SDO Project (08/1710/153)

Information for choice: what people need, prefer and use

Executive summary for the National Institute for Health Research Service Delivery and Organisation programme

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prepared by

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Executive Summary

Background

Choice is at the heart of all Government health policies but is meaningless without information. Information is pivotal to people's experience of choice and self-management. To make optimal choices with confidence and to build on their existing self-management strategies people need the right information, at the right time, with the right support to use it.

We already know that people want information but not necessarily for making choices and that people facing complex treatment choices often prefer decisions to be made on their behalf by a well-informed and trusted health professional.   SDO 08/1710/153 was commissioned to understand the *types of information* that people take account of when making choices, the f*ormat of information* that they prefer, and *whether preferences vary* systematically according to socio-economic status, ethnicity, gender and age.

Aims

The research aims were:

1. To examine the kinds of information that people need, prefer and use in relation to choice;

2. To investigate their response to, and use of, different types of information available in different formats; and

3. To investigate whether views, preferences and reported use of different types and formats of information vary systematically according to socio-economic status, ethnicity, gender and age.

About this study

The research was conducted in three iterative stages and focused on two types of information, 'general facts' and 'personal experience'. These were considered in the context of choices faced in up to five contrasting health issues which have different implications, are faced by people at different life stages and in different states of health.

We conducted: secondary qualitative analysis of 184 transcripts from narrative interviews conducted for www.healthtalkonline.org (stage 1); 12

focus group discussions and 9 individual interviews with a total of 62 people (stage 2); and a survey of 82 women making antenatal screening decisions, 104 carers of people with dementia, and 340 people with lymphoma (stage 3). In stages 1 and 2 we focused on five health issues (antenatal screening, ending a pregnancy for fetal abnormality, screening for sickle cell disorder or thalassaemia, caring for a person with dementia, and lymphoma) and in stage 3 on three (antenatal screening, caring for a person with dementia, and lymphoma).

Key findings and implications for policy, practice and research

Implications for policy

Findings from all 3 stages confirm previous research which shows variability in the ways and extent to which people: (a) expect and prefer to be involved in decisions about their health care; (b) think they are offered choices by health care providers; (c) have options that they consider meaningful; and (d) receive or obtain, use and value information in thinking about decisions. Information was, of course, seen as critical for choice and decision-making but stage 1 analysis showed that it was also valued in its own right.

Respondents in stages 2 and 3 of the research were able and willing to distinguish between 'general facts' and 'personal experiences' information and said that both are important for decision-making. However, respondents also spoke of the need to be careful and discriminating in their use of both 'general facts' and 'personal experiences' information; people generally expected that 'general facts' information should underpin health care decisions but said that 'personal experiences' information could add value in various ways and may have a unique role in some circumstances.

Implication 1: Taken together these findings lend support to policy initiatives to provide high quality information on health care and efforts to: enhance the accessibility of different types of information (both 'general facts' and 'personal experiences'); to improve signposting to high quality information sources, and to facilitate appraisal of information quality. They also suggest that more emphasis could be placed on the provision of well-collected, balanced, information based on personal experience than is currently apparent.

Throughout our study we found that carers of people with dementia perceived a dearth of information when they needed to make decisions about where their relative should live.

Implication 2: These findings reinforce the importance of improving the availability and accessibility of information on particular health

issues (such as dementia) or to support people facing particular types of decisions (such as where a relative should live).

Findings from the third stage of the study found, unsurprisingly, that the reported use and perceived value of both 'general facts' and 'personal experiences' information was higher among younger and more educated people. However, we also found surprisingly high levels of reported use of the internet for health information, even among older people facing difficult decisions (although internet 'chat rooms' were not rated highly as a source of information).

Implication 3: Taken together these findings suggest that current investment in internet-based information resources is well founded but that continued efforts to make this information accessible and relevant to all, regardless of social position, are justified.

The first and second stages of our study in particular highlighted the fact that people often need more than information about health care options and their implications to support them as they face decisions. Many people, particularly when faced with life-threatening illness, need help to interpret information, guide them through decisions, and provide emotional/moral support.

Implication 4: These findings suggest that policies and initiatives that emphasise the provision of information to support 'independent' choice-making by patients run the risk of overlooking the importance of supportive professional-patient interactions, and may lead to deterioration in decision quality and patient experience.

Implications for health professionals

Our findings indicate that people generally regard their health professionals as very important sources of information about health issues and think they should provide clear and honest information about their health care options. However, most people can and do also draw on information from other sources including the internet.

Implication 5: It is important for health professionals to be aware of and respond to the legitimate expectations that people have of health information providers but also to have opportunities to 'work with' patients to enhance their ability to make effective use of information from other sources.

