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Do NHS Libraries Have a Role in Providing Information for Patient Care?

June 2008

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Institute for Health & Social Care Research

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Do NHS Libraries Have a Role in Providing Information for Patient Care?

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Contents

Acknowledgements

Executive Summary

Introduction

Ten years ago, the UK government outlined a strategy that aimed to 'ensure that patients, carers and the public have the information necessary to make decisions about their own treatment and care' and suggested that the 'NHS has a major responsibility to provide or enable access to relevant and reliable information' (DH 1998). Given that one of the main roles of an NHS Library is the provision of access and training to health information for NHS staff and that health librarians are skilled in accessing, using and to some extent understanding health care information, to some it may seem a logical step for NHS Libraries to be involved in the provision of health information to patients. This may not necessarily mean opening up the library to patients, but supporting other NHS staff to provide information to patients. However there are also issues about duplication, appropriateness and implementation that should be taken into consideration when examining the role of the NHS Library in providing information for patient care. This report describes a project that aimed to explore these issues by asking:

- What public sector based information services are currently provided to patients and carers in the North West and by whom?
- What are the views of key stakeholders regarding:
  - o Whether NHS Libraries should provide information to patients and carers?
  - o Whether NHS Libraries could provide information to patients and carers?
  - o What type of services could be offered?
  - o What roles could NHS Libraries play?
- If NHS Libraries were to provide information to patients and carers, what would be needed to facilitate and/or support them?

By answering these research questions, the report aims to provide:

1. A 'map' of the provision of public sector based patient information services in the North West
2. An overview of stakeholder views regarding the role of NHS Libraries in the provision of information to patients

Methods

A self-report survey was developed, and administered electronically across stakeholder groups to enable comparative analysis of different perceptions. This was combined with a comprehensive Internet search of Trust and Public Authority websites to generate a deeper understanding of what current information services were available to patients. The survey was emailed to 218 stakeholders (57 Directors of Nursing; 26 Directors of Public Health; 67 Patient Advice and Liaison Managers (PALS); 50 NHS Library Managers; and 26 Public Library Managers).

Key Findings

A total of 83 (39%) of returned questionnaires were usable. The results highlighted both quantitative and qualitative data regarding the perceptions of the different stakeholders and together with the information gained from the Internet searches provided an 'indicative map' of the public sector based patient information services available in the North West.

- There is a wide range of services and initiatives available with the aim of providing information to patients but service provision throughout the region is neither equitable nor systematic.
- There is an inconsistency of knowledge amongst stakeholders regarding the availability of services.
- Six NHS Trusts confirmed that their libraries already provide access to patients. There are five examples of dedicated patient information libraries and a wide range of partnership initiatives between the NHS and the Public Library sector to provide information to the public.
- The majority of stakeholders believed that patients should have access to NHS Libraries.
- A small majority believe it is realistic that NHS Libraries provide information to patients. There are significant differences between the views of NHS Librarians and other stakeholders groups. The former are less likely to agree that patients should have access to NHS Libraries and that it is realistic that NHS Libraries provide information to patients.

- NHS Librarians concerns are centred on funding, inappropriateness of resources, clinicians and patients sharing facilities, lack of training in dealing with patients and the implications of providing information to patients.

- There were mixed views on how facilities should be organised. A separate area for patients within an NHS Library was seen as more preferable than shared facilities although this was still not an attractive option to some NHS Library Managers.

- The main barrier to NHS Libraries providing information services to patients is a lack of funding.

- Current resources are aimed at NHS staff, however the majority of stakeholders did not believe these were inappropriate for patients.

- NHS Librarians were less likely to agree about the appropriateness of current resources and stressed the need for increased funding to purchase both appropriate resources, additional staff to be able to cope with the increased demand on services and training to deal with a different type of enquirer and enquiries.

- The majority of stakeholders perceived that PALS should play more of a frontline role in providing information to patients and NHS Libraries could be used as a backup or supporting role. However there was disagreement as to how this should be achieved.

- The majority of NHS Libraries are already supporting clinical staff in the provision of patient information and there is a clear role for NHS Libraries to provide this type of support. More promotion in this area would increase the library profile.

- A few libraries are already providing information directly to patients by a range of means. There is some support for these methods to be adopted by other libraries.

- All stakeholders were positive about the role that public libraries could play in providing patient information.

- Public libraries are clear about their role in "signposting" the public to quality resources but not providing medical advice or guidance.

- Public library staff have customer service and enquiry skills to help the public find information but would value more specialised training from NHS Librarians.

- There are a number of opportunities for collaboration between the NHS and Public Libraries, including NHS Librarians providing training and support in specialised health resources and the potential opportunity for public libraries to provide training in customer care issues.

Conclusion and Recommendations

Although the aim of this project was to focus on the role of the NHS Library in providing patient information, three successful models of information provision are operating within the region and were highlighted and discussed throughout:

- NHS Library provision of information to patients
- The dedicated patient information library
- Partnerships between NHS and public libraries

- Co-ordination amongst the plethora of services provided is needed. A forum to enable the sharing of information regarding the availability of services, good practice and roles of different providers amongst stakeholders would reduce duplication and confusion.
- The dedicated patient information library has support, but is likely to be costly.
- Further collaboration and partnerships between NHS and Public Libraries are viewed positively are a potentially viable option and should be explored further, building on the links and lessons learned from the NW NHS Public Libraries Partnership Project.
- The majority of stakeholders were in favour of the provision of patient information by NHS Libraries, provided adequate funding to cover resources and training are identified.
- Information sharing/training from libraries that already provide access may be a useful step forward in encouraging more NHS Libraries to explore different ways of providing patient information.
- A clear role for NHS Libraries needs to be established (as public libraries have done). This would give NHS Libraries clear operational guidelines and help identify areas of training that need to be developed.
- NHS Libraries are already demonstrating that they play an important role in the provision of patient information by working with clinicians, this role should be widely promoted to maximise the impact that they are making. Links with PALS should be established or extended to examine how the two services can work together and provide mutual support.

Chapter One

Introduction and Background

Background

Ten years ago, the UK government outlined a strategy that aimed to 'ensure that patients, carers and the public have the information necessary to make decisions about their own treatment and care' and suggested that the 'NHS has a major responsibility to provide or enable access to relevant and reliable information' (DH 1998). More recently the government went a step further, suggesting that patients should become more involved in decision-making and planning their own but to achieve this they 'must have the necessary skills to access, understand and use information' (DH 2004, DH 2008). There are compelling reasons that providing information to patients about their condition or treatment is beneficial. These include supporting self care and recovery rates, thus reducing cost to the NHS, helping patients understand their conditions and treatments, supporting the choice agenda, contributing to improved quality of life, and contributing to the wider public health agenda in terms of improving the health of the population (Stewart 2006). Furthermore patients using digital information services have reported that after accessing health information, they feel better informed, reassured, more prepared for medical consultations and more aware of healthy lifestyle issues (CIBER 2004).

It has long been acknowledged that both patients and carers consider clinicians providing the direct patient care as the most important source of information and support (DH 1998). Additional sources of information that are both reliable and accredited are also needed (DH, 1998) and as a response NHS Direct was established (Helpline, Online and Digital TV). NHS Direct has proved to be successful, with one report noting that the online service has emerged as one of the most used (Internet) health service in the UK, considered to be 'trustworthy by users' (CIBER 2004). NHS Direct has recently been supplemented by 'NHS Choices' a website that draws together information for patients from a range of NHS organizations to provide patients with information about their health in addition to local services. However the wider consumer health or patient information movement predates the government strategy documents and initiatives and information

has been available to patients from a wide range of organizations and sources for a number of years. Discussing this is beyond the scope of this report.

Stewart (2006) describes a wide range of providers of information to patients including: NHS organizations, local authority providers (including public libraries), commercial suppliers including the media and the Internet, voluntary and charity organizations. He concludes that although there are multiple providers of information and multiple channels through which information is provided services lack strategic co-ordination and ownership leading to duplication of effort and ineffective use of available resources.

One of the main roles of an NHS Library is the provision of access and training to health information for NHS staff. Health librarians are skilled in accessing, using and to some extent understanding health care information to some then it may seem a logical step for NHS Libraries to be involved in the provision of health information to patients. In 2005, the National Library for Health (NLH) proposed 'to extend NHS Library services to patients and the public for the first time' (NLH 2005), but did not clarify how this was to be achieved. This may not necessarily mean opening up the library to patients, but rather supporting others to provide information to patients. This has been recognised in the recent review of NHS Library Services (Hill 2008) which notes that both the public and patients have the right to access 'the same knowledge and evidence base as professionals.' It also observed that 'NHS Libraries are already crossing boundaries by beginning to provide patient information in a range of ways but both resource and capacity issues become significant if this is to be considered part of the main work of health libraries' (Hill 2008).

A previous study (King and Hornby 2003) highlighted mixed views from North West NHS Librarians on the provision of information to patients. Librarians fell into two groups, both recognizing the need for patient information, but one group willing to be involved providing funding, relevant resources and trained staff were in place; the second group opposed the view that patient information was part of their remit. Given that NHS Libraries have been subject to many changes since this first study was undertaken and in light of recent policy developments (Hill 2008) it was timely to examine again the views of NHS Librarians regarding the provision of information to patients. It was decided to broaden the scope of the research to include views other than NHS Librarians to generate

a clearer understanding of wider perspectives and ideas on how different services, roles and forms of information provision can collaboratively meet the information needs of patients. The views of key stakeholders identified by the commissioners (including Directors of Public Health, Directors of Nursing, Patient and Liaison Managers, NHS and Public Library Managers) were canvassed. This research report describes this study with the aim of answering the following research questions.

Research Questions

- What public sector based information services are currently provided to patients and carers in the North West and by whom?
- What are the views of key stakeholders regarding?
  - o Whether NHS Libraries should provide information to patients and carers?
  - o Whether NHS Libraries could provide information to patients and carers?
  - o What kind of services could be offered
  - o What roles could NHS Libraries play?
- If NHS Libraries were to provide information to patients and carers, what would be needed to facilitate and/or support them?

Aims

By answering the research questions, the report aims to provide:

1. A 'map' of the provision of public sector based patient information services in the North West
2. An overview of stakeholder views regarding the role of NHS Libraries in the provision of information to patients

Study Definitions

- Public sector based is defined as NHS, local authority and public libraries for the purposes of this project

- Patient information is defined as information about a particular condition or intervention that patients or their families or carers may find useful. This term is used throughout the report to describe 'information for patients or carers'
- Key stakeholders include: Directors of Public Health, Directors of Nursing, Patient and Liaison Managers, NHS and Public Library Managers

Chapter Two

Literature Review

Introduction

A brief literature review was undertaken to contextualize the research and identify potential tools that could be used in developing the survey instrument. A search of LISA was conducted using the term 'patient information' from 2002 onwards. The search highlighted a dearth of studies focusing on the provision of patient information by NHS Libraries but did locate material on the information sources used by patients and highlighted a range of models used for providing information services to patients. This also informed study development and fed into the discussion. The results of this brief review are highlighted below.

The provision of patient information services by NHS Libraries

One study was located that discussed the provision of patient information by NHS Libraries (King and Hornby 2003). This was a survey, with 33 respondents, conducted in the North West region, to examine the role that health librarians could play in helping patients find information. It examined the type of library and users, access to information for patients, librarians' attitudes to provision of information to patients and their knowledge of other sources available. The majority of librarians believed they could recommend quality information sources to patients, but also highlighted practical problems in allowing patients to use health libraries. These included appropriate resources, facilities, funding and lack of staff time. The discussion and conclusions of the paper focused on ways that health libraries could be involved in the provision of information in other ways (rather than physical access to the library). These included the development of online services such as websites with links to good quality resources, evaluation of websites to produce lists of good quality resources tailored to the needs of patient groups and collaboration with Trust staff involved in the provision of patient information including PALS and clinicians writing patient information leaflets. It was also suggested that the key to NHS Librarians developing a role within patient information was co-

operation and innovation. It was recognised that librarians need to take a pro-active approach and suggest to Trust members how they can become involved in the provision of patient information.

What information sources do patients use?

Limited information was found on the information sources used by patients. Although it is likely that a more focused search on the information needs of patients may have produced more evidence relating to sources, this was believed to be outside the remit of this particular project. A systematic review of the information sources used by cancer patients (Ankem 2006) reviewed 12 articles and concluded that health care professionals, information leaflets and family and friends were the most used sources of information. However books, health care professionals and information leaflets were found to be the most helpful. The Internet and support groups were the least used. The studies ranged from 1996 to 2002 and this finding may alter over time. The author concluded that it is necessary to gain an in-depth understanding of the sources cancer patients use in order to develop successful patient information interventions. Brawn (2005) conducted a small survey of US Consumer Health Librarians in an attempt to evaluate patients' information needs. The most popular services provided included computer access (for Internet use and word processing), information leaflets, ability to use laptops, children's area, free delivery of materials, photocopier and fax, medical databases and help in locating information. When asked what users seemed to need or want most from the consumer health library the summarized responses included: information on disease conditions, information on navigating the health care system, miscellaneous non medical reference information (e.g. travel directions), a quiet place to escape, printed material to share with a patient and the rest of the family, computer access for email or research, information about medical tests, recommendations and evaluations of doctors. It was also reported that doctors appeared to need or want: assurance that a quality service and materials were provided, a consultation service on patient education material, a place to refer patients for additional information and instruction in navigating the Internet. Unfortunately the reliability of this survey was limited, lacking the appropriate detail of responses that were based solely on the librarians' perceptions of what patients and doctors wanted from the consumer health information service, rather than seeking the views of the stakeholders themselves.

CIBER (2004) examined the use of digital health information services focusing on three sources, the Internet, kiosks and digital TV. This was a large scale, long term project made up of a range of small studies (including one on the use of NHS Direct online) however the results have been produced as a summary report. It concluded that the best platform for delivering health information to the vast majority of the population is digital TV as it reaches a broader audience and its use is less inhibited than other platforms. This is followed by the Internet which is described as 'excellent for the expert patient' and finally information kiosks. The report is easily digestible and contains a large amount of evidence about the usability of each of the sources, together with detailed profiles of those who use them and recommendations to improve the usability of each platform. However as the developments in this area are so fast changing, there is a danger that its findings may soon, if not already, become dated. Evidence is also provided regarding the information needs of the digital service users. CIBER categorises online users as 'the alternative remedy user' the 'staying fit and healthy user', the 'keeping up to date user' and the 'I'm ill but I want to know more user' (CIBER 2004), descriptions which to an extent describe the reasons that patients seek information and may help shape the development of sources and services for patients. The majority of online users were seeking information on specific conditions or illnesses. Other reasons for online searching included: gathering information in relation to a doctors visit, to look for information about nutrition, advice or weight control, look for information about alternative medicines, information about sensitive topics that are difficult to talk about, mental health issues such as anxiety or depression, innovative or experimental treatments and to diagnose or treat a medical condition on their own (CIBER 2004).

Models of patient information services

Patient information libraries

Three models of specific patient information libraries were described. Truccolo et al (2006) describe a cancer patient library in Italy which has subsequently been used as a model for establishing a further 20 services throughout the country. The service has two components – a cancer information part and a recreational book library that operate within the institutes' medical library. A skilled intermediary (psychologist trained in information science) is appointed to the cancer information point and provides patients and family with

information targeted to their information needs regarding cancer. The information is scientifically valid, current and written in straightforward language. The resources include print and electronic and have been recorded in a national database of literature for cancer patients. The service is publicised via leaflets within the hospital, the hospital website and by word of mouth. A survey to users aimed to evaluate its usefulness and perceptions about the quality of information and service received. Patients reported using the library to find information on general aspects of the disease, treatment or rehabilitation, psychological aspects for managing their condition, nutrition and diet and prevention of further tumours. The majority expressed satisfaction regarding the information and service received, indicating that the information provided them with a clearer understanding of the illness and treatment and the ability to ask the doctor specific questions.

Hammond (2005) described a different model of patient library, purpose built and located within the entrance hall of a large US hospital. This was a collaborative venture funded by the regional health system and co-ordinated and supported by the local academic and hospital libraries. The service is staffed by a qualified medical librarian and supported by volunteers, trained by the librarian. A range of marketing and publicity approaches are described including workshops with patients and clinical staff. Resources include PCs, Internet access, electronic resources, magazines, newsletters books and videos. There is also an area aimed at children with appropriate resources and a private room for consultation or viewing audiovisual material. The article describes the advantages offered by a specialized patient library and outlines the lessons learned in developing the service and establishing the partnerships needed to ensure its continued success.

Another US specialized patient information service, operating within a cancer centre was described (Volk 2007). The service is also managed by a qualified librarian, supported by volunteers and is visited by 3500 users each year. A variety of services are provided including a reference service, patient information leaflets, books audiovisual material, bibliographies on specific cancer types and 'supportive care topic guides'. The service also provides 2 more in-depth services – an information packet service which provides a 'packet of information' including brochures, handouts and other relevant material to inpatients following requests and relayed via nurses on the clinical unit where the patient is based. An expert searching service is also offered to in- and outpatients to answer requests that cannot be satisfied from the existing leaflet collection. The paper describes

an evaluation of the expert searching service which demonstrated that user satisfaction was very high and provided unique information that patients were not able to locate on their own. The information provided helped patients better understand their condition, improved communication between the patient and medical staff and improved their ability to tolerate their condition.

Library Partnerships

In addition to the dedicated patient information libraries described within the literature, other models whereby health libraries can support the provision of patient information were described.

Wessel et al (2003) describes a US National Library of Medicine funded project in Western Pennsylvania where the academic medical library provided training to public librarians on finding health information. The project was deemed successful as it achieved a relatively high level of participants from public libraries, positive course evaluations, perceived increased comfort level with health related reference queries and the increased use of MEDLINEplus and other quality health information resources. This initiative was part of the same funding analysed by Ruffin et al (2005) in a study that examined the effectiveness of methods and approaches used in 53 consumer health information outreach projects funded by the US National Library of Medicine in 2000. The aim of all the projects was to improve access to electronic health information for the public and involved medical and public libraries in partnership with a wide range of community organizations to provide training in the use of MedlinePlus, other health information resources and Internet access in a range of settings.

The range of different projects and partnerships are described and include 13 projects, which aimed to target health professionals and make them aware of resources available to support patient education. The authors concluded that the projects led to significant benefits despite minor setbacks and unexpected problems. These included: increased awareness of health libraries and the recognition that they are a source for assistance. Collaborations between health and public libraries led to a public library perception of the hospital and academic libraries as resources for medical information and this in turn led to resource sharing and reference requests. Management at the institutions involved gained a greater appreciation of the library and what it was able to provide. The addition of

consumer health information to library websites raised the health library's visibility and librarians benefited from an expansion of their personal networks that crossed professional boundaries. On the other side of the coin some projects needed to overcome disinterest or overwhelmed library staff due to the additional responsibility of providing consumer health information. Some projects ran into funding problems and had to draw on the library budget in order to fulfil the commitments agreed for the project.

In the UK a pilot project was undertaken to create access to the National electronic Library for Health (NeLH) in public libraries (McNicol and Nankivell 2002). The project took place in two case study public library authorities, where demand for the service and patterns of use were investigated. The project report concluded that a significant amount of staff training was required to allow library staff to help users effectively. Few users were able to find the information they needed without assistance, this was in part due to the lack of an effective search facility available on the site. Given the more recent developments in the National Library for Health (previously NeLH), this type of problem may be no longer such an issue. A number of suggestions put forward to improve the usability of the NeLH interface for patients included a system to deal with common medical names and the availability of information leaflets for printing, issues that are now perhaps likely to be addressed with changes to the NHS Choices website. Local and national infrastructure concerns were also highlighted, again some of which may be overcome through the proposed changes to NHS Choices and the improved functions of the National Library for Health. The need for staff training was also acknowledged.

In the North West the need for training has more recently been addressed to some extent by the NHS NW public libraries partnership project (Nair 2006a, 2006b). An initiative funded by NW HCLU and the then Cumbria and Lancashire Strategic Health Authority to establish partnerships (working relationships) between NHS Libraries, public libraries and social services. It aimed to provide NHS staff with access to electronic resources via public libraries and the public with access to quality health information. NHS Librarians provided training, booklists and ongoing support to the public librarians resulting in a number of working relationships. The project was enthusiastically received by participants and it was noted that progress was faster in areas where relationships already existed, however some authorities delayed participating in the programme. A number of lessons were learned, including the need to get all stakeholders on board whilst acknowledging

they are already operating within a number of stresses and constraints. Another UK example of partnerships between public libraries and the NHS is the Department of Health's 'Information Prescription' Project (2008). According to the project website *'From 2008, information prescriptions will be offered to everyone with a long-term condition or social care need, in consultation with a health or social care professional. Information prescriptions will guide people to relevant and reliable sources of information to allow them to feel more in control and better able to manage their condition and maintain their independence.'* They provide a series of signposts or links to information. Pilot projects are operating throughout the country including in the North West Manchester Public Libraries and Manchester PCT.

