

Attitudes to Health Information and Public Involvement in Healthcare

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Ill health in Northern Ireland is well documented. On a number of important indicators the people of Northern Ireland are both sicker and less well served by health services than other regions of the UK. Understanding the way they obtain and use health related information may be helpful in overcoming this disadvantage.

Such health related information is now directly available from print and broadcast media and via the Internet alongside the traditional professional sources. It has been estimated (Brown, 2002) that at least 10,000 Internet sites purport to offer health related information. In 2001, more Americans accessed Internet health information every day than visited a doctor or other health professional (Pew Research Center, 2001). In the UK, the National Electronic Library for Health, as well as NHS Direct are designed to allow patients access to information, support and referral to services without encountering the traditional health information 'gatekeepers': GPs and hospital Accident and Emergency departments. Government policy documents regularly assert that this provision will help the NHS to cope with increasing need and demand for health care without increasing costs.

Greater and more accessible information is also viewed by the Government as a key part of the strategy towards 'user empowerment'



and the concept of user and public involvement is at the centre of health policy. In Britain, the National Health Service (NHS) Plan (Secretary of State for Health, 2000) has been followed by a flurry of activity including the development of a Commission for Patient and Public Involvement, Patient Advocacy and Liaison Services, Patients' Forums and a new Independent Complaints and Advocacy Service. To date there has been less progress in Northern Ireland although decisions about new health care structures will include proposals to develop 'consumer representation' (DHSSPS, 2002).

As NHS managers and providers respond to this policy direction, the 2001 Northern Ireland Life and Times Survey assessed how the public of Northern Ireland accessed information on health care, how much they knew about how health care is organised and the extent to which they wished to have a say in health policy.

Where do people access information?

Almost a third of respondents had spent time in the previous twelve months seeking out health related information. As might be expected older people and people with long term disability (or caring for someone with long term disability) were more likely to have done so. People with better educational qualifications were also more likely to have looked for health related information, but neither social class nor gender made a significant difference. As Table 1 shows, doctors and health professionals were by far the most popular source of information with 87% of respondents approaching them.

Table 1: Sources of health information

A doctor or other health professional	87%
The Internet	18%
Books	18%
Leaflets	15%
A friend or relative who is a health professional	12%
A pharmacist	11%
Someone who practices alternative medicine	10%
A support group	6%
Another friend or relative	5%
A telephone helpline	2%
Other	2%

Note: Respondents could identify more than one source and so responses add to more than 100

The next most used sources were books (18%), the Internet (18%) and leaflets (15%). Similar rankings were obtained when people who had not actually sought health related information in the last twelve months were asked where they would go if they found they needed to. Comparable figures for Internet use by Europeans and Americans are 32% and 43% respectively (Datamonitor, 2002).

Respondents who had used, or would use, the Internet to find health information were significantly more likely to be younger, better educated, in a non-manual occupation, and able to access the Internet at home. While gender did not make a significant difference, both the Datamonitor (2002) and the Pew Research Center (2001) studies suggest that women are more likely than men to use the Internet to seek health related information. They also note that women are particularly likely to seek out information on behalf of another family member. In England, use of NHS Direct (by telephone or Internet) reflects exclusion of older and disadvantaged groups and there is some evidence that women make more use of it than do men (O’Cathain et al, 2000).

Respondents were asked to imagine that their GP had told them that they might have a serious illness but that further tests would be needed. They were then asked whether they would seek out further information or would just rely on what they had heard from the doctor. Just over a third (36%) said they would seek more information.

These people were more likely to be young, better educated and in a non-manual occupation, and also more likely to be female. As Table 2

shows, the most popular source of information was the Internet (38%), closely followed by books (34%) - both sources being well ahead of health professionals.

Those respondents identifying the Internet were younger, better educated, in non-manual occupations, and had access to the Internet at home.

Internet information could be useful in two ways, firstly to back up or validate the information that has come from traditional sources, or secondly to help patients understand and come to terms with what their doctors tell them.

Table 2: Sources of information that might be used to seek additional information on a specific illness

The Internet	38%
Books	34%
A friend or relative who is a health professional	28%
A doctor or other health professional	27%
Leaflets	15%
Another friend or relative	10%
Someone who practices alternative medicine	10%
A support group	8%
A telephone helpline	7%
A Pharmacist	6%
Other	1%
Don't know	1%

Note: Respondents could identify more than one source and so responses add to more than 100

Doctor knows best?

The proportion of people identifying their doctor or another health professional as the best source of information and advice suggests that

the Northern Irish public continues to place considerable faith in the medical profession. In order to test this further, respondents were asked whose statement on BSE (or mad cow disease) they would have most confidence in - see Table 3.

