

○ Accessing information about health and social care services

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Executive Summary

This is the second of two research studies on patients' information produced for the Department of Health by the Picker Institute. The first, published in 2006¹, found that few health information materials included a clear presentation of the likely outcomes of treatment, a discussion of clinical controversies and uncertainties, or an understanding of the patient's decision-making role. Thus, they did not go very far to help patients make decisions.

This new study examines how patients, service users and carers currently find out about locally available services and how to access them.

Key Findings

1. Health professionals – who are often responsible for first diagnosis, or are an initial port of call for help with a condition – do not **systematically or proactively** provide their patients with information about accessing local services
2. There is a lack of **co-ordination** between information providers across boundaries – geographical, sectoral and organisational. It is rare for an individual or an organisation to take responsibility for providing relevant information about the entire range of services available
3. There is a lack of effective **signposting**. There is no shortage of information – a significant amount of information is being designed and produced – but the service user is often left to dig it out for themselves, and may not know what it is they need to know
4. The **types** of information most commonly requested by service users include:
 - details of voluntary sector support groups
 - support for the family or carer(s)
 - condition-specific services
 - the financial benefits available, and how to claim them
 - how to comment on or complain about services
5. With regard to the **quality** of information provision:
 - users report that most telephone information points offer a friendly service, but do not always lead to helpful or appropriate information
 - most health and social care websites contain useful information, but some are poorly designed
 - some telephone advice services and websites fail to update regularly
 - social care services appear to perform better than health agencies in offering information in various formats, thus making them accessible to people with disabilities

¹ Coulter A, Ellins J, Swain D, Clarke A, Heron P, Rasul F, Magee H, Sheldon H. *Assessing the quality of information to support people in making decisions about their health and healthcare*. Oxford: Picker Institute Europe, 2006

Recommendations

I. Health and social care services should establish a new type of information provision – signposting and navigation.

“It isn’t just having access to the information – sometimes you need help to know what to have access to.” [Person with diabetes]

Patients and service users – and their families and carers – need timely, personalised help to navigate the routes to relevant information. They should not be abandoned at the point of diagnosis; or when moving across sectoral boundaries (for example, from healthcare into social care); or when relocating geographically.

The Picker Institute therefore recommends that:

- each local area should have a central, easily identified information contact point. This would be staffed by people who are skilled in online searching, to act as a conduit to more specialised and personally relevant information services
- this information point should be responsible for gathering and disseminating information on all health, social care and voluntary sector services within the local area (that is, the common local authority/primary care trust area)
- a new cadre of local ‘information brokers’ should be created – who can provide leadership and coordination across boundaries.

II. Health and social care services need to raise their standards in providing timely, relevant information to patients and service users, their families and carers.

“You are not told anything, you have got to find it out for yourself” [Person with MS]

The Picker Institute recommends that:

- professional staff should receive training to enable them to understand service users’ information needs; how to access relevant information; and when to provide it
- professional staff need to make themselves aware of all relevant voluntary sector services for their client groups, and to take a proactive role in disseminating this information
- professionally-staffed services should make information provision a higher priority and resource it adequately
- systems are required to ensure that telephone enquiries are dealt with promptly and followed up when necessary. Such systems might include agreed quality standards that can be effectively monitored.

III. The presumption should be to supply the best information at the user's request -- artificial barriers to providing information about service availability should be removed.

"I was told very harshly that [this organisation] wouldn't be able to answer anything unless I was referred by the social service" [Ethnic minority 'mystery shopper']

The Picker Institute recommends that:

- information requests should not be refused on the grounds that the potential service user has not yet been formally referred.

IV. Health and social care website standards need improvement.

"Links to relevant sites were incredibly difficult to find and these sites often didn't yield any relevant information" [Online researcher]

The Picker Institute recommends that:

- Websites, as well as other information sources, should wherever possible be accessible to all, including people with sensory and learning disabilities, and people from ethnic minority groups
- Websites should provide useful links onward to other relevant sites, especially those of voluntary sector groups.

Important note: the research participants

This report describes the 'better end' of the range of service user experience in trying to access information.

The research participants were people who had spent long enough navigating the information pathways to have become 'expert information seekers'. They had come a long way since first receiving diagnoses or the onset of their or their family member's conditions. They were, on the whole, highly motivated, articulate and assertive.

People newly coping with the need to get service information, or who do not have the same personal skills and qualities, are likely to struggle even more.

The services designed to help people at the point of need seem, all too often, to throw them back onto their own resources.

"I was given no information about my diabetes at all, other than a quick chat with the dietician on day one, when I was in such a state of shock... it just went completely above my head." [Person with diabetes]

1 Introduction

1.1 Study aims

The 2006 White Paper, *Our Health, Our Care, Our Say*, identified a need for high quality information to help people choose and access services. The Department of Health promised to:

“review the provision of health and social care information to ensure that people who use those services have the information they need, when they need it, and in a wide variety of formats. We will do this in partnership with people who use health and social care and their representative organisations, and we will also consider methods of helping people navigate round the many different services.”

The Picker Institute was commissioned to assist in this process by carrying out two studies. The first of these, which was published in 2006, looked at the content of health information for patients and the public and assessed the extent to which an accreditation system might help to raise quality standards.² The second study, the subject of this report, evaluated the accessibility of information about health and social care services, involving service users and carers as active participants in the research process.

The study was designed to address three key questions:

- How do patients, service users and carers currently find out about locally available services and how to access them?
- To what extent are local information resources well signposted so that people can find the information for themselves?
- What additional support is required to enable people to find information about services that is appropriate to their needs?

1.2 Methods

There were four components to the study:

1. Focus groups with service users and carers to determine their information needs and to identify any problems they had encountered in accessing information.
2. Mystery shopping assessments by service users and carers to determine how easy, or difficult, it is for users to find relevant information by telephone. Local research

² Coulter A, Ellins J, Swain D, Clarke A, Heron P, Rasul F, Magee H, Sheldon H. *Assessing the quality of information to support people in making decisions about their health and healthcare*. Oxford: Picker Institute Europe, 2006

partners in each of the study sites validated the findings from the mystery shopping exercise.

3. Online searches to identify and evaluate ease of access to relevant health and social care information sources on the internet.
4. Survey of local health and social care professionals and information providers to assess the extent to which they are well-informed about local services and what, if any, additional support they need to act as 'signposters' to these services.

1.3 Participants

The study focused on the needs of several user groups, selected to represent the diversity of information needs:

- older service users and carers in minority ethnic groups
- people with long-term physical conditions (diabetes/multiple sclerosis) and their carers
- people with a long-term learning disability (autism) and their carers
- people with a sensory impairment (hard of hearing) and their carers.

In the event, it proved impossible to organise any focus groups or in-depth interviews with people who were profoundly deaf or hard of hearing within the limited time available, but the availability of information resources for people with sensory impairments was assessed in the online searches and via the survey of health and social care professionals.

1.4 Setting

The study was carried out in four localities, selected to represent different characteristics and diverse populations: Cornwall, Oxford, Sandwell and Southport (see Table 1). In selecting these areas for the case studies we aimed for geographical and social balance, while ensuring that the particular groups mentioned above were well represented.

Picker Institute researchers worked with local community groups in Oxford to recruit service users and carers to assist with the study. Oxford-based service users and carers helped with the identification of information needs, the development of scenarios for the mystery shopping exercise and the online searches, and some of them acted as mystery shoppers. In addition, service users/carers in each of the other three sites (Cornwall, Sandwell and Southport) were recruited to act as research partners to validate the information obtained about health and social care services in their local areas.

Table 1: Study sites

Locality	Description	Health services	Social services	Study focus
Cornwall	Rural county; pop. 513,527; 99% white; poorest area in UK with lowest GDP.	Cornwall Partnership Trust; Cornwall & Isles of Scilly PCT	Cornwall Dept. for Adult Social Care; Cornwall Dept. for Children, Young People and Families	Mental health/ learning disabilities – service users and carers
Oxford	City in Oxfordshire and county town; pop. 134,248; fairly large ethnic minority population – 4.8% S Asian, 2.5% Afro-Caribbean, 1.8% Chinese. 87.1% white.	Oxfordshire PCT; Oxford Radcliffe NHS Trust; Oxfordshire Mental Health Trust	Oxfordshire Social and Community Services	All four groups
Sandwell	Metropolitan borough in West Midlands; pop. 286,300; large ethnic minority pop. – 14% S Asian, 4% Afro-Caribbean	Sandwell & West Birmingham Hospital NHS Trust; Sandwell PCT	Sandwell Adult Services and Health; Sandwell Education and Children's Services	Ethnic minority elders and carers
Southport	North west coast (Merseyside); pop. 93,000; large retired/ elderly population – 40% aged over 55.	Sefton PCT; Southport & Ormskirk Hospital NHS Trust	Sefton Health and Social Care Directorate; Mersey Care NHS Trust	Long-term physical conditions – service users and carers

Details of the methods and results for each of the components of the study are described in the following chapters.

2 Information needs and information-seeking experiences

2.1 Background

It can be generally assumed that all patients, carers and service users require information about the availability of and access to health and social care services in their local area. However, as a large body of existing research demonstrates, both service and information needs can vary considerably from patient group to patient group, and even from person to person.^{3, 4} An understanding of the variation and complexity of these needs is essential for effective signposting to relevant information sources and local service providers. It is equally important to recognise and address the barriers that people face in trying to find appropriate information and services.

In order to probe these issues in detail, a series of focus groups was conducted with three distinct user/carers groups⁵. Participants were recruited through relevant community or voluntary organisations in the Oxfordshire area. Details of the focus groups are summarised in Table 2.

Table 2: Focus group participants

Group	Participants
Ethnic minority older people	<ul style="list-style-type: none"> focus group involving four older Asian women who care for a relative or spouse focus group involving six older West Indian and Afro-Caribbean women living in sheltered housing.
Long-term physical conditions	<ul style="list-style-type: none"> focus group involving six people diagnosed with multiple sclerosis in-depth telephone interview with person recently diagnosed with multiple sclerosis focus group involving three people with diabetes and one carer.
Autism/learning disabilities	<ul style="list-style-type: none"> focus group involving five parents of children or young adults diagnosed with autism.

³ Coulter A, Ellins J. Patient-focused interventions: a review of the evidence. London: The Health Foundation, 2006

⁴ Coulter A, Ellins J, Swain D et al. Assessing the quality of information to support people in making decisions about their health and healthcare. Oxford: Picker Institute Europe, 2006

⁵ To address the information searching experiences of people with a sensory impairment, numerous attempts were made to organise discussions and interviews with the deaf and hard of hearing community, but unfortunately it proved impossible to organise these within the limited time available.

The overall purpose of the discussions was to:

- look at how patients, service users and carers currently find out about health and social care services in their local area
- explore how easy or difficult it is for these groups to get the information they need
- identify what extra help might make it easier for people to find out about services in their local area.

In addition the focus group discussions were used as a basis for developing scenarios to be used in the mystery shopping assessments and the online searching exercise. All discussions were guided by a set of open-ended questions (see Appendix 1 for the topic guide) and, with the participants' permission, were recorded and fully transcribed.

2.2 Information needs and preferences

The focus groups began with a discussion about information needs and people's preferences for when and how they would like to find out about services in their local area. A common theme in these discussions was the high value that was placed on information, both as a means to better understand how to manage health problems but also to guide people in accessing an appropriate mix of support and services. Participants spoke at length about the importance of obtaining information soon after they received a diagnosis or assumed a caring role, at precisely the stage when the health and social care system can seem most complex and confusing. However, many were also keen to point out that the need for information is ongoing, and that staying well-informed and up-to-date about relevant services is a long-term process. This is especially so when the individual is dealing with a chronic health problem, where service requirements may change as the condition alters or worsens over time. It is also an issue for children with learning disabilities – as people in the autism group pointed out – given that service needs and eligibilities change as children become young adults.

Information needs change over time and are very diverse. Participants had sought information on a wide variety of general and specialist services. However some common themes emerged. Information most commonly requested included the following:

- local voluntary and support groups
- nursing or respite care
- specialist healthcare facilities and/or professionals
- medicines
- financial benefits and allowances.

Everybody we spoke to had, at some point, tried to find out about services available in their local area, be they GP, dentist, specialist health, social care or voluntary sector services. Most wanted at least basic details in the form of contact names, addresses and telephone numbers, and opening times. Information about eligibility and application processes (where appropriate) were also mentioned, particularly in relation to benefits and allowances. Some people also wanted to prepare for eventualities by finding out about services that they or the person they were caring for might need in the future. As one participant told us:

"I think that's why I would like to have some information (from social services) so that I know what they can offer in the future if I need them" [Autism group participant].

In terms of *how* people want to receive information, again a range of responses was given. All the groups talked about the importance of face-to-face contact, which provides an opportunity both to gain information and to raise any concerns or ask questions. Focus group participants said they wanted to know about the suitability and scope of local services as well as basic (eg contact) information, and the former can only really be given in person. Finding one individual who is able to help in accessing information and making enquiries was seen as particularly valuable, although many people had not achieved this in practice. Written information materials were also seen as important for use as a reference, but also because things that are said during meetings or consultations can be forgotten or misremembered. Younger participants were more likely to see the internet as a useful information resource than those who are older. Both groups of ethnic minority older people commented that they did not use the internet, nor did they envisage wanting to do so in the future. Conversely, many of the parents of children with autism – who were younger in age – actively sought out information via the internet, particularly when looking for services that are not mainstream to the NHS or local authority. However, they expressed concerns about the quality of internet information:

"If it's on the net we are not really sure whether it's reliable or not, so that's the biggest hurdle." [Autism group participant]

Some participants had contacted voluntary sector organisations to make enquiries about health or social care. In general, local voluntary organisations or community groups were seen as having the best local intelligence and therefore more useful than their national equivalents.

2.3 Experiences of looking for local services information

Focus group participants were asked to talk about their experiences of searching for information on local services and to comment on the challenges that they and others face in finding relevant information at the right time.

Information provision

Many participants said that although there is a great deal of information on local services, it is an uphill struggle to find out about relevant services in the first place. Knowing *what* information to look for is key to accessing the necessary help. Once you know how to navigate the system there are plenty of individuals willing to help, but making the initial contacts was felt to be difficult.

"It isn't just having access to the information – sometimes you need help to know what to have access to." [Diabetes group participant]

People reported that information had rarely been offered to them routinely. Instead it was left to them to specifically request it. Participants described how difficult it can be to advocate for yourself, especially when you are trying to build relationships with the people you depend on for services and support.

"You are not told anything you have got to find it out for yourself." [MS group participant]

Information is given out in an ad hoc way and it is very common for professionals to inform people of services and support long after they have already found it out for themselves. Many participants described how they were forced to rely on their own efforts and some had become quite expert in the process and were well-informed about the options available to them. This was evident in several of the groups but particularly so in the autism group where several parents said they had become 'information sponges' - looking for information everywhere and reading anything relating to autism in the hope of finding out more about services and available help.

"Even articles you see in the newspaper, if somebody gives you an email address or something like that, you just follow up everything." [Autism group participant].

The timing of information provision is almost as important as the information itself. Some people reported being given information at the same time as their diagnosis when they were unable to fully 'take it on board' as they were just coming to terms with their situation. Others commented that the nature of their condition meant that their needs would change over time and they felt they were given information at a time when it was irrelevant but that it might be useful at a later stage.

"I was given no information about my diabetes at all other than a quick chat with the dietician on day one, when I was in such a state of shock. I can't remember anything she said at all. ...it just completely went above my head. I went in for a kidney thing and I came out with diabetes." [Diabetes group participant]

Finding Information

Some groups did not know where to go to get local services information. Participants reported that finding your way into the system can be very difficult and being able to articulate service needs can also be a challenge, particularly when you do not know what services are out there or what you could benefit from.

"The services are very patchy and once you get into them there are lots of really helpful people who want to help you ... the problem is for people like us it is actually knowing the way into the system..." [MS group participant]

A number of participants expressed concerns for others in similar situations to themselves who may have lower levels of health literacy and might lack the same levels of assertiveness. They felt that it was important that everyone had equal access to services and therefore favoured a more consistent approach to information provision.

"I only go [to the clinic] once a year and I never see the same person unless I ask to, but this is something - if you understand the system - but it is a bit self directed... That is all very well if you are articulate and assertive and you know what you want and have an idea of what the answers are and then you try and steer the course in that way." [Diabetes group participant]

For many people their GP is the first point of contact and those with 'general' health needs see their GP and the GP's surgery as a starting place for the information they need.

"My particular doctor's surgery always has a lot of leaflets in there, always...different leaflets for different things, you know, so you can find out whatever you need." [Ethnic minority group participant]

However, those people with more specific, longer term needs felt GPs were, on the whole, not always able to provide the specialist information or advice required for their particular situation. Others mentioned their distrust of information they had been given, saying they frequently used the internet for verification purposes.

Support from local groups

Faced with a lack information from their service providers, participants who belonged to local support groups saw interaction with other patients and carers as a key source of information which provided considerable benefits. People are able to use these forums as an opportunity to learn about various treatments and therapies and also to find out about the services they can access. Participants emphasised that local networks can be much more useful in offering information specific to their area as there can be wide variation in local practice depending on where they live.

"I didn't know anything about [care] managers either until someone told me and I went to the Social Services." [MS group participant]

Particular challenges

Participants described particular difficulties in obtaining information about benefits and financial support. Without a consistent process to inform people about benefit entitlements some people only discovered they might be eligible for help by accident or by talking to others.

"That's how I found out – a friend of mine was working at the DSS⁶ and she sent me the forms and said 'fill them in for goodness sake.'" [MS group participant]

Participants reported that they were often required to provide information in a 'bureaucratic' format and in a way that did not necessarily fit their particular situation. For example, the benefits application process for 'disabled' children is more suitable for physically disabled children than those with learning disabilities.

Another major difficulty reported in the focus groups was the challenge people faced in gathering information on alternative treatments and therapies and services not provided by the NHS. Many felt that GPs sometimes acted as a barrier to finding out about non-mainstream services when they did not believe they would be beneficial. It can also be hard to find information about services that are not provided by the NHS, for example privately run counselling and psychotherapy services.

A number of participants with long-term conditions reported that whilst there is information available for their physical symptoms, their emotional needs are often ignored, thereby making it difficult to access psychological therapies or emotional support.

