%</td>
<td>175</td>
</tr>
</tbody>
</table>

Information delivery

Although 65% claimed that they had access to a computer within their department, there seemed to be a preference for paper-based delivery of information by internal mail. Doctors formed the group most supportive of computer-based delivery (Table 6).

Table 6: Preferences for information delivery

<table>
<thead>
<tr>
<th>Category</th>
<th>Doctors</th>
<th>Nurses</th>
<th>PAMs</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Via computer</td>
<td>36.6%</td>
<td>25.3%</td>
<td>13.9%</td>
<td>27.5%</td>
</tr>
<tr>
<td>Via intnl. mail</td>
<td>62.0%</td>
<td>58.7%</td>
<td>58.3%</td>
<td>59.5%</td>
</tr>
<tr>
<td>At the library</td>
<td>18.3%</td>
<td>14.7%</td>
<td>16.7%</td>
<td>16.5%</td>
</tr>
<tr>
<td>Other</td>
<td>1.4%</td>
<td>10.7%</td>
<td>5.6%</td>
<td>6.0%</td>
</tr>
</tbody>
</table>

Role of the library in supporting EBM (Section D)

When asked their opinion on the attitudinal question stating 'I do not feel I have sufficient time to visit the library', 85 respondents agreed. One respondent from the PAMs category commented that they had so little time
available during working hours to visit the library that they were forced to go in their own time, which included the lunch break, after work or at weekends.

Real or imagined barriers to the use of EBM

When asked about their response to some of the identified barriers to using EBM (Table 7), most respondents thought that lack of time was one of the biggest. Over half the sample population thought that lack of training was a barrier, and almost half thought that lack of appropriate information might be a barrier. However, a more valid way of obtaining this information may have been to ask respondents to state what they felt could possibly be a barrier to the use of EBM, without unduly influencing their response, by giving them a list of options to tick. In an attempt to overcome this bias, respondents were once again asked about the possibility of available time being a problem to using EBM, in another set of the attitudinal questions. Results from this set suggested that lack of time may not be quite the handicap as indicated in Table 7.

Table 7: Perceived barriers towards the practice of EBM

<table>
<thead>
<tr>
<th>Category</th>
<th>Doctors</th>
<th>Nurses</th>
<th>PAMs</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time available</td>
<td>60.6%</td>
<td>57.3%</td>
<td>63.9%</td>
<td>59.9%</td>
</tr>
<tr>
<td>Lack of info.</td>
<td>46.5%</td>
<td>49.3%</td>
<td>41.7%</td>
<td>46.7%</td>
</tr>
<tr>
<td>Lack of training</td>
<td>32.2%</td>
<td>70.7%</td>
<td>44.4%</td>
<td>51.6%</td>
</tr>
<tr>
<td>Other</td>
<td>5.6%</td>
<td>9.3%</td>
<td>5.6%</td>
<td>7.1%</td>
</tr>
</tbody>
</table>

If lack of time is a problem, to some extent one solution might be the use of mediated EBM searches by information professionals. Participants were asked about their preferences for such mediated searches. On the whole, the doctors preferred to do their own searching: more so than the nurses and
PAMs. When asked if they thought that the library could find all the relevant research articles required, most were undecided and many disagreed (Table 8). Most of those disagreeing were doctors. This unfortunately indicates the lack of confidence some doctors have in the ability of the information professional to find clinical evidence. It is not known if this is due to the misconceptions of the doctors or due to their previous experience of mediated searching.

Table 8: The results from the attitudinal questions in section D

<table>
<thead>
<tr>
<th>Attitudinal statement</th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Undecided</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>Total no. of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>The librarian can find all the relevant research articles required to support EBM</td>
<td>3%</td>
<td>22%</td>
<td>52%</td>
<td>21%</td>
<td>2%</td>
<td>175</td>
</tr>
<tr>
<td>The internet has more information than the library about EBM</td>
<td>0%</td>
<td>12%</td>
<td>80%</td>
<td>7%</td>
<td>1%</td>
<td>173</td>
</tr>
<tr>
<td>I don't feel that I have sufficient time to visit the library</td>
<td>9%</td>
<td>48%</td>
<td>11%</td>
<td>29%</td>
<td>2%</td>
<td>176</td>
</tr>
<tr>
<td>The library already has the resources available to support EBM</td>
<td>2%</td>
<td>21%</td>
<td>66%</td>
<td>19%</td>
<td>1%</td>
<td>170</td>
</tr>
</tbody>
</table>

When asked if they were satisfied with the information received at the library, 80% of the sample said that they were. In addition, 87.6% of the sample said that, if possible, they would prefer to have access to the library's information sources on a computer within their department.

Discussion

EBM is a process of turning clinical problems into questions and then systematically searching, appraising and using all the relevant research findings as the basis for clinical decisions. Despite over one-third of the health care professionals professing lack of understanding of the meaning of the term EBM (Table 1), the majority believed that research findings are more important than previous work experience in deciding the most appropriate treatment regime (Table 5). It thus seems that many of these health care professionals are already in agreement with some of the principles involved in EBM.
The lower levels of awareness among the nurses might be due to lack of understanding of the term 'evidence-based medicine', and the use of the term 'medicine' might have led some to assume that the term EBM was not applicable or transferable to nursing practice. At the time of the study, the term in common currency was 'evidence-based medicine', but 'evidence-based practice' might be a term that nursing professionals and PAMs would prefer as more inclusive. All health professionals, and managers, have a role to play in evidence-based health care; nursing, for example, is a discipline distinct from, but complementary to medicine. While much medical treatment may or may not be supported by good evidence, there is much less evidence concerning the outcomes of nursing care, though initiatives such as the journal *Evidence-Based Nursing* will help [34]. The EVINCE project [16] found that the main areas of practice affected by information provided were evaluation of practice outcomes and the nature of the relationship between nurse and patient, reflecting the importance to nursing professionals of evidence-based practice based on the integration of clinical experience and patient reported data with research evidence.

However, the agreed difficulties cited by many of the respondents as barriers to the practice of EBM in this study cast doubt on whether they practise EBM, in the sense of regularly checking whether the interventions used are supported by the best evidence available in the literature. Certainly, the doctors seemed most aware of the term, although less sure of the trust policy objectives. Possibly, as indicated in another study [35], many treatments given to patients may already be 'evidence-based'.

The results also showed that the doctors preferred to carry out their own literature searches, and that health care professionals in general seem keen to use computers and have access to the libraries' facilities within the clinical setting. The availability of time to visit the library is obviously considered a problem, and access to its resources on a computer is a possible answer to this dilemma. Recent UK Department of Health policy developments should
enable more clinicians to have access to EBM resources via the Internet or hospital intranets. However, computer networking within the NHS is complicated by clinicians' concerns about the security and confidentiality of patient records, which means that progress is slow.

Doctors made more frequent use of the hospital library than other health professional groups, echoing the findings of North American studies [36, 37]. Those who used the library appeared satisfied, but the danger for the information service provider is the 'low expectations, low reward' cycle which is indicated in the uncertainty expressed about the ability of a librarian to find relevant research articles (Table 8). Comments added to the returned questionnaires indicated that nursing staff wanted more nursing journals and that the PAMs thought the collection was strongly biased in favour of the medical literature. The majority was undecided about the strength of the collection of EBM resources in the library (Table 8), which is not altogether surprising, as some of the resources were comparatively new at the time and many health professionals find personal visits to the library difficult. The 'low expectations, low reward' cycle might be particularly damaging if health professionals are unwilling to ask for support in searching the databases to ensure that they do find the best evidence. User education has to made relevant to the clinical and educational needs of the health professional, and the objectives of any educational programme should take account of the frequency - or rather present infrequency - of such searching.

Limitations of the study

This study investigated the attitudes of health care professionals towards EBM by asking them their opinions, using a postal questionnaire made up of closed-type questions. Many studies (e.g. [381]) of the value of information services to clinicians have relied upon self-reported data rather than objectively verifiable observations, as such observations are difficult to obtain. Interviews would have helped to verify some of the opinions expressed and library-use statistics might have helped to confirm some of the usage profiles indicated.
Conclusion

The study gave an overview of the status of EBM at an NHS trust hospital and showed some confusion about the meaning of the term and implications for practice among different professional groups. However, in view of the bias within the methodology, the results should be interpreted with caution.

The results of the survey showed a need for a more proactive regime to promote the availability of the resources, and value-added services to support EBM. In particular, the study demonstrated the need to promote the ability of the librarians in helping health professionals to find and appraise the necessary research evidence to practice EBM. It would thus be useful to repeat the survey to monitor how attitudes and awareness might change after the introduction of critical appraisal courses run by information service staff, preferably in conjunction with provision of information services at the desk-top. Recent developments at the same trust hospital include setting up (via OVID) access to MEDLINE and full-text journal databases from hospital wards and from home (for those health professionals with an Internet connection there), but there has been no full-scale evaluation of this service to date.

Although the health care professional is likely to be interested in practicing EBM, the importance of the literature evidence has to be placed in the broader perspective which integrates the personal clinical knowledge and experience with the evidence from evaluated research. The nature of that tacit or personal knowledge may differ from that of the professional in business or commerce, but any information professional seeking to manage the knowledge base of health care must take that knowledge into account when planning services. Otherwise, as this study indicates, there is likely to be a large gulf between perceptions and reality concerning the skills and services the health information professionals can offer the clinicians.
Note

The questionnaire layout makes it unsuitable for reproduction as an Appendix. Please contact Ruth Lewis for a copy via the contact author.

References


[21] A. Wilkin, Users and Uses of Medical Literature Services: An Assessment with Special Reference to the Evaluation of a Clinical Librarian Experiment in the UK (Guy's Hospital Department of Surgery, London, 1982).


Paper 12

“New tricks for old dogs”
Providing an electronic Acute Current Awareness Service for clinical staff within the hospital setting within the UK


<http://www.icml9.org/program/track1/?lang=en>
"New tricks for old dogs?" Providing an electronic Acute Current Awareness Service for clinical staff within the hospital setting

The universal drive to encourage all healthcare staff use best available evidence to make clinical judgements as described in the work of David Sackett on Evidence Based Medicine, can only be regarded as a positive move for both patients and healthcare professionals alike. This concept has been seized upon by the National Health Service in the UK. One such initiative is the Acute Services Current Awareness Service (ASCAS) a web based service hosted by the Greenfield Medical Library, Nottingham, UK. The scope of the service is decidedly broad, there are nine sections: In the news; New Reports and Guidelines; Research and Development, Continuing Professional Development; Medicine; Surgery, Nursing, Women and Children and Diagnostic and Allied Health. These sections are regularly updated using information obtained via the monitoring of over 150 key websites. ASCAS is available to all clinical staff regardless of discipline, rank or occupation, thus dispelling any idea that it is only for the “doctors”. The Department of Information Science Loughborough, UK are contributing to monitoring of information for inclusion and also undertaking the evaluation of the use and effectiveness of the service. Questions to be asked in the evaluation will centre on how effective the users found the information provided by the service in their everyday practice. The evaluation will also seek the opinion of non users about their reasons for non use. Early results show that users of the service have been drawn from more professions than the medical staff including: Occupational Therapists, Physiotherapist, Managers, Lecturers and Midwives. This can be regarded as encouragement that the service is not viewed as exclusive medical territory. The evaluation commenced in July 2005. It is anticipated that the successful usage that has been already reported will be confirmed suggesting that a traditional current awareness service can be reinvented and “old dogs can team new tricks".
"New tricks for old dogs"
Providing an electronic Acute Current Awareness Service for clinical staff within the hospital setting within the UK

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Introduction
For some 15 years there has been a powerful drive in the UK to encourage clinical staff of the NHS to improve the delivering of clinical care by using information effectively. The Patients Charter, 1992, can perhaps be seen at the vanguard of this movement as it enshrined the idea of providing information for patients. This has subsequently developed into the formal framework of Clinical Governance used in the NHS for providing assurances of the quality of care that patient can expect to receive in the clinical environment. The major driver for the implementation of Clinical Governance is to found in the New NHS Modern and Dependable, which set standards and monitoring systems to guide clinical judgement and also for the assessment of clinical care. Two important pillars and essential elements of Clinical Governance are Evidence Based Medicine and Continuing Professional Development (CPD). The aim of evidence based medicine is to ensure that the current state of knowledge and the best standard of evidence is used by clinical staff used in the treatment of clinical conditions. This stems
from the original work by David Sackett. CPD is designed to affirm professional competence through life-long learning activities, updating existing knowledge and skills. These two requirements of Clinical Governance have enormous implications for the provision and use of high quality clinical information within the NHS.

Library and Information Services within the NHS
The NHS is administratively divided into regions, Trent is the administrative region of the focus of this study. Within the regions other subdivisions of administration exist. In the primary sector general practitioner services are brought together to constitute Primary Care Trusts. Provision of services in the secondary sector are provided by Hospital Trusts. Clinical information is routinely provided to clinical staff via the NHS or academic library services. In the secondary sector the norm is for a library to be operating from the same site as the hospital. There are approximately 400 service points in the NHS in the UK. The library may be an integral part of the NHS or an academic library which is aligned to the local university. In the primary sector General Practitioners may have access to a hospital library or clinical library services, depending upon local provision and service level agreements. The provision of information and library services to clinical staff is varied and variable throughout the NHS. The pressure to develop improved and focussed clinical information services within the NHS has resulted in the development of Clinical Librarian services.

The role of Clinical Librarianship in the NHS
It was during the 1970's that the first attempt was made to introduce the concept of CL in the UK at Guys Hospital in London. Since then the development of the CL in the UK in the NHS has been a slow and rather chequered process. Clinical Librarianship (CL) has today established itself as the main form of service concerned with the provision of medically focused, highly case specific information to clinicians. However, the role of the CL is not routinely found in the many NHS libraries. However, good example of practice exist throughout the UK, one of these is the service provide by the University of Leicester Hospitals (UHL), whom operate across three hospital
sites meeting clinicians information needs. Work currently being undertaken by the Librarians at UHL indicates that there are approximately 20 plus CL’s working in the NHS in 2005.

The contribution made by CL to Clinical Governance is a main justification for employing a CL; four major activities stand out which directly support the Clinical Governance programmes, these are:

i. Searching for evidence and clinical guidelines in support of the work of groups involved in the development and implementation policies, protocols, and service recommendations.

ii. Organising training and hands-on workshops aimed at developing the knowledge and searching skills of physicians in the use of digitised information systems and other health-related information resources or database.

iii. Provision of current awareness services targeting specifically clinicians to help them keep up-to-date with developments in the respective fields. Amongst others, this service includes content page services, alerts of updates on key NHS government websites and also selective dissemination of information services.

iv. Online enquiry services which provide answers to specific question related treatment, diagnosis and prognosis of various conditions through telephone fax and also email.

