White Rose Research Online

eprints@whiterose.ac.uk
https://eprints.whiterose.ac.uk
Universities of Leeds, Sheffield and York

Deposited via The University of York.

White Rose Research Online URL for this paper:
https://eprints.whiterose.ac.uk/id/eprint/3706/

**Article:**
Baxter, K, Glendinning, C and Clarke, S (2008) Making informed choices in social care: the importance of accessible information. Health & social care in the community. pp. 197-207. ISSN: 1365-2524

https://doi.org/10.1111/j.1365-2524.2007.00742.x

**Reuse**
Items deposited in White Rose Research Online are protected by copyright, with all rights reserved unless indicated otherwise. They may be downloaded and/or printed for private study, or other acts as permitted by national copyright laws. The publisher or other rights holders may allow further reproduction and re-use of the full text version. This is indicated by the licence information on the White Rose Research Online record for the item.

**Takedown**
If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.

UNIVERSITY OF LEEDS
University of Sheffield
UNIVERSITY of York

# Making informed choices in social care: the importance of accessible information

**Authors**

Kate Baxter, PhD., Research Fellow, Social Policy Research Unit, University of York

Caroline Glendinning, MPhil, Professor of Social Policy, Social Policy Research Unit, University of York

Sue Clarke, BA, Research Assistant, Social Policy Research Unit, University of York

This article was published by Blackwell publishing in their journal *Health and Social Care in the Community* in 2008. The full reference is:

Baxter, K., Glendinning, C. and Clarke, S. (2008) Making informed choices in social care: the importance of accessible information, *Health and Social Care in the Community*, 16, 2, 197-207.

The definitive version is available at www.blackwell-synergy.com

http://www.blackwell-synergy.com/doi/abs/10.1111/j.1365-2524.2007.00742.x

White Rose Research Online :http://eprints.whiterose.ac.uk/3706/

**Corresponding author:**

Kate Baxter

Research Fellow

Social Policy Research Unit

University of York

Heslington

York

YO10 5DD

Email: kb515@york.ac.uk

Tel: 01904 321950

White Rose Consortium ePrints Repository :http://eprints.whiterose.ac.uk/3705/

**Abstract**

The current policy trend is to encourage greater choice in the use of welfare services. To make informed choices, people need information. The process of finding and using information has costs for individuals in terms of effort, time and material resources. These costs are different for different people and impact on their use of information in different ways. Thus the accessibility of information is important in ensuring those people who need to make choices can do so in an informed way. This paper discusses the importance of information in making informed choices about social support by drawing on the findings of a scoping review of government research and development activity on the accessibility of information about adult social care services. The scoping review was carried out in spring 2006. Details of recent, current and planned projects were obtained through discussions with staff in government departments, government agencies and other related organisations identified using a snowballing technique. Forty two contacts were made. Eleven research and 36 development projects were identified that aimed to investigate or improve the accessibility of information about social care services. A limited literature search was undertaken on information needs in areas not already under investigation by government. Eighteen articles were identified. Information and helpline staff from six voluntary organisations gave their views on the accessibility of information about social care services. Our findings show that there is no government-related or other recent research evidence on the specific information access needs for some user groups and services, for example people from ethnic minority

White Rose Consortium ePrints Repository :http://eprints.whiterose.ac.uk/3705/

groups. For other user groups, such as people with chaotic lifestyles, there is evidence on information needs but no current or planned development projects to address these needs. The implications for the costs of finding and processing information to aid informed choices are discussed.

**Keywords:** information, access, informed choice, social care

## Introduction

Increasingly, the general public and users of welfare services expect, and are expected, to play a greater role in decisions about the care and support they receive. In England, the government has presented a vision of social care where services help to maintain the independence of individuals through giving them greater choice and control over the way their needs are met (Department of Health 2005; 2006). In health care, patients are being given a choice of place and timing for some hospital treatments (Department of Health 2004). Choices in welfare services are not restricted to the UK, nor to younger people who might be expected to be more comfortable in the role of active consumers; many OECD countries, including Japan, the USA, Canada and Australia as well as European countries, have introduced more choice and flexibility for older people needing long term care (Lundsgaard 2005).

It is against this policy background that the Department of Health (DH) in England commissioned a scoping review to identify the range of government-sponsored or government-funded research and development projects focussing on the accessibility of information about adult social care services. The purpose of the review was to map work in progress as well as recently completed or planned work, and to identify any gaps in activity where new research might be needed. The review was unusual in that its main focus was on government or government-commissioned research and development activity, supplemented by a limited review of

the literature only in areas where there was no recent government research.

This paper draws on the findings of the scoping review to discuss the importance of accessible information in making informed choices about social support. The paper begins by considering the importance of information in making informed choices and examining how the costs of accessing information may result in its unequal use. This discussion draws on debates about choice in health, social care, housing and education, and is selected to be relevant in particular to individuals making decisions about social care. The methods and findings of the scoping review are then presented, followed by a discussion of the findings in the context of the importance of accessible information in aiding informed choice. The paper adds to the debate about increased personal choice in the welfare state by discussing how attempts to increase the availability of information are affected by the different costs to individuals of accessing information.

