

Policy Research Primer

○ At a crossroads without signposts

The struggle to access information about health and social care services

This is a summary of a report by the Picker Institute for the Department of Health: "Accessing information about health and social care services."

This research is distinctive because it takes a service user's perspective of the struggle for information.

It includes focus group discussions with people including older ethnic minority women, people with multiple sclerosis and diabetes, and parents of autistic children.

It sends service users 'mystery shopping' for the information they need about services in different areas of England. It compares online searching to this telephone exercise.

It validates these findings with experienced service users living in each of the geographical areas, and it surveys information providers to get their viewpoint.

The research questions

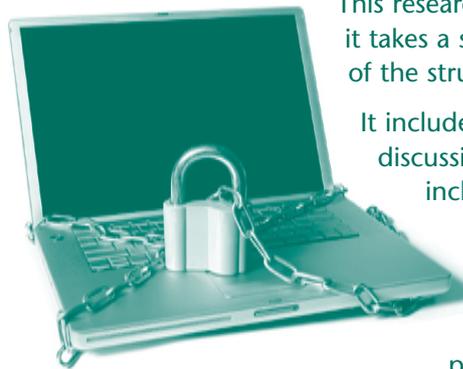
- How do patients, service users and carers find out about local health and social care services?
- Is the information well signposted?
- What additional support do people need to find appropriate services?

The research methods

- Focus groups with service users and carers
- Mystery shopping by service users and carers
- Online searches of health and social care websites
- Survey of 370 health professionals and information providers

KEY FINDINGS

- **Health professionals** – who are often responsible for first diagnosis, or are a first port of call for help with a condition – do not systematically or proactively provide their patients with information about the variety of local information services.
- **There is a lack of coordination** between information providers across boundaries – geographical, sectoral and organisational. It is rare for an individual or organisation to take responsibility for providing relevant information about the whole range of services.
- **There is rarely a sheer lack of information** – a significant amount is being produced – but the service user is left to dig it out for themselves because it is not well signposted.
- **The most common types of information** that service users are trying to access are:
 - 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.
- **With regard to the types** of information provision:
 - Users report that telephone information points offer a friendly service, but do not always lead to useful information
 - Most health and social care websites contain some useful information, but some are poorly designed
 - Some telephone advice services and websites fail to update their material regularly
 - Social care agencies appear more likely than health agencies to make information accessible to people with disabilities, by providing information in a variety of formats.



Service users frequently encounter confusion, barriers and false trails as they try to find out what services could help them to live with their condition or care for their family.

Little information is provided on diagnosis or at the start of a caring role, leaving service users to start out on their own. Too often, the services supposed to help at the point of real need throw people back on their own resources.

The report concludes that 'to gain a reliable picture of all relevant services, one would have to invest considerable time, effort and ingenuity'. This is a demanding investment for people diagnosed with diabetes, parents of a child with learning difficulties, elderly Asian women caring for their husbands or anyone in hard-pressed circumstances.

And there are solid walls put up by the system – such as the refusal to give out information until the caller has been formally referred to the service by, for example, a GP or social services.

There is no shortage of health and social care information. But it is difficult to access and there is a shortage of personalised help. The biggest challenge is finding information about services relevant to your own needs. Knowing what services are available and what information to search for is the key.

Service users find themselves standing at a crossroads in their lives – without any signposts to indicate the right direction of travel.

It should be noted that this report actually describes the 'better end' of the information searching spectrum.

These research participants had spent long enough navigating their own information pathways to have become 'expert information seekers'. They were, on the whole, highly motivated, articulate and assertive. Many highlighted concerns for people newly coping with the need to get service information, or who do not have the same personal skills and qualities, as they are likely to face an even tougher struggle.

The research report makes recommendations as to how health and social care services can put this right.

Its main message is that people need timely, direct and personal assistance to find the quickest paths to the services they are seeking. This support should be provided proactively, at a single, easily identifiable point in the system. It is time for health and social care services to make a new service – navigation – a high priority for their patients and service users.



It isn't just having access to the information – sometimes you need help to know what to have access to.

Person with diabetes

Information needs

Focus group participants said they valued information, not just to understand how to manage health problems, but also to access an appropriate mix of support and services. They wanted it soon after they received a diagnosis or took on a caring role, at precisely the stage when the health and social care system can seem most complex and confusing. Because their needs and circumstances change over time, they want information at other stages too.

All the focus groups cited the importance of face-to-face contact as an opportunity to gain information and to raise concerns or ask questions. It enables people to get beyond the basics (such as contact details) to find out the things they really need to know – like whether a service is really designed, or appropriate, or available for them.

They placed a high value on finding one individual to help them access information and make enquiries – unfortunately, many had never actually experienced this.

The mystery shoppers backed this up. Even where they encountered frustrations, unanswered calls and buck-passing, they could accept it if they eventually got through to a person who could really help them.