To gain knowledge of the information needs of clinicians, various strategies have been employed by many clinical librarians. Depending on the setting, CLs, have been assigned to specific medical teams, have being involved in ward rounds, referral meetings, outpatients clinics, team meetings, and educational meetings as evidenced by Reid and Ikkos. The aim is to provide them with the opportunity for developing first hand understanding of information requirements of physicians.

These positive developments have not gone without challenges some of which have been highlighted by Roderick and Roderick. Sargeant and Harrison have also pointed out obstacles, such as differences in the perception of the responsibilities of CLs from other members of staff which prevent them from being considered as an integral part of the clinical team.
The evidence of these challenges would suggest that a lot still remains in to be achieved in terms of a cultural shift within the NHS if Clinical Librarians are to gain recognition and acceptance.

**Focus and Background of the Project**

Electronic clinical information provision at the Greenfield Library at the University of Nottingham is the focus of this project. The Greenfield Library at Nottingham does not have a Clinical Librarian in situ, possibly the missing link in the chain to the provision of Clinical information. It can however, boast a Medical Librarian and several clinical subject specialists i.e. Nursing and Medical who provide the clinical information focus for clinical staff. The library is fully engaged in the provision of first class information for clinical staff.

Prior to the beginning of this project the Medical Librarian at the Greenfield Library was aware of a variety of NHS Libraries, regional initiatives that had been introduced by various libraries and health knowledge managers to provide access to health information resources and to also promote knowledge sharing amongst staff. For example within the Trent Work Force, (personnel working within the designated administrative NHS region of Trent) primary care librarians and knowledge managers from across Trent and South Yorkshire have been sharing information and resources to produce monthly information bulletin on management issues such as "The Trent Information Bulletin" and related "Daily Health News" since 2001 with regular feedback received from customers.

Against this background and coupled with her serious concerns the Greenfield Medical Librarian recognised that whilst current awareness services existed for Primary Care staff within the Trent region an equivalent service was not in place to support the clinical information needs of other staff groups working in the secondary sector i.e. the acute NHS trusts within the Trent region. The project formulation grew from these observations. Funding was subsequently sought and successfully obtained from the Trent Workforce Development Confederation. The aim of the project was to develop and provide a current awareness service for acute clinical staff within the Trent region.
Acute Service Current Awareness Service (ASCAS)
The Acute Service Current Awareness Service (ASCAS),is a multi-disciplinary information service, it is a web-based information service and it was developed by the Greenfield Medical Library, Nottingham and is jointly managed by the Department of Information Science, Loughborough University.

The Greenfield Medical Library provides a range of library and information services to employees of University Hospital NHS Trust, Queen's Medical Centre, Nottingham City Hospital NHS Trust and Nottinghamshire Healthcare NHS Trusts. The project started in August 2004 and was launched in November during the UK National Health Libraries Week . Following several consultations with clinicians in four acute trusts in the region to agree on the format and content of the service, the main aim and objectives of the service emerged as:

Aim: To improve and enhance access to high quality resources for academic and NHS staff and students;

Objectives:

i. To facilitate access, independent of the location of the users 24/7

ii. To provide value for money and avoid the need for duplication by other library/NHS staff groups.

iii. To improve cross-institutional collaboration between the NHS and HE

iv. To complement services provided in other subject disciplines

v. To enhance the role of information professionals in supporting the NHS workforce

vi. To identify relevant content in consultation with health professionals working within the confederation

vii. To promote the service via several websites including Nottingham University, Trent Electronic Library for Health and BIOME
The ASCAS service monitors over one hundred and fifty key websites highlighting new report and guidelines relevant to the clinical information needs of NHS staff. This data is analysed and formatted appropriately by the medical librarians and subsequently delivered to the desk top of staff. There are nine searchable categories. Four of these focus on general interests:

- Health news;
- New reports and guidelines; published by agencies such as the Department of Health.
- Research reports; from journals and scientific meetings including sources of funding for research and development and a category which focuses on
- Continuing Professional Development,(CPD) essential for appraisal and revalidation.

The other categories are focused on the clinical and nursing issues:

- Medicine;
- Surgery;
- Women and Children;
- Nursing ;
- Diagnostics and Allied Health.

The service is hosted on the website of Nottingham University and can be accessed via a link. The service has been advertised via a banner on the Trust website, and also through presentation, flyers and personal contacts.

Evaluation of ASCAS

Six months after the service was launched, this evaluation was carried out to gain feedback about the service from staff members.

Study Objectives

The specific objectives of the evaluation exercise were as follows:

i. To determine the users of the service;
ii. To establish the subject headings most popularly used;
iii. To determine the motivation for the use of the service;
iv. To assess the relevance and level of satisfaction of the service;
v. To gain some insight about reasons for non-use of the service;
vi. To determine areas of possible future improvement.

The evaluation started in July 2005, and is still ongoing. This article reports the preliminary findings emerging from the evaluation exercise.

Research Methodology
The number of potential users of the ASCAS service within the Trent workforce, i.e.: (those personnel working within the designated administrative region of Trent in the NHS) dictated that a quantitative method was deemed most appropriate to capture the most data from a comprehensive range of users and non users. The data collection tool used was a questionnaire to be delivered electronically. The second reason for the use of the survey method was the benefit it would provide for analysis of data which could be extrapolated to the wider target population within the Trent work force. The use of the questionnaire as a method of data collection is consistent with other evaluation exercises on health information provision within the NHS evident from work carried out by Nicholas, Huntington and Williams \(^{ix}\) Ebenezer \(^{x}\) Webster & Williams. \(^{xi}\)

Sample population
The sample population for this evaluative study was the Trent workforce. This is a potentially huge numbers running into some thousands of staff. This total population was deemed by the research team to be outside the scope and remit of the proposed study. Therefore, the research team decided to concentrate on sampling those members of staff working within one of the largest NHS Trusts in the region; the Queen's Medical Centre, Nottingham (QMC). Principally because it is situated on the same site as the Greenfield Medical Library, it was thought that it would be known to staff as a major clinical information provider.
Sample size
The research team decided to use Consultants and Senior Nursing staff working at the Q.M.C as the sampling frame for the evaluation exercise. The Chief Executive of the QMC was contacted and permission sought and gained to administer the questionnaire to clinical and nursing staff. The total sample size was 440 clinical and nursing staff; including Ward Managers, Head Nurses and Matrons and Consultants.

Sample method
The main sampling strategy proposed was to obtain a Random sample. However, as is outlined in the description of the questionnaire distribution a Convenient sampling method was employed.

Questionnaire distribution
Difficulties were experienced in obtaining a comprehensive list of clinical and nursing staff from the NHS organisation, constituting the sample set. Therefore, two different approaches for questionnaire distribution were used to elicit response from users and non users.

The protocols existing within the NHS regarding contacting individual members of staff initially influenced the research team to use a third party, the P.A of the Chief Executive at Q.M.C to circulate an email to the sample set informing them of the evaluation exercise. Via the email staff were asked to go to a free website my3q rform.com hosting the questionnaire to complete and submit it online. The initial email also asked that the evaluation request was cascaded down to other members of staff within the organisation.

Secondly the research team used a direct approach to engage respondents. A list of personnel showing initial interest in a current awareness service had been provided by the Greenfield Medical Librarians team to the research team. Personnel on this list were all emailed individually to ask them to complete the questionnaire. This second mailing was undertaken a month after the first.
Questionnaire Design

The questionnaire had six major sections and was designed to target both users and non-users of the service. The first part of the questionnaire was focused on gathering background information of respondents. This was to assist in building a profile of the users in order to draw comparison between different types of user. The second part of the questionnaire covered subject interest aimed at assessing the subject areas which were most popular to respondents. Section three was designed to understand issues connected to motivation for use of the service. Section four focused on questions of user satisfaction. The fifth and sixth sections requested suggestions about possible areas of improvement and non-use respectively.

Interim Study Results

Background of respondents

The results show that respondents come from a fairly mixed specialist background including some senior officers. The job titles provided includes Consultant Neurologist, Head Occupational Therapist, Consultant Surgeon, Head of Continuing Professional Development, Sister, and Consultant Physician. The actual specialities listed includes, Neurology, Medicine, General Surgery, Professional Education, Ophthalmology, Respiratory Medicine, Healthcare Professions Education. Incidentally the specialist background of respondents is also identical to the subject headings used for the service.

Subject interest

When asked to specify their subject area of interest, the analysis of respondents preferences revealed interest in both broad and specialised subject areas. The broad subject areas listed were again similar to the subject headings of ASCAS. They include Integrated Medicine, Current issues in healthcare, Professional Development, Paediatric services and Nursing. The greater majority of respondents were however interested in more granulated subject areas. For example one respondent, a Neurologist, reported his specific subject interest as movement disorder, cognition and neuro-
degeneration. Another respondent, Surgeon gave his area of interest as, Transplantation, Day Surgery, Endocrine Surgery. Other specialised subject areas which emerge from the analysis include, cardiac rehabilitation, head injury, sepsis, lung cancer, and chronic obstructive pulmonary disease (COPD). The evidence from the analysis of subject interest suggests that most of the respondents are interested in general as well as specific health topics.

Service Usage.

Of the total number of respondent, it emerged that a high proportion have never used ASCAS for the eight months it has been running. The percentage distribution of usage is as follows.

<table>
<thead>
<tr>
<th>Use of ASCAS</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
</tr>
<tr>
<td>Yes</td>
</tr>
</tbody>
</table>

Fig. 1

Of the 22.2% who indicated that they use ASCAS, half (50%) reported that they use the service on a weekly basis whilst the other half said they only visit the ASCAS site on a monthly basis. The popular subject areas which were browsed included news items, new reports and guidelines, continuing professional development, nursing, and diagnostic and allied health.

Three motivations emerged for using the service. They are: personal development; teaching and keeping up to date. No indication was given for use of ASCAS for clinical decision making.
Of the large proportion (77.7%) who have never used ASCAS, reasons for non-use are follows:

**Non Use of ASCAS**

![Pie chart showing reasons for non-use of ASCAS](image)

- 57.1% Unaware of
- 28.5% Problem accessing service
- 14.2% No reason

**Fig. 2**

As shown in the pie chart close to 60% are unaware of the service whilst about another third have problems accessing the service. No reasons were assigned by the rest of the respondents for not using the service.

In answer to "How do you keep up-to-date?" non-users of ASCAS reported the following: (Fig 3)
Non users methods for keeping up-to-date

![Bar chart showing percentages of non-users methods]

- 25% Consult colleagues
- 18% Seminar Workshop Conference
- 18% Subscription to alerting service
- 12% Monitoring websites
- 12% Academic and NHS library
- 9% Email distribution list
- 6%

Judging from the fact that the majority of the respondents were senior members of staff, it is not surprising that they subscribe to journals in their own field.

**Service Satisfaction**

Of the proportion of respondents who use the service, the greater majority reported that they were quite happy and satisfied with the service. The reason for satisfaction was reported to include the following: coverage of subject area of interest; relevance of information provided and up-to-date of information. Others indicated that they found the abstract quite informative and also that the service was very easily accessible to them. All the users of ASCAS were unanimous that the service was excellent and that they are more likely to recommend it to others.
**Areas of possible improvement**

Both users and non-users of the service suggested that the service should be advertised more widely and also that email alerts should be set up. The non-users however added that the subject area of ASCAS should be expanded and also that the service should be made more accessible.

**Interim Observations**

The initial method of questionnaire delivery may not have been the most optimum to use. It is recognised that in using a third party another level of bureaucracy and complexity is added for the respondents. However, the research team was influenced in their choice of data collection instrument to be a questionnaire delivered electronically for several reasons. First, the level of access statistics for ASCAS within the initial months of the launch of the service indicated that a sufficient number of clinical and nursing staff was accessing the service to provide an acceptable level of response for evaluative purposes. Secondly, the research team were informed that many of the clinical and nursing staff had access to email and p.c. Thirdly, previous research had shown this to be a successful method in capturing an adequate response rate.

The early results display a relatively low response rate this can be attributed to several factors:

- In reality acute NHS hospital staff do not all have individual access to a p.c or email;
- Some email addresses were incorrect causing the message to bounce back;
- The email from the P.A of the Chief Executive of QMC would have had carried a limited authority but it may have been lost amongst many more important or relevant hundreds in an inbox. One Deputy Director of Information Services in a Hospital Trust anecdotally reported that he received 250 emails per day;
- Some respondents had difficulty in accessing the free website
Key factors can be considered as:

- The ASCAS service had not been sufficiently promoted to encourage use by the clinical and nursing staff prior to commencing the evaluation exercise;
- The ASCAS service does not have a clinical champion, this is essential if the service is to gain credence and use amongst clinical and nursing staff, as detailed by Harrison and Sargeant xi in 2002.

All the users are enthusiastic about the service and think it excellent, however, it is too early in the study to assess if the initial project aims have been successfully met. Evaluation continues... it would seem that "old dogs cannot learn new tricks", just yet.

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NHS and social care interface: a study of social workers' library and information needs

Janet Harrison, Mark Hepworth and Pam De Chazal, 2004.

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NHS and social care interface: a study of social workers' library and information needs

JANET HARRISON*, MARK HEPWORTH and PAM DE CHAZAL

This article reports on a study of the information needs of social workers based in an acute NHS Trust. The perceived gap in library and information service provision is reviewed, and future models of service delivery are proposed. The social workers were part of the multi-disciplinary team within each hospital. The methods of data collection were a questionnaire, focus groups and semi-structured interviews. Results suggest that the social workers were information poor in terms of access to information sources and yet information to assist their role was required on a wide range of subjects. Also, information skills, including an understanding of libraries and services amongst the sample population, needed updating and developing. Lack of Internet access was a significant barrier to obtaining information. Little evidence of a research culture was found; information seeking tended to be verbal via face-to-face contact. Conclusions emerging from the research indicate that a closer working relationship between NHS librarians and social workers is required to promote a better understanding and acknowledgement of the specific needs of this client group. The need for information resources to be developed on key topics has been highlighted. A robust IT infrastructure is required to enable easy and rapid access to the knowledge base from the desktop. This should be augmented by the provision of information skills training. Finally, this research found that a cultural shift is required if social care decisions are to be based on the best available evidence.