**Information for informed choices**

In order to make an informed choice, one needs to build up a picture of the available options and compare the advantages and disadvantages of each. It has long been recognised that not enough is known about what information people want or could reasonably use in making choices (Ovretveit 1996). Simply increasing people's opportunities to make choices is meaningless unless the options are accompanied by accessible

information (Corrigan 2005); exercising informed choice requires 'understandable, relevant and high-quality information' (Rosen *et al*. 2005, p. 18). Poor information has been shown to limit the effectiveness of competition and thus choice in UK health care (Propper *et al*. 2006) and, linked with the high costs of obtaining and processing information, has been shown to contribute to the low take-up of choice policies in western European health systems (Thomson & Dixon 2006). To be truly accessible, information needs to be both physically and cognitively accessible.

Whilst it is evident that information helps people to make informed choices, what is less apparent is who uses information and how. People are different, they have different information needs at different times and different formats of information are necessary to satisfy these individual needs (Worth *et al*. 2000). Information sources and formats should reflect this diversity.

Some argue that policies to encourage choice in health care can decrease inequity if properly designed (Dixon & Le Grand 2006); others claim that inequity may be exacerbated (Appleby *et al*. 2003). The accessibility of information is one important factor that can affect the uptake and outcomes of choice and thus unequal utilisation of available services. A lack of accessible information may mean that people are unaware of the choices available, or of the implications of those choices, and are hence not able to make an informed choice. Those people who have the most

cognitive and material resources use these assets to find relevant information to support informed choice and thus increase their inherent advantage (Corrigan 2005, Rogers & Mead 2004, Lent & Arend 2004). Information aimed primarily at trained professionals is especially difficult for lay people to understand (Gann & Needham 1992). The costs associated with finding and accessing information make it a challenge to ensure that people who are less able to access information are not disadvantaged, or at least to limit such effects. Information is not readily available without effort; there are costs associated with the time, energy and self-education required to find and use information (Lent & Arend 2004) and these costs will be different for different people. There are three strands to this cost argument.

First is a paradox. When it comes to finding information to help in decision-making, it helps to know what services are available, and what information is available about those services, before trying to find it (Ware *et al*. 2003, Gann & Needham 1992). People who have little information at the outset are likely to find the subsequent accumulation of information more time consuming and costly than those people who already possess relevant information. This information void and the cost of filling it may encourage people who lack resources and knowledge about how to find information to rely on habit rather than to search for new information. The decision to rely on habit or make a new choice is related to socio-economic status (Lindbladh & Lyttkens 2002). Although a decision based on habit may be satisfactory, it will not necessarily be the best. This

relationship between resources, habits and choices applies to all aspects of life, but in relation to finding and using information about social care services, the implication is that those people with a lower socio-economic status (often people who are most in need of social care and support) are more likely to use the information sources they have always used to inform their decisions. This could mean that they are inadvertently excluded from new sources of information. Thus existing inequalities may be increased unless the costs of finding information are decreased sufficiently to encourage those people relying on habit to change their habits.

The second strand of the cost argument is that, even for people with a high existing level of knowledge, or a high level of material or social capital, an exhaustive search of the information available in relation to any one choice would entail enormous costs and is therefore not achievable. A rational individual would work out how much information was necessary to make a sufficiently good quality decision and stop searching when that level of information acquisition was reached (Schwartz 2004). In economic terms, this would be where the marginal cost of collecting information equalled the marginal benefit from having that information (Elster 1986). However, as Elster further points out, when one stops collecting information, there is no way of knowing the value of additional information that is available but has not been collected. The current move in the UK towards promoting the use of 'expert patients' (Squire & Hill 2006) is one way of helping to overcoming this problem by assisting people in knowing both where to start and when to stop looking.

The third issue that relates to the costs of accessing information is bounded rationality. This is a term used to describe the limited human capacity to compute and process information. This capacity is different for different people, but the essential point in relation to using information to inform choice making is that there is little point in overloading oneself with information as one will not be able sensibly to make choices based on all of it. There comes a time when an individual has to make a decision on the information available so far rather than take the time to collect more information (Elster 1986). A challenge for information providers is to offer information in such a way that individuals are not faced with a 'mass of hard-to-understand' information (Appleby *et al*. 2003, p. 25) where the most appropriate cannot be found (or at least cannot be recognised when it is found) or where piecing together the different findings to create the bigger picture is not manageable. There is a balance to be made between reducing the costs of finding information to such an extent that more people find more information, and managing the costs of processing this additional information.

The quality of information is also important. People often use information from familiar sources, but these may not be the most accurate. There is evidence that anecdotal and informal sources of information such as friends' and families' experiences often weigh more heavily in people's decision-making than official, non-biased information based on more wide-ranging surveys (Schwartz 2004, Rosen *et al*. 2005). There is a danger that people will make choices based on information that is least costly to


White Rose Consortium ePrints Repository :http://eprints.whiterose.ac.uk/3705/

access and from trusted sources, but which is not necessarily the most accurate or reliable. Even information sources that people believe are reliable may not be so; Schwartz (2004, p. 55) quotes a recent study by the RAND Corporation about the quality of health-related websites: it finds that 'with rare exceptions, they're all doing an equally poor job', providing information that can be inaccurate and misleading. Importantly, Schwartz reports that surveys show these web sites influence the decisions of about 70 per cent of people who consult them.