Problems can also arise when the services needed cut across organisational or sector boundaries. This frequently leads to a situation where no one organisation takes a lead responsibility and it becomes harder to find out about the full range of services on offer.

⁶ Department of Social Security

Service users can find themselves being passed to and fro between agencies in their quest for information. This was a particular concern for parents of children with autism who reported that it is easy to feel as if you are falling through the gaps when there is poor co-ordination between service providers.

[In response to question about who should provide support] "Well...education thinks [health] should, health thinks it should be social services and social services said 'it's education' so you're back on the same..." [Autism group participant]

2.4 Suggestions for improvement

Focus group participants had a number of suggestions for improvement:

Getting the right information at the right time

Information about care and care providers should be given proactively soon after the point of diagnosis, for example a basic information pack listing all relevant services, specialist providers and their contact details would be useful. Information should be much better targeted so that it is received at the right time and is relevant. Details of changes to services should also be made readily available. People would like to receive regular reminders regarding check-ups and screening as appropriate.

"...as things progress – it would be good if there was a system which allowed them to access information as and when they needed it or be reminded by it" [MS group participant]

Everyone should be offered information relating to the services that they are eligible to receive.

A central contact point

Many people suggested the need for a key contact point for finding information, be that a person (eg GP, SENCO⁷) or a place (eg a central information point, one-stop-shop).

Better co-ordination between organisations

Better co-ordination between different agencies is required to improve awareness of different services and to help signpost people effectively between sectors and organisations. Having somebody who acts on your behalf to liaise across the various service providers and agencies was suggested as a potential solution to the problem of poor co-ordination.

More support for local voluntary groups

Participants viewed local voluntary support groups as a valuable resource for their information needs. Many felt that these groups should be better supported and advertised more widely to those who could benefit from their services.

Improved signposting

People want information that is reliable and trustworthy. Many felt the internet should play a key role in appropriate signposting and suggested the possibility of developing NHS websites for specific patient groups. Participants also stressed the importance of signposting to

⁷ Special Educational Needs Co-ordinator

information on complementary and alternative therapies; better guidance on the use of these therapies, and better availability of the therapies themselves.

3 Mystery shopping assessments

3.1 Background

Mystery shopping is a user-centred method of evaluating service performance and quality. It is defined by the Market Research Society as:

The use of individuals trained to experience and measure any customer service process, by acting as potential customers and in some way reporting back on their experiences in a detailed and objective way.⁸

While mystery shopping has been widely employed by market researchers for many years, few studies to date have applied it to the health and social care sectors⁹. In part this is because of the difficulties of using mystery shopping to assess complex systems of care rather than one-off consumer products or episodes of retail service. These issues are discussed in more detail below. Nonetheless, with careful development and management, mystery shopping can play an important role in better understanding user experiences of health and social care services and in identifying areas for improvement.

The purpose of mystery shopping in this project was to:

- explore how easy or difficult it is for people to find out about key local services
- assess the extent to which local service providers and organisations are able to signpost people to appropriate information sources
- compare how different organisations respond to queries about local services, and identify best practice
- document the experiences and outcomes of information searching from a user perspective.

There were various factors complicating the mystery shopping assessments which should be acknowledged and their effects on the research process understood. First, mystery shoppers were recruited from the Oxford area but carried out their 'shops' in one of three study areas: Cornwall, Southport and Sandwell. The main reason for this was to ensure that shoppers did not come into contact with individuals or organisations who they were known to, or who they might need to contact in the future. For reasons of practicality and feasibility, the mystery shopping was therefore conducted by telephone rather than in person.

We encountered issues around divulging personal information and preserving shoppers' integrity. As we anticipated, many of the organisations our shoppers spoke to wanted to tailor the information to the specific query. To do so, they asked for personal information from the

⁸ Market Research Society. Guidelines on customer mystery research. London: MRS, 2003

⁹ Moriarty H et al. Mystery shopping in health service evaluation. British Journal of General Practice. 2003; 53 (497): 942-6

shopper such as their name and address, medical history and details of the services they were currently using. Our main concern was that people were able to give plausible and consistent answers to these questions. We therefore advised shoppers to answer questions truthfully based on their own personal circumstances where appropriate, or else to politely decline to answer questions where they were not comfortable providing such information.

A final, and very important concern, was about the work that we would potentially create for organisations who were contacted by our mystery shoppers. There is a tension between conducting realistic mystery shops which organisations respond to like any other public enquiry, and limiting the time organisations spend compiling and providing information given that it is for research purposes only. According to the Market Research Society's guidelines on mystery shopping, "*The average length of time spent with a staff member should reflect a normal transaction in the relevant market.*" Maximum times for telephone mystery shops are provided in the guidelines, but only for the retail, manufacturing, leisure, automotive and financial sectors. We advised our mystery shoppers to request only basic information from the organisations they spoke to, and to decline offers of any additional services.

3.2 Recruiting mystery shoppers and devising scenarios

The majority of the mystery shoppers were recruited from the focus groups that were held to identify key information issues and barriers. In the case of non-English speaking service users, focus group discussants reported that they generally asked another person – usually a family member or link/support worker – to find health and social care information on their behalf. Given this, mystery shops for this group were conducted by the members of staff in relevant community organisations. Overall, 11 mystery shoppers were recruited including:

- three people with multiple sclerosis
- two people with diabetes
- three people caring for a child or young adult with autism
- three link/support workers.¹⁰

In accordance with standard market research practice, all shoppers were remunerated for their time. Participants received £120 of gift vouchers, £60 per shop completed. In addition to receiving detailed written guidance on conducting mystery shops (Appendix 2), each shopper was personally briefed by a researcher during which time specific concerns or queries were addressed.

The selection of mystery shoppers is important in relation to the generalisability of the study findings. In general, the people who conducted mystery shops had themselves spent a number of years actively seeking out information about health and social care in their local area. Many were used to contacting organisations and articulating their information needs, and were not unaccustomed to encountering barriers in finding out about the availability and accessibility of local services. It is possible that the outcomes of these mystery shopping assessments might have been different had the participants been less experienced information seekers, for example people who have recently received a diagnosis or taken up a

¹⁰ Originally, four people with multiple sclerosis and four people caring for a child with autism were recruited to conduct mystery shops. However, due to reasons of ill-health and other commitments, two people were unable to participate. One link/support worker conducted mystery shops with two scenarios (i.e. four shops in total). Hence a total of twelve distinct scenarios were used in the mystery shopping assessments.

caring role. In view of this, we would argue that our findings represent the 'best case' scenario.

The Market Research Society recommends that mystery shopping scenarios should be:

- relevant – designed to test specific service behaviours that are the focus of the study
- credible – mimics natural consumer behaviour in the market concerned
- practical – simple, brief and appropriate
- safe – shoppers are not asked to do anything illegal or which threatens their personal safety
- objective – the majority of questions in the feedback form should focus on factual information.

To ensure relevance and credibility, all scenarios were based on the focus group discussions about the types of local services information that people had looked for in the past or expected to look for at some point in the future. Focus group participants were asked to comment on the realism of the draft scenarios. For each scenario, a sheet was drawn up to guide the mystery shop that included:

- background context to the scenario
- the core question – eg "I'm looking for details of carer support services in [area]"
- details of the specific types of information shoppers should look for – eg names and contact details of service providers, information about costs, eligibility criteria
- an initial contact telephone number.

The core topics for the mystery shops are listed in Table 3, and the full scenario sheets that were provided to shoppers are given in Appendix 3.

Since the shoppers were making enquiries in a region different from the one in which they live, it was necessary to devise scenarios that were based on an assumed move to the area of enquiry. This took the form of: *"I'm considering moving to [area], and am trying to find out about local services in advance."* Given that most of the shoppers had significant and ongoing health or social care needs, it was not unrealistic that they would be trying to find out about the availability of local services at such an early stage. Indeed, one of the shoppers (in the Autism group) commented that she had made preliminary enquiries of this kind some time before she moved to the Oxford area from her previous home.

Table 3: Mystery shopping scenarios

Multiple sclerosis

Area	Scenario
Southport	Information on making adaptations to the home
Southport	Support groups for carers and arranging respite care
Southport	Information on neurology services at the local hospital and details of specialist MS nurses

Diabetes

Area	Scenario
Southport	Support groups for people with diabetes and information on self management programmes
Southport	Details of GP practices specialising in diabetes and specialist diabetes services

Ethnic minority older people

Area	Scenario
Sandwell	Information on care homes
Sandwell	Applying to receive 'meals on wheels'
Sandwell	Information on respite services for Asian carers
Sandwell	Finding a GP practice with an Urdu/Punjabi health advocacy or link worker attached

Autism

Area	Scenario
Cornwall	Availability of therapy or counselling services for children with autism and their families
Cornwall	Out of school services for children with autism
Cornwall	Respite care for children with autism

3.3 Developing the methodology and assessment tools

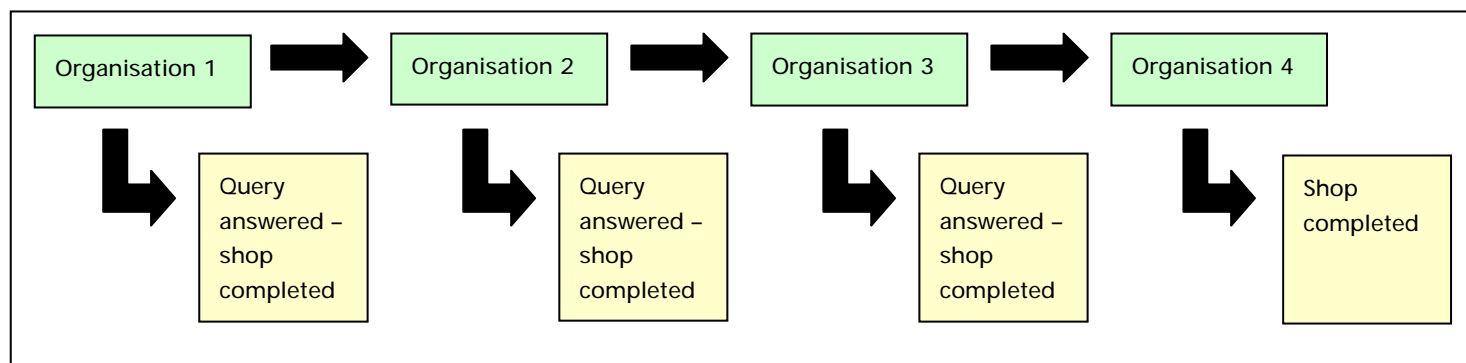
Most mystery shopping in the commercial world revolves around individual customer episodes, but this approach was unsuitable for the purpose of assessing the provision of local services information. We were focusing on the *process* of information searching and retrieval, rather than individual purchasing episodes. In particular, we were interested in how organisations signposted people to appropriate information sources, and the efficiency and outcomes of this process. Moreover, the experiences reported during the focus group discussions led us to believe that shoppers would need to contact more than one organisation to find answers to their queries about health and social care services. Indeed, many people reported spending long periods – during which time they contacted many different organisations – trying to find out about the availability of and access to services in their local area.

To capture the procedural nature of information searching, and also to ensure the exercise was feasible, shoppers were asked to contact up to a maximum of four different organisations during each shop. They were given a contact telephone number for the first organisation; if somebody at this organisation was unable to provide them with the necessary information, the shopper asked for details of another organisation to contact with regard to their query. The entire shop was completed when:

- sufficient information was provided to answer the query
- or the shopper had spoken to four different organisations
- or the shopper had been directed to an organisation they had already spoken to and no other organisation was suggested.

All participants conducted two mystery shops, both using the same scenario but each from a different starting point. While the purpose of this approach was to provide a point of comparison, we were also interested to see whether and how signposting to local services differed according to the initial point of contact (health, local authority, voluntary sector). In practice, it was difficult to reliably compare findings for the two mystery shops. Nonetheless, some participants did report that the process, experience and endpoints of their information searching differed substantially from shop 1 to shop 2 (see section 3.4).

Figure 1: The mystery shopping process



Shoppers were asked only to request information that could be given verbally over the telephone, or materials sent by post. Equivalent online mystery shops were subsequently conducted with the same scenarios (see chapter 4), to establish the availability and quality of local services information on the internet. In practice many people might use both telephone and internet to find out about local services, but distinguishing between the two in this way was felt to be useful to enable a comparison between them in terms of utility and outcomes.

A process for participants to report back the findings of their mystery shops was devised using a structured questionnaire. In accordance with the Market Research Society's guidelines, many of the items in the questionnaire aimed to probe the 'objective' elements of the mystery shop, including the number of organisations contacted, whether the organisation was able to answer the query and details of any information provided. The questionnaire also provided participants with an opportunity to comment on more subjective factors, in particular their opinions on how helpful and friendly they felt the organisations they spoke to were. These customer service aspects of health and social care are particularly important to service users, as we discovered during the focus group discussions. The feedback questionnaire can be found in Appendix 4.

3.4 The process of information searching

With regard to the process of information searching, the mystery shopping assessments were specifically concerned with two issues. Firstly, whether local organisations were themselves able to provide information to answer our shoppers' queries, and secondly, if they were unable able to provide this information, could they signpost shoppers to other organisations who would be able to help. The feedback questionnaires that our shoppers completed provided an insight into the journey that each took in trying to find answers to their questions about local services, and the main results are presented in Table 4.

Table 4: Results of mystery shopping exercise

Multiple sclerosis

Scenario	Starting point	Number of organisations contacted (max of 4)	Sufficient information found?	Results
Information on making adaptations to the home	Local authority	1	Partially	Twenty minute wait to speak to customer care. Telephone number given for an occupational therapist, who would provide specific advice on adaptations following a home visit and assessment. Cost information provided and caller told waiting list for occupational therapist can be as long as six months if case is considered non-urgent.
	Voluntary sector	3	Yes	Information on home assessment, loan of equipment and associated costs.
Support groups for carers and arranging respite care	Local authority	4	Partially	Organisation four (local voluntary group) provided details of its carer events, holiday and respite care services, and associated costs.
	Health	3	Partially	Details of carer help and advice services. Also recommended to speak to a further organisation (a local voluntary support group), who the shopper had already contacted during the previous shop.
Information on neurology services at the local hospital and details of specialist MS nurses	Health	2	Yes	Was advised to contact local specialist neurology centre where MS nurses were based. Spoke to MS nurse who provided details of the MS clinics and the average waiting time. Also found out about clinical trials taking place in the region.
	Health	3	Yes	Details of local support group and the same local general hospital as shop 1. Support group provided details of specialist neurology centre who the shopper had already contacted in the previous shop. They also suggested contacting MS Therapy Centre in the region but had few further details.

Diabetes

Scenario	Starting point	Number of organisations contacted (max of 4)	Sufficient information found?	Results
Support groups for people with diabetes and information on self management programmes	Voluntary sector	3	Yes	Contact details of a local support group, including opening times and staff names. Received booklet about managing diabetes, and given details of how to find educational courses via the local PCT.
	Health	3	Yes	Contact details of local support group, including telephone number, venue, dates and times of meetings. Information about how to register with a GP in the area, and details of an information and advice service in the local area provided by diabetic nurses.
Details of GP practices specialising in diabetes and specialist diabetes services	Health	4	Partially	One organisation provided information about a GP with a special interest in diabetes. Another gave details of a local podiatry clinic, including waiting list and registration process. All attempts to call contact about optometry services were unsuccessful.
	Health	1	Partially	Details of three GPs with special interest in diabetes provided. However, one was actually based in another area of the country and a fax rather than telephone number was provided for another.

Ethnic minority older people

Scenario	Starting point	Number of organisations contacted (max of 4)	Sufficient information found?	Results
Information on care homes	Voluntary sector	1	No	First organisation referred caller to their district branch, but the phone number was incorrect. Caller re-contacted organisation one for another telephone number, but was told that they were unable to help any further.
	Health	1	No	Calls made during public health alert (following death of Alexander Litvinenko), and caller unable to speak to anybody at organisation one. A pre-recorded telephone message recommended non-urgent callers alternatively access information via the organisation's website. Website did not contain the required information.
Applying to receive 'meals on wheels'	Local authority	2	Yes	Details of service, application process, cost and type of meals.
	Local authority	2	Yes	Details of service, delivery dates, placing orders, costs and types of meals. Brochure sent.
Information on respite services for Asian carers	Local authority	3	No	First three organisations unable to provide details of respite care for Asian carers. Third organisation signposted back to the first organisation.
	Health	4	No	None of the organisations were able to provide relevant information. Final organisation would only provide information if the person was referred to them by social services.
Finding a GP practice with an Urdu/Punjabi health advocacy or link worker	Voluntary sector	2	No	Second organisation was unable to provide information, and did not signpost caller to another source of help.
	Health	1	No	Organisation one arranged to call with contact numbers, but no call received over two weeks later.

Autism

Scenario	Starting point ¹¹	Number of organisations contacted (max of 4)	Sufficient information found?	Results
Availability of therapy or counselling services for children with Autism and their families	Health	4	Partially	Final organisation only able to provide telephone number of organisation providing activity breaks. Caller told that their GP would refer to a counsellor or therapist as appropriate.
	Voluntary sector	1	No	Organisation one arranged to send list of counsellors and therapists. However, they sent a list for the Oxfordshire area rather than the region in question. Useful background literature sent on 'Choosing a counsellor' and 'Approaches to counselling and psychotherapy'.
Out of school services for children with autism	Voluntary sector	2	No	Organisation one provided details of a local support group, which organises social trips during the school holidays, and also suggested that caller's social worker directly contact social services in the relevant area. Two answerphone messages left for the local support group, neither of which had been returned over a week later.
	Health	4	Partially	After "going round in circles", organisation four reassured caller that they would be able to provide relevant information. Arrangements made for the appropriate member of staff to call back, but call never received.
Respite care for children with autism	Local authority	2	Yes	After being passed round individuals at organisation two, caller finally spoke to somebody who was able to answer all their questions about respite care services. The information they provided included recommendations about specific services, contact details, and additional advice about schooling in the local area.
	Health	2	No	Second organisation suggested doing an internet search, or calling organisation already contacted during shop one.