INTRODUCTION

Leicestershire, Northamptonshire and Rutland Strategic Health Authority (LNRSHA), as one of the 28 new bodies established by the Department of Health in 2002, is responsible for the strategic direction of local health care provision. In achieving the delivery of high quality, evidence-based practice, the LNRSHA local implementation strategy management board for Information for health (Department of Health, 1998) highlighted the important issue of access to library and information services for social workers within the workplace. No local baseline audit existed, and there was a perceived gap in service provision for this user group.

The purpose of this study, therefore, was to address these issues. Specifically, the objectives were to:

- conduct an information needs analysis of social care professionals based at the University Hospitals of Leicester NHS Trust (UHL);
- review the perceived gap in library and information service provision for social workers; and

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NHS and social care interface:  
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and information needs

Janet Harrison*, Mark Hepworth and Pam De Chazal

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- review the perceived gap in library and information service provision for social workers; and
- propose future models of service delivery that are relevant and responsive to user needs and that will support evidence-based social care.

Commencing in February 2002, the study was conducted over a six-month period until July 2002. The study reviewed the information needs and provision of library and information services for adult social work teams based in the University Hospitals of Leicester NHS Trust (UHL).

**Background to the Study**

The *NHS Plan* (Secretary of State for Health, 2000) recognizes that ill health cannot be separated from poverty, inequality and social exclusion, and sets out how social services and the NHS should come together with new agreements to pool resources. New Care Trusts would be established to commission health and social care in a single organization.

Through the Care Standards Act 2000, the Government established a new national infrastructure for quality in social work. This comprised the existing Social Services Inspectorate (SSI), the National Care Standards Commission (NCSC), the General Social Care Council (GSCC), the Training Organisation
for Social Care (TOPSS) and the Social Care Institute for Excellence (SCTE). The Department of Health promotes the integration of the work of the new national bodies with that of the Local Government Association, the Association of Directors of Social Services, Social Services Inspectorate and the wider Department of Health through its Social Care Quality Programme.

In the context of this study, SCIE is particularly relevant. Established in October 2001, its purpose is to develop and promote knowledge about best practice in social care. It provides reviews of evidence from research, and disseminates the knowledge base through good practice guides and the electronic library for social care. The imperative for evidence-based practice in the social services was thereby clearly established.

In order to fulfil the Government's aim that social care decisions must be based on the best available evidence, it follows that social workers must have quick and easy access to the evidence.

Methodology

The literature review suggested that a combination of methods would be effective in assessing social workers' information needs and for modelling future service provision. Neigel (2000), for example, employed a questionnaire survey to determine the utilization of information resources and to explore the general information-seeking behaviours of different healthcare professionals. Forrest and Robb (2000) employed both quantitative and qualitative methods in their investigation into the information needs of doctors-in-training at the Cairns Library. A questionnaire survey, supplemented by one-to-one interviews for more in-depth observations, produced two clear findings: firstly that more time was required to find and obtain information; and secondly that information sources should be accessible where and when they were needed. The findings from the two data collection methods provided the framework on which to design library services that would support users within the evidence-based framework. In contrast, (Glitz et al., 2001) used focus groups to plan library and information services around identified information needs, and concluded that these are an effective tool for planning, information
needs assessment and decision making.

**Methods selected for this study**
Combining the results achieved from two or more methods is a process known as triangulation. By continuous cross-checking, a deeper insight is acquired and the quality of the findings is improved. As this study was exploratory in nature, both quantitative and qualitative methodological tools were employed. A questionnaire survey was conducted and was followed up by focus groups and in-depth semi-structured interviews.

The questionnaire was intended to elicit the nature and type of information that social workers need in order to carry out their jobs. It also sought to ascertain what information resources and services they would find useful. The questionnaire was designed to be quick and easy to complete, with special attention being paid to its length and the layout on each page. Specifically, the questionnaire contained sections relating to the following:

- basic job details;
- computer and Internet access,
- subject-specific information;
- how information is obtained;
- current and future library service provision.

The questionnaire was piloted with a group of social workers, and their comments were incorporated into the final version. The questionnaire was to be anonymous, with strict confidentiality being assured.

As the researchers were not supplied with individual staff lists, distribution of the questionnaire was effected in one of two ways. Each team manager was asked to choose whether the researchers could attend part of a team meeting to explain the purpose of the research and to distribute the questionnaires personally. Alternatively, the questionnaires could be posted to the team managers who would undertake their distribution on the researchers' behalf.
A letter confirming the arrangements was sent to the team managers.

All staff involved in the study were provided with a pack which contained:

- a written outline of the project;
- a covering letter explaining the questionnaire and giving an assurance that all responses would be treated in strict confidence;
- a questionnaire;
- a prepaid envelope (if the questionnaires were distributed on the researchers' behalf).

The data were analysed using SPSS™ a statistical package commonly used by social scientists.

Focus groups were selected as a qualitative methodological tool to identify critical situations for social workers, and their current use of information in these situations. Emphasis was placed on:

- exploring in more depth issues that were highlighted from the questionnaire analysis;
- posing questions that were not suitable for inclusion in the questionnaire;
- cross-checking findings that arose during the course of the focus groups and interviews.

The focus groups were arranged by contacting the individual team managers by telephone. The purpose of the focus groups was explained and an assurance given that confidentiality would be maintained throughout. One hour was requested for the focus group itself, plus an additional 15 to 30 minutes prior to the meeting which would serve as a general 'ice breaker'. Permission to tape record the proceedings was sought, and a letter confirming the arrangements was sent to the team managers.

On two occasions it was considered impractical by the team manager to
conduct a focus group. Semistructured interviews with these two team managers were therefore arranged. The questions asked at the interviews were the same as for the focus groups. Again, permission to tape record the proceedings was sought.

**FINDINGS**

**Response rate**
Of the 59 questionnaires that were distributed 35 were returned, giving a response rate of 59%. As the questionnaire was anonymous, it was not possible to send follow-up letters urging non-responders to complete the questionnaire. Despite this, the response rate was considered sufficient to permit valid statistical analysis.

**Population profile**
Eighteen respondents (51.4%) were employed by Leicestershire County Council and the other 17 (48.6%) by Leicester City Council. Of these, 11 (37.4%) were based at Leicester General Hospital, 15 (42.9%) at Leicester Royal Infirmary and nine (25.7%) at Glenfield Hospital.

Direct client care accounted for more than 60% of a social worker's time, although for senior social workers, this was not the case as administration accounted for over 70% of their time. A striking finding was that 0.4% of respondents were engaged in research.

**Subject coverage**
Social workers require information on a very wide range of subjects. However, particular emphasis is placed on the subjects set out in Table 1.

<table>
<thead>
<tr>
<th>Subject</th>
<th>% respondents rating subject extremely important</th>
</tr>
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<tbody>
<tr>
<td>Older people</td>
<td>96</td>
</tr>
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</table>
It was clear from the focus groups that information gathering is essential at the point of assessment of the client. This requires liaison with a range of people and services including general practitioners, occupational therapists, physiotherapists, medical and nursing staff, and external organizations such as housing associations and the police. Information is gathered by the social work team from the client about their condition and social circumstances prior to hospitalization, and there is a constant exchange of information with the client and their relatives and carers. A knowledge of the client's medical condition is also required since this may help to determine the care that is required. It is crucial for the benefit of both the client carers/relatives and the social worker, however, that any medical information should be understandable and in lay persons' terminology.

The increasingly complex information requirements were also discussed in the focus groups and are typified by the following example:

If somebody has had a stroke ... I think we know what we're doing operationally in terms of the Community Care Act and our responsibilities, but the person you're working with says 'I want to know more about strokes' and you need to know, for instance, that the Stroke Association do produce a whole range of very useful leaflets and pamphlets and it would be useful for us to have that quality of data for ourselves.

Social workers also need to be aware of the different care packages and their costs, especially current local authority initiatives, as they have to justify why they have selected a particular package.

We're expected to [make decisions about best value]
because we’re made aware when we’re putting together care packages that we have to look at prices in those packages. Approval will come at different levels of management depending on how much that care package is going to cost.

**Computer and Internet access**

Respondents were asked whether a computer and printer were available to them, and whether they had Internet access in their office. An astonishing finding is that no-one has access to the Internet (Fig. 1).

**Figure 1. Percentage of respondents having computer and Internet access**

<table>
<thead>
<tr>
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<th>Percentage</th>
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<tbody>
<tr>
<td>E-mail</td>
<td>40%</td>
</tr>
<tr>
<td>Printer</td>
<td>80%</td>
</tr>
<tr>
<td>Internet</td>
<td>100%</td>
</tr>
<tr>
<td>Computer</td>
<td>80%</td>
</tr>
</tbody>
</table>

Frequent reference was made by the social workers to the lack of computer provision and Internet access in the workplace.

I asked for it - to have access - and was told that you need to present a business plan as to why you need Internet access.

A friend, who is in computers in America, said ‘Why don't you just put down you want to be in the 21st century’. It seems the whole world is connected, while the social services....... In contrast, some of the respondents feel somewhat threatened by the electronic environment. The view was expressed that they would hate to have a computer on their desks. There is also a fear that they would be expected to type their own reports and letters and this was seen as an additional pressure on their time. It is also apparent that in some cases there is a poor
understanding of information technology, its capabilities and its terminology. For example, some social workers were unclear about the difference between the intranet and the Internet.

**Use of printed and electronic resources**

Practice guidelines and directories are referred to on a daily basis. Some social work teams produced a procedures manual. The staff knew where it was located and used it frequently. Similarly, some departments stored a range of information leaflets which were well organized and easily accessible. It was felt that by having a manual it would save time and the social workers would not be 'reinventing the wheel all the time, and not having to ask all the time'.

Most of the social workers read *Community Care* 'Which has quite a lot of information that's relevant to us', but do not tend to read any other journals. The need for frequent referral to government legislation was emphasized strongly by all the social workers, and it was clear that access was needed to the relevant material. In the words of one social worker:

> A lot of legal issues which we really struggle with because we don't have access I guess to the literature to have a look as to what the legal status is.

It was not surprising to find that more than half the respondents never use the Internet, although some would use Internet resources more frequently if they had access (see Fig. 1). As one social worker said:

> I think it would be useful to have access to the Internet ... there are a lot of Web sites that are given on articles that you've read, you can look deeper there, but at the moment you can't - you're stuck.

The majority of social workers were unfamiliar with bibliographic databases such as Caredata, MEDLINE, CINAHL and ASSIA, although a few had used these whilst training but no longer did so as practitioners.
A dependence on textbooks was also not elicited. On direct questioning, there did not appear to be any core texts although the respondents did express the need to refer to a range of books for teaching purposes and to keep up-to-date. No titles or authors or specific texts were identified.

Library usage

Figure 2 shows that three-quarters of respondents do not use the hospital libraries. This finding is not surprising since, officially, they do not have access to this facility. Only three respondents use their employer's library daily or weekly, whilst over half never use this facility. Infrequent use is made of public and other libraries by this client group. It is acknowledged that valuable resources are available through public libraries such as the People's Network (www.peoplesnetwork.gov.uk).

However, this client group is not positioned to routinely utilize these off-site resources, although notable exceptions were found:

Yes I go down to my local library and I have to say that very often I discover things down there. I found out about the HIMP health improvement programmes and found a great big folder available on the shelves. I started leafing through and said 'there's some very interesting stuff here that's very relevant to my practice'. I've now got it in my office. No doubt we've got it up at County Hall but in terms of reading it and having it in a manner that you can just lay your hands on and so on ... I suspect there are individuals like me that work out their own information system.
The focus groups highlighted the need for on-site library provision to support evidence-based practice. However, some social workers are concerned that their current work schedules would prevent them from having the time to visit the library. There is generally a poor understanding of libraries and the services that they provide.

Information skills
The majority of respondents (78%) would value training in identifying information sources, whilst two-thirds would value knowing what information tools are available to locate information, and knowing how to use these tools. Respondents were less enthusiastic about training in evaluating the quality of published material. Fewer than one third did not consider they needed basic computer skills training.

Usefulness of information services
Respondents were asked to think about the type of information services that they might find useful. Figure 3 shows that access to specialists who could provide subject expertise was considered extremely important by three-
quarters of respondents. A current awareness service, the provision of fact sheets and staff bulletins were also considered to be extremely useful by over half the respondents.

**Figure 3, Usefulness of information services**

![Bar Chart]

**Verbal communication with colleagues**

Much of the information needed by social workers was obtained through talking to colleagues. The majority (84%) sought information on a daily basis from their team managers or other social work colleagues. A high proportion (65%) also obtained information from other health professionals on a daily basis. These results suggest that social workers rely heavily on verbal communication to satisfy their information needs and confirm the existence of a strong verbal culture.

**Barriers to obtaining information**

A conspicuous finding is that 88% of respondents consider that time constraints represent a significant barrier to information use. Almost two-thirds experienced difficulty in accessing information, and felt a lack of library services was a contributory factor. Information overload and a perceived lack of information in an easily usable form were also cited by approximately half the respondents.

Interestingly, despite being infrequent users of both the Internet and electronic
databases, a lack of information skills was not considered a significant barrier by the social workers in this study.

Overcoming barriers
The study set out to elicit solutions from the social workers themselves as to how these barriers might be overcome. Their suggested solutions are presented in Table 2.

Table 2: Overcoming barriers

Solution 1: Library provision
- On-site library access
- Social work library

Solution 2: Organizational interface
- Better communication with other departments
- Clearer understanding of the social worker role by other hospital staff

Solution 3: Improved ICT infrastructure
- Internet access
- More IT
- More resources, i.e. more telephone lines and power points

Solution 4: Provision of information skills training
- IT skills training
- Procedures on how to obtain resources
- Knowledge of how to use information

Solution 5: Improving working practices
- More time to become informed
- Allow study time for access to library
- More development time

**Solution 6: Improved information management**
- Signposting direct users to appropriate information resource
- Better information held on computers
- Need relevant information at workplace
- One person in unit with knowledge of how and where to access information

**DISCUSSION**

**The social work environment**

This study demonstrates that the issues surrounding social workers' information needs, and the ways in which they seek and use information, are complex. It also suggests that solutions are not easily found. Three significant aspects of the working culture of social care teams have emerged. The first is a reliance on verbal communication for the exchange of information. Given that verbal communication is the primary mechanism for information transfer in social work practice, and that library and information services are acknowledged to be based upon electronic and print resources, it is clearly difficult to reconcile the two communication models without a paradigm shift. Some receptiveness to this culture change was however detected. As one social worker said: 'It would be just nice to have the kind of culture where you see this constantly referring to accurate data and the best practice from elsewhere'.