This section has discussed some theoretical and empirical issues related to the costs associated with accessing information and the quality of information. The next sections report the methods and draw out the findings from the scoping exercise, highlighting those relevant to these issues.

**Methods for the scoping exercise**

The review was carried out between January and June 2006. The objectives were to: (1) identify government-funded or commissioned research and development work related to the accessibility of information about adult social care services that had recently been completed, was in progress or planned; (2) undertake a limited review of the research evidence about the accessibility of information in areas where there was no government research activity; and (3) identify any gaps where new research or development projects might be needed. We defined research projects as those aiming to investigate the information needs and

accessibility of information about social care services for users and/or carers. We defined development projects as those aiming to improve the accessibility of information about social care services.

To meet the first objective, the project advisory group, comprising people from the DH and the Office for Disability Issues (ODI), compiled a list of contacts known to be involved with or responsible for research and development projects. Face-to-face or telephone discussions were held with these contacts. Other staff in government departments were identified using a snowballing technique. This technique identified staff from other relevant organisations where discussions also took place. These included the Commission for Social Care Inspection, the Information Centre for Health and Social Care, the Disabled Living Foundation, Jenny Morris Consulting and Action for Blind People. In total, 42 contacts were made.

The purpose of the discussions was not only to identify areas of research and development activity, but also to elicit details of the projects. These details included the aims of projects; relevant findings of recently completed or current projects; scope; and timescale. For the scope of the projects, we were interested in which user groups and types of services were included, and the formats of and methods for disseminating information about these social care services. A written checklist of adult social care service user groups and types of services was used as a

prompt to encourage interviewees to think about a wide range of projects and other relevant contacts.

We compiled a short summary of the main aims, scope and findings of each project identified. These summaries were arranged by user group and by service type, with some projects falling into more than one category. These grouped summaries were used to identify gaps in government activity.

Gaps in both research and development activity on the accessibility of information were identified in the following areas: people with mental health problems; people with HIV/AIDS; people from black and minority ethnic (BME) groups; people with drug or alcohol problems; intermediate care; short breaks/respite care; and day centres/daytime activities. In another three areas, development projects were taking place but there was no government-funded research activity. These areas were people with sensory impairments, domiciliary care services, and equipment and assistive technology.

To meet the second objective, a limited scoping review (Arksey & O'Malley 2005) of the literature was carried out. The aim was to identify research in topic areas where the information needs of service users and/or the accessibility of information were not already being addressed by government-funded research projects, that is, the gaps identified above. The review was not a systematic review of all the available research


White Rose Consortium ePrints Repository :http://eprints.whiterose.ac.uk/3705/

evidence but a limited search of published and unpublished empirical studies relating to information on adult social care services in England, dating from 2000 to 2006.

Searches were conducted across three electronic bibliographic databases relevant to social care. These were ASSIA (Applied Social Sciences Index and Abstracts), Social Services Abstracts, and, for unpublished material and research in progress, Social Care Online. Search terms were developed from the checklists used in the discussions with government contacts. They related to information, social care services, and each of the ten knowledge gaps or topic areas.

Two of the authors read the abstracts of the papers to agree their relevance. Those considered potentially relevant were retrieved and further scrutinized to decide on inclusion in the scoping review. The search strategy generated 365 separate references. Of these, 44 were potentially relevant and 18 were included in the review. The reference lists of the selected papers were checked for any additional articles, but none was found.

Data about information needs of service users and the accessibility of information on social care services were extracted from the 18 selected papers. Most of the papers did not focus specifically on information about social care services, but referred briefly to information as part of a wider set of results. Other data, such as research methods or relevance of


White Rose Consortium ePrints Repository :http://eprints.whiterose.ac.uk/3705/

research questions, were not collected. No attempt was made to appraise the quality of the research papers. Publication in a peer reviewed journal was used as a measure of good quality.

In addition to the interviews with staff in government departments and the literature search, information or helpline managers from nine well known national voluntary sector organisations representing different service user groups were asked to take part in a telephone interview. Six interviews were undertaken. The purpose of the interviews was to elicit their perceptions of the kinds of information people want about social care services and how accessible it is and, in particular, any gaps in the information that is available.

To meet the third objective, the findings from the scoping exercise of government activity, the review of recent literature and discussions with voluntary organisations were considered together to identify areas where new research might be needed. Table 1 presents, by client group or type of service, the numbers of research projects and other evidence (in the form of published papers and voluntary organisations' staff views) and government development projects. Two types of gaps were identified: those where government or other research had identified information requirements but these were not being addressed by development projects; and those where there were not, nor had been, any research or development projects. The main themes that cut across these groups are

drawn out and presented in the following section, with examples from one or two projects to illustrate each theme.

[Insert Table 1]

## Findings from the scoping exercise

### *Sources of evidence*

There was a considerable body of activity across government departments, including many projects prompted by the Cabinet Office Strategy Unit (2005) report '*Improving the Life Chances of Disabled People*'. In total, we identified 47 recent, current or planned government-funded or commissioned projects that aim to investigate or improve the accessibility of information about social care services. Eleven are research projects. Thirty-six are development projects. We identified 18 articles that investigated, at least in part, the information needs and accessibility of information on social care services for adult users and carers. Four of these papers related to information about more than one topic area. Six voluntary organisations gave their views on the accessibility of information.