Focus group on autism

Parents of autistic children said their Special Educational Needs Co-ordinators were highly valued as source of help, and education services were far more useful information providers than either health or social care services. Their major challenge was to get information across these different sectors. Very often they found out about services in ad-hoc ways, through friends, family, newspaper articles, or other materials they 'came across'. They had to 'look everywhere' because agencies did not proactively provide information.

National agencies were of limited use, as they could not signpost to local services. Health professionals were often perceived as a barrier rather than a help, especially regarding information on alternative and complementary therapies, or anything else that was not strictly mainstream medical (such as dietary advice).

Information-seeking experiences

The mystery shoppers tested out the process of searching for information. People with diabetes or MS, carers of autistic children and people caring for ethnic minority elders telephoned councils, health services and voluntary organisations in another geographical area, saying **“I’m considering moving to your area, and am trying to find out about local services in advance.”** These scenarios were based on the earlier focus group discussions. The shoppers conducted two shops each.

On many occasions responses were non-existent or inadequate. Some ‘shoppers’ left messages that were never answered, whilst others had to phone back up to four times. Sometimes this brought the information search grinding to a halt. Anyone with personal commitments would find this a challenge. For people in more urgent or pressing circumstances, this need for time and persistence could simply create barriers to accessing the support to which they are entitled.

Once telephone contact was established, things did not necessarily improve. Many shoppers reported being passed around between organisations, or – particularly in large social services departments – around different individuals within the same

Focus group of people with Multiple Sclerosis

People who had been living with MS for many years said they had difficulty tracking down the specific individuals, such as specialist nurses or care managers, who were responsible for them. Most were not being seen regularly by specialists, who might have relevant information to offer, and they said their GPs as generalists were unable to provide the detailed advice they required.

Overwhelmingly they found things out through other people with MS, rather than from service providers:

“They are the only people who have the information – they don’t give information from anywhere else.”

It was through this route, or by chance, that they discovered crucial benefits information:

“I only found out through other people – they would say I am getting this benefit.”

Their general feeling about the ‘system’ could be summarised as:

“You are not told anything, you have got to find it out for yourself.”

organisation. Sometimes they were referred to an organisation known to work generally on an issue (such as respite care), rather than on the issue relevant to the caller (such as respite care for people with autistic children).

Shoppers were rarely directed to specific individuals within organisations; instead they were given switchboard or general enquiries telephone numbers. Some of these numbers proved to be wrong – or to be fax numbers. As a consequence, the shoppers had to spend even more time finding the appropriate contact within the organisation.

One shopper commented that they **“got the impression they didn’t know where to send me.”** Another, towards the end of their ‘shop’, was directed back to the first organisation they had spoken to – which had been unable to give them the right information in the first place.

Some shoppers found that it was difficult to find information about services without a direct referral from a GP, specialist or social services department. This practice prevents people gathering information in advance to help them make informed choices for the future.

Most of the shopping enquiries were at least partially successful, in that some basic information was collected along the way. A few people found out everything they needed to know.

Organisations were much more likely to be rated as ‘friendly’, rather than ‘helpful’, and it appears that they are rarely equipped to answer more specialised enquiries, that is, to tell people what they most need to know.

There were, however, welcome instances when individuals went out of their way to offer appropriate support:



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.

Mystery shopper with MS

Finding information on the internet

Online searches for the same information proved more successful in a shorter space of time, so people with internet access are likely to have a better chance of success. As internet access is not universal or equally distributed this discriminates against those who may well already be 'information poor' – such as those from disadvantaged groups or older people.

But internet searching does not provide the face-to-face interaction that enables questions to be asked and concerns to be raised. The end point may, again, only be to get general contact details. There is scope for the improvement of health and social care websites, in particular by making information available in a variety of formats to improve accessibility.

There is a significant volume of useful material online but it is redundant if people are unaware that the services actually exist. Our searchers were armed with specific questions to ask about particular services – 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.



... 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.

Person with diabetes

Experiences of mystery shoppers

○ Parent of autistic child searching for respite care

The first shop started at the local council, who transferred the shopper to the county council. The Children and Young People and Family Services Department gave them a number for a Social Services Officer. Answerphone messages to this number were not returned. Finally the shopper was advised to contact an autism advisor. After two unsuccessful attempts they tried the county council's general number again – and this time were transferred to the child disability team who were extremely helpful and provided answers to all their questions.

○ Parent of autistic child looking for out-of-school services for child

A national voluntary organisation provided a number for a local branch. Two calls to this office were not returned within the following week. A second attempt started with the primary care trust (PCT), which suggested contacting Child and Family Services. They in turn suggested an individual attached to the county educational services. It turned out he dealt with school sports – so he gave another number at Child and Family Services. An advisor there said they would arrange for a Social Services Care Manager to phone the shopper. They did not receive such a call.