The second is that social work practice is also intrinsically paper-based. Although most social workers had access to a computer, this was often shared between two or three practitioners. Internet access was found to be non-existent. In this environment computer literacy and information-searching skills in this professional group were generally not advanced. The migration to
an electronic environment, which will include access to web-based information resources and electronic client records, will have dramatic implications for information management and the working practices of this professional group.

Thirdly, the profession is not research-oriented and does not rely on the research literature to direct its practice. In this context, the use of library and information services has not been a priority. The lack of research culture found in this study is typified by the fact that journal reading does not generally extend beyond *Community Care*. This confirms the findings of McCullough et al. (1975). The apparent lack of attention paid by these practitioners to research findings echoes earlier work by Blake et al. (1979), where social workers were reported to be largely 'unenthusiastic' about reading the professional literature and, in many cases, were only familiar with one or two journals, for example *Social Work Today* or *Community Care*.

**Library access and provision**

This study acknowledges that whilst Social Services and NHS staff are part of the same multidisciplinary teams providing health and social care for patients, their access to the knowledge base is vastly different. Although small libraries and resource centres are available to the social workers, these are difficult to access and therefore underused. The libraries provided for the NHS staff are based on all three hospital sites and are well resourced. The social workers, however, do not have access to these libraries.

The inequity in library provision between NHS and Social Services professionals is palpable, and is at variance with the aim to provide an integrated service. In line with the drive for evidence-based medicine, recent legislation sets out the need for social care decisions to be similarly based upon the best available evidence. Against this background, social workers must have access to the knowledge base. The study has shown that on-site library and information services would be valued. Furthermore, since the healthcare libraries in Leicester are well established and already offer a multiplicity of information services, it would be a case of expanding existing
provision rather than developing entirely new services.

Electronic provision of information
The poor use of electronic resources and the complete lack of access to the Internet from the desktop is surprising and at odds with government objectives for the e-society. This lack of availability of the Internet was a source of embarrassment and frustration to the social workers and emphasized the difficulty in readily accessing the external knowledge base. Although there was some reluctance to acknowledge electronic delivery of information, it was recognized that this would be the only practical solution for the inculcation of evidence based social care.

Blackburn (2001) concluded that information technology was the only realistic option for providing the required information to social workers. Several studies have highlighted the richness of web-based resources for these professionals (Bazin, 1999; Summers, 1998; Wilkinson, 1998). Hampson (2001) emphasizes the critical importance of the World Wide Web in integrating access to print and electronic resources. D'Alessandro et al. (1999) emphasize that it is crucial to focus consistently on the population served and to tailor the service to their needs. Extending this thinking process to the extreme, Watson (1996) has proposed a virtual library for social workers.

The growing number of well-organized social work web sites offer enormous potential and undoubtedly warrant further investigation for use and access to this client group.

Existing sites:
- www.elsce.org.uk Electronic Library for Social Care
- www.scie.org.uk Social Care Institute for Excellence
- www.ex.ac.uk/cebs Centre for Evidence Based Social Services
- www.nelh.nhs.uk National Electronic Library for Health
- www.cswe.org Council of Social Work Education
- www.nyu.edu/socialwork/wwwrsw Resources for Social Work
- www.naswdc.org National Association of Social Workers
Multiple source information needs

The study has highlighted the vast array of information required for social work practice. Again this is an echo of earlier work with this client group (Wilson, 1979). The range of requirements spans a wide but relatively shallow landscape from the practical, directory-level information to complex problems demanding access to multiple information resources and agencies. Information was widely perceived to be disorganized, difficult to access and often disseminated in an untimely manner. Social work teams were deluged daily by unsolicited material, as well as official documentation. This produced feelings of confusion and frustration, as much time was wasted in searching for salient information. Electronic resources, for example the existing intranets, were also perceived to be a jumble of information with no clear direction and these would require substantial organization if they are to be of use.

Core collection

The social workers in this study do not rely on journals, databases, textbooks and other research materials. This suggests that the initial investment in social work journals and books could be minimal. However, a core collection needs to be established to facilitate the development of evidence-based practice. Despite direct questioning by the research team, the social workers did not identify core material other than the Community Care Journal. It is suspected that this may be because the social workers are not, in general, library users, and does not necessarily mean a core collection does not exist.

Since the completion of this study it is refreshing to note that the University of the West of England and the Social Care Institute for Excellence (SCIE) have announced the creation of a Social Care research collection (July 2003). This a welcome and timely addition to this sparse field and may go some way to assisting the necessary cultural shift required to incorporate research into practice. Fundamentally, librarians will be provided with guidance on the provision of social work materials.

Since it has been demonstrated that social workers do not, in general, use libraries, it is essential to build a relationship between library staff and the
social workers. Once social workers have access to a library and can utilize multiple information resources, demand for library services may continue to develop and expand. As one social worker pointed out: 'You don't know how good it is until you've tried it'.

Library liaison services
The findings indicated that access to an information specialist would be useful, with a strong emphasis being placed on developing a liaison role between the library and the social work teams. In this way, the problems already identified, such as information management, skills training and collection development, would be addressed.

A study by Wilson and Dunn (1976) explored the provision of specialist information services to social care professionals and identified just 18 local authorities who were providing this type of service. More recently, Bailey et al. (2000) supported the view that the appointment of a professional librarian was crucial in a health/social care setting. It would seem such an appointment of a Social Work Information Specialist would be highly appropriate in 2003.

Training and education
Social workers expressed a wish to be given the opportunity to participate in training courses that are currently only available to NHS staff. Training underpins effective multi-disciplinary team working, the provision of integrated care, and evidence-based social care practice. A whole raft of information skills training is both required and desired by the social workers. This was also highlighted almost a decade earlier by Engeldinger and Stuart (1990). The majority of social workers in this study are acutely aware of deficits in their IT and information skills competencies. These deficits manifested themselves through expressions of fear of using computers, an increasing workload and complicating their working practices. Conversely, some social workers are keen computer users, often performing work-related Internet searches outside the workplace, and would welcome advanced training from information specialists.
CONCLUSIONS

No change?
It would seem appropriate in view of the findings from this study that service providers and employers review the current service provision for social workers to meet their information needs. This study suggests that, astonishingly, in the last 30 years remarkably little has changed in library and information service provision for this client group. The problems identified in relation to meeting the information needs of social workers today are similar to those found in the 1970s. However, there are now innovative solutions available that would have been beyond those with even the widest vision in 1974.

A commitment
The perceived gap in library and information service provision for social care staff is confirmed by this study, and it is concluded that a service level agreement for the provision of library and information services for social workers is essential and needs to be established. A commitment to monitor and evaluate use of services would also be required to accommodate evolving need and allow for development.

A new service: client characteristics
The design and implementation of a new service must be attuned to the characteristics of the targeted client group. These characteristics can be summarized as follows:

- diverse and wide ranging information requirement;
- information overload;
- considerable time pressures;
- strong verbal culture for the exchange of information;
- social workers are not research-oriented;
- minimal library provision;
lack of familiarity with libraries and their services;
poor information skills.

Cultural shift
For evidence-based practice to occur, a cultural shift to use research findings in everyday decision making in practice is required. A management commitment to lead the cultural change must be acknowledged and acted upon. The findings support the view that this change must be managed in a structured manner as it may not occur naturally. A number of ways have been identified to help facilitate this change. These include improved information management, the appointment of an information specialist and the provision of information skills training.

Good practice
In this study, pockets of excellent information management were identified within individual social work teams. This was demonstrated by the comprehensive organization of printed material with easy access for all team members. This exemplar should be mirrored throughout the social work teams.

User solutions
A range of solutions for grouping information into easily accessible forms have been identified. These include the provision of summaries and fact sheets, together with current awareness and alerting services. Discussion groups have also been found to have a place in overcoming information overload, updating practitioners and for exchanging information.

Appointment of an information specialist
There must be library and information liaison at the earliest opportunity with the social work teams to ensure appropriateness of training and to bring about a twoway understanding between the library and social work professionals. A tailored training programme would include a detailed library orientation, the explanation of library terms and media used, and specific hands-on sessions. The findings support the view that an information specialist would be
instrumental in facilitating the necessary culture shift to enable evidence-based practice to become the norm.

**The electronic hook-up**

And finally, a robust IT infrastructure, enabling easy and rapid access to the knowledge base is required to underpin the practice of evidence-based social care. This is the crucial issue for social services and library management to confront and lead.

**References**


Hampson, A. (2001) Laying claim to the virtual space. *Library Association Record*, 103 (2), 112-113


Theme Three

The information behaviour of health information specialists

Papers 14 - 17
GROWING HYBRIDS: TRAINING AND EDUCATION FOR HEALTHCARE INFORMATION MANAGEMENT SPECIALISTS

GROWING HYBRIDS: TRAINING AND EDUCATION FOR HEALTHCARE INFORMATION MANAGEMENT SPECIALISTS

Janet Rolinson, Lecturer, Department of Information and Library Studies, Loughborough University

Janet Rolinson is a Lecturer in the Department of Information and Library Studies at Loughborough University. Her experience is in the information and medical records management field, both within the NHS and as a management consultant. Her research interests include the communication practices of biological researchers and health information for the consumer.

Targeted training and education for information and library studies is, I believe, the only way to provide the specialists to turn the key to unlock the complexities of information provision in the healthcare market of the 1990s.

The wide sweeping, all encompassing, recent reforms from the Griffiths Report (1) to Working for Patients (2) have transformed the NHS from the cosy welfare state model of provision of care, from the cradle to the grave, free at the point of delivery, to the provision of healthcare as a commodity to be bought and sold in the market place, thus raising the need for information to a level of consciousness amongst all professionals engaged in the NHS, to a level that was previously only dreamt about by dedicated information specialists.

The requirement for complete, accurate, timely and relevant information is high on the agenda of all service providers to assist in monitoring, achieving targets and maintaining quality. This requirement is also paramount to the purchasing role to undertake development of healthcare assessment needs of the population. The Information Management & Technology Strategy (IM&T Strategy) (3), launched in December 1992, by the National Health Service Management Executive (NHSME) encapsulated the growing awareness and need for information by announcing better information equates to better patient care. This single corporate decision to implement the IM&T strategy has established the importance of information management in the NHS.

Who are the information specialists?

I am aware that a common definition of who information specialists are is required, however a common understanding of this term does not exist. I suggest that there are two separate types of information specialists that exist within the healthcare market which could be regarded as branches of an information tree. The two branches of the information tree consist of:

Firstly the information specialists who collect data and provide information on all aspects of healthcare activity, who, in this current climate, are credited with a diversity of titles ranging between Business Manager, Information Manager, to Executive Information Specialist, or Director of Finance and Information or any combinations of the words "information and/or management" with any conceivable other.
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Secondly the information specialists who deal with published information and retrieval who may be known as the Librarian or Resources Manager or again any combination of the words "librarian, resources or information" with any conceivable other.

The varying titles highlight the diversity of the specialism within the NHS, and the lack of a common understanding within and outside the NHS is both confusing and frustrating. Comparison of like with like cannot be easily achieved.

The numbers of these specialists in the NHS has not yet been fully established. This is highlighted in the NHS/IN1S survey of 1992 (4) which established a figure of 5,500 IM&T specialists engaged wholly or mainly in activities concerned with: "the specification, analysis, presentation and dissemination of data and other information required for effective business performance and with technical systems necessary to support these activities." This does not include those members of staff engaged in data entry activities, routine medical records activities or those dealing with published
data. This major survey of IM&T specialists has excluded one of the branches of the information tree, that of the library function.

Functions of the two branches:

What does the numerate branch do? The major activities of the information specialists in this branch include:

- the collection of traditional patient activity, financial, case mix and manpower data
- the analysis of the data
- the presentation of the information.

What is information used for? There are three major uses:

- monitoring - what was achieved retrospectively, last week, last month, last year? Were quantitative and qualitative targets achieved?
- operational - are there enough available beds to meet the demand today?
- planning - what are our short, medium and long term planning needs? What service provision do we need in 10 years time to meet the needs of the population?

What does the library branch do? The activities of the information specialists in this branch include:

- the retrieval and dissemination of published information for both primary and secondary sources
- on-line searching
- CD ROM searching
- public information via the Regional Health Information Service
- library services for undergraduate and postgraduate education and training for medical, nursing, Professions Allied to Medicine and other NHS personnel.
What is the information used for? There are six major uses:

- Current treatment
- Planning
- Research
- Education
- Training
- Consumer service

However, identifying the real information needs of the healthcare business is a monumental task as the new healthcare market is still in its infancy.

I believe it is necessary for the fusing together of the two branches of the information tree to develop a "hybrid" information management specialist, who possesses both a knowledge and understanding of the skills required to provide a full information service to meet the needs of the new market. There are recognised basic knowledge and skills for information management in the NHS.

**Basic Knowledge and Skills Required for Information Management in the NHS (5):**

1. Introduction

1.1 Information awareness
1.2 IT awareness
1.3 Information systems choices
1.4 Information planning
1.5 Corporate needs and information strategies and plans
1.6 Promoting an information culture
1.7 Sources for published and unpublished information
2. Information for management

2.1 Information for decision making
2.2 Information for planning
2.3 Information for quality control
2.4 Contracting services
2.5 Office automation
2.6 Management information systems
2.7 Exception reporting
2.8 Problem solving
2.9 DISS
2.10 HISS
2.11 Community information systems

3. Information for medicine

3.1 Bibliographical systems
3.2 Data systems
3.3 Clinical information systems
3.4 Medical informatics
3.5 Epidemiology

4. Information systems

4.1 Information requirements analysis
4.2 Design and specification
4.3 Prototyping
4.4 Procurement
4.5 IT Standards (OSI: CBS)
4.6 System evaluation
4.7 Project planning & management (SSADM / PROMPT / PRINCE)
4.8 Contractor management
4.9 Systems administration
4.10 System maintenance
### 4.11 Software evaluation and selection

### 4.12 Hardware evaluation and selection

### 4.13 PC maintenance

### 4.14 Network supervision

### 4.15 Staff training

### 5. Data collection and analysis

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<td>Körner</td>
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<td>5.3</td>
<td>Observation, questionnaire, interview</td>
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<td>Record and file design</td>
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<td>Database administration</td>
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<td>Statistical techniques</td>
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<td>Data presentation</td>
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<td>Casemix databases</td>
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<td>Output and recording systems</td>
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<td>Patient administration databases</td>
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<td>Marketing information</td>
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### 6. Organisational structure

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<td>Implications for information flow</td>
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<td>6.4</td>
<td>Private and voluntary sector</td>
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<td>Central v local control</td>
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<td>Accountability</td>
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### 7. Healthcare issues

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<td>7.3</td>
<td>Medical audit</td>
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</tbody>
</table>
7.4 Quality control and Performance Indicators
7.5 Facilities management
7.6 Consumer information systems
7.7 Access to patient records
7.8 Access to medical audit data
7.9 Security
7.10 Health education
7.11 Management of change
7.12 Political & social issues in information provision

8. Horizon issues

8.1 New technologies (eg CD-ROM, touch and voice entry)
8.2 New systems (eg networking, expert systems, work stations)
8.3 Training & education (computer based, systems specific, integrated, work stations)
8.4 HCI (Human - Computer Interface)

Delivery of Training:

The principle of delivering appropriate training and/or education to an individual suggests that a training needs assessment should be undertaken by an appropriately trained person. Subsequently a suitable course is developed for the individual.