### *Research evidence and associated government development projects*

This section highlights the main information needs identified by government-related research projects, supplemented by findings from the literature and voluntary sector interviews where appropriate. It also shows how government development projects are aiming to address these identified needs in order to increase the accessibility of information.


White Rose Consortium ePrints Repository :http://eprints.whiterose.ac.uk/3705/

There are too many projects to describe each in detail in a paper of this length. Tables 2 and 3 give the project titles, dates and government departments for research and development projects respectively. More detailed information on specific projects can be found in the full report at www.york.ac.uk/inst/spru.

[Insert Tables 2 and 3]

The main themes identified from the project summaries were that information should be in an appropriate format; targeted at particular people at particular times; easy to locate; personalised; and of high quality. The importance and implications of these five themes for the costs of searching for information are considered in the discussion.

*Appropriate formats for information*

Evidence from a number of projects shows that people want information in appropriate formats, but that appropriate formats vary according to personal circumstances and timing. Examples include the different information needs of young people and older people; the fact that written information is not appropriate for everyone; and that different people's lifestyles affect their ability to access information. Three projects in particular highlighted these needs. The Commission for Social Care Inspection (CSCI) commissioned Information Sources project about different media to impart information about care homes found that, amongst other things, large type, easy to read styles and video formats


White Rose Consortium ePrints Repository :http://eprints.whiterose.ac.uk/3705/

were welcomed by all care users. The DH Patient Information Bank project explored accessible formats of information and highlighted the importance of providing information verbally for people who are visually impaired or whose literacy levels in English or other languages are poor. This project, and Department for Education and Skills (DfES) commissioned UK Online Centres research into support for the use of e-government services, showed the importance of support in using the internet to find information for people with visual impairments or people with chaotic lifestyles, such as drug users or prison leavers.

Many development projects are introducing information in a variety of formats, perhaps in response to these findings. For example, several Section 64 funded projects are introducing telephone helplines alongside internet services. (Section 64 grants are made to voluntary organisations in England whose activities support the Department of Health's policy priorities.) However, few development projects aim specifically to test innovative methods or evaluate their effectiveness. An exception is the Partnerships for Older People Project initiatives which are evaluating the effectiveness of using different formats of providing information to older people, for example the provision of information verbally by older people to other older people. In addition, the CSCI guide 'Social Care: Choosing the Right Care for You' is, like many other projects, being made available on paper and via CSCI's website, but is being made available in languages and formats for people who do not read English and its uptake in these different formats is being monitored.

*Targeted information*

Having appropriate and timely information is important to everyone no matter who they are or what the decision entails. With regard to social care services, having information that is targeted at particular groups of people at the time that they need it can be especially important. The Information Needs of Disabled People project undertaken by the ODI highlighted the need for information to be directed towards people at the time of certain life transitions such as the onset of impairment. For example, people who are about to be discharged from hospital require information about social care services at that time and appropriate to their needs at that time, but they are not always presented with that information. In addition, a published research paper highlighted the need for information to be targeted at groups of people who might otherwise be excluded from or reticent in asking for information (Joseph Rowntree Foundation 2005). The two groups of people mentioned specifically were older people, and carers from black and minority ethnic communities.

One government development project was identified that aims to take information to people rather than merely making it available. This is the Information Prescription project being undertaken by the DH. The aim is to develop the information equivalent to a medical prescription that health and social care professionals can use to provide relevant and timely information to people newly diagnosed with a long term condition or disability.

*Easy to find information*

Evidence from two research projects suggests that information is not always straightforward to locate. For example, one of the findings from the Customer Information Qualitative Research project commissioned by the Department of Work and Pensions (DWP) shows that although the current content of the disabilities section of the Directgov website is broad-ranging, providing information for people with different severities of impairment, this is not immediately apparent; at first sight, it appears to provide information more relevant to people with severe impairments, thus finding information relevant to people with less severe impairments can be difficult. The issue of 'signposting', that is, of directing people to appropriate sections of websites or other information sources, was highlighted also by CSCI's Information Sources research about the use of different media to provide information about care homes. A DWP Carers' Information Needs review also showed, among other things, that providing information about multiple issues in one place would be helpful. In addition to these findings, a recurring theme resulting from the discussions with the voluntary sector organisations was that people often did not know where to start looking for information.

Many government development projects are introducing or further developing single internet sources of information: 'one stop shops'. A number of development projects are aiming to improve the Directgov website. For example, the Department of Communities and Local Government (DCLG) is undertaking the Local Directgov programme to link

information from the Directgov website directly to the relevant pages of local authority websites. This will make finding local information easier for users who will need to learn to navigate the Directgov site only, rather than having to find information on that site and then having to find it again on their local authority site. The Elderly Accommodation Council is developing a web-based One Stop Shop for Care Home Advice. Many Section 64 funded projects are also introducing or further developing one stop shops. For example, Trent Dementia Services Centre is developing a web-based National Information Resource dedicated to providing advice on assistive technologies for people with dementia.