Middleton (2005) describes the advantages of partnership working between public libraries and health and social services, particularly in relation to older people and focusing on a number of initiatives taking place in Gloucestershire public libraries. These include books on prescription schemes, choose and book routine secondary care appointments, library clubs for the housebound or socially isolated older people and providing older people with access and training to use the Internet. The latter includes training older people to order groceries online reducing the burden on home care staff. Middleton argues that public libraries are well placed to serve the health related needs as they are public spaces, with services and skills targeted at meeting public needs and are often within walking distance of GP surgeries and located within the communities. She also recommends a 'champion' within the public library who can forge partnerships and work proactively with health and social care staff.

Summary

This literature review aimed to contextualize the research and identify tools that could be used in the study. There was a lack of information on the provision of information to patients by NHS Libraries. However one useful study was located that had surveyed NHS Librarians on this issue. This survey was therefore used as a basis for the survey described in the remainder of the report and its recommendations for ways forward, together with the models of information provision noted above were incorporated into the questionnaire. The two main models of information provision to patients described in the literature are dedicated patient libraries or partnerships between health and public libraries. These are explored further in the discussion section (chapter 6).

Chapter Three

Methods

Introduction

This chapter outlines the methods used to examine the role of NHS Libraries in providing information services to patients. Following a brief summary of the overall approach each method is described in detail, alongside the target population characteristics of the key stakeholder groups, to provide clarity on how the research was taken forward.

Overall Approach

The focus of the study was to map current public sector based patient information services and compare and contrast the perceptions of the key stakeholders with respect to current and future NHS Library service development. For this both a descriptive and analytical approach was required to draw out the evidence and address the embedded components of the three study research questions:

- What current information services are available to patients?
- What could/should be available?
- What support is required to achieve this?

A self-report survey was developed, informed by existing instruments and current research evidence to administer across stakeholder groups to enable comparative analysis of different perceptions. This was combined with an Internet search of Trust and Library websites to generate a deeper understanding of what current information services were available to patients.

Internet Search

A search of 62 front end NHS Trust websites was carried out to determine what patient information services are offered within each Trust in the North West. The search began with the home page, and examined initially if there was a tab, section or link aimed at patients. If no tab existed searches were carried out using any search engine within the website or clicking on other available tabs to determine what information was located at lower levels. A service was classed as available if it was located within 3 mouse clicks (from the patient specific tab where it existed or the home page if this facility was not available). Three mouse clicks were selected as a cut off point, due to time constraints. Furthermore it was anticipated that users may not continue to search for information if it was not easily available. This is in line with the principle that users of digital libraries exhibit shallow, horizontal 'flicking' behaviour (CIBER 2008, p19).

The services searched were in line with those in the questionnaire survey and can be seen along with an example of the data record sheet in Appendix 1. Additional information describing the services located was stored in a file in Microsoft Word. Websites of 21 North West local authority libraries were searched to identify any "patient information" related initiatives operating within that particularly library authority. Details were stored in Microsoft Word. Free text searches in Google using the terms 'health information', 'health education', 'patient information', 'health promotion' for each region in the North West; Cumbria, Greater Manchester, Cheshire, Lancashire and Merseyside were carried out. Data was recorded in Microsoft Word.

Self-Report Survey

A self-report survey was considered to be the most appropriate method to target the perceptions of a large diverse sample across the North West region, given the time and resources available. The use of a single study instrument adapted slightly for each stakeholder group facilitated cross-group analysis, comparing and contrasting opinions regarding the perceived role of NHS Libraries.

Development of the survey instrument

The development of the study instrument was informed by the literature review, in particular a study performed in 2003 by King and Hornby, which focused on similar aims but represented the perceptions of only one group of key stakeholders, captured 5 years previously. The King and Hornby (2003) instrument provided a clear platform of useful items and concepts upon which to develop the self-report survey. It was therefore considered appropriate rather than deriving an entirely new instrument to replicate and adapt questions that had previously been found to be reliable in extracting data relevant to this study. This increased the criterion reliability of data items. In addition the replication of questions to a similar cohort would also provide the opportunity to compare and contrast opinions and track changes overtime.

The self-report instrument was comprised of 11 questions (see Appendix 2 for example). Questions one and two captured demographic data (job title/organisation), and question eleven provided an opportunity to add further comments regarding the study topic. Additional questions to draw out deeper perspectives of particular stakeholder groups were added as appropriate. For example NHS Library Managers were asked about their needs in relation to providing patient information, PALS were asked about the volume of patient information enquiries they handled and their links with NHS Libraries and public libraries were asked about their role in providing patient information and links with NHS Libraries. The core questions (3-10) that directly explored the study aims are listed below.

1. What information services are you aware of that are currently provided to patients and carers in your Trust? (List of 12 items to indicate whether available/ not available/don't know)

2. Do you know of any specific initiatives or services in the North West that have been developed to provide patients and carers with information? (Open question)

3. How useful do you perceive the following information sources are to patients? (List of 13 items to rate on scale of 1-5 useful/ not useful)

4. What are your opinions regarding NHS Libraries providing information to patients and carers? (List of 21 statements to rate agreement on scale of 1-5 strongly agree/ strongly disagree)

5. Do you think it is realistic to expect NHS Libraries to provide information to patients and carers? (Yes/No question with opportunity to expand on No response)

6. Which of the following services are or should be available from your local NHS Library to patients? (List of 9 items indicate whether available/ not available/should be available)

7. Which of the following services are or should be available from your NHS Library to staff? (List of 8 items indicate whether available/ not available/should be available)

8. Please describe any other services/roles that an NHS Library could offer to staff and patients that would enhance access to appropriate information for patients and carers? (Open question)

The majority of questions provided listed items from which respondents were asked to make a selection. The rationale behind such a structured approach was to generate data that was useful and could be easily compared and contrasted across the different stakeholder groups. Comprehensive lists of data items specific to the question were derived from existing research evidence to enhance criterion reliability. To ensure completeness of data open questions were used to capture new initiatives in operation and suggestions on how services could be developed in the future.

A template of the study instrument was developed using Survey Monkey™ software to facilitate the generation of an easy to use and comprehensive electronic based survey. Survey Monkey™ allows a link to the questionnaire to be emailed to potential respondents. The responses are stored on the Survey Monkey™ server and can be downloaded and imported into spreadsheet programmes such as Microsoft Excel and SPSS.

Before the survey was emailed to the sample, it was piloted on a small group of individuals, a lecturer in public health at Salford University (to ensure that the questions were relevant and comprehensible to public health staff) and two members of the health team at Salford University Library (to ensure that the questions were relevant and comprehensible to librarians). Furthermore the questionnaires were sent to the commissioner's for verification. A number of small issues with question wording were identified and rectified and the group indicated that the questionnaire took approximately 10 minutes to complete.

Identification of target population in the North West

A sample of contact details were provided by the Health Care Libraries Unit drawn from their own databases. To ensure quality assurance of the target population for all stakeholder groups, names, roles and organisations and email addresses were checked manually through Trust websites to ensure accuracy. A comprehensive database of the key stakeholders within the target population throughout the North West was compiled.

There were five distinct groups of professionals that formed the key stakeholders whose opinions and perceptions were considered important to the commissioners of the study (Table 1):

Group	Total Number (N)
Directors of Nursing	57
Directors of Public Health	26
Patient and Liaison Managers	67
NHS Library Managers	50
Public Library Managers	26

Table 1: Stakeholder Target Population – North West

The study focused on information services within the North West thus the target population was located within this geographical region. There were 63 Trusts, 1 Strategic Health Authority, 46 NHS Library services (although some library managers are responsible for more than one library and some library services have more than 1 manager) and 21 public library services within the region. The total number within each stakeholder group that were emailed the study questionnaire is indicated in Table 1.

Where a stakeholder group had more than one representative within the organisation, such as two Library Managers or two PALS performing the same role both were included within the total number.

Recruitment and survey administration

The self-report survey was administered electronically to the total sample across each of the different stakeholder groups. Given the activity of accessing emails is likely to be part of the daily practice for all members of the target population it was considered a fast and

reliable method to use to distribute the electronic survey instrument. A total number of 226 electronic survey emails were sent in January 2008. Of these 32 emails bounced back, these were investigated and incorrect emails rectified for 18. It was not possible to identify correct email addresses for the remaining 14 as such these were excluded from the sample. Therefore a total of 218 emails containing a link to the self-report survey were administered and 'apparently received'.

An introductory email explaining the study and providing a link to the electronic survey was sent to each potential participant (see Appendix 3). In addition each participant was provided with the option to receive a hard copy of the survey rather than an electronic version to accommodate individual preferences and enhance recruitment.

Participants were given two weeks to reply. After this time a second email was sent out, thanking all those who had responded already and reminding non-responders that there was still time to participate. After a further 1 week if there was no response it was assumed that the participant did not want to be involved in the research study. Consent to be involved in the study was presumed on completion and return of an electronic survey

Ethical Considerations

Ethical approval was obtained from The University of Salford Research Governance and Ethics Committee prior to commencing the study.

All survey respondents were anonymous in that no personal details were asked for or recorded within the survey format, the only identifiers being job title and name of organisation. Given that the majority of respondents were invariably the only person performing a particular role within an organisation they could be identified only by the researchers. Further reassurance was provided to respondents in that no individual would be identified by their comments in the analysis and writing up of the study findings and that group perceptions would be used to describe the stakeholder perspectives. It was however, made clear that an organisation where good practice existed would be named within the report but this information could have been confirmed from a number of different sources thus the identity of a respondent remained anonymous.

Data Analysis

The use of the Survey Monkey™ software resulted in the survey data being automatically collated using an Excel database. Simple descriptive statistics using frequencies were used to compare and contrast responses from the different cohorts. Spearman's correlation was used to examine whether significant differences existed between the perceptions of two distinct groups: NHS Library Managers and other professionals (Directors of Nursing, Directors of Public Health and PALS staff).

Qualitative data presented from the open questions (4 and 10) and the additional comments section on Question 11, were analysed separately using thematic analysis to group and explain data items with respect to the underlying question prompt.

Chapter Four

North West public sector based information services

Introduction

A total of 114 questionnaires were returned (53%) (Table 2). This was considered a good response rate, particularly from the library and PALS sectors. Unfortunately a number of the questionnaires were unusable due to missing data, particularly PALS and NHS Library Managers, reducing the usable response rate to n=83 (39%). This was disappointing and it was unclear whether this was due to technical problems (a number of emails were received noting technical problems) or whether respondents had decided not to complete the questionnaire. The technical problems were investigated and rectified if it was an issue with the questionnaire itself (e.g. unable to proceed past a required field) or queried with the Survey Monkey Help Desk who indicated that the missing data may be due to respondents using the forward and back buttons on their browsers (rather than the forward and back button on the questionnaire itself).

Group	Total Number Returned N= (%)	Usable N= (%)
Directors of Nursing	18 (33%)	14 (25%)
Directors of Public Health	9 (35%)	7 (27%)
Patient and Liaison Managers	31 (51%)	19 (31%)
NHS Library Managers	41 (84%)	31 (63%)
Public Library Managers	15 (65%)	12 (52%)
Total	114 (53%)	83 (39%)

Table 2: Response Rates

What public sector based information services are currently provided to patients and carers in the North West and by whom?

The results presented in this section are collated from a range of sources. Stakeholders were asked to note on the questionnaire whether their Trust provided access to a range of information resources or services for patients. Responses were mixed and bound by the underlying knowledge of the respondent, with some indicating a distinct lack of knowledge of available patient information services. Furthermore responses of stakeholders within the same Trust sometimes conflicted, calling into question the accuracy of their knowledge. Internet searches were also used to identify sources, however these were not always easily located, particularly within the 3 mouse click cut off point. Combining the information from all the sources was a pragmatic approach that provided some level of verification, but still may not be entirely accurate or comprehensive.

An indicative (rather than comprehensive) map of the information services available to patients in each Trust is presented in Tables 3-5. The 'map' has been colour coded according to the weight (or accuracy) that can be placed on the evidence provided. In general, green highlights that the service has been confirmed as available; amber shows availability has been indicated but not confirmed; red indicates confirmation that the service is not available; and white indicates no information was provided or located about the service in question. The rationale for confirming availability varied slightly between columns. For example if the column refers to NHS Library services more weight was given to the accuracy of the response of the NHS Librarian. The rationale for generating the weightings (colour codes) for each column is provided in Appendix 4, together with an alphabetical listing.

Availability of PALS

PALS services are widely available (confirmed in 55 Trusts and indicated in 3 further Trusts). When asked about enquiries received relating to patient information, 19 PALS responded, 13 of which (68%) provided details and percentage figures of patient information enquiries. The responses were varied and the volume of patient related enquiries ranged from 1-75%, the mode being 5% and 10%, mean 22%, indicating that on the whole patient information enquiries for PALS represented a low volume of their

workload. Eighteen PALS provided details of the types of patient information they provided or where they referred patients to (Figure 1). The majority provide patient information leaflets, refer to websites of charities and support groups and provide helpline numbers. Eight provide access to databases and the Internet and thirteen carry out database or Internet searches on behalf of patients. Only 2 refer patients to NHS Libraries whilst 12 refer patients to the public library.

Figure 1: Patient information services offered by PALS
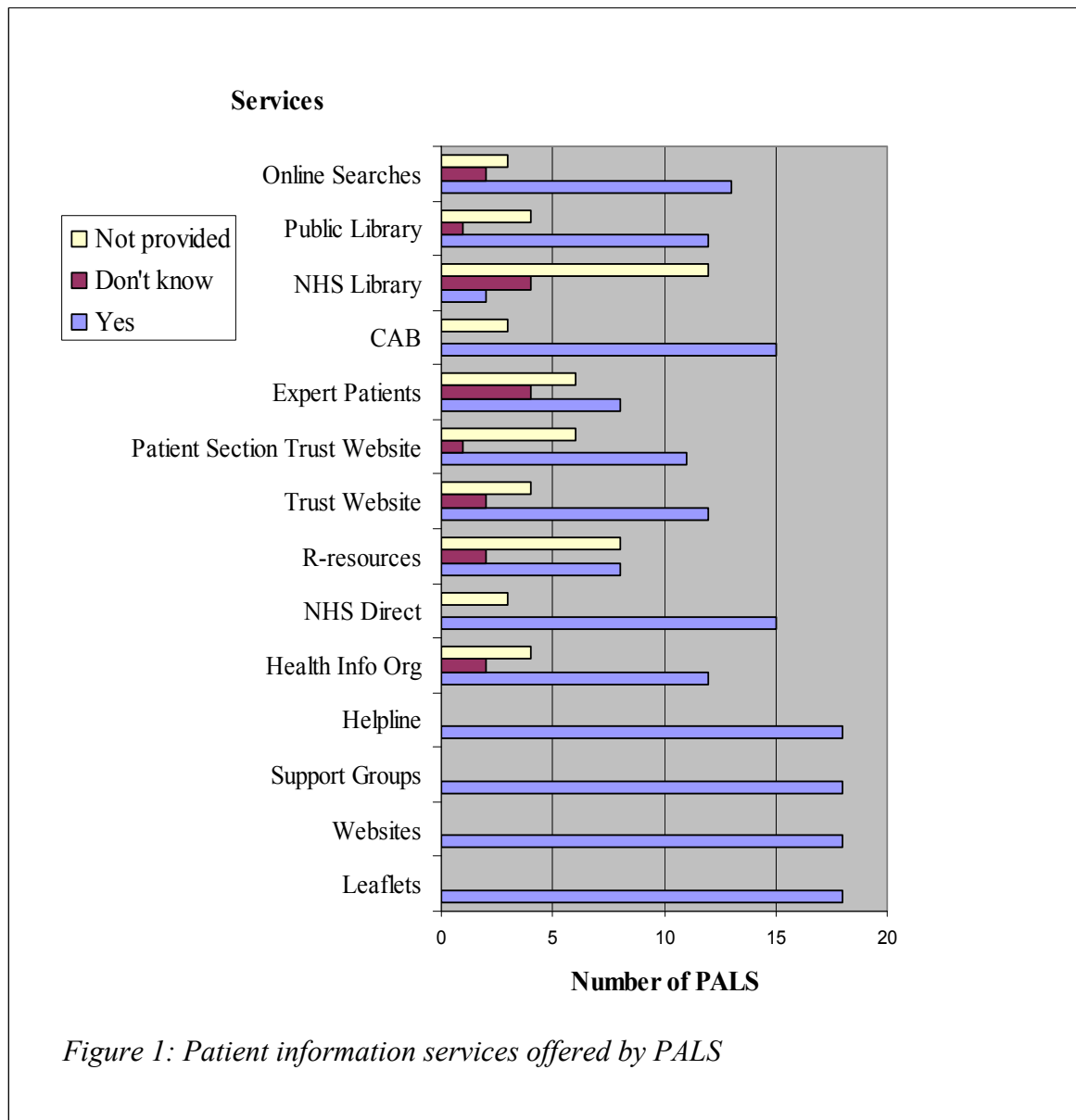
Provision of patient information leaflets

The majority of respondents to the survey confirmed that clinical staff were responsible for providing information leaflets to patients. Although, 15 respondents identified that

information leaflets were also available to patients via their organisations' websites, with a further one indicating their trust also proposed to develop this website resource service later in 2008.

Links from Trust website to appropriate information services

When analyzing the data, appropriate information services were taken to include NHS Direct, NHS Choices, charities and support groups as well other sites that may provide useful patient information. The majority of Trusts provided some form of link to appropriate services (46 confirmed) however in some cases the link to NHS Direct or NHS Choices was simply in the form of an icon on the home page. Unless a patient is aware of the role of NHS Direct or NHS Choices they may not realize that this is a source of information relevant to them.

Specifically designed patient information website linked to Trust website

Following the manual website check, it was decided to adopt a wide definition of 'patient information website' and include any Trust website which had a tab or link to a site specifically for patients. In a large amount of cases general information was provided such as waiting times, car parking facilities, what to do as an outpatient, rather than information about specific conditions. Examples of Trusts providing more comprehensive patient information include: *Bolton PCT; Christie Hospital Foundation NHS Trust; Royal Liverpool Childrens' NHS Trust*. A collaborative venture between all Trusts in Cumbria provides a patient information portal for patients throughout Cumbria.

http://www.cumbria.nhs.uk/home/home.aspx

A similar portal is provided in Wirral, which provides access to a large store of information for patients on local health services and condition specific information.

http://www.wirral.nhs.uk/index.aspx

The wide definition of 'patient information website' may account for some of the discrepancies between stakeholders' responses. Forty six Trusts (confirmed) that they had a patient information website, 4 confirmed that there was no patient website and patient sections could not be located on a further 6 websites, suggesting that at least 10 Trusts do not provide any information for patients via their website.