¹¹ Starting point key

Health: includes general practices, hospitals, PCTs, acute trusts, national NHS services

Local authority: includes county and district councils, libraries

Voluntary sector: includes national patient charities, local user groups, professional bodies, Citizens Advice Bureaus

As Table 4 shows, the mystery shopping assessments were conducted with varying degrees of success. Some enquiries were more straightforward and easy to answer than others, but the process of information searching also appears to be influenced by where you start from. One common problem was that shoppers left answerphone messages or were told by an organisation that somebody would call them back, but no follow-up call was received. Interestingly, one person commented that waiting for a phone call that never came was *"pretty typical of my experience in real life"*. Some shoppers proactively called the organisation for a second (and even a third or fourth) time, and often managed to make some headway as a result. However, we did not require shoppers to do this and in some cases the process of information searching ground to a halt because of this problem. It may be that the enquiries were not always deemed to be a priority, because they were prospective rather than urgent requests for information about local services. Nonetheless, responding promptly and effectively to public enquiries should be a minimum standard to which all organisations adhere regardless of the context.

Our findings suggest that organisations are not always appropriately or efficiently signposting callers to relevant sources of information. Many shoppers reported being passed around between organisations, or around different individuals within a single organisation; the latter was most often reported in relation to large social services departments. Where signposting occurred, it was often to another organisation that was known to generally work in the area of concern (eg respite care), rather than being the best source of information in relation to the specific query that was being made (eg respite care for children with autism). Few callers were signposted to specific individuals within organisations, but instead were given switchboard or general enquiries telephone numbers. As a consequence, they had to find the appropriate contact within the organisation themselves which could be very time consuming. One of our shoppers commented that she *"got the impression they didn't know where to send me"*; another, towards the end of their shop, was signposted back to the first organisation they had spoken to and who had been unable to give them the information they required.

It is important to note that situations such as these were not necessarily felt by shoppers to be a problem, particularly when they eventually found someone who had the time and expertise to provide detailed information about the service in question. For example, some time after they had commenced their shop, one participant reached an individual who was described as follows:

"He was very patient with all my questions, and answered them all taking great care to detail. He even proceeded to describe the nearby towns and suggested to me where the best respite care services were...It's great to know that people as sincere as him are working in these departments." [Shopper 03, Autism]

Another commented that:

"After speaking to four people at [voluntary organisation], my overall impression is that they are a very friendly, helpful organisation and gave me nearly all the information I asked for. My only criticism is that it took three phone calls to get it." [Shopper 01, Diabetes]

A further issue, relating to the specific type of enquiry used in the mystery shopping, is that some organisations generate and tailor information from their databases based on the address or postcode of the caller. One shopper who was enquiring about services in Southport told us:

As I had no postcode to give, 'Liverpool' was typed into [organisation's] database but came up as 'not recognised'. Therefore they were unable to give me any information [Shopper 02, Multiple Sclerosis].

While this would not create difficulties where an individual is looking for services in their local area, it does hinder attempts to find information in advance of moving to a new area or on behalf of a friend or relative who lives in another part of the country.

Some shoppers found that it was difficult to find information about services without a direct referral from a GP, specialist or social services department. In other words, access to information about certain services is restricted because of the requirement to come through a formal referral and/or assessment process. Certainly, there are good reasons why organisations might want to provide detailed information and application forms following direct contact with an individual. However, this practice hampers people gathering information in advance of making choices about which services they want or need to use, or finding out about how to access services they may need at some point in the future.

A further problem that arose was that some shoppers were signposted to relevant organisations but given incorrect telephone numbers or fax numbers.

Although the process of information searching did not always run smoothly, most of our shoppers were able to find at least some information with regard to their query and a small number found everything they needed to know. Basic information about local services can be accessed with a little time and effort, but most organisations our shoppers contacted were not equipped to deal with very specialist enquiries. As might have been expected, locally-based organisations were generally more knowledgeable and had better information about services in their area than national equivalents. This echoes the findings from the focus groups, and indicates that local groups have a major role to play in signposting health and social care services and should be resourced accordingly. We also found examples of signposting between health, social care and voluntary sectors, although the focus group discussions suggest that in practice it can be difficult to access multiple services where they cross sectoral boundaries.

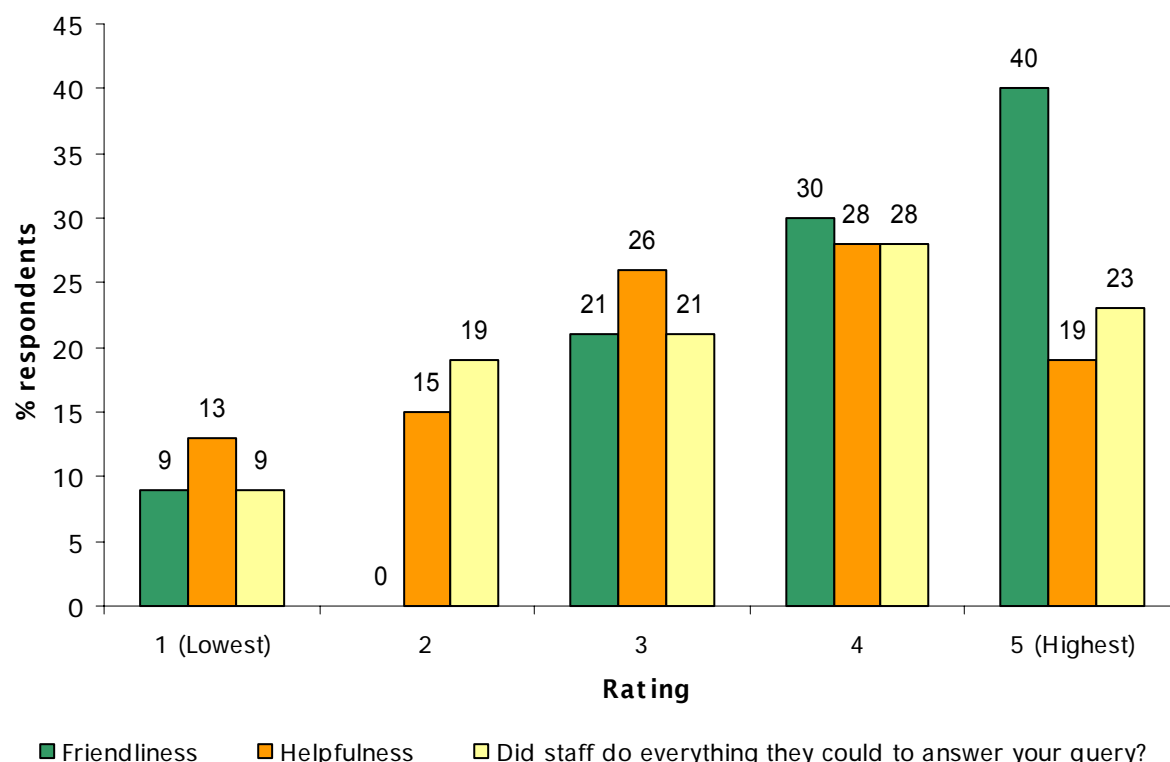
3.5 The experience of information searching

As well as questions about the process of looking for information about local services, we also asked shoppers to comment on their interactions with staff. Three questions in the feedback form were included to record experiences; these were:

- How friendly were the people you spoke to at this organisation?
- How helpful were the people you spoke to at this organisation?
- Do you think the people at this organisation did everything they could to help you?

People completed ratings for each organisation they spoke to during their two shops; the overall findings are presented in Figure 2.

Figure 2: Mystery shopper experience ratings



People were more likely to regard the organisations they spoke to as friendly than helpful. Over a quarter of our shoppers gave organisations a helpfulness rating of 1 or 2, at the lowest end of the scale. Additionally, they felt that almost one in ten organisations did very little if anything to answer their query. Conversely, 70% of organisations received a friendliness rating of 4 or 5.

It is clear from the comments recorded on the feedback questionnaires that a willingness to provide assistance and a generally helpful attitude was most important to our shoppers. Indeed, these qualities contributed to a positive experience of information searching even where an organisation was unable to provide details of services in response to the shopper's query. Looking at these ratings by type of organisation (health, local authority, voluntary sector), there are few differences in terms of helpfulness but the voluntary sector was more highly rated for friendliness. To illustrate, 85% of voluntary organisations were rated 4 or 5 for friendliness, compared to 57% of health-related organisations and 63% of local authority organisations.

Unfortunately, we were also told about a small number of negative experiences. For example, our shoppers made the following comments:

"The person who answered the phone [at organisation] was extremely rude and treated me like a complete fool." [Shopper 01, Ethnic Minority]

"I had to repeat my questions and was told very harshly that [organisation] wouldn't be able to answer anything unless I was referred by the social service." [Shopper 02, Ethnic Minority]

"I was transferred to [department] where a lady said 'I don't know why you are moving to [area] as it's not the best place for resources.'" [Shopper 03, Autism]

"The receptionist – who was male and very unfriendly sounding – put me through before I could clarify what was going on. I found the first contact very off-putting." [Shopper 02, Diabetes].

4 Finding relevant information on the internet

4.1 Background

Thirty percent of people report the use of websites as a source of health related information¹² and this figure is only set to increase. The latest Social Trends report found that 56% of UK households have internet access and more than two thirds of these are broadband connections¹³. This gives a very large number of people who are likely, at some time or another, to search the internet for health and social care information.

A series of internet searches was carried out to identify relevant sources of health and social care information on each of the topic areas in the three localities. The main purpose of this was to evaluate the accessibility of internet information in each of these areas while comparing results with the data gathered from the parallel telephone mystery shopping exercise.

4.2 Method

Using the telephone mystery shopping scenarios (see Appendix 3) as a starting point, researchers attempted to find answers and relevant information via online searches alone¹⁴. This exercise was designed to assess the process that information seekers might go through to reach a suitable conclusion, either by finding enough information to answer their query, or finding contact details signposting them to a relevant source of further information.

Researchers followed the guidance detailed in Appendix 5. They carried out a series of internet searches using the Google search engine to identify sites containing information that might be relevant to their scenario. All likely links were followed to see how long it took to find the information needed to answer their query. This searching process was recorded on a feedback form (see Appendix 6).

Details of all of the website links were recorded by the researchers so that they could be considered for further evaluation in the second stage of the online searching (see section 4.6).

In order to mirror the process that people might follow when searching for information of this kind, a time limit of 45 minutes was imposed on each online search. Searches were deemed complete when either enough information had been found to answer the original query or 45 minutes had elapsed.

¹² Ellins J, Coulter A. How engaged are people in their healthcare? London: Health Foundation, 2005

¹³ Office for National Statistics. Social Trends 36. London: Palgrave Macmillan, 2006

¹⁴ Fourteen distinct scenarios were developed for use as part of the online searching and telephone mystery shopping exercises. Online searches were carried out for each of these scenarios but two of the telephone mystery shops were not completed.

4.3 Results

Table 5: Results of internet searches

Multiple Sclerosis (MS)

Scenario	Number of sites visited	Total time taken to complete search (mins)	Suitable endpoint reached	Results
Details of local MS support groups	2	15	yes	Information on two support groups in the area and brief description of the support offered.
Information on making adaptations to the home	2	20	yes	Contact details of two social services departments.
Information on neurology services at the local hospital and details of specialist MS nurses	2	25	yes	Contact details for local specialist neurology centre. Waiting times for neurologists. Details of relevant research being undertaken.
Support groups for carers and arranging respite care	1	20	yes	Contact details for the careline to find out more about respite care. A named contact for details of carer support services.

Diabetes

Scenario	Number of sites visited	Total time taken to complete search (mins)	Suitable endpoint reached	Results
Support groups for people with diabetes and information on self management programmes	5	17	yes	Contact details of regional diabetes Support Group. Links to diabetes education programmes but no information on their location.
Details of GP practices specialising in diabetes	8	37	yes	One GP with a specialist interest in diabetes (part of group practice) and details of hospitals with specialist clinics for a variety of diabetic problems eg podiatry. Phone numbers, frequency of clinics and staffing details were available.

Ethnic Minority Older People

Scenario	Number of sites visited	Total time taken to complete search	Suitable endpoint reached	Results
Information on care homes	2	6	yes	A list of 31 care homes within one mile radius of specified location with general details of the home, number of places, types of ownership (private, voluntary etc), the manager's name and links to recent Commission for Social Care Inspection (CSCI) assessment reports. Also signposted to Adult Care Team (who you contact for a care assessment), the PALS service, Age Concern and the local Citizens Advice Bureau. Guidance about financial issues and a checklist of 'what to look out for in a care home'.
Finding a GP practice in the area with a Urdu/Punjabi health advocacy/link worker attached	5	45+	no	Details of GPs in area but no information on health support workers. Public Information Network site had lots of information and provided some potential telephone numbers to call but it is unclear if they were appropriate. Came across directory of culturally specific services for Asian Carers and details of how to access them but this was three years old.
Applying to receive 'meals on wheels.'	1	3	yes	Details of four adult teams in the area who can arrange meals on wheels (including opening hours and contact details), information about what 'meals on wheels' is and who can receive the service. The webpage also signposted to related information about keeping warm in winter and direct payments.
Information on respite services for Asian carers	2	6	yes	Details of local facility providing respite specifically for Asian carers. Information included details of languages spoken, opening times, Halal food and prayer rooms.

Autism

Scenario	Number of sites visited	Total time taken to complete search	Suitable endpoint reached	Results
Availability of therapy or counselling services for children with autism and their families	1	40	yes	Details of child and family service. Also information on parent support groups.
Availability of carer support services in the local area	3	32	yes	Details of family support care team, a parent befriending scheme and a parent support group.
Out of school services for children with autism	3	35	yes	Details of a voluntary organisation running out of school activities for children with autism Information on local early years autistic spectrum disorder (ASD) services. Also links on local support groups which did not provide specific details on out-of-hours services but would have provided a useful starting point.
Respite care for children with autism	1	30	partly	Information on Family Support Care (a family based 'respite' service for children who have a disability). Carers' Support Worker for the local area. Details of staffed respite care house for up to four children. Details of referral procedures. Contact details of the local social service office.

Table 6: Summary of internet search results

Topic/Issue	Average number of sites visited	Average time taken to complete search (mins)	Success rate
Multiple Sclerosis	1.75	15	100%
Diabetes	6.5	20	100%
Ethnic Minority Older people	2.5	25	75%
Autism	2	34.25	87.5%
All	3.2	23.6	90.6%

4.4 The online searching experience

Due to the large number of variables (topic area, region of the country, complexity of the scenarios and the relative efficiency of individuals' searching techniques), it is hard to make firm generalisations about the relative ease or difficulty of finding relevant information on the internet. However, the experience of the researchers varied quite considerably. The shortest search took just three minutes whilst the longest successful search took 40 minutes to complete.

Several of the searches led directly to relevant information on the first website visited, whilst others involved a large number of sites before satisfactory information was identified. The maximum number of different sites visited during a search was eight.

There appears to be no direct correlation between the numbers of sites visited and the time taken to find relevant information. For example:

The '*details of GP practices specialising in diabetes*' scenario was completed in 37 minutes but the searcher had to visit **eight** different websites to reach this point.

The researcher looking at '*the availability of therapy or counselling services for children with autism and their families*' took 40 minutes to find sufficient information but only looked at **one** website.

This could be explained by the website's failure to signpost effectively. Researchers reported that some websites were much easier to navigate than others.

"Links to relevant sites were incredibly difficult to find and these sites often didn't yield any relevant information."

"Search facility on council website made searching easier."

Websites encountered in these searches were evaluated more closely (see section 4.6) to assess their layout, clarity and ease of navigation.

4.5 How successful was the online searching?

The vast majority of searches (91%) were described as reaching a successful end point. Only one search was felt to be unsuccessful, although it did provide details that could have led to more information:

Scenario	Results
Finding a GP practice in the area with a Urdu/Punjabi health advocacy/link worker attached	Details of GPs in area but no information on health support workers. Public Information Network site had lots of information and provided some potential telephone numbers to call but it is unclear if they were appropriate. Came across directory of culturally specific services for Asian carers and details of how to access them but this was three years old.

The high success rate of the online searching suggests that, on the whole, information on locally available services is available on the internet. However to find this information searchers need to know how and where to look for it. They also need to be aware of the services and facilities that are potentially available to them.

"This wasn't a particularly easy search although there was a lot of very useful information available."

"Good clear information provided on this site although might be easier if you know the questions to ask."

4.6 Accessibility of website information

It is possible to find a large amount of information relating to health and social care services using the internet alone, but the usefulness of the websites depends on how easy they are to navigate. A subset of websites was selected for further evaluation. Researchers revisited the websites to examine the steps that organisations have taken to help signpost people appropriately to information on local services.

The websites chosen for this assessment represented a number of different types of information provider, including voluntary sector organisations, NHS trusts, local authorities and national health and social care information sources. We chose not to include any Primary Care Trust (PCT) websites in this evaluation because many were under reconstruction due to mergers and service reconfigurations. The information available on a number of PCT websites was found to be either incomplete or in the early stages of development.

Researchers were asked to look at each website in detail to assess the following:

- ease of navigation
- clarity of structure and layout
- accessibility
- information in other formats
- recent updates
- links to other sources of information.

Their findings were recorded on a pre-prepared feedback form (see Appendix 7) and the results are presented in Table 7.

4.7 Results

Table 7: Summary of internet search results

			Accessibility of website							Information formats available					
	Navigation Score /5	Clarity & layout /5	Large Text	Audio/Sound	Text only	Browser settings	Telephone helpline	Textphone	Other languages	Audio	Video/DVD	Other print	Other languages	Links to other organisations	Last updated (as of Dec 2006)
Local Authority 1	4	4	✓			✓	✓		✓					✓	Late 2006
Local Authority 2	2	2										✓			
Local Authority 3	5	5	✓		✓	✓								✓	
Local Authority 4	4	3	✓	✓	✓	✓	✓		✓	✓		✓	✓	✓	Oct 2006
Local Authority 5	5	5		✓	✓		✓				✓			✓	
Health and Local Authority Partnership	5	4			✓										Dec 2006
Regulatory Body	5	4		✓		✓	✓	✓	✓			✓	✓	✓	Nov 2006
Health 1	4	2	✓	✓	✓	✓	✓	✓						✓	
Health 2	4	4	✓	✓		✓	✓	✓	✓				✓	✓	
Health 3	4	4					✓							✓	
Health 4	4	3	✓												
Health 5	4	5			✓										Dec 2006

			Accessibility of website							Information formats available					
	Navigation Score /5	Clarity & layout /5	Large Text	Audio/Sound	Text only	Browser settings	Telephone helpline	Textphone	Other languages	Audio	Video/DVD	Other print	Other languages	Links to other organisations	Last updated (as of Dec 2006)
Voluntary Sector 1	3	3												✓	
Voluntary Sector 2	5	5	✓	✓	✓	✓	✓		✓					✓	Variable Sept 2006
Voluntary Sector 3	4	4					✓		✓				✓	✓	2006
Voluntary Sector 4	5	4				✓	✓						✓	✓	

4.8 Ease of navigation

Researchers were asked to assess how easy it was to navigate the websites by providing scores out of five for 'ease of navigation' and 'clarity and layout'. On the whole many of the websites assessed scored highly. Two sites scored maximum marks with a number of other sites scoring at least four out of five for these criteria. Researchers reported that those that achieved higher scores were well laid out, uncluttered and had a consistent design throughout. Hyperlinks were obvious, search functions were provided and it was easy to retrace your steps.