The NHSTD/NHSME Strategy for Information Management and Technology Training issued in 1989 recommended that there should be training and education for 800,000 NHS staff. This represented approximately 80% of all NHS staff I suggest that this is still a viable figure for 1993. I am concerned today with the training and education of the Information Management Specialists upon whose skills for the effectiveness and the efficiency of the NHS depends. It is obviously highly desirable to undertake individual training needs assessments for all of the 800,000 staff involved, however, this may not be wholly
practical or cost effective. Therefore targeted training for specific groups of staff is the affordable and realistic alternative.

There are three principal methods of delivering training - internal, external or a combination of both. Internal local events can be run by internal staff, assuming that the skills are available, or by bringing in experts from outside to either deliver or facilitate training. The main thrust of the 1992 IM&T strategy is for training to be undertaken at local level.

A combination of internal and external methods of training delivery is demonstrated by Open and Flexible Learning Programmes. These allow students to study at their own pace within their own environment, in conjunction with higher education institutions who subsequently award the qualification. This method of education has obvious advantages for the student and the NHS, as study can more easily be meshed in with varying work patterns in a way that is impossible with the traditional delivery of higher education.

**Statement of Recognition:**

The NHS Training Directorate (NHSTD) has initiated a project to develop and implement a recognised professional qualification for Information Management and Technology staff employed or contracted to work in the NHS. The qualification will be known as the `Statement of Recognition (SoR) for IM&T Specialists in the NHS`.

The Statement will be a method of giving formal recognition to the range of experience, skills, educational and vocational qualifications that IM&T staff can acquire, or that they may have already acquired by defining a framework of "modules" which must have been completed successfully by individuals seeking the award. In the longer term the award may be linked with grades of membership of the proposed professional Association of IM&T staff.
It is envisaged that three levels will comprise the SoR. To date the foundation level has been articulated. Levels Two and Three are in the development stage.

In conjunction with the NHSTD, the Department of Information and Library Studies at Loughborough University are establishing a database of all higher education institutions who provide, at any level, a course, or courses, pertaining to health information management.

Higher Education:

Universities are, I suggest, the place to provide education and training for both branches of the information management tree to develop the information management hybrid. The strengths of the Universities are:
- skills in the delivery of higher education
- expertise in library management and functions
- experience in dealing with "soft data" (6)
- statistical analysis and presentation - management theory
- research in aspects of healthcare services
- IT skills
- established communication networks, both national and international
- and ultimately for the student and sponsor a recognised qualification

Established courses are available in healthcare information management at:

- Aberystwith, University College of Wales
- City University, United Medical & Dental Schools
- Derby University
- Glasgow University
- Manchester University, Health Services Management Unit
- Keele University
- Warwick University
In recognition of the need for suitable undergraduate and postgraduate education in information management for healthcare, the NHSTD has assisted in facilitating the development of several courses including those at Derby, Manchester and currently in the Department of Information & Library Studies at Loughborough University an MSc in Information Management in Healthcare which will commence in October 1994.

Development of the Information Manager Hybrid:

To ensure the development of the information management hybrid, I suggest it is necessary to:

- fuse together the two branches of the information tree.
- establish an IM&T profession recognised within and outside the NHS.
- educate and train staff at all levels appropriate to their needs and the needs of the NHS.

You all have some of the skills required to develop the healthcare information management hybrid and I would urge you now to seize the opportunities presented within education and training to acquire the remainder. If you falter I fear the hybrid will become an endangered species before it is propagated.

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3. National Health Service Management Executive / Information


A clinical librarian can support clinical governance


*British Journal of Clinical Governance, 6(4), 248-251*
Background
Clinical governance (Secretary of State for Health, 1999) requires NHS Trusts to ensure that evidence-based practice is supported and applied routinely in everyday practice. To keep abreast of relevant developments and inform their practice with current research evidence, clinicians are estimated to need to read “17 articles per day, every day of the year”, an impossible task for even the most dedicated clinician (Davidoff et al., 1995). Barriers to accessing the information required to practice evidence-based health care have been identified (Pyne et al., 1999) as:

- time: clinicians have recognised that the searching process can take two hours out of their busy day;
- lack of knowledge of the most relevant database to search and the best way in which to search it; and
- access to IT facilities, with a lack of investment in hardware and software in the clinical setting.

In a recent editorial, Davidoff and Florence (2000) suggested that “Many questions arising in clinical encounters that can, and should, be answered on the basis of evidence from the published literature are ... never addressed.” Clinical librarians have been addressing such questions in America since the 1970s by participating in ward rounds, responding to the questions by providing backup literature on specific clinical conditions (Algernissen, 1974; Lamb, 1974; Marshall and Hamilton, 1978). Until recently (Lusher, 1999) there have been few studies of the concept in the UK.

Pilot project
Local Implementation Strategy funding from the Health Authority provided the opportunity to further examine the role the clinical librarian could have in supporting evidence-based practice. Two 0.5wte (whole time equivalent) clinical librarians were assigned to two departments each (Nephrology/Stroke Unit, Neonatal Intensive Care/Obstetrics and Gynaecology) to attend ward rounds and audit meetings offering an expert literature search service. The specific objectives of the pilot project were to:
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- establish if the clinical librarian service would be used by clinicians;
- test the Lusher (Lusher, 1999) and Vanderbilt (Giuse et al., 1998) models that placed the clinical librarian at the ward rounds;
- determine the required speed of response to questions;
- identify the level of contact required to maintain a link with the clinical team; and
• find out if clinicians wanted the librarian to filter the results of the search, hand picking full text articles and providing a summary of the results in the form of a digest.

Methodology

A scoping study (Lewis, 1998) carried out in 1998 had identified clinicians interested in the clinical librarian concept. Their willingness to participate, the views and suggestions of the hospital medical director and our wish to support a range of departments/patient groups within the hospital, were the criteria used to select clinical departments for inclusion in the project. A first step was to meet lead clinicians to identify places where discussion of clinical issues takes place, e.g. ward rounds, audit meetings, case conferences, nursing and professions allied to medicine (PAM) meetings. Clinical librarians attended as many as possible to raise awareness of the service and get to know how the teams work.

The lead clinician within each of the selected areas acted as "champion" of the clinical librarian service, encouraging staff to make use of it. The clinical librarians committed to searching MEDLINE, EMBASE, Cochrane Library and evidence-based resources on the Internet for each request. Other databases were used as appropriate. The results of the search ranged from a comprehensive list of references with abstracts, a filtered list of references with a digest of the findings, to selected full text articles. A copy of the search strategy used to search each database was included with a second copy retained in the library. An Access database of clinical questions, subject terms, databases used and summaries was developed as a management tool and to provide feedback to clinicians on frequently asked questions and areas of uncertainty.

The service was evaluated by collecting usage statistics and by seeking the views of those involved. A questionnaire about the search results was sent out with the summaries for each question. A further questionnaire was sent to all members of the clinical teams seeking their overall views of the service. They were asked to rate the search results and the impact of the information
on a number of aspects of clinical practice. Lead clinicians were interviewed to identify their views of the service as a whole.

Results

Use of clinical librarian service by clinicians

Over six months, 23 searches per month were carried out by the clinical librarians. This was in addition to the average 25 searches a month performed by the existing literature search service based in the library, which remained unchanged during the period of the project. Examples of the questions answered by the clinical librarian were:

- Are there any studies comparing the effects of bolus versus slow infusion of indomethacin for patent ductus arteriosus (PDA) in neonates? The references identified were reported as influential in changing practice.
- What evidence is there to identify the optimum time to switch from IV to oral antibiotics? This was used in the development and validation of local guidelines, rationalising the use of antibiotics in the hospital.
- An obstetric patient presented with an advanced ectopic pregnancy, possibly in a rudimentary horn of the uterus. A search of the literature provided case evidence that allowed conservative management of a rare and unusual presentation.

The impact of information

Although positive about the value of the searches, the response to the "individual search" questionnaire was poor, 10 per cent (14/136), possibly reflecting the lack of time clinicians have to deal with issues not directly related to patient care. However, 15 people returned the more detailed "evaluation of service" questionnaire that was widely distributed in the departments involved.

Of those who commented, 73 per cent (8/11) of respondents indicated that the information provided by the clinical librarians had an impact on patient
care; 64 per cent (7/11) indicated that the information had an impact on teaching. A further 60 per cent (6/10) indicated that the information had an impact on case presentations; and 46 per cent (5/11) indicated that the information had an impact on research. A total of 30 per cent (3/10) indicated that the information had an impact on management; and 27 per cent (3/11) indicated that the information had an impact on publication.

These numbers are very small but accurately reflect the perceptions of both the clinicians interviewed and the clinical librarians on how the information provided was used. Clinicians were clearly aware of the landmark studies in their own field of expertise. The clinical librarian service in this project was used to find the evidence on rare and unusual cases, support the development of new guidelines, update existing knowledge and support teaching.

**Preferred location of clinical librarians**

Ward rounds were useful places to make initial contact with a large number of clinicians. Attendance at ward rounds put questions in context, aiding the retrieval of relevant articles and provided the opportunity to increase the librarian's level of clinical knowledge. However, ward rounds are very time consuming and the clinicians did not feel that the librarian was being used effectively by attending full ward rounds. Weekly audit meetings and other clinical meetings were identified as appropriate locations for the clinical librarians as they were multidisciplinary and raised questions about the evidence base of current treatments and services. The only exception to this finding was Neonatal Intensive Care. In this unit ward rounds were an appropriate meeting place for the clinical librarian.

**Speed of response to questions**

Our expectation was that instant responses to clinical queries would be required. The time needed to carry out a thorough search and evaluate the
results made this difficult to achieve and it was, in fact, never an issue. Time of response varied from two hours to several days, negotiated with the clinician at the time of request. All those who returned "individual search" questionnaires rated "speed of response" as high.

**Level of contact required**

The rapid rotation of clinical staff, especially junior doctors, meant that knowledge of the clinical librarian service was not sustained. Requests eventually stopped when the service was removed from selected departments highlighting the need for the clinical librarian to maintain a presence in the clinical setting. The pattern of contact was dependent on the working practices and regularity of appropriate meetings in each department. As such, the service offered was different for each department and no single model was identified.

**Filtered information**

The project also aimed to evaluate the format for the presentation of the results. Clinicians wanted to be involved in the selection of any full text articles obtained and stated that it was sufficient for the clinical librarian to provide references and abstracts for each search. In cases where a Cochrane review, relevant article or Internet document clearly answered the question, the full text was provided along with the other references. Clinicians regarded the digest as more useful when there was clear evidence to answer a specific question. The digests were valued less when there was no clear evidence.

**Discussion**

We found that clinical librarians can support the Trust's clinical governance agenda by providing the evidence to answer questions raised in the clinical setting. As 73 per cent (8/11) of respondents felt that the information provided by the clinical librarians had an impact on patient care this service is clearly supporting evidence-based practice and risk management. The service also supports continuing professional development with 64 per cent (7/11) of
respondents reporting an impact on teaching and 60 per cent (6/10) an impact on case presentations.

To make clinical librarianship cost effective and less labour intensive early models of this service must be adapted. It is unrealistic to expect librarians to attend all ward rounds, but there is a place for the librarian in the clinical setting and the location will be unique to each department. We recommend the use of audit and other clinical meetings to locate the clinical librarian, confirming previous findings (Gilbert and DeRoy, 1999). There is a need for the clinical librarian to maintain a regular presence in the clinical setting to sustain the service. Without this the answers to questions raised by clinicians may not be pursued.

Clinicians saw the digest as more useful when there was clear evidence to answer a specific question, suggesting that they were rating the evidence available rather than the value of the digest. Grade I research evidence was not always available and it is recommended that summaries are included to highlight the grade of evidence found and the extent of the search. Clinical librarians need to have sound knowledge of research methodology and critical appraisal in addition to their information retrieval skills and knowledge of information sources. They are thus able to support the clinical skills and knowledge of the health professionals at the point of clinical need, overcoming some of the barriers to information use in practice.

From pilot project to full clinical librarian service

Following the pilot project we have been able to secure Health Authority/Trust funding to develop the service over the next three years. Two clinical librarians currently support staff across the three sites of the newly merged University Hospitals of Leicester NHS Trust. Robust evaluation will take place to further assess the impact of the service on patient care and the use of research evidence in clinical practice.

Information about the clinical librarian service, including a bibliography of recent publications can be found at http://www.le.ac.uk/ii/igh/library/clinlib.htm
Conclusions

The key messages to be drawn from this study are:

- a clinical librarian outreach service in the clinical setting can respond to information needs not already met by library services;
- the clinical governance agenda is met by supporting evidence-based practice, teaching and learning and continuing professional development;
- earlier clinical librarian models can be adapted to provide a cost-effective service; and
- the clinical skills and knowledge of health professionals can be complemented by clinical librarians' information skills and knowledge.

References


Clinical librarianship in the UK: temporary trend or permanent profession? Part I: a review of the role of the clinical librarian


*Health Information and Libraries Journal, 21, 173-181*
Clinical librarianship in the UK: temporary trend or permanent profession? Part 1: a review of the role of the clinical librarian

Sally J. E. Sargeant* & Janet Harrison†

Abstract

Background: This paper is the first of a two-part series of articles presenting the role of the clinical librarian (CL) in the UK today. It situates the CL concept historically, and specifically reports the findings from a study in 2002 (Skinner, The Role of the Clinical Librarian in the UK. MSc Dissertation. Loughborough University: Department of Information Science).