Trust Name	Availability of PALS	Availability of other specialist patient information service	Links from Trust website to appropriate info services (inc NHS Direct; charities; support groups)	Provision of patient leaflets on Trust website	Specifically designed patient information website linked to Trust website	Patients allowed to access Trust Library	Access to expert patients
5 Boroughs Partnership NHS Trust	Green		Green		Red	Green	Orange
Aintree University Hospitals NHS Foundation Trust	Green	Patient information group (Green)	Green		Green		Orange
Cardiothoracic Centre – Liverpool NHS Trust	Green	Story board (Green)	Green		Green	Red	Orange
Central & Eastern Cheshire PCT			Green		Green		
Cheshire & Wirral Partnership NHS Foundation Trust	Green		Green	Green			Orange
Christie Hospital NHS Foundation Trust	Green	Cancer Information Centre (Green)	Green	Green	Green	Red	Orange
Clatterbridge Centre for Oncology NHS Foundation Trust			Green		Green	Orange	Orange
Countess of Chester NHS Foundation Trust	Green		Green		Green		
East Cheshire NHS Trust	Green	Patient information officer post. (Green)	Green		Green	Red	Orange
Halton and St Helens PCT	Green		Green		Red	Red	Green
Knowsley PCT	Green		Green		Green	Orange	Green
Liverpool PCT	Green		Green		Green	Green	Green

Trust Name	Availability of PALS	Availability of other specialist patient information service	Links from Trust website to appropriate info services (inc NHS Direct; charities; support groups)	Provision of patient leaflets on Trust website	Specifically designed patient information website linked to Trust website	Patients allowed to access Trust Library	Access to expert patients
Liverpool Women's NHS Foundation Trust	Green		Green		Orange — √ to be introduced 2008	Red	Orange
Mersey Care NHS Trust	Green		Orange	Green	Red	Orange	Orange
Mid Cheshire Hospitals NHS Trust	Green		Green	Green	Green	Red	Orange
North Cheshire Hospitals NHS Foundation Trust	Green		Green		Green	Red	Orange
Royal Liverpool & Broadgreen University Hospitals NHS Trust	Green		Red	Green	Green	Red	Orange
Royal Liverpool Children's NHS Trust	Green		Green		Green		
Sefton PCT			Green				Green
Southport & Ormskirk Hospital NHS Trust	Green		Green		Green	Red	Orange
St Helens & Knowsley Teaching Hospital NHS Trust	Orange		Red		Green	Red	Orange
Walton Centre for Neurology & Neurosurgery NHS Trust	Green		Green		Green		
Warrington PCT	Green		Red		Red		Orange

Trust Name	Availability of PALS	Availability of other specialist patient information service	Links from Trust website to appropriate info services (inc NHS Direct; charities; support groups	Provision of patient leaflets on Trust website	Specifically designed patient information website linked to Trust website	Patients allowed to access Trust Library	Access to expert patients
Western Cheshire PCT	[green]	Carers Link in each GP surgery. Bid for a Community Health Librarian Post [green]	[green]	[white]	[green]	[red]	[orange]
Wirral PCT	[white]	[white]	[green]	[white]	[green]	[white]	[white]
Wirral University Teaching Hospital NHS Foundation Trust	[green]	Hospital Helpline [green]	[green]	[white]	[green]	[green]	[orange]

Table 3: Indicative map – Cheshire and Merseyside

[green]	Confirmed Available: if found via website search or confirmed by relevant stakeholder within that Trust
[orange]	Unsure: Not identified on trust website (within 3 clicks) or conflicting opinions from stakeholders
[red]	Confirmed Not Available: Not found via website search or confirmed by any stakeholder within that Trust
[white]	Unknown: Not confirmed by any source

Key: See also appendix 4

Access to Trust library for patients

This question proved to generate conflicting responses from a number of stakeholders within Trusts. As such a library was only confirmed as providing access for patients (or not) if this information was provided by the Trust librarian (on the basis that their response would be the most authoritative to this question). Six Trusts confirmed that patients were able to access their libraries (*5 Boroughs Partnership NHS Trust; Bolton PCT; Bury PCT; Lancashire Teaching Hospitals NHS Foundation Trust; Liverpool PCT; Wirral University Teaching Hospital NHS Foundation Trust*) and a further eight may be potentially open to patients (confirmed by a stakeholder other than Trust Librarian).

Access to Expert Patients

Access to Expert Patients was an area where stakeholders demonstrated inconsistent knowledge. Nine Trusts confirmed that Expert Patients could be accessed, where the information was located via the Trust website or confirmed by two stakeholders within the same Trust.

Availability of other specialist patient information services

A number of Trusts provided other types of information services to patients in a variety of forms (listed on tables 3-5). Information sources were triangulated using a targeted Google search alongside the questionnaire responses of different stakeholders. Findings are described below and organized by service, condition specific information and methods of working. Figure 2 highlights the distribution of services throughout the region. Although services vary throughout the North West, each region appears to have a particular strength or focus (whether this is by accident or design – for example in relation to public health priorities it is unclear). Cancer and Healthy Living initiatives are more prevalent in Merseyside, there is a range of Mental Health initiatives in Lancashire, there are a number of carers' initiatives in Cheshire and patient libraries, information centres and collaborative partnerships appear to be more prevalent in Greater Manchester. In comparison to the other regions, limited information services for patients came to light in Cumbria.

Trust Name	Availability of PALS	Availability of other specialist patient information service	Links from Trust website to appropriate info services (inc NHS direct; charities; support groups)	Provision of patient leaflets on Trust website	Specifically designed patient information website linked to Trust website	Patients allowed to access Trust Library	Access to expert patients
Blackburn with Darwen PCT	Green		Green		Green	Orange	Orange
Blackpool PCT	Green		Green				
Blackpool, Fylde & Wyre Hospitals NHS Foundation Trust	Green		Green		Green	Red	Orange
Calderstones NHS Trust	Green		Green		Orange		Orange
Central Lancashire PCT	Green		Green		Green		
Cumbria Partnership NHS Foundation Trust	Green		Orange	Green	Green	Orange	Orange
Cumbria PCT			Green		Green		
East Lancashire Hospitals NHS Trust	Green		Orange		Green	Red	Orange
East Lancashire PCT	Green		Green		Orange		Green
Lancashire Care NHS Foundation Trust	Green	Mental Health Helpline. Patient Library Available. Patient Information section on library website	Orange	Green	Green	Red	Red
Lancashire Teaching Hospitals NHS Foundation Trust	Green		Green	Green	Green	Green	Orange

Trust Name	Availability of PALS	Availability of other specialist patient information service	Links from Trust website to appropriate info services (inc NHS direct; charities; support groups)	Provision of patient leaflets on Trust website	Specifically designed patient information website linked to Trust website	Patients allowed to access Trust Library	Access to expert patients
North Cumbria Acute Hospitals NHS Trust	Green		Green		Green		
North Lancashire PCT	Green		Green	Green			Green
University Hospitals of Morecambe Bay NHS Trust	Green		Red		Green		
Wrightington, Wigan & Leigh NHS Trust	Green		Green	Green	Green	Orange	Orange

Table 4: Indicative Map – Cumbria and Lancashire

Patient information groups

Aintree Hospital NHS Foundation Trust has a patient information group that promotes good practice in the development of information for clinical conditions. Members of the public sit on this group to ensure information is patient friendly.

Patient libraries/information centres

There are a number of patient libraries available. *Bolton PCT* has a patient library located within Bolton Central Public Library that improves accessibility in terms of location, available hours, and disabled access. Available to anyone in Bolton over age of 18, the library provides a wide range of health promotion information and resources on over 50 health-based topic areas. Public and PCT library staff collaborate and the PCT shares a joint catalogue with Royal Bolton Hospital Library that is accessible at either site.

http://www.bolton.nhs.uk/public/library/index.htm

The Patient Information Centre (Infopatient) at *Tameside Hospital* was developed as a partnership between the NHS Trust and Public Library Service. It is staffed by a qualified librarian who works with a team of volunteers to provide a variety of information to both in-patients, out patients and carers.

http://www.tamesidehospital.nhs.uk/Pages/Infopatient.asp

The *Christie Hospital NHS Trust* provides a Cancer Information Centre for patients. This is a drop-in centre staffed by a specially trained Cancer Information Nurse Specialist and offers information, practical advice, access to the Internet to obtain a range of booklets, and support to people with cancer, their families and friends.

http://www.christie.nhs.uk/patients/infocentre/default.aspx

Lancashire Care NHS Trust has a patient library. From the limited information available, it appears to offer appropriate book stock, access to computers, and a library website from which patient information leaflets can be obtained, with limited staff resources.

Trust Name	Availability of PALS	Availability of other specialist patient information service	Links from Trust website to appropriate info services (inc NHS Direct; charities; support groups)	Provision of patient leaflets on Trust website	Specifically designed patient information website linked to Trust website	Patients allowed to access Trust Library	Access to expert patients
Ashton, Leigh & Wigan PCT	green		green	green	green	orange	green
Bolton Hospitals NHS Trust	green						
Bolton PCT	green	Patient Library (green)	green	green	green	green	green
Bolton, Salford & Trafford Mental Health NHS Trust	green		red	green	green	orange	orange
Bury PCT	green		green		orange	green	orange
Central Manchester & Manchester Children's University Hospitals NHS Trust	green		green		green	red	orange
Christie Hospital NHS Foundation Trust	green	Cancer Information Centre (green)	green	green	green	red	orange
Heywood, Middleton & Rochdale PCT	green	Books on prescription (green)	orange		green		green
Manchester Mental Health and Social Care Trust	green			green	green		
Manchester PCT	green			green	green		
Oldham PCT	green		green				

Trust Name	Availability of PALS	Availability of other specialist patient information service	Links from Trust website to appropriate info services (inc NHS Direct; charities; support groups)	Provision of patient leaflets on Trust website	Specifically designed patient information website linked to Trust website	Patients allowed to access Trust Library	Access to expert patients
Pennine Acute Hospitals NHS Trust	Orange	Green — Information Kiosks	Green		Green	Red	Orange
Pennine Care NHS Trust	Green		Green		Green		Orange
Salford PCT	Green		Green		Green	Orange	Green
Salford Royal Hospitals NHS Foundation Trust	Green		Green		Green		Orange
Stockport NHS Foundation Trust	Green			Green	Green		
Stockport PCT	Green	Green — Books on prescription	Orange		Orange	Orange	Orange
Tameside General NHS Foundation Trust	Green	Green — Patient Information Centre	Orange	Green	Green		
Tameside & Glossop PCT	Green		Green		Green		Green
Trafford Healthcare NHS Trust	Green		Green		Green	Red	Orange
Trafford PCT	Green		Green		Green		
University Hospital of South Man NHS Foundation Trust	Green	Green — Information kiosks	Green		Orange	Red	Orange

Table 5: Indicative Map – Greater Manchester Area

Cumbria Information
Portal
Cancer Network
PALs work with NHS library
staff

Patient Library
Health Promotion
information Service
Helpline- Mental Health
Cancer Network
Mental Health Websites
Books on prescription
Choose and book scheme

CUMBRIA

Wirral Health Portal
Access to Trust
Library x 3
Patient information
group
Storyboard
Helpline
Cancer Network
Cancer Info and
Support
Joint working with
public libraries for
cancer
Specialist Cancer
Posts

LANCASHIRE

MERSEYSIDE

Greater
MANCHESTER

Access to Trust Library x 2
Patient Library/Information
Centre x3
Books on prescription x 4
Information Kiosk x 2
Mental Health Websites
Collaboration between PCT,
public libraries and NHS
libraries x 2
Health information points in

Specialist posts x 2
Books on Prescription
Cancer Network
Carers information services
NHS Librarians train public
librarians

CHESHIRE

Figure 2: Initiatives and Providers of Patient Information by Region

32

East Lancashire Health Promotion and Information Service provide patient information to anyone living, working or studying in the East Lancashire patch. The centre can be visited by appointment or users can register on the website to undertake searches for information. The website does not work very well and it is not possible to verify from the site which organization is responsible for service provision.

http://www.hpsearch.co.uk/eastlancs/

The Macmillan Cancer Information and Support Centre based at Clatterbridge Centre for Oncology (Wirral) aims to offer information, support and practical help to any person affected by cancer. The centre staffed by a professional and experienced team, supported by trained volunteers, provides a comprehensive library with leaflets, books and tapes, as well as access to the Internet.

Specialist posts

East Cheshire NHS Trust has recently advertised for a Patient Information Officer to be located in the Patient & Public Involvement Department. The role involves the production of patient health information leaflets, booklets and posters; maintaining databases including archiving; and collating evidence to ensure that the Trust can demonstrate compliance with NHS standards.

Western Cheshire PCT have put in a bid for a Community Health Librarian to be based with the PALS team, and to provide a library and information service for patients.

Innovative methods of providing information

Staff at the *Cardiothoracic Centre – Liverpool NHS Trust* have developed 'Story board'; a power point presentation of photographs of the patient's journey for patients with learning difficulties coming in for cardiac surgery. This can be adapted for individual needs.

Books on prescription (bibliotherapy) schemes

A number of Trusts and public library services provide 'books on prescription schemes', collaborative initiatives between PCTs and public library services, where GPs recommend self help books to patients that are made available within the public libraries. These include *Heywood, Middleton and Rochdale PCT, Cheshire Libraries, Stockport PCT, Bolton PCT and Manchester City Libraries.*

Helplines

Two hospitals provide specialist helplines including *Wirral University Teaching Hospitals NHS Trust. Lancashire Care Trust* provides a confidential listening and information giving service about mental health to people in the Blackpool and Fylde, Preston, South Ribble and Chorley areas of Lancashire.

http://www.lancs-mentalhealthhelpline.nhs.uk/

Information Kiosks

Two Trusts, the *University Hospital of South Manchester NHS Foundation Trust* and *Pennine Acute Hospitals NHS Trust,* provide 'Information Kiosks' within their outpatient department. These are touch screen kiosks where patients can access information about their condition.

http://www.intouchwithhealth.co.uk/pphisv2/client/pennine/default.asp

Cancer

The Merseyside and Cheshire Cancer Network, organises and oversees the local implementation of the NHS Cancer Plan. Its website has a patient section which provides a range of information including links into patient and carer support groups. It has also supported initiatives in areas where cancer rates are particularly high, for example in Knowsley the 'No Cancer in Knowsley' initiative includes the appointment of a Macmillan Cancer Information Coordinator and a Health Resources Librarian.

http://www.mccn.nhs.uk/1about/1a-intro.htm

The Macmillan Cancer Information and Support Centre based at Clatterbridge Centre for Oncology is described in the patient libraries section above.

The Wirral Libraries Macmillan Cancer Information Project is a collaborative initiative between Wirral libraries and the Merseyside and Cheshire Cancer Network, offering advice and support for anyone affected by cancer. It will initially be sited in half of Wirral's 24 libraries resourced with self-help materials ranging from leaflets, books and computer resources and websites with links to local sources of support and information. On fixed days a peripatetic information facilitator will provide one to one help, advice and support. Information pathways have been developed to direct enquirers

to sources of information and help. Local partnerships include Health Links, PCTs, Health Promotion service, The Cancer Network, Macmillan Cancer Relief and the Multicultural Centre.

http://www.wirral-libraries.net/display.php?title=evts

The Lancashire & South Cumbria Cancer Network website provides information about local cancer services and links to other organizations providing high-quality cancer information, for patients, their carers and professionals.

http://www.cancerlancashire.org.uk/

The Greater Manchester & Cheshire Cancer Network website provides access to local and national information and resources for patients and people affected by cancer. Resources are presented in a clear, accurate and well written format and aim to provide quality, consistent information, tailored to patients' individual needs at their stage on the care pathway.

http://www.gmccn.nhs.uk/CancerInfo/CancerInfo

Mental Health

Lancashire Care Trust provides a listening and information giving service about mental health, a Mental Health Helpline, for people in the Blackpool, Preston, Chorley and Ribble areas.

http://www.lancs-mentalhealthhelpline.nhs.uk/content/about-us.php

Lancashire County Council social services department also provides access to mental health information on their website.

http://www.lancashire.gov.uk/social-services/adults/mental-health/guide/?id=moreinfo

The *Mental Health in Manchester* website aims to provide easy access to other websites for straightforward information about mental health.

http://www.mhim.org.uk/

Carers

In Cheshire a range of services are provided that are aimed at carers. In western Cheshire there is a Carers Link in each GP surgery, a nominated staff member in all practices who

acts as a contact for all carer issues. GP practices have carer's noticeboards and link closely with the Cheshire Carers Centre who provide advice, support and information for unpaid carers throughout Cheshire.

http://wcheshirepct.nhs.uk

Warrington PCT and Warrington Town Council are working together at a strategic level in relation to carers. The two organisations have jointly developed two strategy documents; Warrington Carers Strategy and Warrington Young Carers Strategy.

Partnership working

There are a number of examples of NHS organizations working with public libraries or local authorities within Merseyside. These include:

Mersey Care NHS Trust and Liverpool Public Libraries have collaborated to provide the "Well Read" collection of books within Liverpool Public Libraries. This initiative provides mental health and Learning disability related self help books to the public.

NHS Library staff have trained public library staff in Cheshire to be able to guide the public on best sources of health information.

Halton and St Helens PCT staff trained public librarians on recommended knowledge based websites and *Halton public libraries* have developed a Health section including leaflets.

A joint initiative between the PCT and town council in Ellesmere Port provides the 'Healthy Living Centre', a drop in centre for information and advice on social and welfare issues.

http://www.lhlc.co.uk

At *Cumbria Partnership NHS Trust* the PALS have teamed up with NHS Library services to provide more comprehensive range of information.

Blackburn public libraries are involved in a range of joint initiatives including a Bibliotherapy scheme, a Macmillan Charity initiative to provide information, Patients

Choice – 'choose and book' initiative, PALS advice sessions in libraries and health promotion including 'Ask about Medicines campaign' and other awareness campaigns, such as Mental Health week.

A number of patient information initiatives, are ongoing within *Stockport* as a result of various collaborations between PALS at *Stockport PCT*, *public libraries* and *NHS Libraries*. This includes a three way project between PALS, the PCT Choose & Book (C&B) Lead and the libraries to train library staff in providing patients with information on 'Choosing their hospital' as part of the Choose & Book system. Patients can then book their appointment on line at the library. 'Self Health @ Your Library' is a bibliotherapy project, a partnership between Stockport PCT and the Library & Information Service through which GPs refer patients to self help resources in the library. GPs use Patient Line and 'Find Out Guide' a Stockport publication comprising a range of local and national information. The PALS Information Service was built on and incorporates an earlier initiative designed to offer information to local people in Stockport.

Collaborative ventures between *Bolton PCT library* and *Bolton public and NHS Libraries* are noted earlier in the patients' libraries and books on prescriptions sections. They include the location of the PCT library in the public library, partnerships between the PCT, Trust and public libraries to share resources and bibliotherapy schemes.

The North West *NHS - Public Libraries Partnership* programme was sponsored and co-ordinated by the North West Health Care Libraries Unit with funding from Cumbria and Lancashire Strategic Health Authority. The Partnership enabled NHS/Social Care staff in the community to use local public libraries to access online resources funded by the NHS. This allowed NHS staff access to information at a time when they needed it, and to pass information on to patients. The public library staff received training from health librarians on sources of reliable health information on the Internet so that any health questions asked in public libraries were answered competently. This programme was mentioned by a number of stakeholders, but initially operated in Cumbria and Lancashire and then was taken up in other areas throughout the region.

Local authority/other local initiatives

In addition to collaborative ventures between the NHS and local authorities, a number of local authorities provide health related resources, these include:

Cheshire County Council who provide a 'Health Advice' section on their website which provides links to wide range of organisations.
http://www.cheshire.gov.uk/socialcareandhealth/health_advice/

Bolton Information Network provides links to local health services and information.
http://www.boltoninfo.net/

The *North West Dental Health Information* website provides access to a range of research based information and resources on dental health.
http://www.northwestdentalhealth.nhs.uk/

The *Manchester Community Health Information* Profiler website provides a single point of access for information about health and related services in Manchester.
http://www.healthprofile.org.uk/(S(0ewn4bjzjamh4o450k4jpgeg))/MChip.aspx

Manchester Public Libraries have set up 'Health Information Points' in all community libraries throughout the city. These are specially branded collections consisting of books, leaflets, recommended websites lists and information on local health services which are promoted by regular displays, exhibitions and events. The public library service has also developed links with health services and voluntary groups to ensure effective dissemination of their information via the public libraries.
http://www.manchester.gov.uk/site/scripts/documents_info.php?categoryID=100010&documentID=454

Summary

There is clear evidence that a wide range of services and initiatives exist, throughout the region, with the aim of providing information to patients. The map of initiatives and services is indicative rather than comprehensive but demonstrates that service provision throughout the region is not equitable, nor systematic. In some cases services were not given a high enough profile and/or were not easy to locate, for example stakeholders

identified some services for which it proved difficult to find further details. In addition, some local patient information services existed that stakeholders were unaware of and therefore did not access or promote. Only a limited number of libraries provide open access to patients within the region (six Trusts), there are five examples of dedicated patient information libraries and a wide range of examples of partnership working. A number of these are between the NHS and public libraries and may have arisen as a result of the North West NHS Public Library Partnership Programme.

Chapter Five

Stakeholder perceptions on the role of NHS Libraries in providing information for patients and carers

Overview

Different professional stakeholder groups were asked their opinion regarding the role of NHS Libraries in providing information to patients and carers. The majority of questions were in the format of statements where responses indicating level of agreement (1-strongly agree to 5-strongly disagree) were prompted. Participants were also provided with an opportunity to comment and clarify their responses. Additional qualitative comments were themed and are presented alongside the quantitative findings to generate a deeper understanding and clarity of participants' perceptions. The perceptions of two distinct groups, the NHS Library Managers and other professions (Director of Public Health, Directors of Nursing, PALS), were correlated to identify if there was a consensus regarding the provision of information to patients and carers.