"Well laid out - plenty of space and uncluttered. Keywords hyperlinked to explanations."

"This site was very easy to navigate as it has broad headings on the left hand side of the screen which can be expanded to show services that are offered...There is an A-Z facility and a search facility which can be accessed from any page within the website."

"Design was simple/basic but consistent and clear. Sections were clearly separated and appeared logical."

In addition some sites used prompts as an approach to signpost the reader effectively:

"It is also very easy to navigate because it uses prompts eg I am a carer...I am looking for a care home... I want to get involved..."

Websites that did not score as highly were either cluttered with too much information

“There’s too much text and too many sections on each page...I just think they’re trying to cover too much in one website.”

or provided unclear links and signposts to other sections or websites.

“Has slightly confusing links on right hand side of the page to other pages within the site.”

4.9 How up-to-date are the websites?

Of the 16 websites reviewed, only half provided the date of their last update – a surprising finding considering how easy this feature is to implement. Researchers reported that it was difficult to have confidence in information material that either gave no indication of when it was produced or was obviously considerably out-of-date.

“Links to newsletters are up to four years old.”

Of those websites that did provide details of their last revision, almost all had been updated in the previous three months, indicating that this feature worked well once it had been introduced.

Providing current information helps to add validity to the content but also encourages the information seeker to use the site again.

“Alongside information about organisations etc, there were also details of courses and other events which helped to give it a sense of being up-to-date and worth visiting on a regular basis.”

4.10 Accessibility of the websites

In order to assess the accessibility of the websites researchers were asked to indicate if they offered any of the following features:

- large text
- audio/sound
- text only
- option to change browser settings
- telephone helpline
- textphone facilities
- information in other languages.

A significant proportion of the websites evaluated had taken steps to address accessibility issues with around half of them offering each of the options listed above.

“Really excellent on accessibility and provision of alternative formats.”

The only feature that was not frequently provided was **textphone**, which was only mentioned on three of the 16 websites.

The approach to accessibility is highly variable however – a quarter of the websites provided six of the seven listed features, while two sites offered none.

“This website did not offer any alternative formats...but includes lots of good information.”

Addressing accessibility of websites is an important step in reducing discrimination and tackling inequalities, so this should be accorded high priority.

4.11 Information in alternative formats

As well as looking at steps taken to improve the accessibility of websites, researchers also looked at whether it was possible to request information from the organisation in any of the following formats:

- audio
- video/DVD
- other print
- other languages.

Very few of the websites readily offered this opportunity with nine out of 16 sites offering none of these alternative formats. If organisations do offer other versions of their information, it is very badly promoted and not at all obvious to the information seeker.

“Translators available if required. Not clear if information is available in other formats-would need to call to find out.”

Again, this is an important issue to address. Service users have diverse needs and preferences in respect of the format of information. Those with lower levels of literacy often prefer audio or video information over written materials.

4.12 Signposting to other information sources

Twelve of the 16 websites provided relevant links to other organisations indicating a commitment to signposting searchers effectively.

“A very good website, lots of information and appropriate links.”

However, there is clear scope for providing better links to voluntary sector providers in some areas. Social care agencies appear to perform better than health care ones in this respect.

5 Comparison of findings from online searching and telephone mystery shopping

5.1 Introduction

In order to validate our earlier findings our research partners in each of the local areas were shown the results of the online searching and mystery shopping exercises. They were asked to comment on whether the findings were broadly as they would expect, if all important information sources had been identified and how up-to-date and reliable the findings were.

5.2 Comparison of findings: multiple sclerosis

Table 8: Results of searches – multiple sclerosis

Scenario	Online searching results	Mystery shopping results
Details of local MS support groups	Information on two support groups in the area and brief description of the support offered	<i>Telephone mystery shop not conducted</i>
Information on making adaptations to the home	Contact details of two social services departments, opening hours and list of aids and adaptations available.	<p>Shop 1: Spoke to Customer Care. Telephone number given for an occupational therapist who would provide specific advice on adaptations following a home visit and assessment. Cost information provided and caller told waiting list for occupational therapist can be as long as six months if case is considered non-urgent.</p> <p>Shop 2: Information on home assessment, loan of equipment and associated costs.</p>
Information on neurology services at the local hospital and details of specialist MS nurses	Contact details for local specialist neurology centre. Waiting times for neurologists. Details of relevant research being undertaken.	<p>Shop 1: Was advised to contact local specialist neurology centre where MS nurses were based. Spoke to MS nurse who provided details of the MS clinics and the average waiting time. Also found out about clinical trials taking place in the region.</p> <p>Shop 2: Details of local support group and the same local general hospital as shop 1. Support group provided details of specialist neurology centre who the shopper had contacted in the previous shop. They also suggested contacting MS Therapy Centre in the region but had few further details.</p>

Scenario	Online searching results	Mystery shopping results
Support groups for carers and arranging respite care	Contact details for the careline to find out more about respite care. A named contact for details of carer support services	<p>Shop 1: Organisation four (local voluntary group) provided details of its carer events, holiday and respite care services, and associated costs.</p> <p>Shop 2: Details of carer help and advice services. Also recommended to speak to a further organisation (a local voluntary support group), who the shopper had already contacted during the previous shop.</p>

5.3 Comments from research partner: multiple sclerosis

- Contact details provided for local voluntary group were incorrect
- Would have expected the caller to have been given contact details of local carers group
- MS nurses play a key role in supporting people with MS and are an important source of information
- Information obtained was broadly as expected, particularly the details relating to local neurology services.

Our local research partner commented that finding information on local services can be haphazard. It is possible to 'strike it lucky' straight away but more often than not, people have to make a lot of telephone calls before they find appropriate help. The process is rarely straightforward.

5.4 Comparison of findings: diabetes

Table 9: Results of searches – diabetes

Scenario	Online Searching Results	Mystery Shopping Results
Support groups for people with diabetes and information on self management programmes	Contact details of regional diabetes Support Group. Links to diabetes education programmes but no information on their location.	<p>Shop 1: Contact details of a local support group, including opening times and staff names. Received booklet about managing diabetes, and given details of how to find educational courses via the local PCT.</p> <p>Shop 2: Contact details of local support group, including telephone number, venue, dates and times of meetings. Information about how to register with a GP in the area, and details of information and advice service in the local area provided by diabetic nurses.</p>

Scenario	Online Searching Results	Mystery Shopping Results
Details of GP practices specialising in diabetes	One GP with a specialist interest in diabetes (part of group practice) and details of hospitals with specialist clinics for a variety of diabetic problems e.g. podiatry. Phone numbers, frequency of clinics and staffing details were available.	<p>Shop 1: One organisation provided information about a GP with a special interest in diabetes. Another gave details of a local podiatry clinic, including waiting list and registration process. All attempts to call contact about optometry services were unsuccessful.</p> <p>Shop 2: Details of three GPs with special interest in diabetes provided. However, one was actually based in Essex and a fax rather than telephone number was provided for another.</p>

5.5 Comments from research partner: diabetes

Scenario 1: Support groups

- Would have expected mystery shopper to have been directly transferred to department that deals with weekend courses for adults
- Was unsurprised that mystery shopper was given the wrong information about local voluntary support groups as they had recently experienced a similar problem arising from that organisation's 'lack of geographical awareness'.
- Had expected that the caller would have been told about the Expert Patient Programme.

Scenario 2: GP specialist

- Experience is that GPs generally seem reluctant to deal with Type I diabetes and usually send people back to hospital clinics
- Provision of podiatry services largely depends on where you live. There is a diabetes podiatrist in the area but there is a long waiting list.

Other than points raised above, the information obtained and the experience of the mystery shoppers was as expected.

5.6 Comparison of findings: ethnic minority older people

Table 10: Results of searches – ethnic minority older people

Scenario	Online searching results	Mystery shopping results
Information on care homes	A list of 31 care homes within one mile radius of specified location with general details of the home, number of places, types of ownership (private, voluntary etc), the manager's name and links to recent Commission for Social Care Inspections(CSCI) assessment reports. Also signposted to Adult Care Team (who you contact for a care assessment), the PALS service, Age Concern and the local Citizens Advice Bureau. Guidance about financial issues and a checklist of 'what to look out for in a care home'.	<p>Shop 1: First organisation referred caller to their district branch, but the phone number was incorrect. Caller re-contacted organisation one for another telephone number, but was told that they were unable to help any further.</p> <p>Shop 2: Calls made during public health alert (following death of Alexander Litvinenko), and caller unable to speak to anybody at organisation one. A pre-recorded telephone message recommended non-urgent callers alternatively access information via the organisation's website. Website did not contain the required information.</p>
Finding a GP practice in the area with a Urdu/Punjabi health advocacy/link worker attached	Details of GPs in area but no information on health support workers. Public Information Network site had lots of information and provided some potential telephone numbers to call but it is unclear if they were appropriate. Came across directory of culturally specific services for Asian carers and details of how to access them but this was three years old.	<p>Shop 1: Organisation one arranged to call with contact numbers, but no call received over two weeks later.</p> <p>Shop 2: Second organisation was unable to provide information, and did not signpost caller to another source of help</p>
Applying to receive 'meals on wheels'	Details of four adult teams in the area who can arrange meals on wheels (including opening hours and contact details), information about what 'meals on wheels' is and who can receive the service. The webpage also signposted to related information about keeping warm in winter and direct payments.	<p>Shop 1: Details of service, application process, cost and type of meals.</p> <p>Shop 2: Details of service, delivery dates, placing orders, costs and types of meals. Brochure sent.</p>
Information on respite services for Asian carers	Details of local facility providing respite specifically for Asian carers. Information included details of languages spoken, opening times, Halal food and prayer rooms	<p>Shop 1: First three organisations unable to provide details of respite care for Asian carers. Third organisation signposted back to the first organisation.</p> <p>Shop 2: None of the organisations were able to provide relevant information. Final organisation would only provide information if the person was referred to them by social services.</p>

5.7 Comments from research partner: ethnic minority older people

- Surprised that the organisation contacted in scenario 1 (care homes information) was unhelpful and had incorrect information as many people are referred there
- It is very difficult and very expensive to get interpreters but there are small, local groups that may be able to provide this information.
- Aware of a regional regeneration programme that works with the local community in the area and covers health related issues.

Our research partner commented that there should be more links between services and agencies so people can find it easier to access services in their area.

“There was talk of having one stop shops in each of the six towns in the area but I am not sure what has happened with that. From my experiences what you have highlighted in your findings is very true, when searching for particular agencies signposting is not very good between them, this has been a personal experience as a resident of [local area] but also as a volunteer where I have had people approach me who cannot get the relevant information.”

5.8 Comparison of findings: autism

Table 11: Results of searches – autism

Scenario	Online searching results	Mystery shopping results
Availability of therapy or counselling services for children with autism and their families	Details of child and family service. Also information on parent support groups	<p>Shop 1: Final organisation only able to provide telephone number of organisation providing activity breaks. Caller told that their GP would refer to a counsellor or therapist as appropriate.</p> <p>Shop 2: Organisation one arranged to send list of counsellors and therapists. However, they sent a list for the Oxfordshire area rather than the region in question. Useful background literature sent on ‘Choosing a counsellor’ and ‘Approaches to counselling and psychotherapy’.</p>
Availability of carer support services in the local area	Details of family support care team, a parent befriending scheme and a parent support group	<i>Telephone mystery shop not conducted</i>

Scenario	Online searching results	Mystery shopping results
Out of school services for children with autism	<p>Details of a voluntary organisation running out-of-school activities for children with autism</p> <p>Information on local early years Autistic Spectrum Disorder (ASD) services.</p> <p>Also links on local support groups which although did not provide specific details on out of hours services would have provided a useful starting point.</p>	<p>Shop 1: Organisation one provided details of a local support group, which organises social trips during the school holidays, and also suggested that caller's social worker directly contact social services in the relevant area. Two answerphone messages left for the local support group, neither of which had been returned over a week later.</p> <p>Shop 2: After "going round in circles", organisation four reassured caller that they would be able to provide relevant information. Arrangements made for the appropriate member of staff to call back, but call never received.</p>
Respite care for children with autism	<p>Information on Family Support Care (a family based 'respite' service for children who have a disability)</p> <p>Carers' Support Worker for the local area</p> <p>Details of staffed respite care house for up to four children. Details of referral procedures and contact details of the local social services office.</p>	<p>Shop 1: After being passed round individuals at organisation two, caller finally spoke to somebody who was able to answer all their questions about respite care services. The information they provided included recommendations about specific services, contact details, and additional advice about schooling in the local area.</p> <p>Shop 2: Second organisation suggested doing an internet search, or calling organisation already contacted during shop one.</p>

5.9 Comments from research partner: autism

The findings from the mystery shopping and online searching were largely as would be expected in this area. Our research partner commented:

- There is very little support for carers of children and young people with autism in this area
- A lack of health and social care infrastructure in the region results in limited access to and availability of services
- Waiting lists for services are very long
- Many people depend on local support groups which are 'terribly underfunded' - in the main their existence relies on the goodwill of dedicated individuals
- Occasionally you will find 'someone good' who will help you and be able to provide appropriate information but that is rare

5.10 Conclusion

The local research partners were largely able to corroborate the results of the online searches and mystery shops. They confirmed that our findings reflected their own experiences and local knowledge. On the whole, the online searches produced more information than the telephone enquiries, but different entry points and different searching strategies produced different results. Some of the mystery shop calls led to very helpful information, but others were fairly or completely unproductive.

These results provide further support for the impression that gathering information on locally available services can be a lengthy and problematic process. It is difficult to identify **all** relevant sources of information and material provided is often incorrect or out-of-date. To gain a reliable picture of all relevant services, one would have to invest considerable time, effort and ingenuity.

6 Information provider survey

6.1 Background

An online survey (see Appendix 8) was developed to gather information on people's experiences and challenges in acting as information 'signposters'. The survey was circulated to members of the Patient Information Forum (PiF); the Association of Social Care Communicators (ASCC); the Public Health Information Representatives Forum (PHIRF); the Long-Term Medical Conditions Alliance (LMCA); and the Chartered Institute of Library and Information Professionals (CILIP – Public Libraries Group). The survey was also circulated to health, social care and information professionals in each of the three study areas.

Respondents were asked to document the barriers that people face in responding to enquiries about local area services, and to suggest ways to improve the provision, accessing and signposting of information.

6.2 Survey respondents

The survey achieved an excellent response with a total of 370 people completing it. Those people who responded work in a range of different sectors, areas of employment and regions of the country. Over a third (36%) of the respondents were employed by a health service provider but a significant proportion worked in either social care (19%), the voluntary sector (24%) or libraries (11%)¹⁵.

¹⁵ Note that throughout the report, percentages have been rounded to the nearest round number. For example 12.8% is rounded up to 13%, while 5.3% would be rounded down to 5%.

Table 12: Respondents by organisation

Organisation type	Percentage of respondents (n=361)
Health Service Provider	36%
Social Care Service Provider	19%
Voluntary Sector	24%
Library	11%
Other ¹⁶	10%

Just over half (52%) of the survey respondents were information specialists whilst 41% worked for health and social services organisations in 'front line' or managerial roles (Table 13). Seven percent of respondents are either volunteers or members of voluntary groups.

Table 13: Respondents by occupation

Job type	Percentage of respondents (n=353)
Health or Social Services professional or manager	40%
Information Specialist	50%
Volunteer or member of voluntary group	7%
Other ¹⁷	3%

Respondents were allocated to an English Government Office region based upon the postcode of their work address (Table 14). These regions were used to create the following four areas:

- North (includes North West, North East, Yorks & The Humber)
- Midlands (includes West Midlands, East Midlands)
- South (includes South West, South East, East)
- London

Eight percent of the respondents worked outside England.

¹⁶ Respondents from this category represent a number of different types of organisations including the following: Research/consultancy, professional body, education, web design, and a BME health policy forum.

¹⁷ Respondents from this category included researchers and advisers.

Table 14: Respondents by region

Area of the country	Percentage of respondents (n=297)
North	29%
Midlands	28%
South	21%
London	14%
Scotland	4%
Wales	3%
Northern Ireland	1%

6.3 Type of information requested

Respondents indicated the different types of information that people ask them to provide. The results are illustrated in Table 15.

Table 15: Type of information requested by region

Information topic	Region				
	All regions ¹⁸ %	North %	Midlands %	South %	London %
Voluntary Sector/Support groups	75	71	75	84	70
Family/Carer Support	65	58	69	71	60
Condition/disease-specific services	64	66	62	64	70
How to comment on/complain about services	63	63	66	67	73
Finance/Benefits	60	55	66	76	47
Health promotion/prevention services	52	62	62	38	60
Education, training and learning	50	59	52	44	43

¹⁸ Includes respondents not working in England

Information topic	Region				
	All regions ¹⁸ %	North %	Midlands %	South %	London %
Respite care	50	51	53	58	30
Residential or long-term care	50	55	47	56	30
Adaptations to home/equipment/occupational therapy	49	51	48	60	23
Counselling/Therapy services	48	47	48	51	50
Mobility/driving/transport	47	44	43	56	40
Self management support services	39	41	45	42	30
Housing	39	36	40	42	30
Complementary/alternative therapies	39	40	42	38	47
Work/employment	35	40	38	33	27
Dental Services	34	33	36	40	37
Finding a GP	34	36	35	31	43
Immigration and asylum	21	23	19	18	23
Finding a walk-in centre	20	25	22	11	20
Other	13	12	6	13	20

People are most likely to request details of voluntary sector support groups with three-quarters (75%) of respondents reporting that they are asked for this type of information. Around two-thirds of respondents had been asked to provide details of family/carer support (65%), condition specific services (64%), how to comment/complain about services (63%) and financial benefits (60%).