Relevance: The impetus for the 2002 study was the awareness of an increase in job advertisements within the NHS for roles seeking to enhance the practice of evidence-based medicine, which included elements of clinical librarianship. Therefore the research was undertaken to establish whether this increase was coincidental, or the beginning of a new professional role for librarians.

Methods: A content analysis of CL job advertisements, examining job titles and duties was undertaken. Twenty-three advertisements were scrutinized, and these results are presented here. As a complementary investigation, a postal questionnaire was sent to a sample of practising CLs in the UK.

Results: Several duties can be classified as core to the role of the CL. However there is a great diversity of duties attached to this core, reflecting an absence of nationally accepted practice.

Conclusion: Further work was necessary to assess current practice and how clinical librarianship can continue to grow at local and national levels. This is addressed in Part Two of this series.

Key Messages

Policy

• Acceptance of diversifying role in medical information provision
• Logistical considerations of CL personnel and their physical positioning within acute settings

Implications for practice

• Establishing national professional guidelines for CLs
Clinical librarianship in the UK: temporary trend or permanent profession? Part I: a review of the role of the clinical librarian

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Abstract

Background: This paper is the first of a two-part series of articles presenting the role of the clinical librarian (CL) in the UK today. It situates the CL concept historically, and specifically reports the findings from a study in 2002 (Skinner, The Role of the Clinical Librarian in the UK. MSc Dissertation. Loughborough University: Department of Information Science). Relevance: The impetus for the 2002 study was the awareness of an increase in job advertisements within the NHS for roles seeking to enhance the practice of evidence-based medicine, which included elements of clinical librarianship. Therefore the research was undertaken to establish whether this increase was coincidental, or the beginning of a new professional role for librarians. Methods: A content analysis of CL job advertisements, examining job titles and duties was undertaken. Twenty-three advertisements were scrutinized, and these results are presented here. As a complementary investigation, a postal questionnaire was sent to a sample of practising CLs in the UK. Results: Several duties can be classified as core to the role of the CL. However there is a great diversity of duties attached to this core, reflecting an absence of nationally accepted practice.

Conclusion: Further work was necessary to assess current practice and how clinical librarianship can continue to grow at local and national levels. This is addressed in Part Two of this series.
Introduction

The clinical librarian (CL) is gradually carving a new model for information provision in today's NHS. However, clinical librarianship is not a new concept worldwide. The CL-or clinical medical librarian (CML) has been recognized as a form of librarianship in the United States for the last 30 years. The concept was pioneered in 1971 by Gertrude Lamb, who identified a need to provide highly specific case information to physicians, with the primary aim to place librarians into the clinical setting at the point of patient care. This experiment was subsequently reported in 1974.¹ American schemes continued to expand and grow, gaining credibility and acceptability.

The UK beginnings

It may be surprising for some to learn that there have been some CL programmes since the 1970s, when the UK also attempted to introduce the CL concept at Guys Hospital, London.² This programme was not successful and was eventually discontinued. It was not until the late 1990s when interest in clinical librarianship started once more to gather momentum. A kick-start for the role was provided by the Cairns Library, Oxford in the shape of a project that involved a CL being assigned to a medical team for 2 months. Later, in 1998, a feasibility study was conducted by the Department of Information Science, Loughborough University³ to investigate the possibility of introducing the CL concept at the Leicester General Hospital NHS Trust. From these early
beginnings, 4 years on in 2002 there were approximately 14 CLs currently practising in the UK, all serving a variety of clinical specialities within their respective NHS Trusts. Clinical librarianship has had a slow and chequered history in the UK and the role is still developing.

**Key observations on clinical librarianship**

But what happened between, and indeed before, that first programme and the resurgence of interest? Although the first CL programme did not appear in the US until 1971, some relevant articles appeared as early as 1956. While attending an international congress on medical librarianship, Archibald Goodall, an American physician, noted the change in librarians' perception of their role. He stated that librarians considered one of their main functions as shielding clinicians from the 'drudgery' of searching literature, checking references and making bibliographies, effectively making themselves responsible for the level of culture at their institutions.4

Although clinical librarianship is centred on specific case information rather than general reading, Goodall’s article was an apt precursor for the developments in health-science librarianship that would later emerge. While dismissing such changes as 'undesirable and unjustifiable', he conceded that there was a place for the librarian in a tutorial role, such as instructing medical students in bibliographic techniques.

In the 1970s, American literature was generally descriptive, informing of progress in CL implementation. Quantitative studies were hugely significant, as various CL programmes were evaluated statistically. Examples of such statistics included information on how much of the librarian's time was spent in clinical meetings, or information seeking preferences of healthcare professionals. Attitudinal issues on all levels, from clinicians to information professionals were not closely addressed, and there was little documentation assessing attitudes of CLs themselves. However, for every piece of positive, or descriptive, literature on clinical librarianship, scepticism emerged later in
the decade. This was not confined to American text; there were similar responses in the UK in 1977, as Jean Farmer wrote shortly before the implementation of a CL scheme at Guys Hospital.\textsuperscript{5} The article provided a brief history of the US schemes and emphasized the importance of clinicians' acknowledgement of a medical librarian as an integral part of the healthcare team. Despite Farmer's enthusiasm, the article generated negative comment from clinicians and also, regrettably, from librarians.

As more CL programmes continued to emerge, retrospective studies and bibliographic resources appeared in the 1980s. Lamb provided a review of clinical librarianship in 1982\textsuperscript{6} and Kay Cimpl undertook a review of the literature in 1985\textsuperscript{7} which carefully documented various stages of CL programme implementation in the US. The first major comment from a CL point of view emerged in 1987 from Gorman-Sullivan\textsuperscript{8}. Amongst other aspects, the research investigated the academic and professional backgrounds of CLs working at that time, their reasons for entering the profession and previous knowledge of medical terminology. Further attitudinal surveys did not emerge until 1991. After a period of time when CL articles seemed to be in decline, the 1990s saw a renewed interest in the subject. Demas and Ludwig published an article that was perhaps the most closely aligned to attitudinal comment.\textsuperscript{9} It placed the CL concept within a mythical framework, and implied that personalized library services were analogous to legendary concepts. Throughout the 1990s, evaluative articles generally became more frequent, and clinical librarianship began once more to enjoy the high profile that it previously acquired in the 1970s. More importantly, it was beginning to attract interest in the UK, which posed the question of whether the profession was gradually being re-launched. Writing in 2000, Grace Cheng produced an argument which did not overtly promote clinical librarianship as a singular profession, but included commentary on librarians adopting additional roles pertinent to clinical librarians. She championed the aspect of integrating information services with other key parts of a larger, parent service, and suggested that the future information professional should 'conduct training workshops to impart knowledge of information resources on the Internet and alternative sources of information
available commercially'. Also in 2000, Frank Davidoff and Valerie Florance approved of information professionals' skills to assist clinicians in formulating and answering enquiries. In the American context, their argument proposed that a new profession be introduced to the medical sector on a national scale that was modelled in clinical librarian programmes. This new profession was the 'informationist'. While acknowledging that clinical librarians were already part of functioning programmes in the United States, the authors emphasized that there were still obstacles preventing librarians from being considered as integral parts of the clinical team. These obstructions were mainly the ambivalence of clinicians about needing help to locate relevant literature and funding issues. Their conching remarks stressed the need for change and for specialist intervention, stating that it was 'unacceptable' for medical information retrieval to remain in 'its current neglected and disorderly state, a poor relation in the family of biomedical research and clinical practice. The concept of the informationist is an idea whose time has come.'

If literature reviews were measures that could chart the rise of clinical librarianship over the years, the most recent review by Winning and Beverley serves to emphasize this. By 2003, enough literature had been generated to conduct a thematic, rather than simply chronological, review. Literature contexts are thus divided into impacts on patient care, clinicians' use of literature and cost effectiveness, to state merely three.

**Drivers for CL services in the UK**

The major drivers for implementation of CL services in the late 1990s are to be found in *The New NHS Modern and Dependable*. These included Clinical Governance, which was introduced in 1998 to provide a way of addressing concerns about the quality of health care. It emphasized to practitioners that the best standard of evidence must be used in support of practice and that the public must be reassured of this. Although issues of quality of service had been addressed in previous initiatives such as the Patients Charter, the requirement to use complete, accurate, up-to-date clinical
information had not previously been spelled out, and the NHS had relied upon the implicit understanding from practitioners that this would be the case. A need was identified to support the pre-existing ideologies of evidence based medicine at a local level. Although Clinical Governance was a Department of Health directive for all Trusts to adhere to, there were still barriers that prevented its effective practice. One of those difficulties was identified in Roderick and Roderick 2001 which concerned the role of the information department in the provision of clinical information. Traditionally, information departments in the NHS routinely handled large volumes of information generated by patient activity. Therefore, dealing with largely textual material would prove at least a challenge and, at worst, great difficulty. Practicalities with the provision, use and location of information included all the usually attributed problems.

However, there are attitudinal aspects that support the need for a CL that are equally important and cannot be ignored. As -Roderick and Roderick explain, nobody would expect a doctor's receptionist to diagnose their condition, and a popular misconception that information analysis is either performed by low-paid administrative staff, or by anyone who happens to be around, often prevails.

The study

Having situated the CL in an historical context, the next logical step was to pose the question, 'what is a Clinical Librarian in the UK?' To help find answers to this, it was becoming obvious that direct questioning of practising clinical librarians was the way forward. However, in 2002 there were very few individuals working in the UK who seemed to fit the traditional CL model according to Lamb and who could be immediately identified as participants. Before selecting appropriate participants for the study, it became necessary to address discrepancies in perceptions of CL responsibilities. Definitive issues were an immediate problem. Was there such a thing as the 'genuine article' clinical librarian'? Related posts that supported the delivery of evidence-based medicine concentrated heavily on developing outreach information skills
programmes and performed literature searches, yet there was often no requirement or consideration of the librarian being part of the clinical setting. This posed a presentational problem, which needed attention before research could be undertaken in individual roles of selected clinical librarians.

To partially overcome this difficulty, it was decided to examine job advertisements for clinical librarians, or indeed any job, which at first glance appeared to support clinical governance, within the preceding 2-year period. A total of 23 advertisements were examined, which presented a list of job titles that were potentially searchable. The vacancies were advertised in the Health Service Journal, the Chartered Institute of Library and Information Professionals Appointments bulletin, and appointments pages in The Guardian. In addition to scanning the advertisements as they appeared in the above publications, relevant human resource offices for the advertising institutions were also contacted to provide further information. Whether applications were still open, or past the stated closing date, all were able provide copies of the full job and person specification.

This helped the identification of CL or equivalent posts, which in turn helped identify participants for questioning. A general request was placed on a new mailing list specifically set up for Clinical Librarians and those with similar duties. As a component of the Joint Information Systems Committee (JISC) web pages, it was an ideal medium for establishing the level of interest in research. It also helped to further identify individuals who were undertaking clinical librarian duties but did not have that particular job title. The initial request asked for general information, including whether the respondent worked fulltime or part-time, and the clinical directorates they served. This was essential as some CL programmes were being externally evaluated at the time of the study and staff in such organizations did not consider it appropriate to participate until their respective results had been published.

To complement this content analysis, a questionnaire was issued to practising CLs in the UK. Although structured, it contained different types of questions-
closed, attitudinal and open. It was designed to establish where CLs worked, their academic and professional backgrounds, and the extent to which predominant themes at recruitment level appeared in the job itself. It was also designed to identify similarities and differences between roles, and sought to procure data that would provide the basis for qualitative semistructured interviews (this data will be discussed in Part II of this series).

What the advertisements revealed

Prior to analysing questionnaire data, a content analysis of the 23 job advertisements revealed the following substantial requirements:

**Job titles.** Job titles alone presented many differences, although some duties that were required of successful candidates were very similar. Consistency in nomenclature is maintained within individual NHS Trusts, but certainly not on a national basis. Unlike the United States, where the role was clearly titled Clinical Medical Librarian, job titles varied immensely in the UK. From the 23 advertisements, only five specifically asked for a ‘clinical librarian’. Others, for example, sought a ‘clinical effectiveness librarian’, with the aim of also providing specific case information to clinicians (Fig. 1).

![Figure 1 No of job titles in advertisements (May 2000-May 2002)](image)

Although the job titles differed, the principal aim of all posts was to provide the best clinical evidence to named staff groups.
appeared through analysis of the job advertisements was the gradual increasing frequency at which they were publicised, as demonstrated in Fig. 2.

![Graph showing number of relevant jobs advertised (May 2000-May 2002)](image)

**Figure 2** Number of relevant jobs advertised (May 2000-May 2002)

**Previous experience.** Most advertisements stated that two years experience in an NHS setting would be desirable, if not essential. Although some specified that this should be post-qualification experience, there was nothing to indicate that librarians who had previously worked in a paraprofessional capacity within an NHS health and medical information setting should not apply. There was also no request that candidates should possess a clinical background.

**Core duties.** The main focus of the investigation centred on what duties CLs were expected to do. From the range of employers who advertised it was realistic to expect differences in duties. Certainly all of the advertisements differed greatly in their respective job descriptions. However, there were seven main areas that were identifiable as common ground. Consequently the following duties were classified as **core**:

- attendance at ward rounds;
- attendance at case conferences;
- attendance at other clinical meetings: this included informal discussions,
addition to case conferences;

- clinical guideline development;
- information searching;
- information evaluation;
- service promotion.

Figure 3 shows the number of advertisements from the total examined that contained each respective core duty.

![Figure 3 Number of job advertisements containing core duties](image)

The tasks that required a presence in the clinical setting were significantly lower than others. Advertisements specifying that ward round or case conference attendance was essential held the title of Clinical Librarian.

**IT familiarity.** As with the job titles, the IT skill requirement in the job descriptions examined posed many variations and demanded different levels of skill and expertise. It also proved to show differences in expectations between the primary and secondary care trusts. The non-NHS employers (e.g. medical schools) paid particular attention to the administration of the library management system (LMS), in addition to requesting familiarity with MEDLINE, CINAHL and other relevant health sciences databases. Others did
not prioritize the need to manage the LMS, but emphasized the importance of relevant database and online searching. One advertisement stated the types of hardware that would be available to the successful applicant. This list included the use of a range of portable technologies and local networks to deliver information in the clinical setting and was the only recruitment correspondence to mention this aspect from those that were examined.

Not surprisingly, given these results, the requirement of CLs to have and continually develop IT competencies was the focus of much informal discussion at the 1st Clinical Librarian Conference in the UK March 2002. The use of hand-held technology in literature searching is one application that has been piloted by some CLs and considered to be a useful addition to their 'toolkit'. However, the local NHS implementation rules once again come into play as this hardware was not, and is not, universally available in all UK CL programmes, thus confirming that fact that some CLs will need different IT skills than others.