It was clear from the findings that significant differences existed between the perceptions of NHS Library Managers and those of other stakeholders regarding the role of NHS Libraries in providing information to patients and carers. The qualitative analysis provided deeper insight into these issues. Considerably more negative comments were put forward than positive ones regarding patient access to NHS Libraries; mostly from NHS Library Managers. Indicative comments have been included as illustrations throughout the text. This is an important group of stakeholders, as the group most potentially affected by the results, therefore it is important to take their comments on board. However these responses should be viewed in context and alongside the quantitative results which show a more positive viewpoint.

The findings have been presented under headings related to the research questions outlined in the introductory section, with an additional section discussing the role of the public library.

Should NHS Libraries provide information for patients and carers?

Is it realistic for NHS Libraries to provide information to patients and carers?
Participants were asked their opinion whether it is realistic to expect NHS Libraries to provide information to patients and carers. A slim majority of participants (52.6%) indicated that it was realistic compared with 47.4% who did not (Table 6).

Role	Yes	No	Total (N)
Directors Public Health	6	1	7
Directors of Nursing	7	4	11
PALS	14	4	18
NHS Library Managers	9	22	31
Public Library Managers	5	6	11
Total	41	37	78

Table 6: Is it realistic?

The majority of participants who perceived it to be realistic were Directors of Public Health, Directors of Nursing and PALS (65.8%). The majority who perceived it to be unrealistic (59.5%) were NHS Library Managers. Indeed there was a significant difference found between the perceptions of NHS Library Managers and other professions (Spearman's Rho .279, p=0.007) regarding whether it was realistic to expect an NHS Library to provide information to patients and carers.

Qualitative comments offered by some participants provide a deeper understanding of the concerns of the different stakeholder groups. Indeed many comments are grouped with the corresponding questions and discussed in more detail later in the chapter. However, to provide a glimpse of the reasons suggested as to whether providing information to patients and carers was a realistic (or not) expectation of an NHS Library, a summary is presented in Box 1.

Two comments from Directors of Nursing highlight the difficulty in assessing whether such a service is realistic or not given that it is an *'unquantifiable task' and 'it may depend on the patient… information can be easily given but the patient may not understand or have further questions to ask.'*

Realistic	Unrealistic
• Because it already works well • If appropriately funded and resourced • If more staff are available • If staff are trained with the appropriate skills • Using the model of separate facility, separate space for patients • If implemented appropriately • Through partnership working, not interfacing direct with patients, signposting of available resources, supporting clinicians	• Lack of funding and limited finances • Lack of appropriate training and skills of library staff • Inappropriate content of books, journals and resources for patients • Already excessive workload difficultly meeting current demands • Time consuming • Patients sharing library facilities with staff is inappropriate • Security issues of patients using library computers • Licences to information sources prohibit public access • Library not the best solution • Role of front line clinicians to give and at the same time explain information to patients not librarians • Other information services available to patient are more appropriate (PALS) • Better to work through clinicians not direct with patients

Box 1: Realistic or Unrealistic – Reasons

NHS Library Managers who felt it was unrealistic, reflected on their own service and the current financial constraints and indicated that the lack of resources within an already stretched service would make it impossible.

'With the present funding arrangements and pressures on many NHS Libraries there are not the resources available to provide a service that is based on quality provision.' (NHS Lib)

'If this is to be developed it needs to be adequately staffed, resourced and so funded - and not slipped in on the cheap.' (NHS Lib)

Some NHS Library Managers saw past the issue of funding, and believed that the service could be realistically developed if it was resourced appropriately. Their suggestions provided an insight into future possibilities.

'In the future, and in general, I think it is realistic for NHS Libraries to provide information to patients and carers, but without underestimating the staffing and training and resources implications. I suspect that the model of a separate dedicated facility for the public, perhaps based with PALS, but supported by the NHS Libraries, may be the best.' (NHS Lib)

'I don't think the resources are available to support this at the moment. I do think however that it would be great to have one (appropriately funded and stocked with relevant material and with staff with the right knowledge) health library service in a Trust / hospital etc for anyone who needs to use it.' (NHS Lib)

Some clinicians and PALS managers were in agreement that the NHS Library was not necessarily the place to be providing patients with information. This was deemed to be the role of the front-line clinician, with the responsibility of synonymously explaining the meaning of the information.

'Most front line staff are trained/able to give out relevant information to patients and carers, if they can't then they shouldn't be in the job' (DoN)

'Front-line staff should be providing relevant information to patients and carers…so they can work through the information with them and answer any questions' (DoN)

'The majority of patients are satisfied with information given by specialist staff. Those who want more detail access the Internet' (PALS)

Access to medical and health information through NHS Libraries

Participants were asked who should have access to NHS Libraries and appropriate medical and health information. The majority of participants 57.1%, agreed/strongly agreed, 24.2% were unsure and 15.7% disagreed/strongly disagreed that an NHS Library should be a source of information for all who need access to books, journals and information about health care (Table 7).

Of the majority, 82% of other professions either agreed or strongly agreed with the statement compared with only 32% of NHS Library Managers. The correlation of perceptions between the two groups was found not to be significant (Spearman's Rho .208, p=0.083).

An NHS Library should be a source of information <u>for all</u> who need access to books, journals and information about health care	Role	SA	A	U	D	SD	Total
	Directors Public Health	4	1	2	0	0	7
	Directors of Nursing	2	8	3	0	0	13
	PALS	6	11	1	1	0	19
	NHS Library Managers	3	7	11	7	3	31
	Total	42		17	11		70

Table 7: Source of information for all who need access to health information

When asked whether NHS Libraries should facilitate access to appropriate medical and health information for patients, the majority of participants' agreed/strongly agreed (72.1%). Of the majority, 90% of other professions either agreed or strongly agreed with the statement compared with only 50% of NHS Library Managers (Table 8).

NHS Libraries should facilitate access to appropriate medical and health information <u>for patients</u>	Role	SA	A	U	D	SD	Total
	Directors Public Health	3	3	1	0	0	7
	Directors of Nursing	2	9	1	0	0	12
	PALS	7	10	1	0	1	19
	NHS Library Managers	5	10	7	7	1	30
	Total	49		10	9		68

Table 8: Should facilitate access to appropriate medical and health information for patients

The difference between the perceptions of the two groups (NHS Library Managers and other professions) was found to be significant (Spearman's Rho -.351, p=0.003). The qualitative comments showed the deeper concerns of, mainly NHS Librarians, of allowing patients access. These concerns related to the changing culture, and different expectations and needs patients may have along with funding issues.

'It would completely change the nature of the library - clinicians wouldn't use them for fear of being collared by patients...' (NHS Lib)

'...Some individuals might have unrealistic expectations and request unreasonable and unhelpful (to them) amounts of information - who is to 'police' this and pay for it?' (NHS Lib)

'In my Trust, the Trust Library Committee and IM&T departments have absolutely vetoed the use of the library by patients' (NHS Lib)

Some were not against the provision of information for patients, just believed that the library was not the most appropriate place.

'I do not think that NHS Libraries should allow patients to enter and use their library resources. This is not to say that NHS Trusts should not provide information services to patients - but it needs to be managed much more carefully than simply asking NHS Libraries to cater to an additional user group' (NHS Lib)

In relation to staff, the majority of participants' disagreed/strongly disagreed (44.2%) that NHS Libraries should facilitate access to appropriate medical and health information for staff only, 32.9% were unsure and 22.9% agreed/strongly agreed (Table 9).

NHS Libraries should facilitate access to appropriate medical and health information for <u>staff only</u>	Role	SA	A	U	D	SD	Total
	Directors Public Health	0	2	1	2	2	7
	Directors of Nursing	0	0	9	3	1	13
	PALS	0	2	4	12	1	19
	NHS Library Managers	3	9	9	9	1	31
	Total	16		23	31		70

Table 9: Should facilitate access to appropriate medical and health information for staff only

Of the majority, 54% of other professions either disagreed/strongly disagreed compared with only 32% of NHS Library Managers group. The difference between the perceptions of the two groups was found to be significant (Spearman's Rho -.317, p=0.008).

Location of patient information facilities

Participants were asked for their perceptions regarding whether clinical staff would prefer not to share the NHS Library facilities with patients. The perceptions were mixed with highest proportion of participants (42.9%) indicating that they agreed/strongly agreed that clinicians would not want to share library facilities with patients, although 35.7% were unsure and 21.4% disagreed/strongly disagreed (Table 10). When comparing the perceptions of the two groups (NHS Library Managers and other professions), 55% of NHS Library Managers either agreed or strongly agreed with the statement compared with 34% of other professions, showing a significant difference between opinions (Spearman's Rho -.297, p=0.012). That clinicians preferred not to share library facilities with patients was the opinion of the majority of NHS Library Managers.

Clinical staff would not want patients to share their library facilities	Role	SA	A	U	D	SD	Total
	Directors Public Health	0	0	3	4	0	7
	Directors of Nursing	2	2	5	4	0	13
	PALS	1	8	7	3	0	19
	NHS Library Managers	11	6	10	4	0	31
	Total	30		25	15		70

Table 10: Clinicians sharing library facilities with patients

The qualitative comments illustrate some strong perceptions that in some cases were echoed by some professional stakeholders but not supported by the quantitative data.

'Physically in the library there may be a conflict for medical staff if patients are in there' (NHS Lib)

'Patients might well see their own doctor/nurse/therapist in the library and try to discuss their case at an inappropriate time and location   Patients might lose faith in clinicians if they see them looking up information in the library' (NHS Lib)

'I am unsure about patients accessing the same library as staff. Our library is a quiet haven for study, training and reading and I think it would put staff off if patients were there also - this is a personal view' (DoN)

A clearer proportion of participants (52.2%) were in favour of a section of the library being organised and stocked with appropriate information for patients, separate to the facilities available for clinicians (Table 11).

'I think a separate patient information centre with qualified information professionals would be ideal' (NHS Lib)
'It's a quiet place for professionals to seek advice. If it was to be used by patients need a separate environment' (DoN)

However, 64% of other professions either agreed or strongly agreed with the statement compared with only 37% of NHS Library Managers, indicating a significant difference between the groups perceptions (Spearman's Rho -0.359, p=0.002).

A separate patient only section with layman books and leaflets should be organised within an NHS Library	Role	SA	A	U	D	SD	Total
	Directors Public Health	2	3	1	1	0	7
	Directors of Nursing	1	7	4	1	0	13
	PALS	2	10	7	0	0	19
	NHS Library Managers	2	9	7	8	4	30
	Total	36		19	14		69

Table 11: Separate patient only section

Although other professions consider a separate section of the library appropriate for patients, the majority of Library Managers are either unsure (23.3%) or disagree/strongly disagree (40%).

Referral of patients direct to NHS Libraries
The issue of whether patients should be referred to NHS Librarians to locate relevant information also highlighted divided opinion. The highest proportion of participants (42%) disagreed/strongly disagreed that patients should be directly referred to NHS Librarians (Table 12). However, this majority consisted of only 30.7% of other professions compared

with 56.6% NHS Library Managers. When the perceptions of the two groups were compared a significant difference was found (Spearman's Rho -.324, p=0.007).

Patients should be referred to NHS Librarians to locate relevant information	Role	SA	A	U	D	SD	Total
	Directors Public Health	0	4	2	1	0	7
	Directors of Nursing	0	6	3	3	1	13
	PALS	3	4	5	6	1	19
	NHS Library Managers	1	3	9	13	4	30
	Total	21		19	29		69

Table 12: Referral of patients to NHS Librarians

Again the qualitative comments provided more depth on the issues involved:

'I don't believe any patients and carers would think to visit a NHS Library to seek information. Most may find it too intimidating and not for them. Also the general content of NHS Libraries would be for professionals rather than the general public, so would be too technical and complicated for the general public to understand' (Public Lib)

'Sometimes, a librarian may find that they have provided information about an illness which is bad news for the patient for example that the prognosis for that illness is very poor. The patient may not yet have been told this by their doctor. This would be an inappropriate way for the patient to receive this information, and library staff are not equipped to provide necessary counselling' (NHS Lib

A similar question suggesting that NHS Libraries should not provide information direct to patients as this duplicates services available elsewhere also indicated divided opinion between other professions and NHS Library Managers (Table 13). The findings indicate that 50% of other professions either disagreed/strongly disagreed with the statement compared with only 27.6% of NHS Library Managers, showing a significant difference between the groups perceptions (Spearman's Rho -.330, p=0.006). This suggests that the majority NHS Library Managers do not perceive providing information direct to patients as their role, when other services exist to perform this function. It may also indicate a lack of agreement or knowledge about the role of the NHS Library or services available.

NHS Libraries should not provide information direct to patients as this duplicates services available elsewhere	Role	SA	A	U	D	SD	Total
	Directors Public Health	0	1	2	3	1	7
	Directors of Nursing	0	4	4	5	0	13
	PALS	0	4	3	9	2	18
	NHS Library Managers	5	10	6	7	1	29
	Total	24		15	28		67

Table 13: NHS Librarians should not provide direct information to patients

Fear of providing misleading information

A further theme was highlighted in the qualitative data, but not examined in the quantitative data and is relevant to the overall issue of whether NHS Librarians should provide information to patients. A number of comments were made regarding the provision of 'bad news', the potential provision of misleading information and information that could be misinterpreted (n=9). Librarians were particularly concerned about their lack of clinical knowledge or that patients may incorrectly perceive them to have clinical knowledge.

'Patients see the NHS as a professional organisation and would not distinguish between information provided by an expert in the clinical field and information provided by a librarian, who has little or no clinical training. Libraries could theoretically provide misleading information as librarians are not trained to provide information to answer patients' questions' (NHS Lib)
'I think library staff would also worry about litigation. If they were to help patients find information which they later misinterpreted, could the librarian be sued?' (NHS Lib)

Summary

The majority of stakeholders believed that patients should have access to NHS Libraries, with a slight majority believing it realistic that NHS Libraries provided information to patients. There were significant differences between the views of NHS Librarians compared to other stakeholders groups. NHS Librarians demonstrated a number of concerns and tended to be more negative regarding issues surrounding the provision of

patient information, this was illustrated from qualitative feedback which highlighted the depth of NHS Librarians' feelings.

There are mixed views on how facilities should be organised. A separate area for patients within an NHS Library was seen as more preferable than shared facilities, although this was still not an attractive option to some NHS Library Managers.

Could the NHS Library provide information for patients?

Putting to one side the issue of whether an NHS Library should provide information for patients, it is essential to look at feasibility. Could the NHS Library provide information for patients? What are the issues that would impact on this information provision and what are stakeholder perceptions? The issues arising focussed on the appropriateness of current resources provided by the NHS Library, funding and training of library staff.

Resources

Participants were asked a number of questions to explore their opinions regarding the resources held in NHS Libraries and whether they were considered appropriate for patients or only pertinent to staff. There was a lack of agreement between participants regarding whether resources held in an NHS Library were appropriate or not for patients.

	Role	SA	A	U	D	SD	Total
The resources held in the NHS health library are <u>not appropriate</u> for patients	Directors Public Health	0	1	1	4	1	7
	Directors of Nursing	0	3	4	6	0	13
	PALS	0	1	12	3	3	19
	NHS Library Managers	6	13	5	5	2	31
	Total	24		22	24		70

Table 14: Appropriateness of NHS Library resources for patients

An equal proportion of participants indicated they agreed/strongly agreed (34.2%), or disagreed/strongly disagreed that resources were not appropriate (34.3%), with 31.4% unsure (Table 14). On closer examination of those who either agreed/strongly agreed with the statement there was 10% of other professions compared with 61% of NHS Library

Manager group. The difference between the perceptions of the two groups was found to be significant (Spearman's Rho -.424, p<0.01).

NHS Librarians were asked further questions about the percentages of their resources that they believed were appropriate for patients. The ranges varied, perhaps indicating the varying views held by NHS Librarians on this issue, 17 (55%) librarians responded to the question. In terms of books and journals the range of resources appropriate was between 0-100%, although the majority (15/17) suggested that only 25% or less of their book stock and 10% or less of their journals were appropriate for patients.

Perceptions to establish whether resources held in NHS Libraries were aimed at staff were also explored. The majority of participants (82.9%) agreed/strongly agreed that they were (Table 15). Of the majority, 77% of other professions either agreed or strongly agreed with the statement compared with 90% of NHS Library Managers. The difference between the perceptions of the two groups was found to be significant (Spearman's Rho -.403, p=0.001).

The resources held in the NHS health library are aimed at staff	Role	SA	A	U	D	SD	Total
	Directors Public Health	1	4	1	1	0	7
	Directors of Nursing	2	8	2	1	0	13
	PALS	4	11	4	0	0	19
	NHS Library Managers	19	9	1	1	1	31
	Total	58		8	4		70

Table 15: NHS Library resources aimed at staff

Participants were asked whether NHS Libraries had appropriate funding to provide information for patients and/or whether appropriate funding should be made available. The majority of participants (53.6%) agreed or strongly agreed that NHS Libraries have no funding to provide information for patients, although 42% were unsure (Table 16). Understandably, 83% of NHS Library Managers, with more knowledge of funding issues, agreed or strongly agreed with the statement compared with only 31% of other professions, the majority of which (71.8%) were uncertain. There was no significant difference found between the perceptions of the two groups (Spearman's Rho -.523, p<0.01).

51

NHS Libraries have no funding to provide information for patients	Role	SA	A	U	D	SD	Total
	Directors Public Health	1	1	4	1	0	7
	Directors of Nursing	3	1	9	0	0	13
	PALS	1	5	13	0	0	19
	NHS Library Managers	19	6	3	1	1	30
	Total	37		29	3		69

Table 16: No funding to provide information for patients

The NHS Librarians' comments demonstrated they were aware of and concerned about all these issues highlighted above. This included the scope and level of information currently provided, however this was tied in with a lack of funding to purchase and staff more appropriate resources, possibly at the expense of their existing client group.

> *'Patient information and information for NHS staff is different in terms of its scope and pitch. Resources to provide information to staff are limited and should not be compromised by spreading the pot too thinly' (NHS Lib)*
> *'Lack of adequate resources, including enough staff (patients might need considerable help to find resources which would be very time consuming)' (NHS Lib)*
> *'Licences for e-journals and databases do not cover people not employed by the purchasing organisation, so they wouldn't be able to access these' (NHS Lib)*

In addition, there was strong agreement between participants with 73% indicating that funding should be made available to help NHS Libraries support patients (Table 17).

Resources should be made available to help NHS Libraries support patients	Role	SA	A	U	D	SD	Total
	Directors Public Health	2	3	2	0	0	7
	Directors of Nursing	2	7	4	0	0	13
	PALS	6	9	3	1	0	19
	NHS Library Managers	12	8	9	1	1	31
	Total	51		18	3		70

Table 17: Funding should be available to help NHS Libraries support patients

The majority of NHS Library Managers (64%) agreed or strongly agreed that resources should be made available, indicating that this is possibly their key objection to providing information to patients.

At the present time, the majority of participants agreed/strongly agreed (48.6%) and 34% were unsure that NHS Libraries find it difficult to meet the needs of clinicians and would in the future without additional resources find it impossible to cope with an increased demand (Table 18). A majority of the NHS Library Managers (68%), either agreed or strongly agreed with the statement compared with 33% of other professions, which indicated a significant difference between the perceptions of the two groups (Spearman's Rho -.305, p=0.01).

NHS Libraries find it difficult to meet the needs of clinicians and would find it impossible to cope with more demand	Role	SA	A	U	D	SD	Total
	Directors Public Health	1	3	2	1	0	7
	Directors of Nursing	0	3	7	3	0	13
	PALS	0	6	10	3	0	19
	NHS Library Managers	6	15	5	4	1	31
	Total	34		24	12		70

Table 18: Increased resources to meet increased demand

The qualitative comments also indicated that lack of funding was a major barrier to NHS Libraries providing information to patients.