Respondents reported that they are much less likely to be asked for information on immigration and asylum (21%) and finding a walk-in centre (20%), but one in five receives these information requests.

Respondents were asked if they often have to provide information on topics other than those listed in our survey. Thirteen percent reported that they also regularly receive other information requests which can include:

- legal rights such as disability discrimination
- eligibility criteria for services and benefits
- interpreting/translation services
- fostering and adoption

- help in navigating the public sector system.

There were few differences in the type of information requests received across the country, but respondents from the South were less likely (38%) to be asked about health promotion and prevention than those in other parts of the country where almost two-thirds of respondents reported requests for this type of information. Compared to the rest of England, fewer people in the London area request details of respite care (30%), residential or long-term care (30%), information relating to adaptations to the home/specialist equipment or occupational therapy (23%).

Regional differences might be due to better routine provision of information on these topics resulting in fewer requests. Alternatively, there may be less demand for these services, or perhaps service users in these areas are less aware of their potential availability.

6.4 Accessibility of information about services

If information is to be effective, well understood and acted upon it is vital that it is tailored to the needs of the user. Provision should be made to ensure that information reaches all groups including people with reading difficulties, sensory impairments and those who do not speak or read English. Other groups who may face issues with accessing information are listed in section 6.5

Respondents were asked to provide details of the various information formats their organisations are able to provide. The results are illustrated in Table 16.

Table 16: Provision of information in alternative formats

Information format	Organisation Type				
	All organisations % ¹⁹	Health service provider %	Social care service provider %	Voluntary sector %	Library %
Print	94	93	100	95	100
Web	86	80	100	81	100
Languages other than English	63	67	98	46	41
Large print	62	47	97	55	70
Audio	46	42	86	25	35
Braille	34	27	89	13	22

¹⁹ Includes respondents working in organisations outside the categories listed.

Information format	Organisation Type				
	All organisations % ¹⁹	Health service provider %	Social care service provider %	Voluntary sector %	Library %
Video/DVD	32	38	45	15	30
Other	5	6	8	3	5
None of the above	1	1	0	3	0

Encouragingly, a significant number of information providers offer information in a variety of formats thereby helping to improve the accessibility of their material. There is however some way to go in this area and no way of telling what proportion of the material is available in alternative formats.

Almost all of the respondents (94%) were able to provide printed information and a high proportion (86%) also provided information online. Around two-thirds of those responding to the survey (63%) offered information in languages other than English, with a similar proportion (62%) providing a large print option. Around one-third of those responding to the survey offered information in braille (34%) or in a video/DVD format (32%).

Interestingly, respondents working in social care were more likely to be able to provide information in each of the alternative formats than those working in other sectors.

Somewhat surprisingly, approximately one third of respondents (30%) working in libraries did not appear to be able to offer information in large print.

Considering the limited resources at their disposal when compared to health and social care providers, voluntary sector organisations performed well on this section of the survey with many of them reporting the ability to provide information in versions other than standard print.

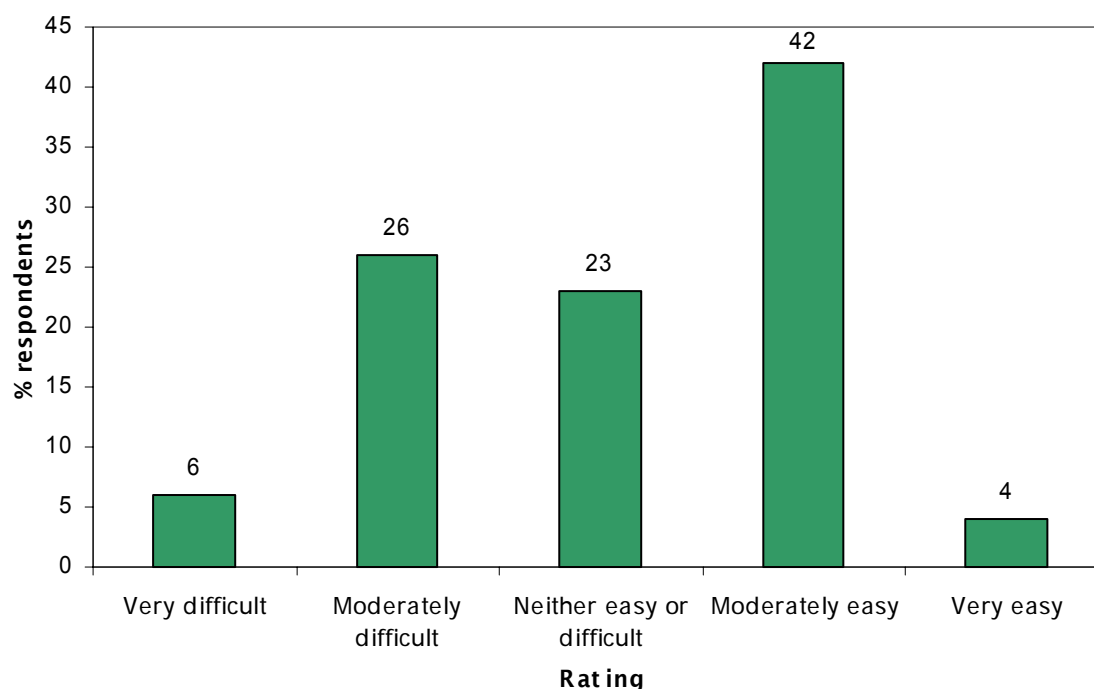
Five percent of respondents reported being able to offer formats other than those listed in the survey. These mainly included British Sign Language and easy-to-read versions for people with learning difficulties.

Addressing usability issues places significant additional demands on information providers, but is imperative if information is to have an impact beyond 'traditional' proactive information-seekers, who are typically English-speaking, middle class and well educated.

6.5 Keeping up to date with local health and social care services

Respondents were asked how easy or difficult they felt it was for people to keep up to date with information about locally available health and social care services. Responses were measured on a five-point scale from *very difficult* (1) to *very easy* (5).

Figure 3: How easy is it for people to keep up-to-date with information about services in your local area?

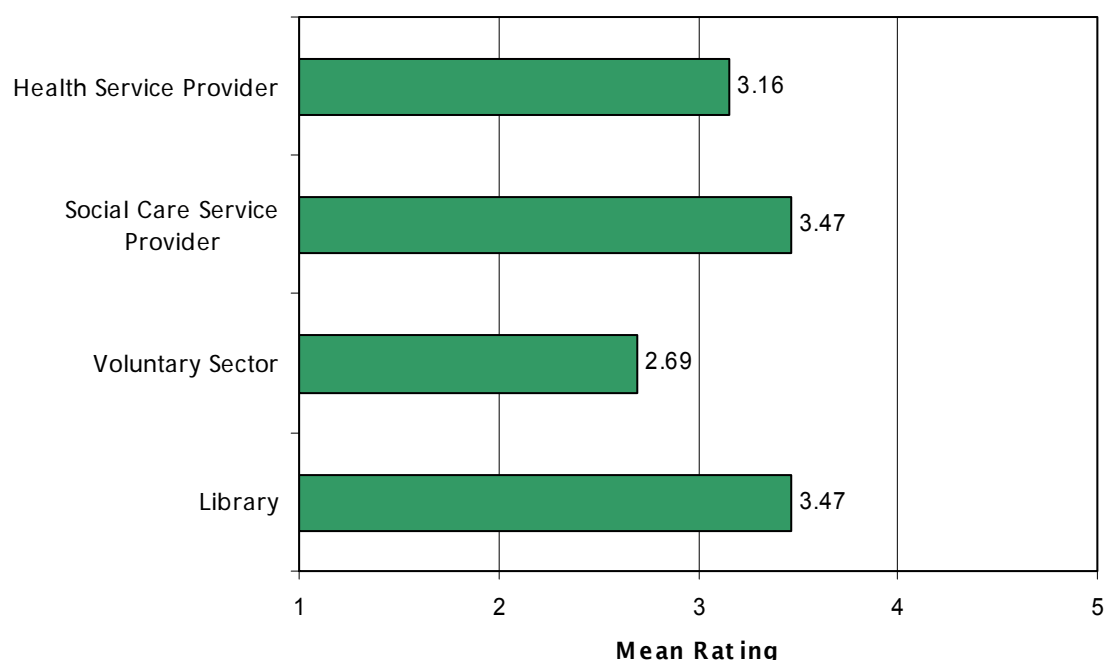


Only a small number believed it is very easy for people to stay up to date with this type of information (4%), however most respondents did not believe it is particularly difficult either (6%). Overall, slightly more believed it was easier (46%) than difficult (32%) yet the fact this latter figure represents the views of one-third of the respondents may be a cause for concern.

There were some statistically significant differences in the ratings according to the organisations that respondents worked for, their role and the region in which they were based.

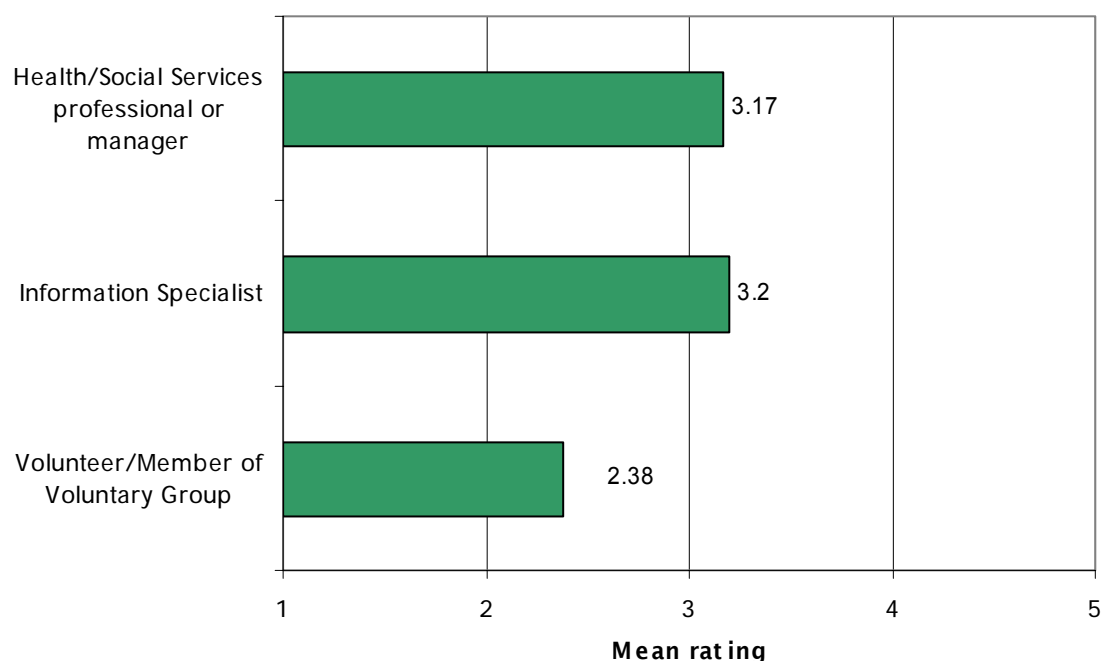
Respondents working in the voluntary sector reported greater difficulty in keeping up-to-date with developments in local services than those working for health and social care providers and libraries (See Figure 4).

Figure 4: How easy is it for people to keep up-to-date with information about services in your local area? by organisation type



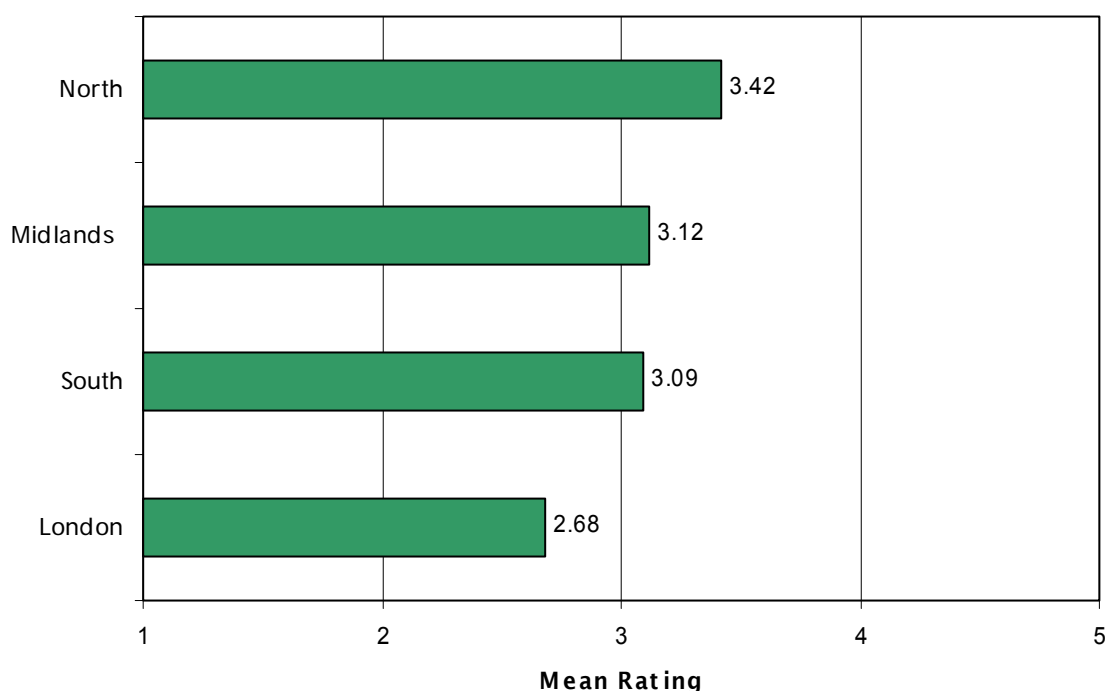
Volunteers and voluntary group members responding to the survey were more pessimistic about the feasibility of keeping up-to-date with information about local services than information specialists and health and social care professionals (See Figure 5).

Figure 5: How easy is it for people to keep up-to-date with information about services in your local area? by job type



The survey also highlighted some differences in the response to this question depending on the area of the country in which respondents work. Those working in London were significantly more likely to believe it is difficult for people to keep up-to-date with services than those respondents working in the north of the country (See Figure 6).

Figure 6: How easy is it for people to keep up-to-date with information about services in your local area? by region



Forty eight percent of respondents provided details of groups that they believe face particular difficulties in finding information about local services. Those groups frequently mentioned include:

- non-English speakers/English as a second language (45%)
- older people (18%)
- those with sensory impairments (18%)
- people with learning difficulties (17%)
- those without internet access (15%)
- those with poor 'information literacy'(13%)²⁰.

However a number of respondents felt that access to this sort of information was difficult for everyone.

"All groups - there doesn't seem to be any joined up work to provide something that contains all relevant information. Everything is patchy and no one knows what other groups are producing." [Information Specialist, North]

²⁰ Some respondents referred to more than one group in their answer to this question.

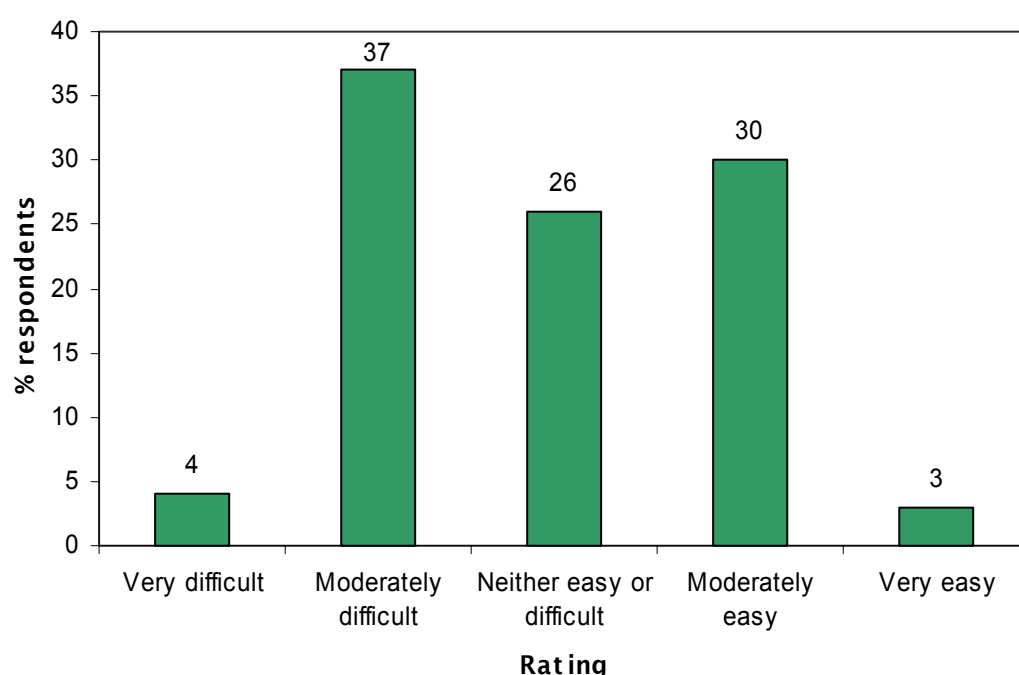
Some respondents felt that difficulties in keeping up-to-date could be a result of providing too many differing sources of information.

“The overload of available information makes it difficult for people to find what they want.” [PPI Forum Development Officer, South]

Having asked respondents to rate how easy it was for the general public and service users to keep up-to-date with local services information, they were then asked to comment on how easy it was for they themselves to stay up-to-date with information and if there were any useful tools available to help them do that.

As before, responses were measured on a five-point scale from *very difficult* (1) to *very easy* (5).