User education. From all of the job descriptions examined, 91.3% (n = 21) required the successful applicant to develop and assist in the delivery of user education sessions, either on a one-to-one basis or to groups. Groups included members of clinical staff, medical students, and other information professionals within the organizations placing the advertisements. It was not always clear whether those appointed would be expected to offer these services to all clinicians within the organization, or only to those working in the clinical directorates specified.

Results from the questionnaire

The sample population consisted of five practising CLs. Four were employed by NHS trusts and one was employed by an academic library. Four were full-time equivalents and one of the participants held a part-time post. The developmental nature of the CL role was reflected in the employment status, as of the five CL posts only one was substantive and the other four were on fixed-term contracts.
Previous academic and professional experience was equally disparate. At undergraduate level, two respondents had studied scientific subjects, one was arts based, one had completed Information and Library Studies as a first degree and one had a clinical background as a registered mental nurse. Three of the respondents had completed a postgraduate degree in Library/Information studies, but when questioned about the contribution that previous academic experience made to the CL role, two of them stated that their postgraduate qualification had not significantly helped.

Reasons for taking the post varied. If already employed by their institutions in another professional information capacity, some respondents had actively been involved in the development of the post that they held. More general reasons included greater financial incentives, more responsibility and preferences for increased/decreased hours. One particularly noted that there was an emphasis on electronic information which was a great motivation to take the job.

Not all respondents had studied modules that specifically addressed healthcare or medical information. However, this was sometimes governed by such modules being unavailable at the time of study, rather than choosing not to. When invited by the questionnaire to comment further on this issue, all respondents felt that many skills learned in both postgraduate and undergraduate study were transferable to the CL role, specifically general reference, searching, presentational skills and IT instruction. However, it was unanimously thought that librarians needed to have teaching and/or training skills incorporated into their professional training, as teaching/demonstrating was a major component of their CL roles. Project management was also cited as a desirable option to undertake in professional training, as CL posts were often fixed-term projects requiring regular monitoring and progress reporting.

Training and knowledge

Three respondents had previous knowledge of medical terminology prior to their CL appointment. Routes to attaining this knowledge or improving on an
existing understanding differed. Although working for academic institutions, some were able to access training through the respective NHS Trusts, by attending short courses that were delivered by clinical staff. Other CLs who had a scientific or clinical background did not require further instruction. Only one respondent did not receive any formal training that assisted the understanding of medical subject terms, and stated that this continued to be a barrier to information retrieval. However, as the job progressed, it was also asserted that confidence levels had increased in asking clinicians for clarification.

Those who had little or no prior knowledge of medical subject heading vocabulary admitted to making slower progress in initial literature searches and needed to check definitions of terms more frequently. In certain cases, such unfamiliarity was assisted by undergraduate study of scientific subjects, but most respondents stated that the process of learning gradually while doing the job was inherent to the role. Experience of searching medical databases was a more unifying question for respondents. One stated a high level of experience, while all others remained at an average level.

**CL service promotion**

Service promotion was largely dependent on the institution and work conducted prior to establishing a CL service. Attaining a suitable balance of promotional activity was a minor concern. All respondents indicated that their initial promotional activities at the start of their contracts were successful in generating the desired response. Generally, in all cases of promotion, prior work had been conducted. However, publicity needed to continue and it was also stated that promoting the CL service too heavily would generate interest that was not commensurate with times allocated to CL projects. The main focus of one project was clinical guideline development, which generated sufficient work not to require further promotion. Promotion also occurred at clinical meetings themselves, but was subject to clinical directors' agreements. Methods of promotion ranged from poster and e-mail reminders to journal clubs, but often appeared at the point of clinical need. Some
programmes even produced their own stationary (e.g. pads of information request forms with service details). Others felt that there was no specific need to promote their service as they only served a limited number of departments.

These activities presented satisfactory results, but it was emphasized that continuous marketing was maintained as some clinical departments had a rapid turnover of staff. Another wrote that there was a need to be at the level of business planning to secure funding for the post and thus continue all types of promotional activity.

Core duties, clinical involvement and information retrieval
For one respondent, quantifying time spent performing certain activities was not possible due to the short length of time in the CL post. Therefore, only four of the five participating institutions are represented in this section. The questionnaire only sought approximations of times devoted to core CL activities, as this could vary from week to week depending on the clinical specialties served. It is also important to state that presenting certain variables statistically was not always possible for certain cases. For example, the Oxford programme serves the Accident and Emergency unit; therefore the question referring to ward rounds does not typify the clinical situation in such a department. In this case, the clinical director did not want the librarian to model the role on the ward round concept. The numbers in the table below present the average times for all participating institutions in hours spent per week on core activities, as reported by the participants (Fig. 4).
### Institutions

<table>
<thead>
<tr>
<th>Core Duties</th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
</tr>
</thead>
<tbody>
<tr>
<td>Case conferences</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Other meetings</td>
<td>1</td>
<td>2</td>
<td>0.75</td>
<td>4</td>
</tr>
<tr>
<td>Clinical guideline development</td>
<td>0</td>
<td>3.5</td>
<td>5</td>
<td>0.25</td>
</tr>
<tr>
<td>Information evaluation</td>
<td>2</td>
<td>3.5</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>Information searching</td>
<td>3</td>
<td>3.5</td>
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<td>10</td>
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<tr>
<td>Service promotion</td>
<td>3</td>
<td>1.5</td>
<td>0.75</td>
<td>0.25</td>
</tr>
<tr>
<td>Ward rounds</td>
<td>5</td>
<td>0</td>
<td>0</td>
<td>4</td>
</tr>
</tbody>
</table>

Figure 4: Time spent (in hours) on core duties per week

**User education and training**

All respondents confirmed that they provided literature-searching workshops to clinical staff, some also provided these services for medical students, but not always. In some cases, other members of library/information staff also undertook this aspect of the role. Critical appraisal skills were a key component within this section and one respondent had actually developed such programmes as part of the CL role.

In NHS trusts, training was often conducted when requested by clinicians, but could also be managed on a drop-in basis. However, critical appraisal sessions needed to be pre-arranged. Alternatively, the user education component within the academic setting was becoming a regular part of the induction for medical students. Only clinicians that belonged to the specialties served by the CL programme were allowed to access the specific workshops from the CL. Others from different specialties could still access instructions generally from within the library's services. One Trust usually conducted journal club presentations in association with evidence-based practice training sessions that were organized by clinicians (e.g. senior house officers). Some sessions were advertised, while others were conducted during ward rounds.
Discussion

There is a moderate degree of congruence between recruitment specifications and working activities of clinical librarians. However, the overall question surrounding the definitive qualities of clinical librarianship in the UK remains. The advert content analysis and questionnaire process revealed interesting views from CLs alluding to their own roles. Some considered their role as adding to the sum of clinical knowledge to help future patients because clinical activity moved so rapidly within the respective specialities served. Positive role definition was also seen as the foundation for presenting evidence of CL service impact. One definition by a participant revolved around the choice or requirement to closely engage in the work of the clinician, such as the participation in the ward round or involvement in the evidence-based practice journal clubs.

Defining the role also presents concerns about the possibility of overlap between CL and non-CL duties. User education and instruction sessions on literature searching and critical appraisal were often part of the CL role, but these operations were carefully planned to avoid duplicating training that was already received from other librarians. This usually applied to CLs who were employed by an NHS Trust, as they had limited contact with medical students and did not assist as frequently with information retrieval instruction. Alternatively, CLs employed by an academic institution did instruct medical students on a regular basis.

With considerations of potential role overlap in mind, one of the surveyed Trusts maintained a very structured CL definition, as there was another member of staff working as a clinical effectiveness librarian at a different site within that Trust. While both roles supported the provision of critically appraised, evidence-based information, the key difference was the CL's presence at the clinical setting. However, this was not the only distinguishing factor. Important differences can also be identified within the structure and ideology of clinical governance. In the case mentioned above, the clinical
effectiveness librarian examined national guidelines and ways of disseminating them, but CL service operated at a local level, serving the Trust. As clinical governance imposes a 'corporate responsibility to provide the best possible quality of healthcare' 16 which ultimately rests with the chief executives of Trusts, this is a significant factor that influences CL definition. It also encourages research into how CL services can fulfil this responsibility. 17 By advocating the introduction of multi-disciplinary teams to address clinical problems, the role is ultimately shaped on a general level. However, when moving from the general to the specific, the requirements of clinical directorates within different NHS Trusts have disparate effects on the role and considerably complicate its definition.

Differences in practice emerge as some librarians were actively practising in the clinical setting and may attend case conferences, while others were not. There are also differences between roles depending on whether the CL had a proactive role in the service development, or if a programme had already been clearly defined before the recruitment stage. Frequently, individuals in the appointing organization who all shared interests in evidence-based practice and clinical governance provided an excellent starting point to introduce a CL service and were seen as champions of the service. In these cases, there was a tendency to align the CL practice with the American models. However, it should be noted that shared interests appeared to be coincidental, rather than part of a planning model.

Other influencing factors that shape the CL role are the clinical specialities served. A diagnostic environment, such as an Accident and Emergency department would not be conducive for a librarian to accompany clinicians, due to the irregular and often frenetic nature of such departments. Another crucial factor is the rate of clinical staff turnover, the regular rotation of junior medical staff, which largely depends on the specialities served. The need to constantly promote CL services within employing trusts is a necessity for some clinical librarians and is easier when specific funding is allocated to produce CL service merchandise. However, such funding cannot be guaranteed. Even if it was automatically available, it is unwise to assume that
the clinical librarians have sufficient time to develop promotion strategies or that they wish to generate more service use that would create unsustainable demand.

**Conclusion**

While clinical governance lends itself perfectly to the aims of a CL programme, it is important to remember that implementation of Department of Health guidelines in the NHS is always governed by local capacity. The impact that this has on CL services is that there are (or can be) fundamental differences between individual roles depending on local circumstances. These differences arise at recruitment stage and continue through to execution of the role in established programmes. Therefore, a clearly defined and nationally accepted professional role may be somewhat hidden from view and considered a very 'rare bird.'

While there are consistencies between job and person specifications and the accompanying roles experienced by the librarians, the diversity of working circumstances and duties was apparent, even in this small sample. Further work was needed to qualitatively investigate the role, as an appropriate succession to this work, which will be featured in Part II of this series, to appear in a future issue.

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Clinical librarianship in the UK: temporary trend or permanent profession? Part II: present challenges and future opportunities


Health Information and Libraries Journal, 21, 220-226
Clinical librarianship in the UK: temporary trend or permanent profession? Part II: present challenges and future opportunities

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Abstract

Background: This article is the second part of a two-part series reporting a study of the role of the Clinical Librarian (CL) in the UK.

Methods: A qualitative method of semi-structured interviews was used to explore in-depth the role of the CL. The interviews provided a rich source of data and give insight into this new and emerging role as practised in the National Health Service (NHS). Similarities and differences are examined between the CL population and reported within themes, specifically: personal qualities and skills required, training for the CLs, marketing the CL service, working in the clinical environment, monitoring and evaluation and the acceptance of the CL in the NHS.

Results: A common understanding of the skills and knowledge required to undertake the CL role was shared by the respondents. However, practice differed as this was often dictated by local circumstances. The study confirmed the need for the CLs to work with clinical colleagues in the clinical setting to enhance patient care.

Conclusion: The importance of using best evidence to support patient care is a message that is slowly becoming the norm in the NHS and the CL role in this practice is demonstrated by this study.

Introduction

This article is the second part of a two-part series reporting a study of the role of the Clinical Librarian in the UK. The quantitative results of the study are reported in part I in the September 2004 issue of Health Information and Libraries Journal of this series. It is the qualitative results of the study that are given in this article, part two of the two-part series. The objectives of the study were to investigate the role of the Clinical Librarian (CL) in the UK. The existing CL population in 2002 was used as the sample set, as defined in the accompanying first paper. This part of the study was designed to identify similarities and differences between CL roles, and also provided opportunities to expand on brief points made in the first paper.

Methodology

In the first part of this study, a structured questionnaire was issued to practising CLs in the UK. The questionnaire contained different types of questions, including closed, attitudinal and open. It was used to identify similarities and differences between CL roles, and also to provide data that would form the basis for the qualitative second part of the study. Five participants were interviewed, who had been drawn from a sample set of CLs in the UK.

It was decided that the best method to expand and develop themes of interest from the questionnaire in part one was to conduct semi-structured

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Clinical librarianship in the UK: temporary trend or permanent profession? Part II: present challenges and future opportunities

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Abstract
Background: This article is the second part of a two-part series reporting a study of the role of the Clinical Librarian (CL) in the UK. Methods: A qualitative method of semi-structured interviews was used to explore in-depth the role of the CL. The interviews provided a rich source of data and give insight into this new and emerging role as practised in the National Health Service (NHS). Similarities and differences are examined between the CL population and reported within themes, specifically: personal qualities and skills required, training for the CLs, marketing the CL service, working in the clinical environment, monitoring and evaluation and the acceptance of the CL in the NHS. Results: A common understanding of the skills and knowledge required to undertake the CL role was shared by the respondents. However, practice differed as this was often dictated by local circumstances. The study confirmed the need for the CLs to work with clinical colleagues in the clinical setting to enhance patient care.

Conclusion: The importance of using best evidence to support patient care is a message that is slowly becoming the norm in the NHS and the CL role in this practice is demonstrated by this study.
Introduction

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It was decided that the best method to expand and develop themes of interest from the questionnaire in part one was to conduct semi-structured interviews with CLs to investigate actualities of their roles. The interviews took place in 2002 and were conducted at the CL's place of work.

These interviews were part of an iterative process to gain the richest data possible. Key questions centred on core duties, available training, key skills and service promotion. In addition to providing a rich stream of qualitative data, the whole exercise provided an ideal opportunity to juxtapose a set of quantitative data and mix the methods appropriately to arrive at a larger picture, thus triangulating the data. They were recorded with the full consent of participants and subsequently transcribed to enable a content analysis of
What professional and personal qualities are required to become a Clinical Librarian?

It should be immediately acknowledged that the role of the Clinical Librarian is a specialist role as emphasized by one of the respondents.

'The CL role is a very specialist role that hasn't been developed and that hasn't been in health information generally'.