'At the moment this service has not been adequately considered and researched. If this is to be developed it needs to be adequately staffed, resourced and so funded - and not slipped in on the cheap' (NHS Lib)

'Depends if you mean now, in the current situation, for my library, or in the future if appropriately resourced. Currently it is not realistic for my Library to provide this service, as we do not have the resources or training... I think it is realistic for NHS Libraries to provide info to patients and carers, but without underestimating the staffing and training and resources implications' (NHS Lib)

Training of library staff

Perceptions were explored to elicit whether NHS Librarians were perceived to have the training to answer patient questions regarding information. The majority of participants agreed or strongly agreed (53.6%) that NHS Librarians are not trained to answer patients' information questions, although 31.9% were unsure of the level of training librarians had undertaken (Table 19).

NHS Library staff are not trained to answer patient questions regarding information	Role	SA	A	U	D	SD	Total
	Directors Public Health	0	1	3	3	0	7
	Directors of Nursing	0	5	8	0	0	13
	PALS	4	6	6	3	0	19
	NHS Library Managers	14	7	5	4	0	30
	Total	37		22	10		69

Table 19: NHS Library staff not trained to answer patient information questions

Of the majority, 41% of other stakeholders either agreed or strongly agreed with the statement compared with 70% of NHS Library Managers, as a result, demonstrating a significant difference between the two groups opinions (Spearman's Rho -.336, p=0.005). This finding is possibly influenced by the high proportion of other professions (43.6%) who were unsure of the training that NHS Library staff received, identified within qualitative comments.

> *'Lack of resources and staff trained in dealing with patients and carers' (PALS)*
> *'Patients and carers might well assume that library staff have specialised clinical knowledge and training and treat information from them as if it were from a clinically qualified person, when this is not the case. In some cases patients would be getting bad / upsetting news. It is not the role of library staff to deliver/discuss this' (NHS Lib)*
> *'NHS Librarians are for the most part not trained to provide information to patients' (NHS Lib)*

The views of NHS Library Managers were investigated further to explore if they could provide information services to patients in terms of the knowledge and training, skills and time that they currently have. The majority (74%) responded and indicated that they have

the knowledge but not the appropriate skills or the time to provide information to patients (Figure 3).
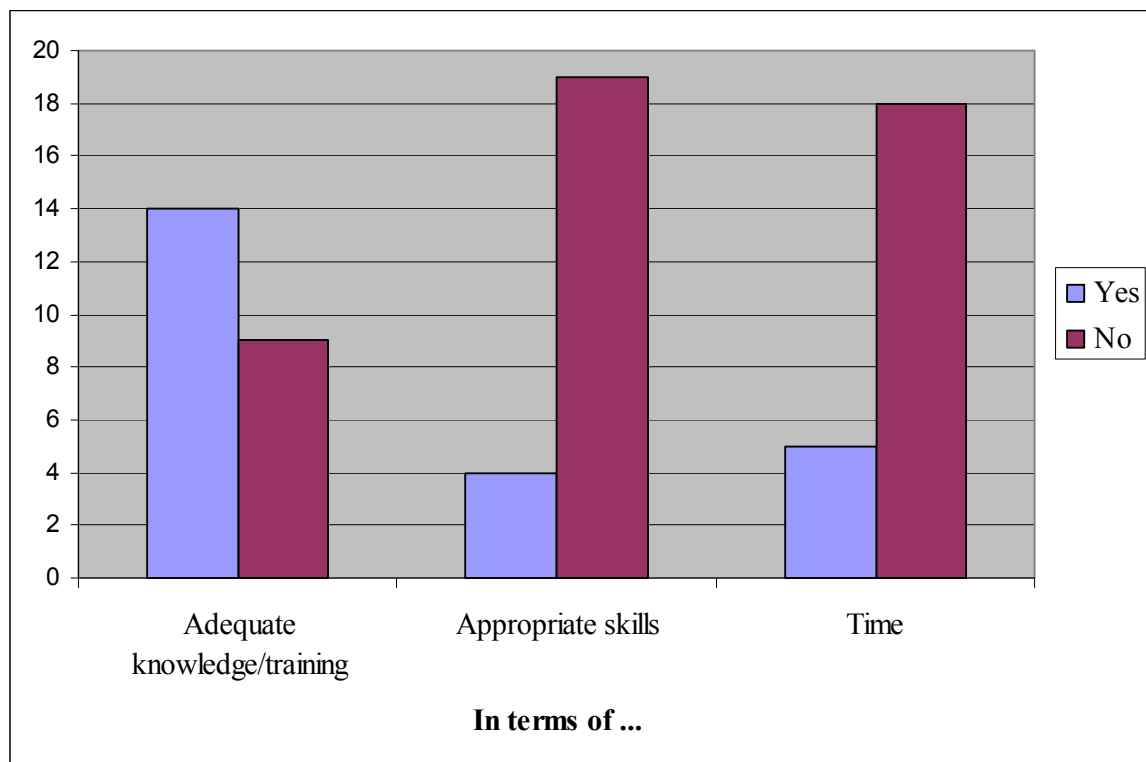
Figure 3: Could NHS Librarians provide information services to patients?

The qualitative analysis provided a deeper insight into their views. Although NHS Librarians were more likely to believe that they (and their staff) had the knowledge to provide patient information:

  'We have the skills to find patient information from reliable sources' (NHS Lib)
  'Most of us could do this with the minimum of training' (NHS Lib)

There are some issues with confidence and customer care that would need to be addressed:

  'This is more about feeling comfortable when doing so rather than training/knowledge, there is some element of self confidence that requires raising.' (NHS Lib)
  'I don't feel 100% confident about this…' (NHS Lib)
  'Not currently a requirement of any job description in our service. Puts a new slant on the role and would put some staff under unwelcome / different stress and pressure'. (NHS Lib)

'Some targeted customer care training could be useful (NHS Lib)

In terms of time some believed that, providing the enquiries were limited they could cope:

'We could fit it in with existing workload if occasional enquiries' (NHS Lib)
'At the moment it depends on the uptake from patients and carers once the service was marketed' (NHS Lib)

However others believed that, adding patients to their remit would be too much, unless properly funded:

'To deal with requests from patients as well without adequate resources for materials and staff would be the point the library service would collapse (NHS Lib)
'My service currently struggles at busy times to provide a good service to staff, so certainly doesn't have time to take on this extra facet and do it properly. (NHS Lib)
We can only just meet demand now' (NHS Lib)

Summary

The main barrier to NHS Libraries providing information services to patients at present is funding. Current resources are aimed at NHS staff however the majority of professionals (except NHS Librarians) did not believe these were inappropriate for patients.

Without additional funding libraries are unable to purchase appropriate resources or employ staff to make the resources available to patients. Training is also an issue, as NHS Librarians believe they do not have the necessary training or skills to provide information to patients particularly in terms of confidence dealing with enquiries from the public. Some library services could cope with demand providing the number of requests from patients was minimal; however the majority do not currently have the time to deal with additional patient requests. To overcome these barriers the provision of funding may make the provision of information to patients more acceptable to NHS Librarians.

What roles could NHS Libraries play? What services could be offered?

Given their expertise, in accessing and locating health information, there may be alternative roles that NHS Libraries could play instead of, or in addition to, providing information directly to patients. To generate a deeper understanding of whether certain methods of patient referral might be considered more appropriate, additional questions were posed.

Referral process

Perceptions were gathered of whether a patient being referred first to PALS or a one stop information service before contacting the NHS Library was a more acceptable approach. The majority of participants (77.1%) agreed or strongly agreed with this method (Table 20).

Patients should be referred to PALS and one stop information services in the first instance before contacting the NHS Library for information advice	Role	SA	A	U	D	SD	Total
	Directors Public Health	1	3	1	2	0	7
	Directors of Nursing	3	7	2	2	1	15
	PALS	5	9	3	2	0	19
	NHS Library Managers	12	14	2	1	0	29
	Total	54		8	8		70

Table 20: Refer patients to other services first for information

This approach was favoured more by the NHS Librarians of which 90% either agreed or strongly agreed with the statement compared with 68% of other professions, highlighting a significant difference between the two groups perceptions (Spearman's Rho -.278, p= 0.034).

> *'It isn't realistic or appropriate to expect direct information provision; however there may be an indirect provision role, working via clinicians and PALS' (NHS Lib)*

The method of patients only being able to access advice and guidance from an NHS Library indirectly through PALS or clinical staff produced a mixed response. Equal proportions of participants (35% respectively) either agreed/strongly agreed or identified being unsure whether this approach was best, with 30% disagreeing/strongly disagreeing

(Table 21). On closer examination the findings indicate a significant difference of opinion between the two groups (NHS Library Managers and other professions) (Spearman's Rho -.456, p<0.01). A greater number of NHS Library Managers 53% favoured this approach compared with only 21% of other professions.

Patients should only be able to request information advice and guidance from and NHS Library indirectly through clinical or PALS staff	Role	SA	A	U	D	SD	Total
	Directors Public Health	0	1	3	1	2	7
	Directors of Nursing	0	2	4	6	1	13
	PALS	1	4	6	7	1	19
	NHS Library Managers	10	6	11	2	1	30
	Total	24		24	21		69

Table 21: Indirect patient access to NHS Libraries through PALS and clinical staff

Links between NHS Libraries and PALS were explored further with the PALS managers, although the numbers of respondents were quite low (Table 22) and indicated that few PALS have active links with the NHS Library.

Question	Yes	No	Total
Do you refer patients to your NHS Library?	2	12	14
Do you use your NHS Library to locate information for patients?	5	12	17
Do you have any other links with your NHS Library?	4	10	14

Table 22: Links between NHS Libraries and PALS

A higher proportion of participants (41.8%) agreed or strongly agreed that NHS Libraries should only be used as a back up service for patients if staff cannot satisfy their request for information (Table 23).

NHS Libraries should only be used as a back up service for patients if staff cannot satisfy their request for information	Role	SA	A	U	D	SD	Total
	Directors Public Health	1	1	1	4	0	7
	Directors of Nursing	1	4	2	6	0	13
	PALS	1	7	4	6	1	19
	NHS Library Managers	4	9	10	4	1	28
	Total	28		17	22		67

Table 23: NHS Libraries used as back up service only

However only slightly lower proportions of participants' disagreed/strongly disagreed (32.8%) or were unsure (25.4%) whether this level of service was appropriate. When comparing the difference of opinion between other professions and NHS Library Managers no significant difference was found (Spearman's Rho -.188, p=0.128).

'I think that PALS should be the first port of call for patients and carers accessing/ requesting information, as feedback and outcomes need recording and logging appropriately. If the request is not straight forward then the library staff could follow up' (DoN)

'It is important to monitor the type of information that is being offered to patients - some of it can be interpreted wrong or difficult to understand. Information should be given on the back of a consultation or when they have had an appointment. Patients who look on the Internet often come to appointments armed with inappropriate information (PALS).

Patients can come to PALS if they are seeking additional information' (PALS)

The majority of participants agreed/strongly agreed (71.4%) that the library was a complementary service to the patient education service where information is specifically targeted (Table 24).

	Role	SA	A	U	D	SD	Total
The library is a complementary service to the patient education service, where information is specifically targeted	Directors Public Health	0	7	0	0	0	7
	Directors of Nursing	2	9	3	0	0	14
	PALS	0	13	4	1	1	19
	NHS Library Managers	4	15	7	4	0	30
	Total	50		14	6		70

Table 24: NHS Libraries complementary to patient education service

Of the majority, 78% of other professions either agreed or strongly agreed with the statement compared with 63% of NHS Library Managers. There was no was significant difference found between the perceptions of the two groups (Spearman's Rho -.078, p=0.521).

Information support for professionals

Participants were asked their opinion of the role of NHS Libraries in supporting professionals to locate appropriate patient information in practice.

The majority of participants (47.9%) agreed or strongly agreed that PALS should consult with their NHS Librarian for advice when locating patient information (Table 25). Although PALS themselves were less convinced, with 73.7% either unsure, disagreeing or strongly disagreeing that they should consult a NHS Librarian for advice. Indeed 90% of NHS Library Managers either agreed or strongly agreed with the statement compared with 40% of other professions, highlighting a significant difference between the two groups opinions (Spearman's Rho -.578, p<0.01).

PALS should consult with their NHS Librarian for advice when locating patient information	Role	SA	A	U	D	SD	Total
	Directors Public Health	0	5	2	0	0	7
	Directors of Nursing	2	4	5	3	0	14
	PALS	0	5	8	5	1	19
	NHS Library Managers	14	14	2	1	0	31
	Total	34		17	10		71

Table 25: PALS should consult with their NHS Librarian for advice

There was, however, improved congruence between opinions that NHS Librarians should be consulted by staff when developing and writing patient information, with the majority of participants (55.7%) agreeing or strongly agreeing with this statement (Table 26).

The NHS Librarian should be consulted by staff when they are developing and writing patient information	Role	SA	A	U	D	SD	Total
	Directors Public Health	1	4	1	1	0	7
	Directors of Nursing	2	5	4	2	0	13
	PALS	3	5	3	8	0	19
	NHS Library Managers	11	8	6	5	1	31
	Total	39		14	17		70

Table 26: Consult with NHS Librarian's when developing/writing patient information

The findings indicated that 51% of other professions either agreed/strongly agreed compared with 61% of NHS Library Managers, although there was no significant difference between the two groups perceptions (Spearman's Rho -.172, p=0.154).

What services should NHS Libraries provide relating to patient information?

The literature indicated a range of services that may potentially be offered by NHS Libraries in relation to provision of information for patients either directly or via clinical staff. It was anticipated that some libraries could already be offering these. To identify which libraries (to supplement information outlined in the previous chapter) participants were asked to identify if they were aware whether the possible service existed within their own NHS Library and if it **did not** whether they perceived it should be available. In practice this question was problematic and led to a number of misunderstandings (see discussion section) therefore the results outlined below should be treated with caution.

A small percentage of libraries are currently offering services directly to patients (Table 27). In those organisations where the service was not perceived to be available, high proportions were in favour of particular services being introduced. Those which gained the highest responses included the provision of a dedicated patient library website and engaging with patient forums and self help groups to act as an information resource.

A similar question was asked in relation to patient information related services provided to staff (Table 28). NHS Libraries can be seen to be already providing information to patients via staff in a number of ways including: training staff to find information, carrying out expert searches and providing advice and guidance for those staff involved in developing patient information. The majority of respondents indicated that the suggested services for patients were already being provided by NHS Libraries or should be provided by NHS Libraries, indicating that this is currently a more realistic method of providing information to patients.

Descriptor of Service	Service available % respondents	Service **should be** available % respondents
Access to NHS Library resources to include a section of the library for patients (with appropriate books, journals and Internet access)	9.3	44.4
Find and evaluate and organise good quality information resources for patients	16.1	54.8
Produce lists of good quality websites, user guidelines, available leaflets, information fact sheets, reading lists	17.5	58.7
Perform expert mediated searches on health topics to obtain appropriate information for patients from high quality specialised websites	10.9	45.5
Train patients to use and search electronic resources to locate their own information	7.1	51.8
Provide an enquiry service for patients to request assistance, advice and guidance in locating health information	11.1	51.9
Send information direct to patients at home	3.9	44.2
Engage with patient forums and self-help groups to act as an information resource	5.2	62.1
Provide services to patients through a dedicated library website	3.4	63.8

Table 27: Availability of services to patients

Descriptor of Service	Service available % respondents	Service **should be** available % respondents
Advice and guidance to staff (clinical/PALS/educators) responsible for developing patient information	60.9	23.2
Work alongside staff (clinical/PALS/ educators) responsible for providing patient information to ensure they have access to up to date high quality resources	59.7	28.4
Perform expert mediated searches on health topics for staff to obtain appropriate patient information	67.6	16.2
Train NHS staff ensure they have the skills and knowledge to search for appropriate information for patients	59.7	20.9
Find, evaluate and organise good quality information resources for patients	41.9	38.7
Produce lists of good quality websites, user guidelines, available leaflets, information fact sheets, reading lists to assist staff	43.3	38.8
Provide out-reach library service for NHS staff (library loans delivered to workplace, literature searches, training and access to Internet resources for staff)	55.2	22.4
Have a dedicated clinical librarian/ information specialist attached, working closely with clinical teams to assist staff in providing patients information	27.3	45.4

Table 28: Availability of services to staff

Summary

There are a number of roles NHS Libraries could play in supporting the provision of information to patients. The majority perceived that PALS should play more of a frontline role in providing information to patients and libraries could be used as a backup or supporting role. However there was disagreement as to how this should be achieved. The majority of NHS Libraries are already supporting clinical staff in the provision of patient information and there is a clear role for NHS Libraries to continue doing this and perhaps to extend and increase the promotion of the services they provide.

A few libraries are already providing information directly to patients in a number of ways and there is some support for this to be extended to other libraries. Engaging with patients forums and providing services through a dedicated library website were suggestions that received the most support.

If libraries provided information to patients and carers, what would be needed to facilitate and/or support them?

The final research question aimed to determine what support NHS Librarians would need if they were to provide information services to patients and carers. The previous chapters have provided some insight into this, highlighting issues such as funding and training. However NHS Librarians were also invited to comment in more detail on what they might need. NHS Library Managers were asked 'Realistically, if your library service was to provide information to patients and carers, what resources would you need?' This question aimed to gain an indication of the support and mechanisms that would need to be in place if NHS Libraries were to take on a more active role in the provision of patient information, whilst acknowledging that it was unlikely to be possible given current constraints and funding. An open ended question was used to gain a deeper understanding of issues and Library Managers were asked to structure their responses in terms of time, skills, resources and other comments.

Not all NHS Library Managers responded and those that did had mixed views: some were positive and suggested that it was all in a day's work and nothing extra was needed; others tried to quantify what was needed, some were clearly apprehensive or against patient access to libraries but nevertheless outlined suggestions.

Time
A number of respondents tried to quantify this in terms of extra staffing needed, whilst some acknowledged that it was difficult to know how much extra time this would take. As well as staff time to provide help to patients, some also mentioned time was needed to build up links with other bodies.

'At least one additional full time, professional member of staff, probably more'

'We would possibly need more staff / restructuring of current roles. Time would be needed to develop effective relationships and processes with local public libraries and with current patient information providers.'

'Time - who knows how much time this might take?'

'Additional staff to spend on this initiative both professional and non-qualified staff.'

'Additional staff time for: dealing with patients; purchasing resources; liaising with PALS and health promotion staff; obtaining leaflets'

Skills

A range of suggestions were made in terms of skills that would be needed (Box 2). These mainly centred on customer care issues, although some of the responses reflected the concerns of some librarians in allowing patient access.

Customer care	*Clinical conditions*
• *Training in dealing with patients and carers'*	• *'Enhanced knowledge of clinical conditions: a doctor will know if a librarian has given them information which is not relevant to the disease they asked about. A patient may not realise the librarian has inadvertently given them something irrelevant or misleading'*
• *'Dealing with challenging behaviour and physical aggression'*	
• *'We don't have the people skills for dealing with people who might have a substance abuse problem or might be highly distressed'*	• *'Awareness of clinical conditions; closer working with clinical staff; would some library staff specialise in this?'*
• *'Customer care'*	*Legal and ethical*
• *'Adequate training to deal directly with patients (although I don't agree that health library staff should!)'*	• *'Legal training to be aware of any liability'*
	• *'The legal ramifications'*
• *'Communication, Liaison and some Counselling skills'*	• *'Knowledge and understanding of legal and ethical implications of service provision'*
Familiarity with sources	*Other*
• *'Developing knowledge of good patient resources'*	• *'Teaching skills (for teaching public, not clinicians)'*
• *'Knowledge of relevant sources and ability to present information in appropriate format'*	• *'Marketing and promotion skills, inc webpage design for public and producing own leaflets etc about local services''*

Box 2: Perceived skills needed

NHS Librarians indicated they would need training in dealing with 'difficult patients' and the legal issues of giving patients information. Some also highlighted the need to become familiar with appropriate sources of information. Depending on the role played by NHS Libraries in the provision of patient information, these may not be needed or will be needed to a greater or lesser degree. For example if NHS Librarians 'signpost' information there may be less of a concern regarding legal and ethical implications of giving information or in-depth knowledge of clinical conditions.

Resources

Suggestions for resources related to physical space, equipment and stock that were more appropriate for the patient audience (Box 3). More PCs and printing resources were also necessary. Some of the comments indicated that the librarians would prefer the physical space to be separate to that used by clinicians.