○ Person with diabetes looking for local support group and information on self-management

This shopper contacted a national voluntary organisation, where the receptionist initially gave

out details of weekend courses, and then referred them to the wrong regional office. Having found the correct regional office, they were given details of a local support group. Pursuing a similar enquiry through the local PCT, the shopper was passed on to a hospital, who then transferred them to the PCT's PALS (patient advice and liaison service). The PALS service provided details of the same local support group.

○ Ethnic minority elder seeking a GP practice with an Urdu/Punjabi link worker

A local older person's charity suggested contacting an advice centre. The advice centre worker could give no immediate advice but promised to call back with telephone numbers. They never did so. The shopper started again by contacting the PALS service, who again promised to call back with useful telephone numbers but failed to do so.

○ Ethnic minority elder looking for respite care services for dependent spouse

The local council referred them to an ethnic minority support service – but it turned out they only supported children, not adults. They suggested another service, but that one provided day and home care, not respite care. This second service gave a number for the local council – back where they started. A second attempt started with the PCT, who provided a phone number for the council social services. This team was unable to help, but gave a number for an adults and communities office – where the shopper was told they could not get assistance unless formally referred by social services.

RECOMMENDATIONS

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

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 centre should be responsible for gathering and disseminating information on all health, social care and voluntary sector services within the local area (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.

Artificial barriers to providing information about service availability should be removed.

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.

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

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.

Health and social care website standards need improvement.

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 – signposting again – especially those of voluntary sector groups.

Focus group of ethnic minority elders

Older people from ethnic minorities felt they had a very limited range of information sources:

“From your GP, your family doctor and if you live in sheltered housing, from the sheltered housing officer and as you say probably a close friend or family.”

This group did not use the internet and had little interest in newspapers. They wanted direct, personal contact:

“Face to face I would prefer that really because it is much better and phone messages can be sometimes one way or the other and then a letter you might not be able to understand exactly what you read.”

“Anything you don’t understand – you have the opportunity to question it and make sure you ask again until you get it right in your mind.”

Context: the value of information

Information is, increasingly, the currency of care. New directions in health and social care promise to put patients and service users at the centre of localised services – choosing and controlling personalised ‘packages’ of care, with help from their professionals.

Such choice, control and empowerment are not possible without reliable, accessible and relevant information about available services and support. This research found that patients, service users and their carers place a high value on such information.

The Department for Health (DH) is now focusing on information provision. In 2006 it commissioned a first study from the Picker Institute, ‘Assessing the Quality of Information...’. This found that:

- 80% of patients actively seek information about coping with health problems
- 75% cite their doctor as the most important source
- one third use the internet
- one quarter use leaflets and books
- around 60,000 organisations provide health and social care information
- the quality of their information varies widely
- few materials include a clear presentation of the likely outcomes of treatment, of clinical uncertainties, or of the patient’s decision-making role.

It concluded that a scheme to accredit the quality of information providers could raise standards.

The DH is actively working on such a scheme. It is also piloting ‘information prescriptions’: health professionals look at a patient’s information needs, and either provide information accordingly or refer them to an accredited information source.

But what this new report shows is that, although a doctor is usually the starting point, patients want more than immediate medical information. They want to know how to cope – and which support services, condition-specific services, and financial benefits can help them.

The voluntary sector is providing some of the services most sought by users. ‘Third Sector Mapping’ by IFF Research for the DH found 35,000 voluntary sector organisations active in health and social care. Most (62%) are in social care, and most are offering advice, counselling and education. But knowing about these services is a real challenge for health professionals, as for patients. Most are small, local (62%) and use volunteer workers.

Therefore if health professionals are to signpost people onwards, they will need information from other sectors – social care, the voluntary sector, other government agencies – and about services which may not be statutory, and could be very local and little-known.

Service users say this problem of ‘crossing boundaries’ is one of the most difficult:



Education thinks health should provide, health thinks it should be social services, and social services said ‘it’s education’ so you’re back on the same...

Parent of autistic child

Crossing boundaries, the report says, ‘frequently leads to a situation where no single organisation takes a lead responsibility and it becomes harder to find out about the full range of services on offer. People can find themselves being passed to and fro between agencies in their quest for information’.

The recommendations here are designed to address all these challenges, and are built upon suggestions from the research participants themselves.

Focus groups, mystery shoppers and information providers agreed on the need for better collaboration, improved signposting and the value of a central information point:



A high profile ‘one-stop-shop’ in each local area specifically to help local people access services and information.

Voluntary sector information specialist

About the Picker Institute

The Picker Institute works with patients, professionals and policy makers to promote understanding of the patient’s perspective at all levels of healthcare policy and practice.

It undertakes a unique combination of research, development and policy activities which together work to make patients’ views count.

It is an independent, not for profit research and development institute with charitable status.

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