Health professionals who have been encouraged to provide 'evidence based' information about health care options and their outcomes may not be aware of the potential value of 'personal experiences' information in relation to decision-making. Our study – especially stage 2 – highlighted the functions that information about personal experiences can serve in helping people to recognise that decisions are needed and need thinking about, identifying options, appraising options (including identifying and reflecting on potentially relevant values and reasons), evaluating and living with decisions, and coping with ongoing health issues.

Implication 6: In recommending sources of information health professionals may like to consider that 'personal experiences' information may be particularly helpful to people in identifying and appraising options (including imagining what it might be like to live with a decision) and coping with an on-going health problem.

However, the study also found that people say they are critical and selective in using information for decisions. For example, they are aware of potential bias in information provision, where the provider may have 'an agenda' or vested interest in encouraging selection of a particular option

Implication 7: This finding suggests that if health professionals do make recommendations to access information based on personal experience they should make it clear that they do not mean that particular individual stories should be used as exemplars to be copied.

As noted in the implications for policy, people facing complex and difficult health care decisions often have support needs that will not be met by information alone. The guidance and emotional support that can be derived from caring and facilitative interpersonal interactions with trusted health professionals remain important contributors to patients' decision-making experiences. This is probably particularly the case for people facing life-threatening illnesses (such as lymphoma), or emotionally difficult circumstances and decision situations for which the available information is complex and may seem contradictory (such as decisions about whether or not to end a pregnancy due to fetal abnormality, or where and how to ensure a relative with dementia is well cared for).

Implication 8: Information provision is important, but so are 'talking it through' and being a caring presence.

Finally, analysis of data from stage 1 and 3 showed considerable diversity in the extent to which people receive or obtain, use and value information in thinking about decisions; there was more variation in reported information use between health issues and decisions than in people's socio-demographic characteristics.

Implication 9: It is good to respond to individuals' own personal information needs which are more likely to be contingent on their health issues and the decisions they face rather than on their age, gender or socio-economic position.

Implications for research

We found that 'personal experiences' information had a number of valued uses in relation to decision-making. In the course of our investigation, it became increasingly apparent that 'personal experiences' information is highly diverse, and includes, for example, information about experiences of health conditions, of the processes and outcomes associated with different health care interventions, and of making and reflecting on health-related decisions.

Implication 10: Further research could usefully investigate the uses and values of 'personal experiences' and 'general facts' information in a more differentiated way.

We have shown that people are careful and critical in their use of information but the internet means that access to many different 'new' types of information is proliferating. Little is known about how people using some of the new forms of health information such as patient and user reviews, ratings and feedback (as in the type comparisons found on travel websites such as 'Trip Advisor' - http://www.tripadvisor.co.uk) to help in the evaluation of NHS services or health information exchanges on social networking sites.

Implication 11: Research on whether and how people use tools such as patient and user reviews, ratings and feedback to make comparisons and decisions about health and health care (compared to similar tools used in their leisure pursuits) could usefully guide policies on provision and quality ratings.

While internet 'chat rooms' were not a highly rated source of information for respondents in our studies, internet use was surprisingly high, even among older respondents. Social networking groups related to health continue to proliferate and are likely to be a potent source of personal experiences information. Again, little is understood about their use, value or impact.

Implication 12: Detailed understanding of how participation in social networking health groups might influence views, and the ways in which they operate on behaviours, would help guide future policies and recommendations.

Respondents talked of decisions taken over time and through interaction with varying information sources and social and professional contacts.

Implication 13: A prospective study of the dynamic of health-related decision making and the influence of different kinds of information on outcomes at different time points could help professionals target informational support.

Finally, the new Government is keen that the NHS and social care agencies makes the most of existing sources of information by signposting and recommendations rather than direct provision.

Implication 14: Evaluation of the range of approaches to revised quality rating systems so that the information can be trusted and is user friendly will be important.

Conclusions

The findings support continued investment in increasing access to high quality information on health care and the important role of health professionals in mediating that information. They also suggest that more emphasis could be placed on the provision of well-collected, balanced, information based on personal experience than is currently apparent.

Addendum:

This document is an output from a research project that was commissioned by the Service Delivery and Organisation (SDO) programme whilst it was managed by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO) at the London School of Hygiene & Tropical Medicine. The NIHR SDO programme is now managed by the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton.

Although NETSCC, SDO has managed the project and conducted the editorial review of this document, we had no involvement in the commissioning, and therefore may not be able to comment on the background of this document. Should you have any queries please contact sdo@southampton.ac.uk.