Physical space	*Stock*
• *'Accommodation for the service, whether part of existing library or a separate service (pleasant space, with good quality furniture etc)'* • *'Space to display and for users to sit'* • *'A physical space …completely separate from the NHS Library. It is not appropriate for patients and staff to use the same library…completely different premises would be required…could be combined with similar/ PALS services'* • *'Designated area…new/renovated buildings and furnishing'* ***Staff*** • *'Clinical Specialist Nurse to work alongside us. They could deal with patients and we could help them access the information - library staff would be 'back room''* • *'Ideally also a specialist librarian'*	• *'Up to date patient literature'* • *''Stocks of patient information leaflets, books aimed at patients'* • *'We have nothing specifically purchased although plenty of Internet resources'* • *'Adequate access to resources that include both physical and electronic'* • *'Dedicated resources such as books, journals pamphlet…and computers'* ***Electronic resources, PCs and printing*** • *'Funding for documents supply (ILLS and journal article photocopies)'* • *'PCs for patient carers to use who do not have home access'* • *'If computer facilities were provided to patients… could not be on NHS net…would require separate connection Internet'* • *'Lots of paper and toner for printing out information!'* • *'Costs towards licence subscriptions'*

Box 3: Perceived resources needed

Summary

Provided funding and support was available to provide information to patients some NHS Librarians were able to specify how this might be used. The suggestions, however, are based on their perceptions of what is needed and a role which has not been clarified. These factors should be taken into account when considering the responses. The perceived support needed included employing extra staff, training in customer care, obtaining stock more suited to patient needs, purchasing PCs and licences for electronic resources. They also suggested that physically more space was likely to be needed for additional stock and to provide a separate area for patients.

Role of Public Libraries

The role of public libraries was not a specific research question considered within the project, however a number of questions were included on the survey to explore the role of Public libraries. Public librarians were also surveyed providing a wealth of qualitative data and it was therefore decided to present these findings separately.

More appropriate resource for patients

The perceptions of participants were explored on the role of public libraries in locating information for patients, as a more appropriate location than NHS Libraries. A higher proportion of participants, but not a majority, (49.3%) agreed or strongly agreed that public libraries were a more appropriate place for patients to locate health information (Table 29).

	Role	SA	A	U	D	SD	Total
Public libraries are a more appropriate place than NHS Libraries for patients to locate health information	Directors Public Health	3	3	0	0	1	7
	Directors of Nursing	1	4	4	3	1	13
	PALS	0	5	6	7	1	19
	NHS Library Managers	10	8	7	4	1	30
	Total	34		17	18		69

Table 29: Public libraries are a more appropriate place

However, 60% of NHS Library Managers either agreed or strongly agreed with the statement compared with 41% of other professions and the difference between the two groups perceptions was found to be significant (Spearman's Rho -.267, p=0.027).

The same issue was explored qualitatively with public library service managers. They were positive about public library provision of health information and indicated that it was appropriate that public library staff helped users find information about their health and treatment.

'This is a fundamental service objective' (Pub Lib)

'Staff do this all the time - they see that as part of their job' (Pub Lib)

'There is a great demand for health information and libraries provide an accessible and neutral environment in which users can either look for information for themselves or ask the staff. ..' (Pub Lib)

Signpost information

The responses also indicated that the issues were more complex than the public library being a more appropriate place. The role of public libraries is to 'signpost' information, in this way they are not likely to be perceived as providing misleading information, as was the concern of the NHS Librarians.

'Public library staff can best help by signposting patients to appropriate help' (Pub Lib)

'Yes in a signposting role linking to quality information and websites' (Pub Lib)

'As long as users understand that we can only signpost and not give medical advice, opinion etc' (Pub Lib)

'If the patient receives information from the hospital library, they may believe that this information is targeted to their specific circumstances, which is unlikely. If they receive information from, for example, a public library, they are less likely to be under this misapprehension' (NHS Lib)

Clarity of role

Public Librarians had clear ideas about the extent of their role, the need to direct to quality information and the training needed by their staff

'What is important is that the staff are well-trained to use appropriate resources to help customers but not to express an opinion or offer advice in any way' (Pub Lib)

'It is appropriate for staff to guide users to the appropriate resources, and all are willing to do this. However staff must be mindful of giving information on such topics as health and treatment, which they are not qualified to do' (Pub Lib)

'Provided that the public library staff have received training from health librarians and that training is regularly updated. Because the Internet is now available in so many homes the public can find health information themselves. The advantage of public libraries guiding the public means that the public use reliable sources of information' (Pub Lib)

They indicated that they did have some of the specialist skills needed to deal with the provision of health information.

'Already trained in customer care, diversity, equal opportunities, disabilities, search and enquiry work, IT literate, Patients Choice and use of health resources through the NHS partnership' (Pub Lib)

'Public library staff should have skills in enquiry work and this forms part of their training. Specific training in health information on the web can also help with a wide range of health enquiries' (Pub Lib)

Partnerships and links

A number acknowledged that links with the NHS were useful in providing training and other resources.

'In partnership with the PCT and the local Foundation Trust, we have ensured that the library staff have the skills to provide health information to users' (Pub Lib)

'Through NHS/Public Libraries Partnership arrangements (collections of health resources) public library staff direct customers to materials that might be useful, and refer to appropriate websites, support groups etc. Customers often need a selection of resources to satisfy an information need, e.g. books about an illness, diet and exercise information, rights and entitlements - holistic approach to satisfying a query' (Pub Lib)

Nevertheless there is an opportunity for these links to be expanded.

'We need to be very careful how we signpost people to this information. The best way to provide information to users is in close collaboration with NHS professionals' (Pub Lib)

'Library staff have skills in searching for a wide range of information some joint training with NHS Librarians on resources available would be useful' (Pub Lib)

'There is always room for better partnership working and training' (Pub Lib)

'Public librarians are keen to provide information and this must be supported by the PCT' (Pub Lib)

Indeed, the majority of participants (82.9%) indicated that public libraries should contact NHS Libraries if they are unable to satisfy a patient request for information (Table 30). This included 87% of other stakeholders who either agreed or strongly agreed with the statement as well as 77% of NHS Library Managers, indicating similar perceptions between groups and no significant difference (Spearman's Rho .027, p=0.825).

Public libraries should contact NHS Libraries by if they are unable to satisfy a patient request for information	Role	SA	A	U	D	SD	Total
	Directors Public Health	3	4	0	0	0	7
	Directors of Nursing	2	8	0	2	1	13
	PALS	5	12	1	0	1	19
	NHS Library Managers	9	15	5	1	1	31
	Total	58		6	6		70

Table 30: Public libraries should contact NHS Libraries for help

Indeed there was some evidence that this is already happening and indications of services that public library managers considered should be available to them from NHS Libraries (Table 31).

Descriptor of Service	Service available N= (%) of respondents	Service **should be** available N= (%) of respondents
Advice and guidance to public library staff	3 (25)	6 (50)
Perform expert mediated searches on health topics to obtain appropriate information for patients from high quality specialised websites	1 (10)	6 (50)
Train public library staff to ensure they have the skills and knowledge to search for appropriate information for patients	4 (33)	6 (50)
Find evaluate and organise good quality information resources appropriate for patients	4 (33)	7 (58)
Produce lists of good quality websites, user guidelines, available leaflets, information fact sheets, reading lists	4 (33)	7 (58)
Act as a referral service for patients whose information requests cannot be satisfied by public library staff	2 (18)	7 (63)

Table 31: Services which NHS Libraries could provide to Public Libraries

Summary

All stakeholders were positive about the role that public libraries could play in providing patient information. NHS and public librarians were particularly positive about this role. Public libraries are clear about their role in 'signposting' the public to quality resources rather than providing medical advice or guidance. Public library staff have both customer service and enquiry skills to help the public find information but value more specialised training from NHS Librarians. There are a number of roles that NHS Librarians can play in supporting public libraries including training in searching health resources and provision of details of quality assured websites. Collaboration between the NHS and Public Libraries is viewed as important as both were seen to have an important role to play and each has strengths that can be maximised by working together to facilitate information provision to patients and carers.

Chapter Six

Discussion

This aims of this project were threefold:

- To investigate what public sector based patient information services are provided in the North West and by whom

- To elicit and describe the views of key stakeholders on the role of NHS Libraries in the provision of information to patients

- To identify what support would be needed to help NHS Libraries provide information to patients

What information services are currently provided and by whom?

Identifying services and being aware

Two methods were used to determine what information services were available and who was providing them. The first involved a questionnaire asking stakeholders to identify what services were available and the second involved a series of Internet searches. This combined approach helped to build up a comprehensive picture of the availability of public sector patient information services throughout the region. It also demonstrated that in reality a number of stakeholders had limited knowledge or gaps in their knowledge and that patient information via Trust web sites is not always easily located (for example within 3 mouse clicks). The first issue is in line with the comments of Stewart (2006) and results in the duplication of services because 'providers do not have a full picture of what others are doing'. To overcome this there is a need to ensure that stakeholders have a better picture of the patient information available, although it is not clear how this could be achieved. Local patient information forums, better co-ordination in the NHS and better promotion of services from those involved in providing patient information may perhaps be a step forward to ensuring that stakeholders are better informed. A forum already in existence may be an appropriate vehicle for this task, for example the Consumer Health Information Group of the NLH. If those responsible for providing services and information are ill-informed of what others are doing, it makes their jobs more difficult

and less effective which in turn must make it more difficult and confusing for patients to locate the information they need.

Trust websites

The majority of Trust websites have a patient information tab, and many appear to follow a similar format in terms of the categories of information (or tabs available) on the website. However, once within particular sections of individual Trust websites there is considerable variation in content. The majority provide general public facing information such as car parking, visiting times but no information on health conditions or interventions. This was also the case in Fulda et al (2004) who examined US health institutional websites to determine how selected hospitals and libraries are meeting patient information needs. They noted that 34/49 websites have a designated section of consumer health information, the majority of which was basic, reliable and high quality. Four libraries provided consumer health information but 11 did not provide any. There are a few notable examples of North West Trust websites that provide information relating to patients conditions or interventions, these include, amongst others, *Bolton PCT, Christie Hospital NHS Foundation Trust and Royal Liverpool Children's NHS Trust.* These Trust websites could be used as exemplars for other Trusts who wish to build up the patient information component of their websites, although it would be useful to establish some guidelines and clear criteria regarding what makes a good website for patient information.

Canvassing the views of patient either individually or within existing groups to find what information they would find useful, would perhaps be a good place to start. Fulda et al (2004) designed a checklist to rate the quality of information on health websites, and this approach could be adopted to identify and assess the quality patient information available on websites throughout the region. There are tools such as DISCERN (Charnock and Sheppard n,d) and Judge (Northumbria University 2007) that help evaluate the quality of patient information; however these do not address the actual content. Standards and guidelines, based on patient information needs, for the provision of patient information on hospital websites would be a useful step forward in ensuring that patients throughout the region have access to the information they need. Although it is not clear whose responsibility this should be or whether it should be tackled at a regional or national level, other key stakeholders could include Connecting for Health, NHS Choices and the National Library for Health.

PALS and clinician roles

In the majority of Trusts PALS are available to provide information to patients, although the amount of patient information enquiries varies dramatically between Trusts ranging from 1-75% of the volume of PALS enquiries. PALS tend to refer patients to a range of sources, although some do provide access to databases and the Internet or carry out searches on behalf of patients. While provision of patient information is the role of PALS, in some Trusts it appears that this service was not used by some patients to seek information. Possible reasons for this could be a lack of need, lack of promotion and/or the availability of other sources, but this was not the focus of this study.

In the majority of Trusts, clinicians are responsible for providing patient information, via patient information leaflets, a role that is seen as an essential part of clinical care. Some NHS Libraries are playing an important role in helping staff develop appropriate patient information resources. There is no doubt that clinicians are perceived to be the most appropriate providers of patient information as they have the clinical knowledge and are available to answer any queries that the patient may have. This role does not diminish, however, if the patient information leaflets or information resources are obtained from a different source. Trusts are increasingly making patient information leaflets available via their websites, making it not just the responsibility of the clinician to share such information but actually allowing a patient to choose for themselves whether they think such information is useful. Providing patient information leaflets or resources direct from an NHS Library or library website could also be a way forward, on the understanding that patients reflect any questions relating to the content of such material back to their clinician.

Patient access to information

Patient access to the Trust library was confirmed in only six Trusts (9.5%) throughout the region, but this figure may potentially be higher as some stakeholders (n=8) other than Trust librarians suggested their NHS Library was accessible to patients and some Trusts have more than one library. This is slightly different to Hornby and King (2003) who found that seven North West NHS Libraries allowed patient access at any time and ten allowed patient access by appointment, and much lower than Mayberry (1994) who identified that 30% hospital libraries allowed patient access.

Dedicated patient information centres or libraries were highlighted in the literature as a potential model of providing patient information (Truccolo et al 2006, Hammond, 2005, Volk 2007). Two of these reports were very descriptive or personal accounts of the services, but Truccolo et al (2006) provided a more in-depth evaluation of the service, which was subsequently used as a model for patient information services provision for cancer throughout Italy. There are a number of examples of dedicated patient information services within the region including *Bolton PCT, Tameside Hospital, Lancashire Care, Clatterbridge Centre for Oncology* and *Christie Hospital NHS* Trust. This model was a preferred method for a number of NHS Librarians. Although this is a potential way forward, it is likely to be the most costly. It would be useful to identify any evaluation reports and costs relating to these services to determine the feasibility and effectiveness of these models. This would help to determine the suitability of these models as a potential way forward for patient information provision throughout the region. A similar, but perhaps less expensive method, is the funding of a specialist post to provide information for patients rather than a dedicated centre. Two Trusts in Cheshire have recently advertised this type of post and an early evaluation of the role and its costs would be useful to compare with the model of a dedicated patient information centre.

Partnership working

The second model of information provision identified in the literature was that of partnership working. In the literature there are a number of examples of this, including in the US a range of projects funded by the National Library of Medicine (Ruffin et al 2005). More notably and more relevant to the North West is the NHS NW Public Libraries Partnership project (Nair 2006a; 2006b) which was funded by NW HCLU and Cumbria and Lancashire Strategic Health Authority. This project was mentioned by a number of stakeholders responding to the survey and a range of collaborations and joint methods of working were highlighted between public and NHS Libraries. It was not clear how many of these collaborations were as a result of the initiative. It has been indicated that this scheme was enthusiastically received but some authorities did not come on board during the course of the project (Nair 2006b). A full evaluation of issues raised and lessons learned during the project would be useful to determine whether this was a useful starting point, an effective method of working or whether more funding is needed to pursue this approach. This is particularly key in view of the recommendation of the Hill report that 'as part of the NHS Choices agenda the Department of Health should lead on developing a

programme of further work to continue the engagement with the public library sector' (Hill 2008). It appears that libraries in the North West may be 'ahead of the game' in this area, although some of the examples of partnership working highlighted in this project as initiatives are between public libraries and PALS rather than between public and NHS Libraries. Partnership working between the NHS and public libraries includes; bibliotherapy schemes such as the National Information Prescription project (DH 2008), choose and book in public libraries, health information points in public libraries, and NHS Librarians training public librarians.

Cancer, Mental Health and Carers

Three key topics of information stood out in terms of services and initiatives provided throughout the region; cancer, mental health and information for carers. Cancer information services are provided throughout the region, although there do appear to be more initiatives in Merseyside than other areas. Mental health is stronger in Lancashire and carers' information initiatives are more prevalent in Cheshire (Figure 2). It is not known whether this is in response to local plans, the needs of the local population, prevalence rates of particular conditions, or active staff with a keen interest in these particular groups that take forward such initiatives. Any of these reasons, amongst others, may explain the inequity of support and availability of information to patients between areas within the region.

Should NHS Libraries provide information to patients?

The survey used a range of questions to determine whether NHS Libraries should provide information to patients. This included asking whether it was a realistic option, whether NHS Libraries should be a source for all or just staff. If libraries were open to patients, is it acceptable for clinicians and patients to use the same space or should there be a separate section for patients? Questions were also posed to determine whether this would be a duplication of services elsewhere. When the responses were viewed as a whole (taking all the stakeholders views into account), the majority believed that patients should be able to access NHS Libraries (72%) and that NHS Libraries should not simply be available for staff. There was a slim majority who believed it realistic for NHS Libraries to provide information to patients (53%). However when responses were analysed by stakeholder

group, there was shown to be significant discrepancies between the views of the NHS Librarians and those of the other professions. NHS Librarians (although not all) were considerably more negative about allowing patients access to NHS Libraries. The depth of feeling was conveyed through qualitative responses which clarified why it was believed to be unrealistic. There were issues with a lack of time, funding, training, security, as well as perceptions that it was inappropriate and duplicating the work of others. This is somewhat in contrast to the view put forward in the recent review of NHS Library services (Hill, 2008) that indicated 'the impression gained is that health librarians would welcome developments, subject to the capacity and resource issues highlighted.' Some NHS Librarians in the region undoubtedly do share this view for example in response to being asked what resources were realistically needed, one NHS Librarian stated:

'Time - no extra needed - all in a days work! Skills - good communicators which library staff should already be!!! Patients are no different to health professionals - they can be moody and grumpy - so the skills needed are the same for any customer! Resources - space to display leaflets etc., access to various evidence based databases.'

However, there is without a doubt a cohort of NHS Library Managers with strong reservations, who believe that providing information to patients is an unrealistic task for their Library to achieve at this time, for whatever reason. It is important that these views are valued and the reasons upon which they are based understood. Further work may need to be undertaken with this group in order to achieve this. However, for such views to be upheld these NHS Library Managers, more than others, need to have first explored all options and different ways in which information services to patients can be established. As policy moves on and successful initiatives are reported, evaluated and demonstrated to be effective at increasing the role of NHS Libraries in providing patient information then the pressure will only increase on those libraries that are not participating.

The issues surrounding patient access to libraries focused on four main themes similar to those highlighted by Hornby and King (2003). These include; difficulties in patients and clinical staff sharing the same facilities, lack of appropriate resources and training in providing information to patients, lack of funding and time and possible misunderstandings by the patients of the information which they may be given. According to Hornby and King, 39% of library managers believed that patients should be

able to use the health library and 61% believed patients should not be able to use the health library (2003). This compared with 50% NHS Librarians in this study who believed patients should have access to the NHS Library (a slight rise since 2003), however 26% disagreed and 23% were unsure. The issue became less clear in this study when similar probing questions were asked in a different way. For example 32% NHS Librarians agreed or strongly agreed that NHS Libraries should provide access for all, 32% disagreed with this statement and 35% were unsure. In addition only 16% believed that it was realistic for NHS Libraries to provide information to patients and 71% believed it was not realistic. It is likely that NHS Librarians were taking practical considerations into account (such as lack of funding and inappropriate resources) when answering this question. Hornby and King (2003) identify the lack of funding as the 'root of the problem' suggesting that there are two groups of librarians – one who recognizes the need for patient information and would be willing to become involved providing resources and training were in place and a second group who recognize a need but do not believe it is their remit. To a large extent, this study backs up this conclusion but also suggests a cohort of librarians who have strong concerns and reservations about the issue who may fall into either of King and Hornby's groups.

The views of NHS Librarians were in contrast, however, to the other stakeholders where 90% agreed or strongly agreed that patients should have access to NHS Libraries. In terms of clinicians and patients sharing library facilities, views were mixed, overall 43% agreed clinical staff would not want to share, 36% were unsure and 21% disagreed. However, when analysed by stakeholder group, there was a significant difference between the views of the librarians (55% agreement) and the other stakeholders (34%). This is a surprising finding, given that the majority of the other stakeholders could be viewed as representing the 'clinician viewpoint'. However, it is acknowledged that those surveyed had strategic rather than 'coal face' clinical responsibilities. The majority of NHS Librarians were not in favour of a separate section for patients within their library, which to an extent contrasted with their views that the library should be a source of information for 'all'. Then again this may be an indication that the NHS Librarians were considering practicalities such as space in their answer. This was not confirmed in the qualitative responses, but was corroborated by Hornby and King (2003). Alternatively they may be more supportive of other methods of supporting patient information rather than physical access to the library. Another area where significant views between the NHS Librarians

and other stakeholders existed was in response to the statement 'NHS Libraries should not provide information direct to patients as this duplicates services elsewhere'. Almost 28% NHS Library Managers disagreed with this statement compared to 50% of other stakeholder professions. This may indicate a lack of knowledge and/or communication about other services available, consistent with the findings above, or there may be a similar lack of awareness about what role the library could play or services it could provide on behalf of the stakeholders from other professions. Further investigations with NHS Librarians may be useful to 'tease out' these contrasting views and determine whether practical help may be of use or whether alternative approaches are needed.

Could the NHS Library provide information for patients?