*Personalised information*

Users of information prefer it to be tailored to their own personal circumstances rather than it being a more generic mass of information through which one must navigate. This evidence comes from two DWP research projects mentioned previously: one is the review of carers' information needs and the other the evaluation of the disabilities section of the Directgov website. Both showed that people wanted information that was particular to their own needs. Evidence from the discussions with voluntary organisations and from a published paper (Beverley *et al*. 2004) also suggests that information should be provided in ways that recognise the heterogeneity of people's information needs.

A number of government development projects are addressing the issue of personalised information by developing information sources that are


White Rose Consortium ePrints Repository :http://eprints.whiterose.ac.uk/3705/

interactive and intelligent, allowing people to give personal information and in return be provided with personalised information. Examples include DCLG's online Directory of Supporting People Services which asks a series of questions related to housing support needs and then presents information about relevant local services, and the Disabled Living Foundation's web-based self-assessment questionnaire (SARA) that is used to provide personalised information about equipment to people with low level equipment needs.

*High quality information*

The importance of the quality of information, including its longevity, was highlighted. For example, the DWP project evaluating the disabilities section of the Directgov website showed that users of information need to be assured that the information is kept up to date and is provided by experts.

Government development projects to enhance the quality of information, including keeping it up-to-date, include a DCLG-supported E-citizen Fact Sheet project to encourage local authorities to provide social care information based on standardised templates and a planned DH Information Accreditation Scheme to recognise information providers by introducing a 'kitemarking' scheme. The latter will not only ensure that people have access to high quality information, but that they can see that it is high quality.

***What still needs to be done?***

The findings presented illustrate themes of general importance in relation to the accessibility of information by amalgamating some of the issues arising from government research about the accessibility of and measures to increase access to information, supplemented by recent literature and discussions with voluntary organisations. However, there remain some user groups and types of services for which there is little or no evidence on specific access needs. Box 1 lists the user groups and services about which no government-related research evidence was identified, nor any recent published or unpublished evidence from other sources.

**Box 1: Gaps in recent research evidence**

- people from BME groups
- people with HIV/AIDS
- short breaks/respite care
- day care/daytime activities
- equipment and assistive technologies.

A number of information needs were identified that are not being addressed by government-related development projects. This does not mean that they are not being addressed by other funding bodies or provider organisations. It does, however, highlight the need to take particular care in ensuring that these groups of people are not overlooked in the move to improve the accessibility of information for current and


White Rose Consortium ePrints Repository :http://eprints.whiterose.ac.uk/3705/

potential service users. Box 2 gives a summary of the service users identified as having specific access needs that are not being addressed currently by government development projects.

**Box 2: Gaps in government development projects**

- People from ethnic minority communities, especially older people and carers.
- Carers from rural communities.
- Young carers.
- People with multiple impairments.
- People with fluctuating support needs, such as disabled parents, before they reach crisis point.
- Prison leavers at the time of their release and other people with chaotic lifestyles.
- People with visual impairments.
- Private purchasers of social care services.

## Discussion

This paper has presented the findings of a scoping review about government-related activity to investigate or improve the accessibility of information about adult social care services. The findings have been summarised to show the types of access issues that need to be addressed; how these are currently being addressed; and where there are gaps in government activity.

The research on which this paper is based was designed to meet the specific needs of the Department of Health in England. As such, it focussed on government and government-related research and development projects that were being undertaken at a country-wide level or with country-wide significance. The specific findings of this empirical work in terms of gaps in government activity are applicable directly to England, but the information access needs of particular user groups that have been highlighted are likely to be more widely applicable. The issues of how information is searched for, the costs of doing so, and how these impact on equality in the utilisation of services are relevant to a far wider audience and add to the debate about increased personal choice in the welfare state.

Before discussing the relevance of the findings more widely, two issues related specifically to the government research and development projects identified are notable. First, it is striking that when government policy is encouraging people to make more choices in relation to welfare services and to take more responsibility for outcomes, a relatively small number (11) of the total projects identified (47) were research projects examining information needs or information accessibility. Without this evidence, appropriate development projects to improve accessibility of information for relevant groups cannot be initiated. Whilst government departments are not the only sources of research funding, they are a major source and the accessibility of information is a major policy issue. Second, not all development projects identified, particularly Section 64-funded projects,

included an evaluation element. If projects are not evaluated, there is no way of proving whether they have been effective in achieving their objectives and thus should be discontinued or expanded.

In considering the applicability of the findings of this scoping exercise more widely, as outlined in the introduction to this paper, one of the driving forces for improving the accessibility of information is to reduce the costs of accessing it.

The first issue to consider is the effect of making information more easily accessible on encouraging people to switch from basing choices on habits to basing them on new sources of information. Given that relying on habit is associated with socio-economic status (Lindbladh & Lyttkens 2002), it is likely that those who rely on habit are less able to access information via the internet, either through poorer skills or poorer access, than those people in higher socio-economic groups. Thus, increasing the amount of information available on the internet is not sufficient in itself to encourage people relying on habit to change their habits. We found a gap in government development projects to improve the accessibility of information for people with multiple impairments or chaotic lifestyles. These are likely to be the people for whom information searching is relatively difficult and thus costly. They may therefore be tempted to rely on habit as well. It is thus imperative that their information needs are identified and addressed to ensure existing inequalities in access to and

use of information do not increase as the use of the internet results in a reduction in the costs to others of finding information.