If the number for hospital consultants and GPs are combined, two fifths of respondents (41%) said that they had most confidence in a health professional. Respondents aged over 65 years had slightly more confidence than those in other age groups in their own GP, and had significantly less confidence in scientists working for health research charities. People of ‘no religion’ were more likely than Catholics or Protestants to have greater confidence in the scientists. Across all groups people had least confidence in government officials, journalists working for newspapers and in TV reporters.

It might be expected that the well-publicised evidence of failure of clinical performance, such as the retention of organs, the death of children after heart surgery at Bristol Royal Infirmary and the murder of patients by Harold Shipman would have resulted in an erosion of trust in doctors. In fact, over half of all respondents (58%) strongly agreed or agreed with the statement that ‘there have been so many medical scandals that people just can’t trust doctors as much as they used to’. Only 2% strongly disagreed.

However, while people do appear to be concerned with medical scandals, the vast majority of respondents (89%) agreed or strongly agreed that doctors should be respected for the difficult job they do. In all, data emerging from this Life and Times Survey suggest that public trust in doctors remains intact.



Table 3: 'If each of these people made a statement about mad cow disease - BSE - who would you have most confidence in?'

Scientists working for health research charities	31%
A hospital consultant	21%
Your own GP	20%
A friend who was a health professional	7%
A Government official	5%
A journalist writing in a newspaper	3%
A TV reporter	3%
None of these	5%
Don't know	5%

What do people know about the organisation of health care?

Respondents appeared to have a low level of knowledge about the organisation and working of the NHS - see Table 4. Over half the respondents had heard of the Patients' Charter (53%), while the proportion who knew about their local Health and Social Services Councils (the watchdog bodies in Northern Ireland for health and personal social services) was dismally low (23%).

Table 4: Knowledge about the organisation of health care

Heard of the Patients' Charter	53%
Heard of your local Health and Social Services Council	23%
Heard of the NHS Direct website	18%

Thirty per cent of people did not know who to contact to make a serious complaint about their GP: the majority of respondents opted for the GP or the Practice manager. Twenty-six per cent did not know

who they would contact if they had concerns about having to wait at least 18 months for treatment.

However, as indicated in Table 5, there was strong agreement that people should have a say in health care decisions. Three quarters of respondents (76%) believed that it was essential that people living in an area should have a say if big changes to the health service were to be made. A further 20% believed this to be important.

Opinion was divided on whether 'nowadays the Government is better at involving the public in decisions about health care planning', with 37% agreeing or strongly agreeing that it was, and 40% disagreeing. However, over three quarters of respondents (78%) strongly agreed or agreed that 'nobody takes any notice of the views of local people when deciding to close hospitals'. This may not be surprising given recent and ongoing controversy about plans for acute health care in Northern Ireland. However, they are important findings at a time when decisions are being made about the future configuration of services and NHS structures here.

Table 5: Suppose there were to be big changes to the health service that might affect your own local service - for example, if there was a possibility that your local hospital might be closed. How important do you think it is that people living in the area have a say in decisions like this?

Essential	76%
Important	20%
Neither important nor unimportant	2%
Not important	1%
Not at all important	1%
Don't know	2%



Key Points

- Doctors and health professionals remain the most frequently used source of health related information in Northern Ireland.
- Eighteen per cent of people seeking health information in Northern Ireland use the Internet to find it - substantially less than in other European countries and USA.
- People who use the Internet for health related information are more likely to be from younger age groups, to be better educated, to be in non-manual occupations and to have Internet access at home, reflecting Northern Ireland's 'digital divide'.
- The Internet is the most popular source of health related information for people seeking a 'second opinion' or confirmation of something their doctor has told them.
- There is evidence of high levels of trust and confidence in the medical profession.
- People clearly have a desire to be involved in health care decisions which affect them.
- While responses were split on whether or not the Government is better nowadays at involving the public, the majority of respondents believe that no account is taken of local views in relation to the closure of hospitals.

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The research on which this update is based was supported with funding from The BUPA Foundation.

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The Northern Ireland Life and Times Survey is carried out annually and documents public opinion on a wide range of social issues. In 2001, 1800 adults were interviewed in their own home. Interviews were carried out by Research and Evaluation Services.

The Life and Times Survey is a joint project of the two Northern Ireland universities and aims to provide an independent source of information on what the public thinks about the social issues of the day. Check the web site for more information on the survey findings (www.ark.ac.uk/nilt) or call the survey directors at Queen's University (028 90 273034) with any queries.