Resources

A number of questions were asked regarding the feasibility of NHS Libraries providing information for patients, centring on the resources/stock currently available in the libraries, funding issues and training. There were mixed views on the appropriateness of resources available within NHS Libraries for patients. When examined as a whole equal numbers of stakeholders agreed, disagreed or were unsure about the suitability of resources for patients. Separate examination highlighted that 61% NHS Library Managers but only 10% of other stakeholder professions perceived that resources were inappropriate. Hornby and King (2003) also found that health librarians did not view their library as a useful source for patients. It is a somewhat surprising finding that stakeholders representing clinicians do not perceive this as a problem, but NHS Library Managers do. It is possible that the stakeholders have a lack of knowledge about the resources – but this should not be the case given that the resources are aimed at them. It is also possible that NHS Librarians do not have sufficient awareness surrounding patient information needs. Alternatively their views about appropriateness of stock may be tied up in their beliefs about patient information and access to the library more generally. When NHS Librarians were questioned separately about the volume of their stock that was relevant to patients, there were wide variations but these links have not been investigated. It is also important to consider the patients' viewpoint. Simply because the resources are aimed at staff, it does not mean that they are inappropriate for patients, particularly since many have

Internet access to a wide range of health information, including MEDLINE via PubMed and abstracts of health and medical journals.

Funding

One area where there was agreement amongst stakeholders was funding. The majority agreed that funding was not adequate at present to enable NHS Libraries to provide information to patients. There was strong support for funding to be made available, including 64% of NHS Librarians. This clearly indicates that funding is a major barrier for NHS Librarians, in line with Hill (2008). It was also noted that the current funding for licences of e-resources does not cover patient access and would be a further issue that would need to be overcome. Similarly the majority of stakeholders perceived that librarians are not trained to answer patient enquiries, concurring with Hornby and King (2003). Some of the issues raised included potential misunderstandings regarding clinical information and giving bad news.

In contrast Public librarians indicated that public library staff had enquiry skills (in line with all information professionals) and so were able to handle enquiries from the public. Indeed public librarians also had clear ideas about the boundaries of the public library role in signposting information and not giving medical advice. There appeared to be a lack of consensus regarding the potential NHS Library role, possible concerns about providing information to patients, and the duplication of services indicated by some of the NHS Librarians' comments. NHS Librarians could learn from public librarians on how to deal effectively with such issues as patients asking questions regarding information provided. The provision of a simple but clear operational guideline could reassure library staff regarding their roles and responsibility being limited to providing but not explaining information.

What roles could NHS Libraries play? What services could be offered?

Interfacing with PALS

Hornby and King (2003) indicated that there was some tentative interest in potential involvement in providing patient information and suggested a number of ways in which NHS Librarians could be involved. A number of questions examined stakeholder's

perceptions regarding how NHS Libraries could interface with PALS and other staff, including referrals to the library after first consulting PALS, using PALS as a gatekeeper or filter of enquiries and use of the library as a back up service if other staff cannot satisfy the initial request. The responses to these questions were mixed with neither strong agreement nor disagreement from stakeholders as a whole. There was however stronger support from NHS Librarians on patients consulting PALS first (90% compared to 68% other stakeholders) or PALS contacting them on behalf of patient enquirers (53% compared to 21% other stakeholders). In reality PALS indicated they did not use the library to answer patient enquires and few links had been established. It is therefore difficult to see how this would work in practice without more communication and collaboration between NHS Libraries and PALS or clarity about roles.

Clinician support

There was much stronger agreement for NHS Library involvement in supporting clinicians in the production of patient information leaflets. This is perhaps not surprising given the current role of supporting staff, their longer history of supporting medical staff and the need for patient information to be evidence based. This role is much more closely aligned with their current remit; however it is one that could be more widely promoted as it was not featured as a possible service available in some Trusts.

Patient information

A number of suggestions were put forward for services that NHS Libraries could provide directly to patients (however as is discussed in the limitations below, these should be interpreted with caution). In Trusts where stakeholders indicated that the service was not already available, those services which received the most support included provision of services through a dedicated library website, acting as an information resource to patient forums and self-help groups and producing guides to good quality resources for patients. The production of guides to good quality resources was also the suggestion that received the most support in a similar question aimed at staff. This is something that could perhaps be provided at a regional (or national level) and made available in all NHS Libraries rather than each individual library producing their own guide. Indeed it is likely that such guides are already in existence and could be used more widely.

If libraries are to make patient information available via their websites, they need to have more visibility on Trust websites. The majority of library websites are not visible from Trust home pages or within 3 mouse clicks. The evidence gained from the project as a whole was not rigorous regarding the roles or services that NHS Libraries could play. There is apparently more support in favour of libraries providing information to patients than agreement regarding what role they could play.

What support is needed?

NHS Library Managers provided their views on what support would be needed if they were to provide information to patients. Suggestions included employing extra staff, training in customer care, obtaining stock more suited to patient needs, purchasing PCs and licences for electronic resources. They also suggested a need for separate space for clinicians and patients, a view not wholly supported by the quantitative data. A number of the responses highlighted the concerns of the NHS librarians in providing information to patients, such as legal issues involved in giving patients misleading information. This further highlights the need to clarify the role that NHS Librarians would play and the training they would need to achieve this.

The interface between NHS and public libraries

The recent review of NHS Library services (Hill, 2008) recommended 'as part of the development of the NHS Choices agenda, the Department of Health should lead on developing a programme of further work to continue the engagement with the public library sector' (Recommendation 49, p63). It would appear from the partnerships highlighted above and the knowledge gained in the North West NHS Public Library Partnership Programme that North West health libraries have considerable experience in this area and could play a key role. In addition, there is positive support regarding the involvement of the public library sector (49% overall). There are significant differences between NHS Librarians (60%) and the remaining NHS stakeholders (41%), but positive support from the public library service managers. Certainly from the point of view of (all) library staff, this is an option worthy of further investment and a view supported in other studies (Middleton 2005, Hill 2008). Public librarians clarified their role as 'signposting'

the public to health information, but not giving medical advice. They also suggested that there was a need for training in health information and that this was an area where NHS Libraries could offer support. There was also support (from all stakeholders) that public libraries should contact NHS Libraries if they are unable to satisfy a patient information request. In order to do this it is important that collaborative links and partnerships are in place. The collaborations established during the North West NHS Public Library Partnership project could be developed and expanded in order to achieve these aims.

Strengths and limitations of the research

The strength of this research is in its aim to capture the views of multiple stakeholders with an interest in patient information. This included Directors of Nursing and Directors of Public Health to provide a strategic clinical perspective and NHS Library Managers, Public Library Authority Managers and PALS Managers to provide various information perspectives. Previous research in this area has captured the views of NHS Library Managers (Hornby and King 2003) who are undoubtedly an important stakeholder and the most likely to be affected by the service developments explored. However, to avoid duplication, to understand what groups are doing with respect to patient information and how partnerships and collaborations can be taken forward the views of only one stakeholder are not sufficient. What this research lacks is the patient perspective – one that is a key to the debate – but was not within the realms of this particular study. The combination of a quantitative and qualitative approach produced data, but also rich descriptions of the reasons and feelings behind some of the responses, leading to a better understanding of the contextual issues involved. Care has been taken to highlight the depth of the views involved (particularly amongst the minority of librarians who expressed strong views) whilst at the same time trying to ensure that these did not overshadow the quantitative results advocating that the views of the majority provided a slightly different picture.

The results were limited by the usable response rate (39%); however this is still higher than similar research (Brettle et al, 2005; Barking and Havering, 2007). The low response received from Directors of Public Health and Directors of Nursing indicate that the responses may not be representative of the total sample. Conducting interviews or focus

groups with individuals from the stakeholder groups may have provided a more in depth opinion of the issues. However these methods can be just as problematic, particularly with the recruitment of senior representatives identifying an appropriate time to participate. An electronic survey was therefore considered the most appropriate method to engage this group. The possibility of technical problems was pursued with Survey Monkey™ who suggested that the reason may be that participants were using the forward and back buttons in their browser rather than those in the questionnaire software. A brief 'Google' search did not indicate this was a problem with other users and the software has been used with other populations within the University of Salford, without similar problems. Unusable responses were higher from PALS and NHS Library Managers and it is not known in which direction their views lie and whether complete responses from these groups would have affected the direction of the results.

The brief pilot highlighted only minor wording issues with the survey, however email feedback from participants indicated a number of issues surrounding wording of the questionnaire. There was a particular concern with questions 8 and 9, which a number of respondents perceived as biased (reported in tables 27 and 28) as there was no option to indicate that a service should not be available. When designing the questionnaire this had been a 'trade off' decision against making the questionnaire longer and more complicated. It had been assumed that participants would leave the response blank if they did not believe the service should be available, however a number of participants indicated they would have preferred a box to note this response. The results to these questions should therefore be viewed with caution. Participants also indicated that the questionnaire was too long and the information requested required more consideration than 10 minutes. This was not demonstrated by the pilot testing and it may be a result of having to locate information with respect to staffing, resources and facilities which was not considered at the pilot test. A more in depth pilot with specific Library Managers asking the same information from another region may have highlighted this difficulty earlier and a more realistic time frame on how long the questionnaire would take to complete.

Chapter Seven

Conclusions and Recommendations

Introduction

This research has aimed to determine what public sector based information services are currently provided to patients and carers in the North West Region. Using a survey approach it has aimed to identify the views of key stakeholders of patient information. These include the views of Directors of Public Health, Directors of Nursing, Patient Advice and Liaison Service (PALS), managers NHS Library Managers and Public Library Service Managers. It has explored whether NHS Libraries should provide information to patients and carers and whether NHS Libraries could provide information to patients and carers. If there is a role for NHS Libraries what should it be? What services could they offer? What support would they need to achieve this role?

What information services are available to whom?

A wide range of public sector based patient information services are currently available within the North West and an 'indicative map' of their nature and location has been drawn. The map highlights differences in emphasis and service provision throughout the region. Only 6 Trusts confirmed that their libraries currently allow access to patients. Two other models of information provision were apparent, the dedicated patient information approach and the partnership model. There are five examples of dedicated patient information services and two emerging examples of a specialist role whose responsibility is to provide information to patients within the region. There are many examples of partnership working between NHS Libraries and public libraries and a completed project which aimed to promote co-operation between NHS and public libraries in the region (the North West NHS Public Library Partnership). Partnerships exist between other NHS stakeholders (eg PALS) and Public Libraries, between PALS and NHS Libraries, and three way collaborations between PALS, NHS and Public Libraries which successfully provide information to patients.

Should NHS Libraries provide information for patients and carers?

Overall the majority of stakeholders believed that patients should have access to NHS Libraries and a slight majority also believed that it was realistic for NHS Libraries to provide information to patients. However significant differences were found between the views of NHS Librarians and those of the other stakeholders. A number of NHS Librarians have concerns surrounding the issue of providing information to patients. Fewer NHS Librarians believed that patients should have access to the NHS Library than other stakeholders and there were similar differences in whether it was realistic for NHS Libraries to provide access to patients. There were mixed views surrounding the feasibility of a shared library between clinicians and patients or whether a separate patient area was preferable. NHS Librarians were more opposed to shared facilities than the other stakeholders.

Could NHS Libraries provide information for patients and carers?

The issues that arose in relation to the feasibility of NHS Libraries providing information to patients and carers focussed around funding, skills and training. The main barrier to be overcome is that of funding. NHS Libraries are currently funded to provide information to NHS staff and it was strongly perceived that additional funding would be needed if they were to take on an extended role. This would be used to purchase additional resources, including electronic resources, as the current licensing arrangements prevent patient use. Additional staff would also be needed. The majority of stakeholders agreed that NHS Library resources are aimed at NHS staff, however the majority of stakeholders (except NHS Librarians) did not believe that these resources were inappropriate for patients. Training was also a key issue in terms of feasibility. NHS Librarians do not believe that they have the necessary training or skills to provide information to patients. This includes customer care skills, clinical knowledge and dealing with 'bad news'. Time is also an issue for NHS Librarians. Some believe they could cope with minimum patient information requests; however the majority believe they do not have the time to deal with additional enquiries from patients.

Roles and services

There is a clear role and backing for NHS Libraries to support clinical staff in the provision of patient information. Many libraries are already involved in this, for example helping clinicians find information for inclusion in patient information leaflets. There is an opportunity for further promotion as some stakeholders are unaware that this type of service exists. There were mixed views regarding how libraries and PALS could work together (for example whether PALS should play a gatekeeper role or use NHS Libraries as a backup service) and only a few examples of strong links between PALS and NHS Libraries. There is a need for more dialogue and communication between PALS and NHS Libraries, their roles and how they can support each other and work together. Some ideas for potential services that NHS Libraries could provide were highlighted, including the provision of good quality guides to patient information resources. This may be more appropriate at a regional level, rather than each NHS Library duplicating the effort. The evidence was less rigorous regarding the roles that NHS Librarians could play and the services they could provide.

What support would be needed?

Although NHS Librarians did provide their views on the support needed, funding is clearly essential if NHS Librarians are to extend service provision to patients in addition to staff. This could be used to provide additional resources in terms of staff and resources (although there was a lack of agreement amongst stakeholders on the appropriateness of current resources). Training is also essential. However before either training or funding is provided, it is essential to clarify the role that NHS Libraries would play as this would determine the type of training and likely volume of resources required. Issues surrounding the licensing of electronic resources would also need to be resolved.

NHS and Public Libraries

Both NHS and Public Libraries were strongly positive about the role of the public library in providing patient information. This is particularly encouraging in light of the recent recommendations in the review of NHS Library Services (Hill 2008). The library

stakeholders were more positive about the public library role than the other stakeholder professions. Public Libraries viewed themselves as being accessible and having a clear role as a 'signposter' of health information rather than provider of medical advice and guidance which appeared to contribute to their positive attitude to the provision of patient information. This clarity of role would be helpful for NHS Librarians. Public Librarians were confident that they had the necessary customer service and enquiry skills to provide patient information, however they recognised a need for training in health resources. This is an opportunity for collaborative working that has already been achieved in a number of areas, under the NW NHS Public Partnership project and could usefully be continued and extended. There may also be reciprocal opportunities for public librarians to share experience and training in customer care issues that the NHS Librarians need.

Although the aim of this project was to focus on the role of the NHS Library in providing patient information, three models of information to provision have been highlighted and discussed throughout this report: NHS Library provision, the dedicated patient information library (or role) and partnership working between public and NHS Libraries. There are examples of all of these working successfully in practice and it is unlikely that there is a 'one model fits all' solution. Providing multiple models of services is likely to add to the plethora of patient information services available and some co-ordination is undoubtedly needed. A forum to enable the sharing of information regarding the availability of services, good practice and roles of different providers amongst stakeholders would reduce duplication and confusion. The dedicated patient information library has support from some librarians, but it is likely to be a costly option. An evaluation of the existing services in the region would be useful to provide an overview of the costs and effectiveness of this method of information provision and is an area for further research. Further collaboration and partnerships between NHS and Public Libraries are viewed positively and a potentially viable option. There are opportunities to be gained from reciprocal training and valuable lessons to be learned from the NW NHS Public Libraries Partnership Project. Further research on the best way forward to improve collaboration between the NHS and Public Library sectors is needed.

Finally there was support for the provision of patient information by NHS Libraries. The majority of stakeholders were in favour of this approach, provided adequate funding to cover resources and training were provided. However, it is necessary to ensure that all

NHS Librarians are 'on board', the majority see it as a viable option provided that funding and training is available, but there are a number who may need more reassurance than this. Gaining further information from the Library Managers in the region to determine the issues and concerns involved would be worthwhile. Information sharing amongst libraries in the region that already provide access or have good links with PALS may be useful in helping reduce anxieties and provide ideas. A training event or study day organised by NW HCLU for example may be useful. Collaborations with public libraries could help to overcome the lack of customer care training. A number of librarians suggested a need for training in clinical information and the provision of 'bad news'. This is not the role of the NHS Librarian, but the domain of clinicians. A clear role definition needs to be established and training developed and provided that is suitable to the role. There were mixed views surrounding the roles and services that could be provided, but in public libraries, who perceived a clear role around "signposting" information, the views towards providing patient information were much more positive. There are also issues relating to roles that NHS Libraries can play in supporting PALS. In some Trusts there are good links, however NHS Librarians may need to be much more proactive in working with PALS to demonstrate what they can offer and how the two services can work together and provide mutual support. NHS Libraries are already demonstrating that they play an important role in the provision of patient information by working with clinicians. This role should be widely promoted to maximise the impact that they are making

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Appendix 1 Data Collection Sheet for Trust Websites

	Trust Name	Specialised patient information service on a hospital/PCT site (PALS etc)	Patient information leaflets given by clinical staff	Websites of national charities (NKF, BHF, BACUP	Support groups	Helpline number	Local health information organisation (one stops shops)	NHS Direct (Helpline or Online)	Access to resources in NHS Library(journals, books, databases, Internet access)	Direct links from Trust website to appropriate information sources	Specifically designed patient information website linked to trust sites	Access to expert patients 'role models'	Access to citizens advice bureau
1	**Trust A**	X1		X3	X3			X3		X3	X2		
2	**Trust B**							X1		X1NHS Direct			
2	**Trust C**							X1		X1 NHS Direct	Patient info portal to be introduced X1 2008		

X=number of mouse clicks to locate information

Blank field indicates information not located within 3 clicks

Appendix 2 Example of Survey Instrument

Directors of Public Health

Do NHS libraries have a role in providing information services to patients?

This short survey has been compiled to explore the perceptions of key stakeholders regarding the role of NHS libraries in providing information for patient care. You have been sent this questionnaire as a member of one of the key stakeholder groups - Directors of Public Health and we value your views. It has been sponsored by the North West Health Care Libraries Unit.

Your responses to the survey could influence the future of services provided by NHS libraries in the North West. Return of the questionnaire implies that you consent to participate in the study. The first two questions ask for demographic information - this is in relation to coding and to enable us to publicise good practice initiatives and services. Your responses will not be identifiable in any publication arising from this project.