The internet-based ‘one stop shop’ is a specific example of how information may be provided on the internet. Notwithstanding the fact that some people are excluded, internet-based information services have the advantage that they can be updated quickly and efficiently; accessed at any time and from any computer; and can include large databases of information. They may be particularly useful to some of the groups listed in Box 2, for example, young carers or those from rural communities. There is, however, an important difference between information that can be obtained by those who take the time and make the effort to look for it, and information being easily accessible at little cost. People who rely on habit or who have limited means of searching for information may be excluded from new internet-based one stop shops unless efforts are made to target and support them directly.

This brings us to the second issue for discussion, improving the ability of people to find information that is relevant for them. Our findings show two main ways of increasing the chances of people finding relevant information: targeting information and personalised information systems.

With targeted information, people who would not otherwise have used information may do so. This could be helpful particularly for people with chaotic lifestyles. Targeting information could therefore have the dual


White Rose Consortium ePrints Repository :http://eprints.whiterose.ac.uk/3705/

benefit of increasing the likelihood of people with lower socio-economic status using new sources of information (by reducing access costs and therefore reliance on habit) and increasing the amount of information collected more generally (as more information can be collected for the same effort). At the same time, targeted information should ensure that people are not overloaded with information that is not relevant.

Personalised information also reduces search costs by overcoming the problem of finding and sifting through large amounts of potentially irrelevant information. Again, while making the process more manageable for everyone, those people less able or willing to search for and manage large amounts of information should benefit most, and thus information inequalities may be reduced further.

Third is the issue of bounded rationality. An increase in the amount of information provided by professionals or other 'information navigators' in face to face contact could lessen the effects of bounded rationality if these experts also support people in understanding and using the information to inform their decision making. Indeed, Patient Care Advisors were highly regarded by patients in the London Patient Choice Scheme for their role in guiding patients through the process, helping them to make a decision, and coordinating arrangements between the hospitals (Coulter *et al*. 2005). However, if information is provided without expert support to assess the options, the problem of having too much information to process could be increased. This could be the case especially if more targeted and timely

information results in more information being easily available, for example through schemes such as the information prescription.

The effects of providing personalised information with or without expert support to process it will be different for different people. Those people who usually search for and process a wide range of information themselves will find the total costs to them will decrease as someone else takes on the initial search and some of the processing costs. Even where no one is available to help with processing information, the reduction in the search costs will still mean a reduction in total costs. However, consider those people who rely usually on habit. If these people are provided with further information (at no cost to themselves) and an expert to discuss this information with them (at some time and effort costs to themselves), the total costs to them of making a decision will increase. Where no expert support is provided to talk through and understand the information, the increase in total costs will be even greater. There is, therefore, a balance to be reached; whilst it seems beneficial to reduce the costs of finding information, this should be balanced against the increased costs of processing this additional information. Despite, or perhaps because of, the potential for these increased costs, service users, their carers and staff do want independent systems of information brokerage and support in planning (Maglajlic *et al.* 2000) and there is evidence that those people with experience of using independent facilitators are satisfied with the support provided (Lord & Hutchison 2003). It is surprising in this context that a greater emphasis is not being placed in government-related


White Rose Consortium ePrints Repository :http://eprints.whiterose.ac.uk/3705/

development projects on the role that professional or non-professional experts and other information navigators can play in enhancing and managing people's use of social care information.

Finally, people want to be able easily to find up to date, high quality information. The introduction of schemes to accredit providers of information should go some way to ensuring the reliability of information sourced from certain websites. If signposted well, these accredited websites have the potential to become high quality, trusted sources of information that limit the amount of poor quality information that must be sifted out of a decision process. However, these sites must be well signposted. Accrediting websites is not in itself sufficient. Without reducing the costs of finding these sites through good signposting, there is a risk that the high quality information sites may be lost among the masses of non-accredited sites. People, particularly those less willing or able to access information, may therefore continue to rely on lower cost methods of acquiring information such as asking friends and family.

**Acknowledgements**

The research on which this paper is based was funded by the Department of Health. The views expressed here are those of the authors and not necessarily those of the funding body. We would like to thank the staff who made this research possible by sharing their knowledge on research and development projects or their experiences of accessing information. We also thank two anonymous reviewers for their helpful comments.

**References**

Andersen J. & Doyal L. (2004) Women from Africa living with HIV in London: a descriptive study. *AIDS Care* 16, 95-105.

Appleby J., Harrison A. & Devlin N. (2003) *What is the Real Cost of More Patient Choice?* Kings Fund, London.

Arksey H. & O'Malley L. (2005) Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology* 8, 19-32.

Beverley C.A., Bath P.A. & Booth A. (2004) Health information needs of visually impaired people: a systematic review of the literature. *Health and Social Care in the Community* 12, 1-24.

Corrigan P. (2005) *Registering Choice: How Primary Care Should Change to Meet Patient Needs.* The Social Market Foundation, London.