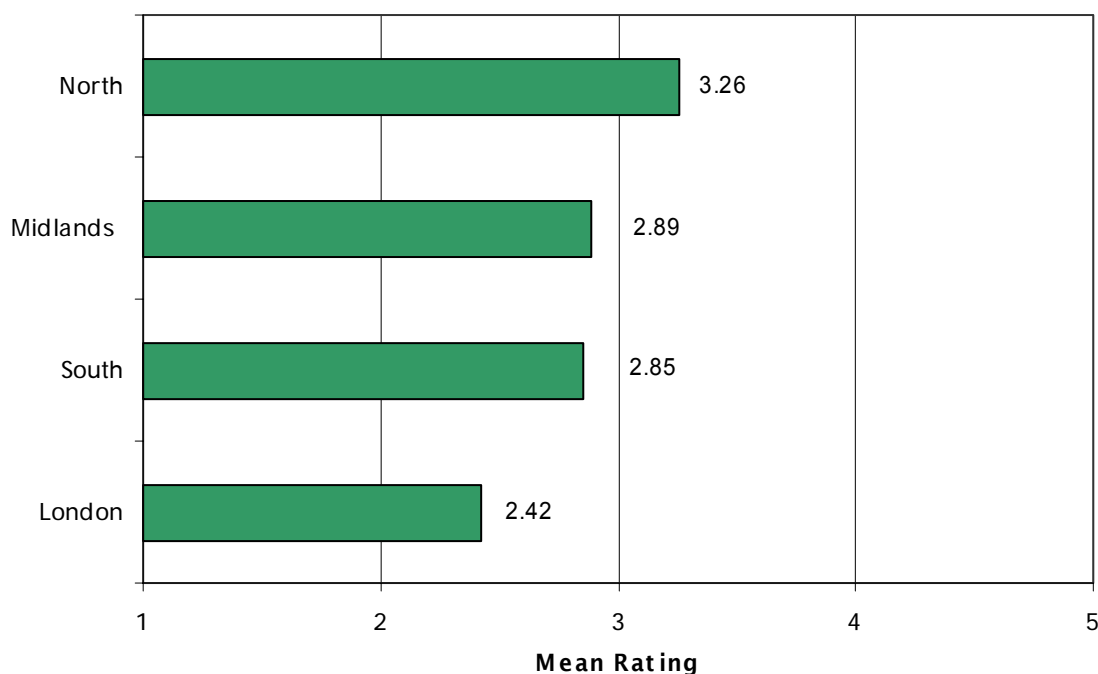
Figure 7: How easy is it for you to keep up-to-date with information about services in your local area?



Only a small number of respondents said they find it very easy to stay up-to-date with this type of information (3%), however most respondents do not believe it is particularly difficult either (4%). Overall, slightly more respondents find it more difficult (41%) to stay up-to-date compared to one-third of them (33%) who find it relatively easy to do so.

Responses to this question did not vary significantly by job role or the organisations that people worked for. However, those respondents working in London were significantly more likely to keep up-to-date with services than those respondents working in the North (see Figure 8). This echoes the response to the previous question where people were asked to rate how easy it was for others to keep up-to-date (See Figure 6).

Figure 8: How easy is it for you to keep up-to-date with information about services in your local area? by region



Respondents use a variety of methods to find out about services available in their local area. The majority of respondents (91%) said they search for information when they need it but at least half (55%) receive email updates. The same proportion (55%) regularly check websites for information. One quarter (26%) of the people responding to our survey report that their organisation provides a directory of local services to help them stay informed.

Table 17: How do you keep up-to-date with information on locally available services?

Method of keeping up-to- date	Percentage of respondents
Search for information when necessary	91%
Email updates	55%
Check Websites	55%
Attend seminars/conferences	45%
Organisation provides directory	26%
Other	10%

Respondents receive email updates from a wide variety of different organisations and individuals. Many people network with colleagues and groups within their local area. National sources of information most frequently mentioned by our respondents include the Patient Information Forum (PiF), Info4local (Information for local government), The King's Fund, Association of Social Care Communicators (ASCC), IDeA (Improvement and Development Agency) and the Social Care Institute for Excellence (SCIE).

Some of the information providers responding to our survey update their resource directories periodically but emphasise that this is a time consuming process. A number use the local media as an additional source of information.

6.6 Challenges in information signposting

Respondents were asked to highlight the greatest challenges they face in signposting people to relevant information sources. Interestingly, only 13% of respondents felt that there was a lack of available services to direct people to. Well over half of the respondents reported that keeping track of changes to local services (59%) and keeping up-to-date about new services (57%) were the greatest challenges they face in effective information signposting.

"Recent frequent changes to NHS and social services structures and responsibilities have left most, including our trained advisors, confused about which authority/agency is now providing which service." [Information Specialist, Voluntary Sector, South]

Almost half (47%) felt that providing the right information at the right time was a main concern. Forty percent of respondents reported lack of time and a similar proportion (38%) cited lack of resources as a barrier.

Other challenges reported included difficulties in finding out about services in other public sector areas (34%), being able to provide information in the right format (33%), and a lack of co-operation between different organisations in the local area (25%). One in five (20%) respondents referred to literacy levels of service users as a particular challenge.

"Main problem is information literacy. It is easy IF you know how."
[Information Specialist, South]

6.7 Recommendations for improving information access and signposting

Respondents were asked to consider ways in which access to information can be improved. The suggestions which emerged can be broadly divided into the following key areas:

Effective promotion of existing services

Many respondents reported that although there is no real shortage of available services, people are frequently unable to navigate their way through the system as they are not aware of what is on offer. A number of suggestions were made to help promote information points and services more widely. These include printing details in the local media and on the reverse of car parking tickets or supermarket receipts.

"A quarterly free magazine delivered with the local free paper. Needs to be simple and easy to read..." [Information Specialist, Health Service Provider, London]

The need to site information resources in accessible public places was often mentioned. A number of respondents referred to the importance of a 'high street presence' and suggested supermarkets, libraries, pharmacies and GP surgeries could be suitable information points. Some had tried to address this issue but faced difficulties in doing so.

"I have only had very limited success in getting GP surgeries to display our leaflets or a poster with web address and customer service centre. Also impossible to brief busy GPs with the range of services (both statutory and voluntary) that are available." [Social Care Service Provider, South]

Others felt that information should be targeted more effectively so that people were told about services at a point when they might need to access them rather than leaving them to fend for themselves. One respondent commented:

"Targeted publicity to relevant groups eg info about local authority care assessment provided automatically when a patient leaves hospital." [Information Specialist, Health Service Provider, North]

It was also suggested that people should be well briefed on what to expect from services once they access them.

Central information source

Many references were made to the need for a widely available and centrally recognised source of reliable, current and good quality information. Respondents suggested that this resource should be available online, face-to-face, via the telephone and in print. This 'one-stop-shop' approach was popular amongst respondents with many raising concerns that both service users and professionals do not know where to begin looking for relevant information. Some suggested the need for a national resource with local branches, others spoke of regional 'Patient Information Centres' whilst an information directory was often mentioned.

"A high profile 'one-stop-shop' in each local area specifically to help local people access services and information." [Information specialist, Voluntary Sector, London]

Improved collaboration between service providers

There is a need for better collaboration between agencies to facilitate the information signposting process. Organisational and geographical boundaries often create a huge barrier in terms of information provision and many respondents underlined the need for better co-ordination amongst and across organisations. Some respondents also spoke of the need to standardise eligibility criteria to simplify the signposting process.

"It would help if there was a consistency of services and eligibility across PCTs and Social Services departments." [Information Specialist, Voluntary Sector]

Setting up networks of public, community and voluntary sector information personnel to oversee the gathering of local information; developing regional forums to share local knowledge and making joint PALS appointments across health and social care organisations

were all suggested as ways to facilitate the exchange and dissemination of information. A number of respondents also felt that a joint health and social care web portal would be a beneficial reference tool.

Staying up-to-date with changes to services can be a lengthy and time consuming process. Efficient systems for updating health, social care and information professionals on changes to services would help to ease this burden. Updates on service provision should happen as a routine matter rather than having to contact agencies on an individual basis.

“More communication and joined up working. This is starting to happen in [Local area] but sometimes we have to trawl the web to find out about local services when they should be automatically informing us of their facilities.” [Information Specialist, Library, Midlands]

Respondents suggested quarterly ‘roadshows’ to showcase available services with regular bulletins as potential methods for keeping information resources current.

More resources

A number of respondents called for more time, money and staff. Although a lack of resources is not seen as the main barrier to effective signposting it is still a significant issue due to the time and effort required to deal with information requests appropriately. A need for dedicated staff and resources was frequently expressed. There is a general feeling that this work should not be seen as an ‘*add on to the day job*’ but given the investment and support it deserves.

Improved accessibility of information

An overwhelming concern of many of the survey respondents relates to the accessibility of information. There is a real desire that practical and high quality information should be available to everyone, not just those with the very highest levels of information literacy. Information should be readily accessible in a variety of formats to suit the needs of the individual.

“At the heart of the problem is the user populations’ diversity in terms of needs, abilities and skills. Access to information has to be multi-media otherwise someone, somewhere will be left out.” [Information Specialist, Health Service Provider, North]

Although the internet is seen as a valuable signposting tool some felt that there should not be reliance on websites alone.

“Don’t assume everyone has access to the internet or is confident or able to use the telephone.” [Information Specialist, Voluntary Sector]

One respondent commented that it is not just information that people need but help to interpret it too.

“It’s not just accessing “information” it is having help, when necessary, to understand / interpret it. Having a local organisation that they could discuss written information with (face-to-face or by phone) - as it relates to their own circumstances is also required for more complex issues. Finding a GP is relatively straightforward. Finding and paying for care in a care home is complex.” [Information Specialist, Voluntary Sector, London]

Delivering information at the right time was raised as a key issue. Respondents felt it was important that people are not overloaded with information all at once but that they are able to easily access it, as and when they need it.

The use of jargon should be avoided and the names of services should be simplified so it is easy to see exactly what they offer. The use of complex terminology can add to the confusion.

“That what ever the service says it does, then that is what it does. So people are signposted not to be let down when they try and access it...people get fed up of being passed from pillar to post.” [Voluntary group member, Midlands]

6.8 Where it's working

Some respondents gave examples of effective approaches they were using or planning to implement to facilitate information signposting.

“We have facilitated Carers Notice Boards in every surgery in our area, use chemists and opticians to publicise services. We support a free market stall each week of the year for use by health and social care service providers and organisations.” [Social Care Service provider]

“We have recently produced a short film about our services primarily for use with the BME community, to get over some of the need for written information. We are working with community leaders over its distribution.” [Information Specialist, Social Care Provider]

“We provide annually two Guides on residential care and care at home. These are very popular and used by staff, partners such as health, voluntary agencies, etc. Because they are so valued, practitioners try and send us information for inclusion in the guides. We also post them on our website.” [Manager, Social Care Service Provider, South]

7 Conclusions

Drawing together the information gathered in this brief three month study, we shall now return to the questions posed at the beginning of this report and attempt to answer them. These were as follows:

- How do patients, service users and carers currently find out about locally available services and how to access them?
- To what extent are local information resources well signposted so that people can find the information for themselves?
- What additional support is required to enable people to find information about services that is appropriate to their needs?

7.1 How do patients, service users and carers currently find out about locally available services and how to access them?

Patients, service users and their carers place a high value on information. Without reliable and accessible information, it is hard to make the best use of available services. Understanding the complexities of the health and social care system is difficult enough for most non-professionals and navigating your way through the maze without adequate information is well nigh impossible. The government is keen to ensure that services are responsive to individual needs and that service users should be able to choose the most appropriate services for them, but choice is meaningless without information. Adequate information provision is the essential key to empowerment of service users.

The survey of health and social care professionals and other information providers revealed a rich diversity of information needs. The information topics most commonly requested by service users included details of voluntary sector support groups, family/carer support, condition-specific services, how to comment on or complain about services, and the availability of financial benefits and how to claim for these, but professionals and information providers also receive a wide variety of additional information requests.

The people we spoke to in the focus groups had mostly made considerable efforts to find out about health and social care services, but many described the struggle to find relevant information as an uphill battle. Many health and social care professionals failed to anticipate service users' information needs. Information about services was not offered proactively as a matter of routine. Instead it had to be extracted by asking the right questions of the right people at the right time. Whilst there is a significant volume of information available, it is only of use if you know how to find it and can navigate your way through it. You have to know what services might be available in order to know what questions to ask, but this is beyond the ken of many service users. Many focus group participants said they had found out about services by accident, others discovered useful information during the course of our discussion groups.

A lack of routinely provided information provision had led many of the service users we met to become expert information seekers. However, these people were, on the whole, highly motivated, articulate and assertive individuals. Those without these characteristics are much less likely to fare well in the quest for information, raising serious concerns about equity of access to local services.

Focus group participants described diverse information needs. Some had looked for basic information such as contact details and opening times, but others had more complex requirements. Many described the information they had needed at an early stage after diagnosis or the onset of disability, but most stressed the fact that they had an ongoing requirement for information and their information needs were continually changing.

A lack of co-ordination between information providers across geographical, sectoral and organisational boundaries was a frequently reported source of frustration. Many service users complained that it is rare for an individual or organisation to take responsibility for providing relevant information about the full range of available services.

These reports of service user experiences were echoed in the mystery shopping exercise. The mystery shoppers were all experienced information seekers and in nearly all cases they were able to gather some information about services that was relevant to their situation, but very few mystery shops resulted in the shopper finding out everything they needed to know.

7.2 To what extent are local information resources well signposted so that people can find the information for themselves?

There is a significant amount of useful information available, but digging it out requires considerable effort because it is not well signposted. Following their initial phone call, mystery shoppers were often signposted to organisations that were not well equipped to answer their questions. A number of organisations failed to respond to messages, while others did not fulfil their promises to call back. In some instances people were given incorrect contact details which led nowhere. Some shoppers reported that they were unable to access the information they wanted because they had been told that it was restricted to those directly referred by health or social services professionals. Whilst there may be good reasons for this, it significantly inhibits users' efforts to gather information in advance of any choices or decisions they might have to make.

Unsurprisingly, regional organisations were generally more knowledgeable than their national equivalents in offering accurate information about locally available services. There were also some good examples of signposting between health, social care and the voluntary sector, but these were few and far between.

The biggest challenges faced by information 'signposters' are keeping track of changes to local services and staying up-to-date. A range of mechanisms are used to keep informed. Many providers said they search for information as and when they need it, but others subscribe to online services or proactively access organisation directories for regular updates.

The online searching exercise demonstrated that it is possible to find a great deal of information about health and social care services on the internet. The vast majority of the

online searches we conducted (91%) reached a successful conclusion either by providing sufficient information to answer the query or by signposting the searcher to another appropriate information source. But many service users do not have the necessary skills in online searching, and a significant proportion of those in greatest need do not have access to the internet.

The experiences of our online searchers varied quite considerably depending on the complexity of their scenario and the quality of the individual websites they visited. Some websites were much easier to navigate than others, with features such as obvious hyperlinks, search functions and a clear and uncluttered design. A significant proportion of websites included out-of-date material or did not report when information was updated, leading to a lack of confidence in its reliability. Many organisations had taken steps to improve the accessibility of their websites by providing information in alternative formats, but many did not provide this facility. Social care organisations performed better in this respect than health service providers.

Whilst there is a significant volume of useful material available online, it is redundant if people are unaware that the services exist. In other words, you have to know what is theoretically possible and which organisations might provide it, before you can find information about how to access it – a classic 'Catch 22'. Our searchers were armed with specific questions relating to the availability of particular services but it is highly unlikely that the average information seeker would be as well-prepared. The internet can undoubtedly play a key role in information signposting, but expert help is required if the majority of service users are to make best use of it.

7.3 What additional support is required to enable people to find information about services that is appropriate to their needs?

There is no shortage of ideas on what needs to be done to improve access to information about local services. Between them the service users, health and social care professionals and information providers who contributed to this study had many suggestions for improvements. The following would appear to be priorities:

Greater recognition of the importance of information

Providing reliable, accessible information is the key to empowering service users to play an active role in their care. Without it, it is impossible to ensure equitable access to services, to empower people to make appropriate choices, or help them self-manage their health and social care needs. Since information for service users is so crucial for achieving current policy goals, it is essential that it is properly organised and resourced.

Better co-ordination between agencies

There is plenty of useful information available at present, but it is chaotically organised and presented. Finding better ways to streamline access to information should not be very expensive, but it will require someone to take responsibility for the task at a local level. Since service users have multiple information requirements and these span sectoral and organisational boundaries, there is a crucial need for effective leadership in this area. We believe there is a need for a new cadre of information co-ordinators or brokers who understand the service user's perspective and have the necessary clout and diplomatic skills

to bang heads together tactfully, to overcome organisational barriers and to encourage sharing of good practice across sectoral boundaries.

Provision of a central information contact point

The service users and mystery shoppers involved in our study demonstrated that with persistence, assertiveness and an adequate knowledge of the likely availability of services, it is just about possible for non-professionals to find useful information about local services. But these characteristics are by no means universal and those who do not possess them require more help to access relevant information. Many service users told us that there needs could have been much more easily met if there was a central contact point for information. This might be an individual responsible for co-ordinating their care, for example a GP, a practice nurse, a care co-ordinator, or a special educational needs co-ordinator in the case of people with learning difficulties, or it might be an organisation, for example a local library, a referral management centre, a PALS service, an Expert Patient programme co-ordinator, a voluntary group, or a designated health or social care department.

Since it is clear that most services nowadays can be identified via the internet, in practice this means that each local area requires someone who is skilled in online searching who can act as conduit to more specialised information services and whose existence is well publicised. This could be a role for the information brokers. One to two people could feasibly gather and disseminate via telephone, internet and printed versions, information on all health, social care and voluntary services in a single county or PCT area, and teams of information brokers could perhaps work together to cover a Strategic Health Authority or Regional Office.

Better training for professional staff

Service users in our study described the common failure of professional staff to anticipate their information needs and to be ready to provide appropriate information as when it is needed. Some said they were given too much information at a time when they were unable to take it in, others said it was offered much too late. This indicates a clear need for better training for professional staff to enable them to understand users' information needs, how to access relevant information and when to provide it.