Most questions can be answered by checking a box and the questionnaire should take no more than 10 minutes to complete

Thank you in advance for your time and contribution to this valuable research study

* 1. Please select your job title

- ○ Director of Public Health
- ○ Director of Nursing
- ○ PALS Manager/Officer
- ○ Patient Experience Manager
- ○ NHS Library Manager
- ○ Public Library Service Manager

Other (please specify)

Directors of Public Health

✱ 2. Please select your organisation (if applicable you may select more than one)

- ☐ 5 Boroughs Partnership NHS Trust
- ☐ Aintree University Hospitals NHS Trust
- ☐ Ashton, Leigh and Wigan Primary Care Trust
- ☐ Blackburn with Darwen PCT
- ☐ Blackpool, Fylde and Wyre Hospitals NHS Trust
- ☐ Bolton Hospitals NHS Trust
- ☐ Bolton Primary Care Trust
- ☐ Bolton, Salford and Trafford Mental Health Trust
- ☐ Bury Primary Care Trust
- ☐ Calderstones NHS Trust
- ☐ Cardiothoracic Centre NHS Trust
- ☐ Central and Eastern Cheshire Primary Care NHS Trust
- ☐ Central Lancashire Primary Care Trust
- ☐ Central Manchester and Manchester Children's Hospital NHS Trust
- ☐ Cheshire and Wirral Partnership NHS Trust
- ☐ Christie Hospital NHS Foundation Trust
- ☐ Clatterbridge Centre for Oncology
- ☐ Countess of Chester NHS Foundation Trust
- ☐ Cumbria Partnership NHS Trust
- ☐ East Cheshire NHS Trust
- ☐ East Lancashire Hospitals NHS Trust
- ☐ East Lancashire Primary Care Trusts
- ☐ Halton and St Helens Primary Care Trust
- ☐ Knowsley PCT
- ☐ Lancashire Care NHS Trust
- ☐ Lancashire Teaching Hospitals NHS Foundation Trust
- ☐ Liverpool Primary Care Trust
- ☐ Liverpool Womens NHS Foundation Trust
- ☐ Manchester Primary Care Trust
- ☐ Mersey Care NHS Trust
- ☐ Mid Cheshire Hospitals NHS Trust
- ☐ North Cheshire Hospitals NHS Trust
- ☐ North Cumbria Acute Hospitals NHS Trust
- ☐ North Lancashire Teaching PCT

Directors of Public Health

- [ ] Oldham Primary Care Trust
- [ ] Pennine Acute Hospitals NHS Trust
- [ ] Pennine Care NHS Trust
- [ ] Royal Liverpool and Broadgreen University Hospitals NHS Trust
- [ ] Royal Liverpool Childrens NHS Trust
- [ ] Salford Primary Care Trust
- [ ] Salford Royal NHS Foundation NHS Trust
- [ ] Sefton Primary Care Trust
- [ ] Southport and Ormskirk Hospital NHS Trust
- [ ] St Helens and Knowsley Hospitals NHS Trust
- [ ] Stockport NHS Foundation Trust
- [ ] Stockport Primary Care Trust
- [ ] Strategic Health Authority
- [ ] Tameside and Glossop Acute Services NHS Trust
- [ ] Tameside and Glossop Primary Care Trust
- [ ] Trafford Healthcare NHS Trust
- [ ] University Hospital of South Manchester NHS Foundation Trust
- [ ] University Hospitals of Morcambe Bay NHS Trust
- [ ] Walton Centre for Neurology and Neurosurgery NHS Trust
- [ ] Warrington PCT
- [ ] Western Cheshire Primary Care Trust
- [ ] Wirral University Hospital NHS Foundation Trust
- [ ] Wrightington, Wigan and Leigh NHS Trust
- [ ] Other (please specify)

3. What information services are you aware of that are currently provided to patients and carers in your Trust?
(Select column 1 if the service is provided, column 2 if you are not sure if this service is available or column 3 if it is not provided)

	YES Provided	Don't Know	NOT Provided
Specialised patient information service on a hospital/PCT site (PALs etc)	◯	◯	◯
Patient information leaflets given by clinical staff	◯	◯	◯
Websites of national charities (eg BACUP, NKF, BHF)	◯	◯	◯
Support groups	◯	◯	◯
Helpline numbers	◯	◯	◯
Local Health Information Organisation (one stop shop)	◯	◯	◯
NHS Direct (Helpline or Online)	◯	◯	◯
Access to resources in NHS Library (eg journals, books, databases, Internet access)	◯	◯	◯
Direct links from Trust website to appropriate information sources	◯	◯	◯
Specifically designed patient information website linked to Trust sites	◯	◯	◯
Access to expert patients "role models"	◯	◯	◯
Access to citizens advice bureau	◯	◯	◯

4. Do you know of any specific initiatives or services in the North West that have been developed to provide patients and carers with information?
Please give details

5. How useful do you perceive the following information sources are to patients?
(Please rate the information sources where 1= very useful to patients and 5 = not useful)

	1 Very Useful	2	3	4	5 Not Useful
Clinical staff	○	○	○	○	○
Patient Advisory Liaison Service (PALs)	○	○	○	○	○
Patient Advocates	○	○	○	○	○
Specialised patient information service on a hospital site	○	○	○	○	○
Patient information leaflets given by clinical staff	○	○	○	○	○
Websites of national charities (BACUP, NKF, BHF)	○	○	○	○	○
Support groups	○	○	○	○	○
Helpline	○	○	○	○	○
Local health information organisation (one stop shops)	○	○	○	○	○
NHS Direct Online	○	○	○	○	○
NHS Library	○	○	○	○	○
Public Library	○	○	○	○	○
Media	○	○	○	○	○

6. What are your opinions regarding NHS libraries providing information to patients and carers?
(Please indicate the extent of your agreement in the corresponding columns)

	Strongly Agree	Agree	Unsure	Disagree	Strongly Disagree
An NHS library should be a source of information for ALL who need access to books, journals and information about health care	○	○	○	○	○
The resources held in the NHS library are not appropriate for patients	○	○	○	○	○
NHS libraries should facilitate access to appropriate medical and health information for patients	○	○	○	○	○
NHS libraries find it difficult to meet the needs of clinicians and would find it impossible to cope with more demand	○	○	○	○	○
The resources held in the NHS library are aimed at staff	○	○	○	○	○
NHS libraries should not provide information direct to patients as this duplicates services available elsewhere	○	○	○	○	○
Patients should be referred to NHS librarians to locate relevant information	○	○	○	○	○
A separate "patient only" section with appropriate books and leaflets should be available within an NHS library	○	○	○	○	○
Clinical staff would not want patients to share their library facilities	○	○	○	○	○
The NHS librarian should be consulted by staff when they are developing and writing patient information	○	○	○	○	○
NHS library staff are not trained to answer patient questions regarding patient information	○	○	○	○	○
PALs should consult their NHS librarian for advice when locating patient information	○	○	○	○	○
The library is a complementary service to the patient education service, where information is specifically targeted	○	○	○	○	○

Patients should be referred to PALs and one stop information services in the first instance before contacting the NHS library for information	◯	◯	◯	◯	◯
NHS libraries should only be used as a back up service for patients if other staff cannot satisfy their request for information	◯	◯	◯	◯	◯
Patients should only be able to request information advice and guidance from an NHS library indirectly through clinical or PALs staff	◯	◯	◯	◯	◯
NHS libraries have no funding to provide information for patients	◯	◯	◯	◯	◯
NHS libraries should facilitate access to appropriate medical and health information for staff only	◯	◯	◯	◯	◯
Public libraries are a more appropriate place than NHS libraries for patients to locate health information	◯	◯	◯	◯	◯
Public libraries should contact NHS libraries if they are unable to satisfy a patient request for information	◯	◯	◯	◯	◯
Resources should be made available to help NHS libraries support patients	◯	◯	◯	◯	◯

7. Do you think it is realistic to expect NHS libraries to provide information to patients and carers?

◯ Yes

◯ No

If NO, Why? (please comment)

8. Which of the following services are or should be available from your local NHS library to PATIENTS?

(Please click in column 1 if the service is aleady available in your Trust, column 2 if you are unsure about the service availability or column 3 if it is not currently available but you think it should be available)

	Already Available	Unsure about Availability	Should be Available
Access to NHS library resources to include a section of the library for patients (with appropriate books, journals and Internet access)	☐	☐	☐
Find, evaluate and organise good quality information resources for patients	☐	☐	☐
Produce lists of good-quality websites, user guidelines, available leaflets, information fact sheets, reading lists etc	☐	☐	☐
Perform expert mediated searches on health topics to obtain appropriate information for patients from high quality specialised websites	☐	☐	☐
Train patients to use and search electronic resources to locate their own health information	☐	☐	☐
Provide an enquiry service for patients to request assistance, advice and guidance in locating health information	☐	☐	☐
Send information direct to patients at home	☐	☐	☐
Engage with patient forums and self help groups to act as an information resource	☐	☐	☐
Provide services to patients through a dedicated library website	☐	☐	☐
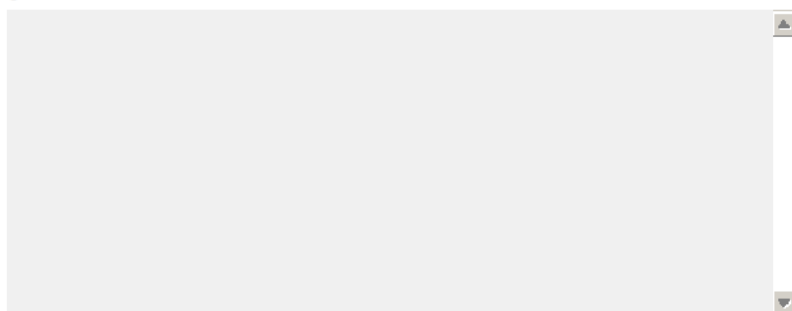
9. Which of the following services are or should be available from your NHS library to STAFF?

(Select column 1 if the service is available, column 2 if you are unsure if the service is available and column 3 if you think the service should be available)
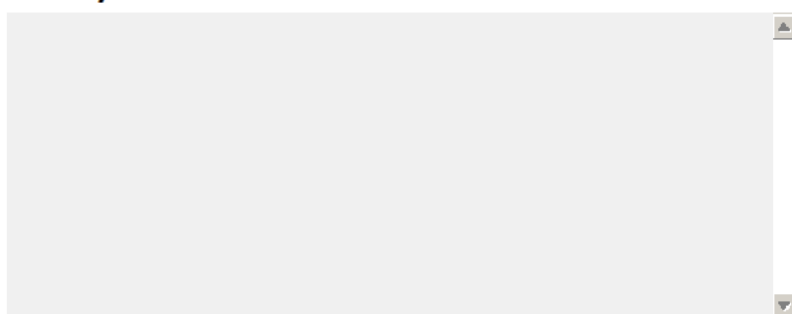
	Already Available	Unsure about Availability	Should be Available
Advice and guidance to staff (clinical/ PALS/educators) responsible for developing patient information	☐	☐	☐
Work alongside staff (clinical/ PALS/educators) responsible for providing patient information to ensure they have access to up to date high quality resources	☐	☐	☐
Perform expert mediated searches on health topics for staff to obtain appropriate patient information	☐	☐	☐
Train NHS staff to ensure they have the skills and knowledge to search for appropriate information for patients	☐	☐	☐
Find evaluate and organise good quality information resources appropriate for patients	☐	☐	☐
Produce lists of good-quality websites, user guidelines, available leaflets, information fact sheets, reading lists, to assist staff	☐	☐	☐
Provide out-reach library service for NHS staff. (Library loans delivered to workplace, literature searches, training and access to internet resources for staff)	☐	☐	☐
Have a dedicated clinical librarian/information specialist attached and working closely with clinical teams to assist staff in providing patient information	☐	☐	☐

10. Please describe any other services/roles that an NHS library could offer to staff or patients that would enhance access to appropriate information for patients and carers?

11. Any other comments

Appendix 3 Email to participants

Dear [insert stakeholder group name]

Patients and carers currently obtain information about their condition or treatment from a range of places. It has been suggested that the role of developing, providing and co-ordinating information to patients is everybody's job and nobody's job*.

The North West Health Care Libraries Unit, who are responsible for the strategic co-ordination of North West NHS Library services have commissioned The University of Salford (Alison Brettle and Paula Ormandy) to map current services and investigate key stakeholders opinions of the role NHS Libraries may have in providing information to patients and carers in the North West.

 A short survey has been compiled to explore the perceptions of key stakeholders' such as NHS Library Managers, Directors of Public Health, Directors of Nursing, Patient and Liaison Managers and Public Library Managers. By examining the perspectives of different groups it will be possible to shape and develop NHS Library services to meet the needs of all users. The survey will also highlight current initiatives and information services that can be shared and if appropriate replicated throughout the North West. Results of the survey will be presented in the form of a report to the funder. An electronic summary will be provided to all stakeholders.

You have been selected to receive this survey as you are a member of one of the key stakeholder groups and your opinion is important. Your responses to the survey could influence the future of services provided by NHS Libraries in the North West. Therefore, would it be possible for you to spare 10 minutes to complete the online questionnaire at the link given below? Completion of the questionnaire implies that you consent to participate in the study. If you would prefer to complete a hard copy questionnaire, please get in touch with Alison Brettle at the address below.

We have asked you for your organisation name. This is in relation to the mapping exercise - to enable us to publicise good practice initiatives and services. Your responses will not be identifiable in any report or publication arising from the project.

For ease of use, most of the questions can be answered by checking a box. Others ask you for information or your opinion. Again the questionnaire should take no more than 10 minutes to complete. If you have any technical problems with the questionnaire please contact Alison Brettle at the address below.

 Please return the questionnaire by xxxx**.**

We thank you now for taking the time to read this email and in advance for your contribution to this valuable research study.

Please click on the link below to access the questionnaire

 http://www.surveymonkey.com/s.aspx?sm=wBx9odBKAiRxAouTIZZxow_3d_3d

 Many thanks for your help

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*David Stewart, Director North West Health Care Libraries Unit
Health Care Libraries Unit, Beech Hill Clinic, Beech Hall Street, Wigan WN6 7HX
Project funder

Appendix 4 Indicative Map

Availability of patient information services in the North West Region (alphabetical order)

Trust Name	Availability of PALS	Availability of other specialist patient information service	Links from Trust website to appropriate info services (inc NHS direct; charities; support groups)	Provision of patient leaflets on Trust website	Specifically designed patient information website linked to Trust website	Patients allowed to access Trust Library	Access to expert patients
5 Boroughs Partnership NHS Trust	green		green		red	green	orange
Aintree University Hospitals NHS Foundation Trust	green	Patient information group (green)	green		green		orange
Ashton, Leigh & Wigan PCT	green		green	green	green	orange	green
Blackburn with Darwen PCT	green		green		green	orange	orange
Blackpool PCT	green		green				
Blackpool, Fylde & Wyre Hospitals NHS Foundation Trust	green		green		green	red	orange
Bolton Hospitals NHS Trust	green						
Bolton PCT	green	Patient Library (green)	green	green	green	green	green
Bolton, Salford & Trafford Mental Health NHS Trust	green		red	green	green	orange	orange
Bury PCT	green		green		orange	green	orange
Calderstones NHS Trust	green		green		orange		orange

Trust Name	Availability of PALS	Availability of other specialist patient information service	Links from Trust website to appropriate info services (inc NHS direct; charities; support groups)	Provision of patient leaflets on Trust website	Specifically designed patient information website linked to Trust website	Patients allowed to access Trust Library	Access to expert patients
Cardiothoracic Centre – Liverpool NHS Trust	Green	'Story board" (Green)	Green		Green	Red	Orange
Central & Eastern Cheshire PCT			Green		Green		
Central Lancashire PCT	Green		Green		Green		
Central Manchester & Manchester Children's University Hospitals NHS Trust	Green		Green		Green	Red	Orange
Cheshire & Wirral Partnership NHS Foundation Trust	Green		Green	Green			Orange
Christie Hospital NHS Foundation Trust	Green	Cancer Information Centre (Green)	Green		Green	Red	Orange
Clatterbridge Centre for Oncology NHS Foundation Trust	Green		Green		Green	Orange	Orange
Countess of Chester NHS Foundation Trust	Green		Green		Green		
Cumbria Partnership NHS Foundation Trust	Green		Orange	Green	Green	Orange	Orange
Cumbria PCT			Green		Green		
East Cheshire NHS Trust	Green	Patient information officer post. (Green)	Green		Green	Red	Orange
East Lancashire Hospitals NHS Trust	Green		Orange		Green	Red	Orange
East Lancashire PCT	Green		Green		Orange		Green
Halton and St Helens	Green		Green		Red	Red	Green

Trust Name	Availability of PALS	Availability of other specialist patient information service	Links from Trust website to appropriate info services (inc NHS direct; charities; support groups)	Provision of patient leaflets on Trust website	Specifically designed patient information website linked to Trust website	Patients allowed to access Trust Library	Access to expert patients
PCT	[green]		[green]		[red]	[red]	[green]
Heywood, Middleton & Rochdale PCT	[green]	Books on prescription	[orange]		[green]		[green]
Knowsley PCT	[green]		[green]		[green]	[orange]	[green]
Lancashire Care NHS Foundation Trust	[green]	Mental Health Helpline. Patient Library Available. Patient Information section on library website	[orange]	[green]	[green]	[red]	[red]
Lancashire Teaching Hospitals NHS Foundation Trust	[green]		[green]	[green]	[green]	[green]	[orange]
Liverpool PCT	[green]		[green]		[green]	[green]	[green]
Liverpool Women's NHS Foundation Trust	[green]		[green]		√ patient info portal to be introduced 2008 [orange]	[red]	[orange]
Manchester Mental Health and Social Care Trust	[green]			[green]	[green]		
Manchester PCT	[green]			[green]	[green]		
Mersey Care NHS Trust	[green]		[orange]	[green]	[red]	[orange]	[orange]
Mid Cheshire Hospitals NHS Foundation Trust	[green]		[green]	[green]	[green]	[red]	[orange]
North Cheshire Hospitals NHS Trust	[green]		[green]		[green]	[red]	[orange]

Trust Name	Availability of PALS	Availability of other specialist patient information service	Links from Trust website to appropriate info services (inc NHS direct; charities; support groups)	Provision of patient leaflets on Trust website	Specifically designed patient information website linked to Trust website	Patients allowed to access Trust Library	Access to expert patients
North Cumbria Acute Hospitals NHS Trust	green		green		green		
North Lancashire PCT	green		green	green			green
Oldham PCT	green		green				
Pennine Acute Hospitals NHS Trust	orange	Information Kiosks (green)	green		green	red	orange
Pennine Care NHS Trust	green		green		green		orange
Royal Liverpool & Broadgreen University Hospitals NHS Trust	green		red	green	green	red	orange
Royal Liverpool Children's NHS Trust	green		green		green		
Salford PCT	green		green		green	orange	green
Salford Royal NHS Foundation Trust	green		green		green		orange
Sefton PCT			green				green
Southport & Ormskirk Hospital NHS Trust	green		green		green	red	orange
St Helens & Knowsley Teaching Hospital NHS Trust	orange		red		green	red	orange
Stockport NHS Foundation Trust	green			green	green		
Stockport PCT	green	Books on prescription (green)	orange		orange	orange	orange
Tameside General NHS Foundation Trust	green	Patient Information Centre (green)	orange	green	green		
Tameside & Glossop PCT	green		green		green		green

Trust Name	Availability of PALS	Availability of other specialist patient information service	Links from Trust website to appropriate info services (inc NHS direct; charities; support groups)	Provision of patient leaflets on Trust website	Specifically designed patient information website linked to Trust website	Patients allowed to access Trust Library	Access to expert patients
Trafford Healthcare NHS Trust	green		green		green	red	orange
Trafford PCT	green		green		green		
University Hospital of South Manchester NHS Foundation Trust	green	Information kiosks (green)	green		orange	red	orange
University Hospitals of Morecambe Bay NHS Trust	green		red		green		
Walton Centre for Neurology & Neurosurgery NHS Trust	green		green		green		
Warrington PCT	green		red		red		orange
Western Cheshire PCT	green	Carers Link in GP surgeries. Bid for a Community Health Librarian Post (green)	green		green	red	orange
Wirral PCT			green		green		
Wirral University Teaching Hospital NHS Foundation Trust	green	Hospital Helpline (green)	green		green	green	orange
Wrightington, Wigan & Leigh NHS Trust	green		green	green	green	orange	orange

Key to colour scheme: Note for each column the confirmation was assessed in a slightly different manner (described below).

General

🟩	Confirmed Available: if found via website search or confirmed by relevant stakeholder within that Trust
🟧	Unsure: Not identified on trust website (within 3 clicks) or conflicting opinions from stakeholders
🟥	Confirmed Not Available: Not found via website search or confirmed by any stakeholder within that Trust
	Unknown: Not confirmed by any source

Availability of PALS

🟩	Confirmed Available: if found via website search or confirmed by a PAL within that Trust
🟧	Unsure: identified by stakeholder other than PAL but not located via website search (stakeholder could be mistaken or may take more than 3 mouse clicks)
🟥	Confirmed Not Available: Not found via website search or confirmed by any stakeholder within that Trust
	Unknown: Not confirmed by any source

Availability of Specialist Information Services (non web based)

🟩	Confirmed Available: Via website search or stakeholder
	Unknown: Not confirmed by any source

Provision of Leaflets on Trust Website

🟩	Confirmed Available: Via website search
🟥	Confirmed Not available: Via website search

Specifically designed patient information website linked to Trust Website

🟩	Confirmed Available: if found via website search
🟧	Unsure: identified by stakeholder but not located via website search (stakeholder could be mistaken or may take more than 3 mouse clicks)
🟥	Confirmed Not Available: Not found via website search or confirmed by any stakeholder within that Trust
⬜	Unknown: Not confirmed by any source

Links from Trust Website

🟩	Confirmed Available: if found via website search
🟧	Unsure: identified by stakeholder but not located via website search (stakeholder could be mistaken or may be problem with definition or may take more than 3 mouse clicks)
🟥	Confirmed Not Available: Not found via website search or confirmed by any stakeholder within that Trust
⬜	Unknown: Not confirmed by any source

Access to Library

🟩	Confirmed Available: if found via website search or confirmed by 2+ stakeholders
🟧	Unsure: identified by 1 stakeholder but not located via website search (stakeholder could be mistaken or may take more than 3 mouse clicks) or disagreement between stakeholders
🟥	Confirmed Not Available: Confirmed by 2+ stakeholders
⬜	Unknown: Not confirmed by any source

Access to Expert patients

🟩	Confirmed Available: If confirmed by Trust Librarian or if found via website search
🟧	Unsure: Identified by stakeholder but not confirmed by Trust Librarian at that Trust
🟥	Confirmed Not Available: Confirmed by Trust Librarian within that Trust
⬜	Unknown: Not confirmed by any source or stakeholder indicated not known