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Patients and care service users left in limbo by failures to provide information

New research shows that patients and care service users are being left struggling to find information about services that could support them.

The Picker Institute, which conducted the research for the Department of Health, says patients with conditions such as MS and diabetes, or who have to care for elderly or disabled family members, are frequently abandoned 'at a crossroads in their lives, without any signposts'.

The Picker Institute is recommending to government that it pushes forward plans for local health and social care providers jointly to invest in a new service – information signposting and navigation. Based on the suggestions of patients, carers and information providers, it urges the establishment of a single contact point in each local area, with trained staff to help people navigate the information jungle.

The research is distinctive because it shows the **service user's eye-view** of the struggle to get information. It sent service users 'mystery shopping' to test pathways to information in the health, social care and voluntary sectors.

The Picker Institute's chief executive, Angela Coulter, who led the research, says:

"The potential service users were frequently pushed from person to person, or from organisation to organisation. They were often left dangling by calls that went unanswered. They encountered sheer brick walls.

"Some service users did have a good result, usually where they could find one individual ready to take responsibility for providing information across the range of services. But too often the services supposed to help people in real need throw them back on their own resources. Patients, service users and carers are left standing at a crossroads in their lives with no signposts to information about the kinds of support they say are vital."

The research report concludes that: *'to gain a reliable picture of all relevant services, one would have to invest considerable time, effort and ingenuity'*. This is unreasonably challenging for vulnerable people who may be newly diagnosed or taking on a caring role.

The Picker Institute notes that the research **under-reports** the service user's battle for information, because the research participants were experienced information searchers, and were articulate and assertive. First-time searchers and disadvantaged groups are likely to struggle even more, and may be deterred altogether before locating the support they need.

The report's key recommendations are based on what service users themselves say they need. They value face to face contact, so that questions and concerns can be raised; help with information navigation; and finding one person or organisation who has information about the full range of local services.

The Picker Institute is therefore calling for:

- Each local health and social services area to establish a central, easily identified information contact point, with trained staff skilled in understanding patients' needs, to act as a conduit to more specialised and personally relevant services
- This centre to be responsible for gathering and disseminating information on all health, social care and voluntary sector services within the local area
- A new cadre of local 'information brokers' to be created, to provide leadership and coordination across geographical and sectoral boundaries
- Health professionals and other front line staff to receive training to enable them to understand service users' information needs; how to access relevant information; and when to provide it

Research note:

Mystery shopping is a market research technique often used by customer-focused businesses such as retailers, to find out how their services are experienced by consumers. This is believed to be the first time it has been used in a major piece of health or social care research.

The 'shoppers' were people drawn from client groups -- such as parents of autistic children, older ethnic minority women caring for their husbands, and people with multiple sclerosis and diabetes. They were given assignments to telephone service providers, not in their home area, saying they were about to move there and needed information about health and social care services.

This mystery shopping exercise was in turn based upon focus group discussions where these care groups described their experiences of finding out about services. It was further validated by cross-checking with service users in the geographical areas being tested.

The research also tested online information searching for comparison, and surveyed 370 professional information providers in the health, social care and voluntary sectors.

Notes to editors:

1. The Picker Institute is an independent charity that works to make patients' views count at all levels of healthcare.
2. This is the second major research study on patients' information which the Department of Health has commissioned from the Picker Institute. The first, published in 2006, examined the **quality** of health and social care information and found that it varied widely, and that a scheme to accredit information providers would help to raise standards. The DH has been working to establish information accreditation since 2005. The DH is also piloting the idea of 'information prescriptions' for patients.
3. The DH will be providing a response to the report. The press officer is Anna Brosnan, 020 7210 4984
4. A 'Picker Primer' briefing document summarising the research is available with this news release.
5. The full research report, *Accessing information about health and social care services*, is available from the Picker Institute on request and will be published online at www.pickereurope.org

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