Service users stressed the need for face-to-face discussion about their need for services and support. They wanted this help from professionals they had come to trust, to supplement the information they were able to find for themselves. Every health and social care professional should be encouraged to embrace their role as a key information provider. This might include promoting the notion that information is therapy, that information provision can contribute to the improvement of health and quality of life outcomes, a proposition supported by a substantial evidence base.²¹

Standards for improved signposting via the telephone

Effective signposting is crucial for telephone enquiries. Those making an initial telephone contact need prompt advice from people who know where to pass their enquiry on to if they don't know the answer themselves. If a query cannot be answered instantly and requires further investigation, the person receiving the call should take responsibility for getting back to the enquirer as promptly and reliably as possible. It is unacceptable to fail to ring back when a promise has been made. Staff may need additional training in how to deal with enquiries about health and social care services. Quality standards for dealing with telephone

²¹ Coulter A, Ellins J. Patient-focused interventions: a review of the evidence. London: Health Foundation 2006

enquiries should be agreed and monitored.

Improved design of websites

Greater attention needs to be paid to the design of websites intended for public use to minimise the number of false trails. Website design has been improving over recent years and we found many good examples, but we also saw websites that were difficult to navigate around, or that failed to consider accessibility issues for those with visual impairments, low literacy levels or lack of experience of electronic searching techniques. All health and social care websites should include links to local voluntary groups as well as clear descriptions of the statutory services that they provide, and these links should be regularly tested to ensure they are up-to-date.

Provision of alternative format resources

As we have seen, information needs are diverse and so are the formats in which people prefer to receive information. A 'one size fits all' approach is never likely to be appropriate. Instead, it is important to make provision for the needs of minority groups. Such provision may include large text versions, audio and video facilities, telephone helplines, textphone facilities, translation services and information in minority languages and in Braille.

Improved promotion of services provided by voluntary groups

Local voluntary groups provide many valuable services, but often these are poorly promoted so it is hard for potential users of the services to find out about them. Many service users are unaware of possible forms of support for people like themselves, so it is unrealistic to expect them to find their own way to these services without help. Health and social care professionals are the most obvious conduit for this type of information. Voluntary groups should make it a priority to inform local health and social care professionals of their existence and for their part professionals must accept responsibility for providing information about these services.

Provision of comprehensive information about all services

Wherever possible, artificial barriers to providing information about service availability, such as the refusal to provide information to people who have not yet been officially referred, should be removed. To learn that information is being withheld from you for bureaucratic reasons or reasons of professional control can be a highly disempowering and dispiriting experience.

Appendices

Appendix 1: Focus group topic guide – Review of the provision of health and social care information

Welcome from facilitator(s)

Introduction

Explain that the purpose of this group discussion is to:

- look at how patients, service users and carers currently find out about local services;
- how easy is it to get the information you need;
- what extra help might make it easier for people to find out about the services they need.

The Department of Health (DH) has asked Picker Institute Europe to carry out this research. We are an independent research organisation working to improve the quality of care from the service users' perspective. We'll be running four focus groups altogether covering a range of different health and social care needs.

The discussion should last about an hour to an hour and a half. We would like to tape record it to make sure we get an accurate record of what is said. Then it will be transcribed and analysed for our report back to the DH. But everything you say will remain anonymous – all names will be removed and no comments will be attributable to any identifiable individual. We would also ask you to respect each other's confidentiality about any personal details shared today.

Any questions before we start? (NB Check everyone has signed consent forms)

We will go round the table to introduce everyone and perhaps you would like to give a brief description of your own situation and why you have come along today.

Themed discussion

Information needs

What sort of information have you needed since you(lost hearing/sight; person you care for was diagnosed; developed health problems etc)?

Probe: nearest health centre, treatments available, support groups, aids and appliances, benefits, residential homes, special education, respite care etc

Information sources

Where did you get this kind of information from?

Probe: health professional, alternative therapists, social services, community or support group, library, information centre, CABx, school, Post Office, faith organisation, internet, media, friends/family, NHS Direct, etc

Who or what were the most useful sources of information?

(Probe: in what way)

Who or what were the least useful sources?

(Probe: in what way)

Access

How easy was it to find the information you needed?

Probe: What kinds of difficulties have you faced trying to get information? Is it more difficult to get certain types of information? Does information from different sources conflict?

Are there any ways in which it could be made easier to get the information you need?

Probe: different formats, internet access, information in other languages, interpreters, central information point/one-stop shop, telephone help-lines, more convenient opening hours for health centres etc, expert patients, advocates, contact with others in same position, local directories

Usefulness

How useful is the information you have been able to get about local health and social care services?

Probe: Have some types of information been more useful than others?

Improvements

How could the provision of information be improved?

Probe: plugging gaps, keeping it up to date, making it easier to understand.

How would you prefer to get information about local health and social care services and other sources of support?

Probe: Face-to-face, print, internet, telephone, text

Any other comments?

Thank everyone for their participation

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Appendix 2: Guidelines for mystery shoppers

General information

- The purpose of the mystery shop is to find out about the information that is provided about local health or social care services. Specifically, we are interested in whether you are able to find sufficient information to answer your query, and how easy or difficult you find this.
- We have asked you to complete two mystery shops. You will be looking for the same information in both mystery shops, but from a different start point each time. Please fully complete the first mystery shop before moving onto the second one.
- Before you commence each mystery shop, make sure you are prepared: if possible find a room where there are no distractions, read over the scenario and feedback questionnaire, and have a pen and paper to hand.

Making the calls

- Please make your calls at any time between 9.30am and 4.30pm, avoiding lunchtimes.
- You should start by calling the telephone number we have provided on the scenario sheet. Each time you call and are unable to speak to somebody in person counts as one attempt.
- You may find that the first organisation you contact is able to provide you with enough information to fully answer your query. If they are not, we would like you to speak to up to three more organisations to try and get the information you are looking for. In other words, it is possible that you may make calls to as many as four organisations for each mystery shop.
- We do not provide you with contact details for second, third and fourth phone calls. Instead, you will need to ask the people you speak to during the mystery shop to suggest who you should contact for further information.
- On your second mystery shop, somebody may give you contact details for an organisation that you have already spoken to. If that person is unable to suggest any other organisations, you do not have to phone this organisation again, and can terminate the mystery shop.
- The mystery shop is completed either:
 - once you have sufficient information to answer your query
 - or when you have spoken to four different organisations
 - or when you have been directed back to an organisation you have already spoken to and no other organisations were suggested.

Asking and answering questions

- Before the mystery shop, think about what information is needed to answer your query. For example, this might include names of services, their location, contact telephone numbers, information about costs, and advice about whether or not you are eligible to use the service.
- All the information you receive during the mystery shop must either be verbal (directly from the person you speak to) or sent by post. If somebody offers online information or suggests looking at a certain website, tell them that you are looking for advice over the telephone.
- You may be asked questions during the telephone calls. If you are comfortable answering these, please do so. If you are not comfortable answering these, politely decline them.
- So that you appear plausible and do not contradict yourself, we suggest you base answers to any questions on your own personal situation.
- People may offer to send you information by post, and we would like you to accept the offer if you are comfortable doing this. Make sure you tell people that you are only looking for basic information at this stage.

Answerphone messages and callbacks

- It is possible that your call reaches an answerphone or voicemail, or you speak to somebody who offers to call you back at another time.
- If you are comfortable doing so, leave an answerphone message (with your query and telephone number) or arrange for the person concerned to call you back. On the feedback sheet we ask you to tell us how long you waited for a return call.
- Alternatively, you can:
 - (where you have reached an answerphone): not leave a message but try the number again at another time
 - (where somebody has offered to call you back): arrange instead a time when you can call them back.
- If you have not heard back from an organisation four days after leaving an answerphone message or arranging a call back, please try calling them again.

Troubleshooting

- You may encounter a situation where you are unsure about how to proceed. For example, you have tried a number five times without success or have left answerphone messages for an organisation that have not been returned. In such situations, please call [name] on Freephone number [xxx] and we can advise you about what to do.

Completing the feedback questionnaire

- Please complete a feedback questionnaire for each organisation you speak to. This means you may have to complete up to four questionnaires for each shop.
- Use the space provided on the final page of the questionnaire to record your overall impressions, and to write down anything important that we have not specifically asked you about elsewhere.
- Once you have completed both shops, send your completed questionnaires back to us using the Freepost envelopes provided. If you are sent any information following your phone calls, please also send this to us using the Freepost envelopes.
- We would also like to speak to you in person, to talk about your experiences and overall impression of trying to find information about local health and social care services. Please can you call [name] on Freephone number [xxx], we envisage this call will take no longer than half an hour.

Reimbursement

- We are very grateful for your time, and would like to pay you £60 for each mystery shop (£120 in total). We will send you vouchers to this value once we have received your completed feedback questionnaires.

Appendix 3: Mystery Shopping Scenarios

Multiple Sclerosis: Mystery Shop 1

Are there any support groups in the area for people with MS?

You are hoping to move to the Southport area. At this stage you are looking for information on any local support groups for people with MS.

You will need to find out:

- What support groups are there?
- Contact details for these support groups
- Details of when and where the groups meet
- Are there any costs to be a member of these groups?

You may be asked:

- Where you're moving to
- If you're already a member of a support group

If you are asked questions you do not wish to answer, or offered services that you do not wish to receive, politely decline these and say that you are just looking for basic information at the moment.

The person you speak to may offer to send you some information – agree to this but emphasise that you are only looking for basic information at the moment.

Your initial question is:

"I'm trying to find out if there are any support groups in the Southport area for people with MS."

Your first phone call is to: Mystery shop 1:

Organisation:

Telephone number:

Mystery shop 2:

Organisation:

Telephone number:

Please ensure you have read the guidelines and feedback questionnaire before you make the telephone call.

Multiple Sclerosis: Mystery Shop 2

How could I get help in making adaptations to the home?

You have MS and you are hoping to move to the Southport area. You will need adaptations to be made to your home to help you. At this stage you want to find out what you will have to do to make arrangements for these adaptations.

You will need to find out:

- Who you should contact for more information?
- How long you would have to wait to see them?
- Would you have to pay for these adaptations?

You may be asked:

- Where you're moving to
- When you're moving
- If you've had adaptations made to your current home and what they were
- If you are working

If you are asked questions you do not wish to answer, or offered services that you do not wish to receive, politely decline these and say that you are just looking for basic information at the moment.

The person you speak to may offer to send you some information – agree to this but emphasise that you are only looking for basic information at the moment.

Your initial question is:

"I am soon hoping to move to Southport. I have MS and I will need to have adaptations made to my home. Can you tell me how I can find out more information about this?"

Multiple Sclerosis: Mystery Shop 3

Finding out about Neurology services in the local area for people with MS

You have MS and you are hoping to move to the Southport area. You want to find out about the Neurologists and Neurology services at the local hospital and if any trials are being conducted there. You also want to know if there are any specialist MS nurses at the hospital.

You will need to find out:

- What are the neurologists and neurology services like at the local hospital
- If any MS trials are being carried out
- Are there any MS specialist nurses at the hospital
- Contact details for the MS nurses
- How would you arrange to see them?
- Is there a waiting list to see them?

You may be asked:

- Where you're moving to
- When you're moving

If you are asked questions you do not wish to answer, or offered services that you do not wish to receive, politely decline these and say that you are just looking for basic information at the moment.

The person you speak to may offer to send you some information – agree to this but emphasise that you are only looking for basic information at the moment.

Your initial question is:

"I am soon hoping to move to Southport. I have MS and I want to find out more about the neurology services at ... hospital."

Multiple Sclerosis: Mystery Shop 4

Finding out about support in the local area for carers of people with MS

Are there any support groups for carers in the area? How would I find information on arranging respite care?

You will need to find out:

- What support groups there are?
- Contact details for the support group
- If the groups are general or specialist for MS carers
- How to find out about respite care options?
- Who to contact to be assessed for respite care provision?
- Who to contact to arrange respite care?

You may be asked:

- Where you're moving to
- When you're moving
- How advanced your MS is
- If you have any current arrangements in place for respite care.

If you are asked questions you do not wish to answer, or offered services that you do not wish to receive, politely decline these and say that you are just looking for basic information at the moment.

The person you speak to may offer to send you some information – agree to this but emphasise that you are only looking for basic information at the moment.

Your initial question is:

"I am soon hoping to move to Southport. I have MS and I want to find out more about support services for my husband/wife/partner."

Diabetes: Mystery Shop 1

How would I find a GP in the area that specialises in diabetes? Are there any other specialist diabetes clinics/facilities in the area?

You are hoping to move to the Liverpool area. At this stage you are looking for information on whether there are any GP practices with GPs or nurses that specialise in diabetes and whether there are any other specialist diabetes clinics or facilities.

You will need to find out:

- If there are practices in the area with GPs or nurses who specialise in diabetes
- Contact details for these practices
- Are they currently accepting new patients?
- What is their catchment area?
- Contact details for any specialist clinics/facilities (e.g. a diabetes specialist nurse, dietician, podiatrist or optometrist)

You may be asked:

- Where you're moving to
- What type of diabetes you have (i.e. Type 1 or Type 2)
- Whether you are currently receiving care from a GP/nurse specialist (or attending a specialist diabetes clinic)

If you are asked questions you do not wish to answer, or offered services that you do not wish to receive, politely decline these and say that you are just looking for basic information at the moment.

The person you speak to may offer to send you some information – agree to this but emphasise that you are only looking for basic information at the moment.

Your initial question is:

"I'm trying to find out if there are any GP practices in the Liverpool area with GPs or nurses that specialise in diabetes."

Diabetes: Mystery Shop 2

Are there any support groups in the area for people with diabetes? I'm also interested to find out if there are any education/self management programmes in the area for people with diabetes?

You are hoping to move to the Southport area. At this stage you are looking for information, on behalf of your wife who has diabetes, on whether there are any support groups for people with diabetes and if there are any education/self management programmes in the area.

You will need to find out:

- What support groups are there?
- Contact details for the support groups
- Details of when and where they meet
- Are there any costs to be a member?

Details of any self management programmes

- How to join the programmes
- Are there any costs involved?
- Is there a waiting list to join?

You may be asked:

- Where you're moving to
- What type of diabetes your wife has (i.e. Type 1 or Type 2)
- If she is already a member of a support group and/or participating in a self-management programme.

If you are asked questions you do not wish to answer, or offered services that you do not wish to receive, politely decline these and say that you are just looking for basic information at the moment.

The person you speak to may offer to send you some information – agree to this but emphasise that you are only looking for basic information at the moment.

Your initial question is:

"I'm trying to find out if there are any support groups in the Southport area for people with Diabetes."

Ethnic Minority Older People: Mystery Shop 1

Finding out about care homes

In this scenario, you are looking for a care home for an elderly relative in the Sandwell area. At this stage you are looking for basic information, including details of costs, waiting lists, criteria for acceptance and any special facilities.

Your relative is female, and does not have any specific medical problems at this time. She is in her eighties and lives in Tipton.

You will need to find out:

- Location and contact details of care homes
- What the cost will be
- Whether there is a waiting list
- What the criteria are for being accepted
- If there any special facilities

You may be asked:

- How the person is related to you
- About their general state of health, are they mobile, do they require any nursing care

If you are asked questions you do not wish to answer, or offered services that you do not wish to receive, politely decline these and say that you are just looking for basic information at the moment.

The person you speak to may offer to send you some information – agree to this but emphasise that you are only looking for basic information at the moment.

Ethnic Minority Older People: Mystery Shop 2

Where can I find a GP that has an Urdu/Punjabi health advocacy worker attached to the practice?

You are calling on behalf of a client who currently lives in the Oxford area. She is an older Asian woman, who is considering moving to West Birmingham. Specifically, she is thinking about relocating to the town of Sandwell or somewhere in the surrounding area (see map for details).

Your client will be moving with her husband, and neither of them speaks English.

It is very important that the area she moves to has adequate services for Asian people. Given this, you are trying to find out on your client's behalf about the availability of GP's in the area that have health advocacy workers attached to them.

You will need to find out:

- Contact details of GP's with health advocacy support workers
- What languages the health advocacy support workers speak?
- What times the health advocacy support workers are at the surgery?
- Whether the support worker would interpret for the patient during the consultation?

You may be asked:

- Where your client currently lives (answer: Oxford)
- What language she and her husband speaks (answer: Urdu/Punjabi)
- How old they are (answer: in their sixties)

If you are asked questions you do not wish to answer, or offered services that you do not wish to receive, politely decline these and say that you are just looking for basic information at the moment.

The person you speak to may offer to send you some information – agree to this but emphasise that you are only looking for basic information at the moment.

Ethnic Minority Older People: Mystery Shop 3

Finding out about meals on wheels

In this scenario you are looking for information about meals on wheels. You are hoping to move to the Sandwell area and would like to find out about the meals on wheels service and if you are eligible. At this stage you are only looking for basic information about how to apply.

You will need to find out:

- How to apply for meals on wheels – is there a form?
- Who will assess you and how long will it take before they come to see you?
- How much does it cost?

You may be asked:

- Where you live
- Whether you live alone
- Whether you have a disability or illness which prevents you cooking
- If you have a social worker

If you are asked questions you do not wish to answer, or offered services that you do not wish to receive, politely decline these and say that you are just looking for basic information at the moment.

The person you speak to may offer to send you some information – agree to this but emphasise that you are only looking for basic information at the moment.

Ethnic Minority Older People: Mystery Shop 4

Finding out about respite care for Asian carers

You are calling on behalf of a client who currently lives in the Oxford area. She is an older Asian woman, who is considering moving to West Birmingham. Specifically, she is thinking about relocating to the town of Sandwell or somewhere in the surrounding area (see map for details).

This woman will be moving with her husband. He has dementia and your client provides day-to-day care for him.

It is very important that the area she moves to provides adequate services for Asian carers and their families. Given this, you are trying to find out on her behalf about the availability of respite care services in the local area.

You will need to find out:

- What respite care is available
- Would the respite care be culturally appropriate – e.g. Halal food, prayer rooms
- If there is a waiting list for respite care
- Contact details for the service providers

You may be asked:

- Where your client currently lives (answer: Oxford)
- If you are already receiving respite care services (answer: yes, although you are not sure what type of respite care she is receiving)
- How old is the person you care for? (answer: in his late sixties)

If you are asked questions you do not wish to answer, or offered services that you do not wish to receive, politely decline these and say that you are just looking for basic information at the moment.

The person you speak to may offer to send you some information – agree to this but emphasise that you are only looking for basic information at the moment.