Coulter A., Le Maistre N. & Henderson L. (2005) *Patients' Experience of Choosing Where to Undergo Surgical Treatment: Evaluation of London Patient Choice Scheme.* Picker Institute, Oxford.

Department of Health (2004) *"Choose and Book" - Patients' Choice of Hospital and Booked Appointment. Policy Framework for Choice and Booking at the Point of Referral.* Department of Health Publications, London.

Department of Health (2005) *Independence, Well-being and Choice: Our Vision for the Future of Social Care for Adults in England.* Department of Health, London.

Department of Health (2006) *Our Health, Our Care, Our Say: A New Direction For Community Services.* Department of Health, London.

Dixon A. & Le Grand J. (2006) Is greater patient choice consistent with equity? The case of the English NHS. *Journal of Health Services Research and Policy* 11, 162-166.

Elster J. (Ed.) (1986) *Rational Choice.* Basil Blackwell, Oxford.

Gann B. & Needham G. (1992) *Promoting Choice. Consumer Health Information in the 1990s. Report of a Conference 28th - 30th September 1991 at Loughborough University.* Winchester, Consumer Health Information Consortium.

Joseph Rowntree Foundation (2005) *Implementing Direct Payments in Mental Health.* Joseph Rowntree Foundation, York.

Lent A. & Arend N. (2004) *Making Choices. How Can Choice Improve Local Public Services?* New Local Government Network, London.

Lindbladh E. & Lyttkens C.H. (2002) Habit versus choice: the process of decision-making in health-related behaviour. *Social Science & Medicine* 55, 451-465.

Lord J. & Hutchison, P. (2003) Individualised support and funding: building blocks for capacity building and inclusion. *Disability & Society* 18, 1, 71-86.

Lundsgaard J. (2005) *Consumer Direction and Choice in Long-Term Care for Older Persons, Including Payments for Informal Care: How Can it Help Improve Care Outcomes, Employment and Fiscal Sustainability?* OECD Health Working Papers No. 20, OECD Publishing. doi:10.1787/616882407515.

Maglajlic R., Brandon D. & Given D. (2000) Making Direct Payments a choice: a report on the research findings. *Disability & Society* 15, 1, 99-113.

Ovretveit J. (1996) Informed choice? Health service quality and outcome information for patients. *Health Policy* 37, 75-90.

Propper C., Wilson D. & Burgess S. (2006) Extending choice in English health care: the implications of the economic evidence. *Journal of Social Policy* 00035, 537-58.

Rogers A. & Mead N. (2004) More than technology and access: primary care patients' views on the use and non-use of health information in the Internet age. *Health and Social Care in the Community* 12, 102-110.

Rosen R., Curry N. & Florin D. (2005) *Public Views on Choices in Health and Health Care. A Qualitative Study.* King's Fund, London.

Schwartz B. (2004) *The Paradox of Choice. Why More is Less.* Harper Collins, New York.

Squire S. & Hill P. (2006) The expert patients programme. *Clinical Governance: An International Journal* 11, 17-21.

Thomson S. & Dixon A. (2006) Choices in health care: the European experience. *Journal of Health Services Research and Policy* 11, 167-71.

Ware T., Matosevic T., Hardy B., Knapp M., Kendall J. & Forder J. (2003) Commissioning care services for older people in England: the view from care managers, users and carers. *Ageing and Society* 23, 411-28.

Worth A., Tierney A.J. & Watson N.T. (2000) Discharged from hospital: should more responsibility for meeting patients' and carers' information needs now be shouldered in the community? *Health and Social Care in the Community* 8, 398-405.

**Table legends**

Table 1 Numbers of research projects, other evidence and development projects by client group and service type

Table 2 Research and investigation projects

Table 3 Development and implementation projects


White Rose Consortium ePrints Repository :http://eprints.whiterose.ac.uk/3705/

**Table 1 Numbers of research projects, other evidence and development projects by client group and service type**

| Client group or service type | Research and other evidence* | | | Number of government-related development projects* |
|---|---|---|---|---|
| | Number of government-related research projects | Number of published papers identified | Number of voluntary organisations interviewed | |
| Older people | 3 | n/a | 1 | 9 |
| People with long term conditions (all ages) | 1 | n/a | 1 | 2 |
| Physically disabled people | 4 | n/a | 0 | 3 |
| People with learning difficulties | 1 | n/a | 0 | 3 |
| People with mental health problems | 0 | 3 | 1 | 0 |
| People from BME groups | 0 | 1 | n/a | 0 |
| People with HIV/AIDS | 0 | 2 | 0 | 0 |
| People with drug or alcohol problems | 0 | 1 | 1 | 0 |
| People with sensory impairments | 1** | 4 | 1 | 2** |
| Carers & informal providers | 1 | 1*** | 1 | 1 |
| | | | | |
| Residential care | 1 | 1*** | n/a | 1 |
| Domiciliary care | 0 | 3 | n/a | 1 |
| Short breaks and respite care | 0 | 0 | n/a | 0 |
| Day centres & day time activities | 0 | 0 | n/a | 0 |
| Intermediate care | 0 | 2 | n/a | 0 |
| Equipment & assistive technology | 0 | 1 | n/a | 4 |
| Advice & information centres | 1 | n/a | n/a | 1 |
| | | | | |
| Others (not specified in advance) | | | | |
| - direct payments | 0 | n/a | n/a | 2 |
| - legal rights & entitlements | 0 | n/a | n/a | 2 |
| - disabled parents | 0 | 1 | n/a | 3 |
| - vulnerable people | 0 | n/a | n/a | 1 |
| Others (not group specific) | 3 | n/a | n/a | 11 |