Surprisingly, attaining chartered status was not considered essential for a CL role by some employers. Neither was professional experience of health care information provision. One interviewee had sought opinion on prerequisites for the CL role for the purpose of facilitating professional development workshops, and made the following discovery:

'I was really surprised because I'd made the assumption that anybody working as a CL would have to have NHS experience. However, someone pulled me up on that and said that you didn't have to. It made me realize that there are lots of different ways of approaching it'.

Generally it was believed that personal qualities were more important than 'actual knowledge'.

These personal qualities or skills were described in detail by the respondents and included the following:

- the ability to build and maintain good professional relationships with the clinicians;
- willingness to ask questions;
- the ability to learn, understand and take pleasure in learning;
- a natural interest in clinical and scientific issues.
Knowledge required for the role of Clinical Librarians was considered to be:
Some (unspecified) knowledge of anatomy and physiology;
• origins and meanings of medical terms;
• project management;
• literature-searching experience; knowledge of evidence-based practice;
• research methods (both quantitative and qualitative);
• epidemiology.

This shows that the practising CLs think that there is a great diversity of skills and knowledge required to undertake the role effectively.

Developing the CL role: ‘growing your own’
The study shows that the knowledge and skills expected by the respondents to undertake the CL role is copious and, -taken together, may seem like a ‘wish list’. In fact, the ready-made CL may not be out there in the marketplace to recruit. Therefore, it would seem appropriate for organizations to offer training on appointment and or via professional development to the CLs to ensure that their services develop appropriately. Certain types of training were clearly identified by the respondents and it was acknowledged by the CLs in the study that, while they may not have all of the skills required to fulfil this role, their willingness to undertake training was unanimous. As was to be expected in the NHS, access to training was found to be inequitable and individual CL statements reflected this. Respondents were of the opinion that ability to access and receive formal training in the NHS depended upon fortunate circumstances rather than essential aspects of the job.

‘Because we developed the service, it was very much a case of us identifying what we needed. I’m lucky because if I identify required areas of training we have the budget to be able to do it. For example, I lead the critical appraisal training and we’re in the best position to know what’s needed. It may be different for others who enter a pre-existing post.’

Alternatively, for one respondent, the opportunity to attend training courses
such as critical appraisal and basic biology courses were not automatically offered. However, this was qualified by adding that any training needs were accommodated, and that managers were generally supportive. A course that the CLs strongly recommended as a most appropriate tool for equipping any prospective CL in literature searching was the Programme for Encouraging Clinically Effective Practice in Trent (PRECEPT), run by the School of Health and Related Research (ScHaRR), at Sheffield University.

Working in the clinical setting?

The study was conducted with the expressed objective to discover the similarities and differences between CLs in the UK. It was found that the respondents in the study were working in very different ways within their own hospitals. Clinical directorate policy often dictated CL activity. For instance, one CL stated that she was not required to be present at ward rounds, whereas other CLs were. This was not unexpected from this population and environment as it is the recognized norm in the NHS that practice differs from Trust to Trust.

However, all of the CLs reported working in ways that could be readily identified as traditional Librarians undertaking all of the following tasks:

- to assist in the development of clinical guidelines;
- researching previous and existing clinical guidelines;
- conducting intensive literature searches;
- creating a database of clinical questions to include examples of clinical questions for which high-grade evidence had been found;
- to answer enquiries promptly within an appropriate time frame for the user;
- user education and training.

The respondents were all of the opinion that they were working as professional librarians, but there was some doubt whether all were working as
CLs according to the successful American models. American CL programmes, such as the Vanderbilt University programme, repeatedly expound the benefits of the CL having a presence in the clinical setting and market it as a key role. One CL did not participate in ward rounds, as the clinical director did not desire this. When asked if she had faced any definitive challenges about her post, the following response was recorded:

'Nobody else has challenged it, although I would definitely challenge it myself. I don't think I am a clinical librarian, and it's interesting because there was a guideline development meeting in the emergency department that I went to and the director referred to me as "departmental librarian", which I think is more relevant to what I am.'

Other respondents were, however, allowed more involvement in the clinical setting. This applied to one CL working within the labour suite of an obstetric and gynaecological team. The labour suite was described as 'a series of small rooms where women would deliver' and this CL would stand outside of the room where most of the clinical discussions took place. It was felt that there was no need for the CL to intrude on the patient's privacy by way of introduction. The only patient contacts the CL had were those on the neonatal unit. Occasionally, patients were aware of the CL presence on the intensive care unit (ITU), but it was expressed that nobody deemed it necessary to explain why. The CL certainly felt that hearing the discussion in the clinical setting leading to the construction of the information enquiry was a definite plus, and assisted in searching for relevant evidence.

**Service promotion/marketing**

It is acknowledged in library marketing literature that library service promotion is fast becoming an essential element for information professionals. The respondents confirmed this view as they were all concerned with promotional activity in some way.

The case for service promotion depended once again upon local
circumstances. The interviewing process revealed that fear of over-promotion was a concern for some of the respondents arising from an environment where knowledge is not routinely shared. Specifically problems that emerged were identified as:

- an increased workload for the CL;
- an expanded service that was unsustainable;
- lack of physical library space.

The question of an increased workload resulting from promotion was palpable for some CLs who felt they already managed heavy demands on their time and could not see how anything else could be fitted into their schedule. Combined with this was the lack of physical library space. Some thought that successful promotion could mean vast increases in numbers of users in the library and could create a service demand that was unsustainable.

The client base for the CL service was agreed amongst the respondents as a combination of Medical, Nursing, Allied Health Professionals (AHPs) and Management. This also included all spectrums of the professions from fully qualified staff to undergraduate/postgraduate students. The usual pattern of rotation for junior medical staff between specialities was acknowledged to be 6 weeks for medical students, 6 months for senior house officers (SHOs), and 1 year for registrars; the rotation was usually on a rolling programme so that staff groups did not change simultaneously. This rapid turnover of medical staff within the hospitals generated two quite opposing views to promotion of the service from the CLs.

Negative and problematic views of promoting a service to an ever-changing workforce was expressed. One CL found it difficult to initiate and maintain relationships with staff in the time frame available. Of the medical staff group, this CL thought that the registrars were the most 'stable' group to promote to, as they would be working in the NHS Trust for the longest time. The view of this CL may have been influenced by the previous post held where the participant had worked mainly with nursing staff who were not subjected to the
same pattern of rotation as the medical staff, so it was easier to build stronger relationships and to execute more informal service promotion.

In contrast, another CL did not perceive rapid medical staff turnover as problematic. Instead, it was viewed as a positive aspect, as the introduction of new junior doctors provided a chance to revisit the ward and 'retell the story'. This CL often visited other hospital sites within the Trust and found that clinicians there were already aware of the CL service. However, it was also emphasized that there was no room for complacency in assuming that everyone knew of the CL service, as this was not always the case.

'I once went onto ITU. I expect junior doctors not to know me so I was introducing myself. However, I met one of the dieticians and she was unaware that my service was available to her as well. It made me realize that I always had to be aware that not everyone will know of the service perhaps they were not there when I happened to talk about it.'

Successful methods for promotion were suggested by the respondents as:
- identifying one or more staff within the trust to work with and/or a 'champion' i.e. the Education Director;
- establishing an evidence-based journal club.

Factors that assist promotion were an existing culture of using evidence-based practice. Examples of this were given, one being the appointment of a Registrar in Clinical Evidence. Also, opportunities for marketing the service occurred in clinical settings, e.g. ward rounds when midwives participated in training of students. The process of ensuring that such training ran smoothly included incentives such as provision of certificates as proof that they had attended the ward round, and encouraging them to join in with literature searches. Such initiatives were very successful. Overall, the desired effect was to maximize the efficacy of the ward round process, so that instead of it being a single aspect of the training, it was followed by questions, searches,
appraisal and feedback, ultimately maintaining a high profile for the CL service.

Another key factor in the promotion of the CL service was merchandising. One participant produced specific merchandise, and had autonomy in designing and ordering these items within a designated budget. A specific leaflet detailing the service provided by the CL and pens with the service telephone number were produced amongst other items, to maximize service promotion. This CL also explained that meetings had been held with other staff from similar projects in the region, and that other departments had decided to follow suit after sharing promotion and merchandising ideas.

Value for money-monitoring and evaluation
The respondents in the study were well aware that their practice was regarded as new and unusual within the hospital. Therefore, perhaps it was not surprising to find that CLs were collecting vast amounts of data detailing the workings of the CL service. This usually followed the well-established NHS pattern of counting and collecting everything 'just in case we need it and the established practice of NHS librarians collecting data to inform the annual statistical return. This information behaviour can be traced back well before the Information Management and Technology strategy 1992\(^6\) and 1998\(^7\) to Korner in 1984.\(^8\)

The data being collected was varied and included:
- the number of databases searched;
- the number of hits on MEDLINE, Cochrane and other relevant resources;
- details of the time taken to conduct enquiries;
- the time between the received enquiries and time when information was required;
- number of inter-library loans generated;
- evaluation of training sessions.
A wish from one of the participants to collect statistics about gate entries to library was expressed, to try and establish if the CL service was generating more daily use from staff in the departments than the CL service. However, this was conceded as not technologically possible at that time.

Satisfaction with the CL service by the users was found to be of great importance to CLs and was monitored by the respondents. However, it was stressed that critical incident reporting was the most important evaluative exercise that should be undertaken. The overall aim was to identify critical incidents where clients used the information and benefited from it. To inform this activity, feedback forms were sent to service users and those returned usually contained positive responses. It was acknowledged by the respondents that one of the problems working with busy clinicians was that they seldom had time or inclination to discuss an information enquiry that had already been resolved. Therefore, feedback forms to measure the satisfaction of the CL service did not always hold the same priority for the clinicians as for the CLs.

When questioned about factors that could persuade clinicians that the CL service was worth retaining, the respondents emphasized that a major factor was to support clinical effectiveness and clinical governance through understanding evidence-based practice and lifelong learning, and that statistics alone would not substantiate this.

Discussion

Embedding the CL in UK health service culture

It is debatable what qualities and key skills a clinical librarian should have. Certainly, the results from this study are not intended as a blueprint, but are offered as guidelines for this, based on the opinions of practising CLs. It is, however, apparent that the overriding requirement for any CL is the ability to initiate and develop credibility and strong working relationships with clinical staff.
The literature\textsuperscript{9,10} and responses of this research revealed that a culture shift within the NHS was essential to the continuation and growth of CL services. To gain acceptance for the CL as part of the clinical team, increased visibility for the librarian in the clinical environment was a major consideration in projecting the CL profession forward. CL services are becoming embedded within organizations, as the CLs who participated in this research have illustrated, but many more programmes need to be implemented throughout the NHS to ensure that this branch of the profession gains recognition within the NHS and the Library and of Information discipline.

A great resistance to change on the part of front line clinicians makes the change work practices harder to introduce, and participants noted that this was still apparent in their organizations. However, there are certain drivers in place that will exert increased pressure on clinicians to be more accepting of the evidence-based culture, including the CL role. These drivers include Clinical Governance and government guidelines such as \textit{Building the Information Core}.\textsuperscript{11} The guidelines alone will not be sufficient to change the culture. There is still a lot of work to be done by CL to change the hearts and minds of clinical staff to persuade them of the value of a good CL service. The title of CL, however, did not always seem to be sufficient evidence of expertise to persuade clinical staff in the UK to allow the respondents to practice in the professionally recognized way of their opposite number in America. Gaining recognition for the CL within the NHS workforce will be slowly won, typically with small local victories or success stories. A partnership with the clinical staff must be encouraged to assist this. In 2000, it was noted in the United States that articles about clinical librarianship appear in both medical and library literature, often authored jointly by librarians and physicians.\textsuperscript{12} Working together in this way must be seen as a positive step forward. Ways of maximizing collaborative projects on literary levels should be investigated.

If promoting the CL service was seen as an optional challenge for the CLs \textit{in situ}, then measuring effectiveness and value for money was seen as a
necessity, but a very difficult necessity. The degree of client satisfaction identified in the results of individual trust evaluation exercises was thought to be invaluable by respondents when presenting a case to management for the continuation of the CL service. However, to accurately measure the activity and efficiency of a CL service, the information systems for gathering responses from the users must be developed to be as unobtrusive as possible at local levels.

It is acknowledged that, for any monitoring and evaluation exercise, local circumstances should always be considered. An example of this is detailed in the report by ScHaRR on the Clinical Librarian service, for The University Hospitals for Leicester NHS Trust but clearly some national norms need to be established. A change in the routine statistics collected by the NHS to assess library performance is required to reflect this new activity. A possible way of addressing this requirement would be to introduce new performance indicators within the annual NHS Library return to adequately reflect the role of the CL (e.g. time spent on ward rounds).

Conclusion

The lack of a national profile is one that must be addressed by the profession. However, specialized training for this role needs to be identified and managed if national acceptance and norms are to be established. Currently, the academic institutions do provide good generic knowledge and transferable skills at postgraduate level to equip students to become a CL on graduation.

Benefits or usefulness to the end user need to be clearly identified. The evidence lies in the lack of common agreement amongst CLs, and their presence, use and value in clinical settings. There are different parameters governing CLs, making it difficult to present a cohesive sense of service to others within the NHS. Therefore, it is imperative that the use of the CL service engenders a change in practice, and new practices that serve to improve patient care must be monitored and evaluated. A specific professional group is potentially a way forward for this, such as the creation of
a new group for clinical/evidence-based librarianship within the Chartered Institute for Library and Information Professionals (CILIP). However, in addition, the good practice of the CL service must be broadcast throughout the undulating terrain of the NHS and not merely in the traditional environment of the library and information press, professional or academic.

The role of the CL is expert and complex, demanding a combination of skills and knowledge. It can be viewed as a cross between detective and barrister. In the case of a clinical enquiry, the facts of the case need to be found and the resulting information synthesized and retold to the jury. This combination of skills and a forceful pro-active approach is not one that has usually been associated with the library and information profession. However, the time has come to shout loudly about the benefits of a CL service and demonstrate its worth. Otherwise it is feared that the skills of the CL will be sacrificed on the altar of knowledge management or knowledge improvement or health informatics, all purporting to be able to perform the duties of the CL, but failing to exercise them adequately or indeed without that understated, unobtrusive charm of the professional librarian.

References


**Key Messages**

**Policy**

- New Performance Indicators are required to reflect the growing and developing role of the CL service in the NHS.
- Create a new branch specifically for CL services within the Chartered Institute of Library and Information Professionals (CILIP).
Implications for Practice

- Core duties to be established in the UK for Clinical Librarians.
- Continuing Professional Development (CPD) for Clinical Librarians.