Autism: Mystery Shop 1

Finding out about therapy or counselling services for children with Autism

You are considering moving to South West Cornwall. Specifically, you are thinking about relocating to the town of Truro or somewhere in the surrounding area (see map for details).

You would be moving with your family, including one child who has Autism.

It is very important that the area you move to provides adequate services for children with Autism and their families. Given this, you are trying to find out about the availability of therapy or counselling services in the local area.

You will need to find out:

- What types of counselling and therapy services are available for children with autism (e.g. cognitive behavioural counselling, art therapy, music therapy)
- Will you have to pay for these counselling or therapy services
- If you have to pay or make a contribution, what will the cost be
- Contact details for the service providers

You may be asked:

- Where you currently live
- If your child already receives therapy or counselling
- What type of therapy or counselling you are trying to find out about
- What age your child is and how long he/she has been diagnosed for

If you are asked questions you do not wish to answer, or offered services that you do not wish to receive, politely decline these and say that you are just looking for basic information at the moment.

The person you speak to may offer to send you some information – agree to this but emphasise that you are only looking for basic information at the moment.

Autism: Mystery Shop 2

Finding out about carer support for parents of children with autism

You are considering moving to North East Cornwall. Specifically, you are thinking about relocating to the town of Bude or somewhere in the surrounding area (see map for details).

You would be moving with your family, including one child who has autism.

It is very important that the area you move to provides adequate services for children with autism and their families. Given this, you are trying to find out about the availability of carer support services in the local area.

You will need to find out:

- What carer services are available
- What type of support do these services provide (e.g. counselling, family support)
- If there are any local carer support groups
- Contact details for the service providers and support groups

You may be asked:

- Where you currently live
- If you are already receiving carer support
- What form of carer support you are trying to find out about
- What age your child is and how long he/she has been diagnosed for

If you are asked questions you do not wish to answer, or offered services that you do not wish to receive, politely decline these and say that you are just looking for basic information at the moment.

The person you speak to may offer to send you some information – agree to this but emphasise that you are only looking for basic information at the moment.

Autism: Mystery Shop 3

Finding out about out-of-school services for children with autism

You are considering moving to West Cornwall. Specifically, you are thinking about relocating to the town of St Ives or somewhere in the surrounding area (see map for details).

As you have two teenage sons with autism, it is very important that the area you move to provides adequate services for young adults with autism and their families. Given this, you are trying to find out about the availability of out-of-school services in the local area.

You will need to find out:

- What out-of-school services are available for children with autism
- If these activities are available in both term-time and holiday periods
- If the services have age restrictions
- Contact details for the service providers

You may be asked:

- Where you currently live
- If your sons already participate in out-of-school activities
- What type of out-of-school services you are trying to find out about
- What age your sons are and how long they have been diagnosed for

If you are asked questions you do not wish to answer, or offered services that you do not wish to receive, politely decline these and say that you are just looking for basic information at the moment.

The person you speak to may offer to send you some information – agree to this but emphasise that you are only looking for basic information at the moment.

Autism: Mystery Shop 4

Finding out about respite care for children with autism

You are considering moving to South East Cornwall. Specifically, you are thinking about relocating to the town of Looe or somewhere in the surrounding area (see map for details).

You would be moving with your family, including one child who has autism.

It is very important that the area you move to provides adequate services for children with autism and their families. Given this, you are trying to find out about the availability of respite care services in the local area.

You will need to find out:

- What types of respite care are available (e.g. in-home, residential)
- What facilities and activities they offer
- If there is a waiting list for respite care
- Contact details for the service providers

You may be asked:

- Where you currently live
- If you are already receiving respite care services
- What type of respite services you are trying to find out about
- What age your child is and how long he/she has been diagnosed for

If you are asked questions you do not wish to answer, or offered services that you do not wish to receive, politely decline these and say that you are just looking for basic information at the moment.

The person you speak to may offer to send you some information – agree to this but emphasise that you are only looking for basic information at the moment.

Appendix 4: Mystery shopping assessments - feedback questionnaire

PLEASE READ 'GUIDELINES FOR MYSTERY SHOPPERS' BEFORE YOU BEGIN

MYSTERY SHOP 1 (organisation 1)

Please fill this form in immediately after completing the telephone mystery shop

Name

Which organisation did you call?

What was their telephone number?

Section 1: Date and time of call

Please remember:

- You will need to record the number of attempts it takes before you speak with somebody
- The call counts as an attempt if:
 - it is not answered after 1 minute
 - the line is engaged
 - or you go through to an answerphone
- You must leave at least an hour between attempts
- If you are not able to speak to somebody after five attempts, then the mystery shop is completed

	Attempt 1	Attempt 2	Attempt 3	Attempt 4	Attempt 5
Date of call					
Time of call					
(Please tick which applies)					
Call was answered					
Went through to answerphone					
Line was engaged					
Call not answered after 1 minute					

Section 2: Getting through to somebody who could help you

1. From the time you made your first call to this organisation (attempt 1), how long did it take for somebody to handle your query?

- (i) My query was handled straight away ☐
- (ii) The same day ☐
- (iii) The following day ☐
- (iv) 2-4 days later ☐
- (v) 5-7 days later ☐
- (vi) More than 1 week later ☐

2. Which of the following did you experience during this time (please tick all that apply)?

- (i) I left an answerphone message ☐

In total, how many answerphone messages did you leave.....

- (ii) Somebody arranged to call me back ☐

In total, how many times did somebody arrange to call you back.....

- (iii) My call was transferred ☐

In total, how many times was your call transferred.....

Section 3: Handling your query

3. Who handled your query?

- (i) Receptionist or telephone operator ☐
- (ii) A nurse or other health professional ☐
- (iii) Social worker or other social care professional ☐
- (iv) Librarian ☐
- (v) Staff member of a local voluntary group ☐
- (vi) Don't know ☐
- (vii) Other (please specify below) ☐

.....

.....

4. Were they able to give you the information you required?

- | | | | |
|-------|---|--------------------------|------------------|
| (i) | Yes, completely | <input type="checkbox"/> | Go to question 5 |
| (ii) | Yes, partially | <input type="checkbox"/> | Go to question 5 |
| (iii) | No, but they suggested other people or organisations who I should contact with my enquiry | <input type="checkbox"/> | Go to question 6 |
| (iv) | No, they were unable to help me | <input type="checkbox"/> | Go to question 6 |

5. What information were you given?

- | | | |
|-------|---|--------------------------|
| (i) | Service name(s) | <input type="checkbox"/> |
| (ii) | Contact details (for example: address, telephone number, website) | <input type="checkbox"/> |
| (iii) | Details of opening times | <input type="checkbox"/> |
| (iv) | Staff contact name(s) at the service | <input type="checkbox"/> |
| (v) | Other | <input type="checkbox"/> |

Please detail below the exact information that you were given (please refer back to the instructions on the scenario sheet):

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

Section 4: Overall impression

Note: for questions 6-8, please circle only one number between 1 and 5

6. How friendly were the people you spoke to at this organisation?

1 2 3 4 5

Not at all friendly

Very friendly

7. How helpful were the people you spoke to at this organisation?

1 2 3 4 5

Not at all helpful

Very helpful

8. Do you think people at this organisation did everything they could to help you?

1 2 3 4 5

No, not at all

Yes, completely

9. Is there anything else you would like to tell us?

.....

.....

.....

.....

.....

.....

.....

.....

Don't forget to contact xx on 0800 xxx xxxx when you have completed your mystery shops

.....

Appendix 5: Online Searching Process Evaluation guidance

Review of provision of health and social care information

Online Searching - Part 1 Process Evaluation Guidance Material

The purpose of this stage of the research is to mirror the telephone mystery shopping exercises. Using the mystery shopping scenarios as a starting point you will attempt to find answers/relevant information via online searches alone.

At this stage we **just** want to assess the process you go through to reach a suitable 'conclusion'. Once this stage is completed, the content of the websites you have visited will then be evaluated.

What you'll need

A scenario sheet highlighting the key information you are looking for
A copy of the online searching template spreadsheet

What to do

- 1) Make a note of the time so that you can record how long it takes you to complete the exercise. **(Please don't spend more than 45 minutes on each scenario search)**
- 2) Decide upon the Google search terms you will use, based on the scenario you are working with:
eg If you are looking for NHS dentists in Oxford - your key search terms might be *NHS Dentist Oxford*
Record this as a response to question 2 on the spreadsheet
- 3) It is important just to look at websites which appear relevant to the scenario you are working with. Click on the first **relevant** link you see on the Google search returns page.
- 4) Copy and paste this web address (section after question 6)

Record the outcome of what you find on this site by putting yes in the appropriate box and then follow the appropriate instructions:

- a) If you find the answer/enough information: your search is then complete
- b) If you do not find sufficient information to answer your query, and there are no useful links to other sites. Then return to the Google search page and click on the next relevant link in the list, and follow above instructions from point 4.
- c) If you do not find sufficient information to answer your query, but the website offers a promising link to another site. Then click on this link, and follow above instructions from point 4.
- d) If you don't find any useful information return to the Google search and click on the next relevant link in the list

Copy and paste this web address into the spreadsheet below the previous web address entry

- 5) If your first Google search terms are unsuccessful please enter new search terms in response to Question2
- 6) Your search is complete when either:
 - a) You have found enough information to answer your original query/scenarioOr
 - b) 45minutes has elapsed
- 7) Complete questions 3-6 on the spreadsheet. Please include as much description as you can to assist the comparison of your online searching experience with the parallel telephone mystery shopping experience.
- 8) Save your completed spreadsheet

Appendix 6: Online Searching Process Evaluation feedback form

Online Searching - Part 1 Process Evaluation Feedback Form

1) Scenario 1: <i>Write scenario details here</i>	
2) Google search terms used: terms used: 1 2 3 4 5 <i>[Insert row(s) to add more search terms]</i>	
3) How long did it take you to complete this search <input type="text"/>	Maximum of 45 mins
4) Did you find enough relevant information to reach a suitable conclusion? <div style="text-align: right;"> Yes, completely <input type="text"/> Yes, partly <input type="text"/> No <input type="text"/> </div>	
5) What conclusion/end point did you reach? (please give details e.g. further sources of information, service details, telephone number etc.) <i>[double-click to enter text]</i>	
6) What was your experience of searching like? (How easy did you find it? Were there any particular things that simplified the search or made it more complicated?) <i>[double-click to enter text]</i>	

Website Records:			
Website address: Cut and paste website URL here			
Search outcome:	Found relevant information	<input type="checkbox"/>	Search completed
<i>Put 'Yes' in one box only</i>	Found only partial information with no useful link	<input type="checkbox"/>	Return to Google search
	Found promising link to another site	<input type="checkbox"/>	Follow link to new website
	Didn't find any relevant information	<input type="checkbox"/>	Return to Google search
Website address: Cut and paste website URL here			
Search outcome:	Found relevant information	<input type="checkbox"/>	Search completed
<i>Put 'Yes' in one box only</i>	Found only partial information with no useful link	<input type="checkbox"/>	Return to Google search
	Found promising link to another site	<input type="checkbox"/>	Follow link to new website
	Didn't find any relevant information	<input type="checkbox"/>	Return to Google search
Website address: Cut and paste website URL here			
Search outcome:	Found relevant information	<input type="checkbox"/>	Search completed
<i>Put 'Yes' in one box only</i>	Found only partial information with no useful link	<input type="checkbox"/>	Return to Google search
	Found promising link to another site	<input type="checkbox"/>	Follow link to new website
	Didn't find any relevant information	<input type="checkbox"/>	Return to Google search

Appendix 7: Website Evaluation Feedback Form

Review of the provision of health and social care information Website evaluation

Organisation:

Web address:

1) What type of organisation was this?

- ☐ Health
- ☐ Local Authority
- ☐ Voluntary Sector
- ☐ Other (Please specify)

2) On a scale of 1 to 5, how easy was it to navigate this website?

Not at all easy

Very Easy

1

2

3

4

5

Comments:

3) On a scale of 1 to 5 Did the website have a clear structure and layout?

(Look for consistent design, aids to finding information, emphasis of important points, illustrations where appropriate, clear separation of sections)

Not at all easy

Very Easy

1

2

3

4

5

Comments

4) Did this website provide any of the following (tick all that apply)?

- ☐ large print
- ☐ audio/sound
- ☐ text only
- ☐ option to change browser settings (e.g. to change size, colour or type of font or to change background)
- ☐ details of a telephone helpline
- ☐ details of textphone
- ☐ other languages

5) Was it possible to request information in any of the following formats:

- ☐ audio
- ☐ video/dvd
- ☐ alternative print formats (eg Braille, large text etc)
- ☐ other languages
- ☐ other (Please specify)

Comments

6) Did the website feature any dates or details of its last update?

- ☐ Yes Details _____
- ☐ No

7) Did this website include details of/ links to any further sources of information?

- ☐ Yes (➔ go to question 7a)
- ☐ No

7a) If yes were these (tick all that apply)

- ☐ External sources of information
- ☐ Further details relating to the same organisation

Any other comments

Appendix 8: Survey of Information providers



Review of provision of health and social care information

The Department of Health has asked the Picker Institute to carry out a study to review the current provision of health and social care information.

The key aims are to determine:

1. How patients, service users and carers currently access information about local services
2. The extent to which local information resources are well signposted so people can find information themselves
3. What additional support is required to enable people to find information about services that is appropriate to their needs

As part of this study we are inviting health, social care and information professionals to take part in a short survey. By completing this survey you will help us to assess the current level of information support for users, carers and professionals and how it might be improved. The survey should take about 5 minutes to complete.

Any information you provide will be kept confidential. Responses and comments that are included in the final report will be anonymised and will not be attributable to any named individual.

Thank you in advance for your help.

Q1 Which of the following best describes the organisation that you work for?

- ☐ Health service provider-NHS
- ☐ Health service provider-private/independent
- ☐ Social care service provider-statutory
- ☐ Social care service provider-private/independent
- ☐ Inspectorate/regulator
- ☐ Research/consultancy
- ☐ Voluntary organisation
- ☐ Professional body
- ☐ Other (please specify below)

Q2 Which of the following best describes what you do?

- ☐ Health professional
- ☐ Social care professional
- ☐ Manager in an organisation providing services
- ☐ Service commissioner
- ☐ Librarian or information professional
- ☐ Volunteer/group member
- ☐ Other (please specify below)

Q3 What is the first part of the postcode of your work address?
eg OX18

--	--	--	--

Q4 Does your role involve signposting people to information about health and social care services?

- ☐ Yes, it's what I mostly do
- ☐ Yes, it's one of the things I do
- ☐ No, not at all

Q5 What sort of information about local services do people ask you for?

Please tick all that apply

- | | |
|--|--|
| <input type="checkbox"/> Condition/disease-specific services | <input type="checkbox"/> Finding a GP |
| <input type="checkbox"/> Financial/benefits | <input type="checkbox"/> Finding a Walk in Centre |
| <input type="checkbox"/> Work/employment | <input type="checkbox"/> Health promotion/prevention services |
| <input type="checkbox"/> Mobility/driving/transport | <input type="checkbox"/> Self management support services |
| <input type="checkbox"/> Respite care | <input type="checkbox"/> Complementary/alternative therapies |
| <input type="checkbox"/> Residential or long-term care | <input type="checkbox"/> Dental services |
| <input type="checkbox"/> Housing | <input type="checkbox"/> Adaptations to home equipment, occupational therapy |
| <input type="checkbox"/> Immigration and asylum | <input type="checkbox"/> How to comment on/complain about services |
| <input type="checkbox"/> Education, training & learning | <input type="checkbox"/> Not applicable |
| <input type="checkbox"/> Voluntary sector/support groups | <input type="checkbox"/> Other |
| <input type="checkbox"/> Family/carer support | |
| <input type="checkbox"/> Counselling/therapy services | |

Please specify what other information about local services people ask you for

Q6 Are you able to provide information in any of the following formats?

Please tick all that apply

- ☐ Print
- ☐ Web
- ☐ Large print
- ☐ Braille
- ☐ Audio
- ☐ Video/DVD
- ☐ Languages other than English
- ☐ None of the above
- ☐ Other (please specify below)

Q7 How easy or difficult would you say it is for people to find information about locally available health and social care services?

- ☐ Very easy
- ☐ Moderately easy
- ☐ Neither easy nor difficult
- ☐ Moderately difficult
- ☐ Very difficult
- ☐ Don't know

Are there any groups that face particular difficulties in finding information about locally available services?

Q8 How easy or difficult is it for you to keep up-to-date with information about services in your local area?

- ☐ Very easy
- ☐ Moderately easy
- ☐ Neither easy nor difficult
- ☐ Moderately difficult
- ☐ Very difficult
- ☐ Don't know

Q9 How do you keep up-to-date?

Please tick all that apply

- ☐ I receive email updates
- ☐ I regularly check websites
- ☐ I attend seminars/conferences
- ☐ My organisation provides a directory
- ☐ I search for information when I need it
- ☐ Not applicable
- ☐ Other

Q9a Please specify who you receive email updates from

Q9b Please specify which websites you regularly check

Q9c Please specify the other ways you keep up to date

Q10 What are the greatest challenges you face in signposting people to relevant information sources?

Please tick a maximum of **FOUR** options

- ☐ Providing the right information at the right time
- ☐ Providing information in the right format (e.g. other languages, audio, Braille etc)
- ☐ Keeping track of changes to local services
- ☐ Keeping up-to-date about new services
- ☐ Finding out about services in other public sector areas
- ☐ Lack of resources
- ☐ Lack of time
- ☐ Lack of available services
- ☐ Levels of literacy/comprehension among service users
- ☐ Poor cooperation between organisations/agencies in the local area
- ☐ Not applicable
- ☐ Other (please specify below)

Q11 Can you recommend any ways in which people could access information about health and social care services more easily?

Q12 What additional resources would help you signpost people to information about local health and social care services more effectively?

Q13 How easy or difficult would you say it is for people to find information about locally available health and social care services?

- ☐ Very easy
- ☐ Moderately easy
- ☐ Neither easy nor difficult
- ☐ Moderately difficult
- ☐ Very difficult
- ☐ Don't know

Are there any groups that face particular difficulties in finding information about locally available services?

If you are happy for us to contact you for further information about your responses or if you would like to receive a copy of the final project report please insert your name and email address here.

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making patients' views count