* Some projects and papers are included in more than one category of client group or service type

** These projects were identified after the literature search

*** These articles were identified from literature searches in other client or service groups

n/a Published papers not search for in these categories and no voluntary organisations were approached for views

## Table 2 Research and investigation projects

| Project title | Dates | Department |
|---|---|---|
| Improving Services, Improving Lives. Evidence and key themes. A Social Exclusion Unit Interim Report | Published 2005 | DCLG |
| UK Online Centres. Supporting delivery of e-government services | Published 2005 | DfES |
| Evaluation of Individual Budget Pilots | Ongoing | DH |
| NSF for Long-term Conditions Information Strategy | Strategy published 2005 | DH |
| Patient Information Bank: Exploring Accessible Formats | Completed 2006 | DH |
| Quality of health information for patients and public | Completed 2006 | DH |
| Carers' Information Needs – A Review | Completed 2006 | DWP |
| Directgov Disabled People and Carers' Franchise - Customer Information Qualitative Research | Completed 2006 | DWP |
| Information Needs of Disabled People Project (Phase 1) | 2005 - 2006 | ODI |
| Information Sources Market Research | Completed 2005 | CSCI |
| Wider Option. Report of a research project into intensive support schemes for direct payments | Published 2005 | NCIL |
| Knowledge Review on Support for Disabled Parents | Ongoing | SCIE |


White Rose Consortium ePrints Repository: http://eprints.whiterose.ac.uk/3705/

## Table 3 Development and implementation projects

| Project title | Dates | Department |
|---|---|---|
| Directory of Supporting People Services | Ongoing | DCLG |
| E-citizen Fact Sheet Project (with Oldham Council) | Ongoing | DCLG |
| Local Directgov Programme - Connecting Local Authorities to Directgov | Ongoing | DCLG |
| Carer's Help Line | Planned | DH |
| Community Information Bank | To begin in 2006 | DH |
| Health Search Engine | Being planned | DH |
| Information Access Project – Providing information to people with neurological and other long-term conditions | 2004-2006 | DH |
| Information Accreditation Scheme | Implementation by end 2007 | DH |
| Information Prescription Project | Being planned | DH |
| National Library for Health for Specialist Libraries Information Support - Neurology | 2006-2008 | DH |
| One Stop Shop for Care Home Advice for Older People (funded by HSBC but overseen by DH) | 2006 | DH |
| Partnerships for Older People Projects | Ongoing | DH |
| Social Care Link | Proposed | DH |
| SWISH – Smarter Working in Social Care and Health | 2005-2006 | DH |
| Valuing People Support Team | Ongoing | DH |
| DIAL Raising Quality and Achieving Accreditation project - DIAL UK | 2002-2005 | DH (Section 64) |
| Disabled Parents Rights Handbook Project - Disabled Parents Network | 2001-2005 | DH (Section 64) |
| Health and Social Welfare Project (Community Care) - The Disability Law Service | 2002-2005 | DH (Section 64) |
| Website Information project - Disability Alliance | 2002-2005 | DH (Section 64) |
| Which Powered Wheelchair project - Research Institute for Consumer Affairs | 2003-2005 | DH (Section 64) |
| English Dementia Services Development Centre Web project - Dementia Voice | 2004-2006 | DH (Section 64) |
| Elders Project – RESPOND | 2005-2007 | DH (Section 64) |
| Epilepsy Information Network - National Society for Epilepsy | 2003-2006 | DH (Section 64) |

Continued overleaf


White Rose Consortium ePrints Repository: http://eprints.whiterose.ac.uk/3705/

| | | |
|---|---|---|
| Eye POD/National Eye Clinic Support project - Action for Blind People | 2006-2009 | DH (Section 64) |
| Health Information Project - Spinal Injuries Association | 2005-2008 | DH (Section 64) |
| House Adaptation Advisory Service project - Centre for Accessible Environments | 2003-2006 | DH (Section 64) |
| Localised Country-Wide Database Project - StartHere | 2004-2007 | DH (Section 64) |
| My Pregnancy, My Choices - Change | 2005-2007 | DH (Section 64) |
| National Information Resource of Assistive Technologies for People with Dementia - Trent Dementia Services Centre | 2005-2008 | DH (Section 64) |
| Technology Advisory Project - SENSE | 2005-2008 | DH (Section 64) |
| Understanding Community Care Charges - Disability Alliance | 2005-2006 | DH (Section 64) |
| Directgov website – over 50s section | Ongoing | DWP |
| Link Age Plus | To begin 2006 | DWP |
| Social Care: Choosing The Right Service For You | Published 2006 | CSCI |
| SARA self assessment tool (DLF, previously DH) | Ongoing | Disabled Living Foundation |