

Patients, Professionals and the Internet: Renegotiating the Healthcare Encounter

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

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Executive Summary

Background

The internet is frequently portrayed as the harbinger of fundamental change in the nature of healthcare consumption and delivery. The impact of the internet cannot, however, be considered in isolation from broader social change. Central to this has been the emergence of an embedded consumerist ethos. When coupled with a policy agenda where choice is central, the internet provides the mechanism by which patients can challenge health care providers. Yet there is a paucity of methodologically robust and socially contextualised evidence regarding patient use of the internet in acquiring health information, and how this shapes the consumption of health services. Particularly critical is the nature of the linkage between accessing information and changes in attitudes, behaviours and service usage.

Aims

The aim of this research was to examine how patient use of internet information impinges on the utilisation of healthcare services. The research had the following objectives:

- to quantify the extent, and patterns, of patients use of the internet as a health information resource and identify the factors leading to variations in behaviour.
- to identify the search strategies employed by patients in accessing internet health information internet and the evaluative approaches used in assessing information quality.
- to analyse the content and dynamics of virtual health communities and how participation in such communities is integrated into engagement with health services.
- to document the evolving nature of patient-professional interaction arising from patient access to health information and the subsequent format of the healthcare encounter.
- to assess the effect of changing patient access to information and changes in the healthcare encounter on patterns of patient decision making and health behaviours.

About this study

The research comprised four discrete but inter-connected studies employing a combination of quantitative and qualitative approaches. The four studies were:

- Longitudinal study: Patterns of patient-professional interaction.
- Short-term study: Prevalence of patient internet information usage.
- Short-term study: Patient information searching and evaluation.
- Short-term study: Dynamics of virtual communities.

To anchor the research in terms of information availability, patient vulnerability, treatment options and service structures, the research focused on four tracker conditions: breast and prostate cancer, diabetes and depression.

Key findings

Patient behaviours are changing as a result of independent access to specialist technical information and the lived experiences of other patients. However, it is apparent that assumptions of wholesale change in patient behaviour and challenging of health professionals are unduly simplistic. Accepting that current behaviours represent a generational shift, it would appear unrealistic to design service provision on the basis of emergence of an active citizen-consumer type patient. Neither will professional authority necessarily be eroded to the extent suggested by more radical proponents of informational empowerment. Anchored in such a perspective, three unifying themes emerge:

- *Increasing diversity in patient expectations and behaviours.* Rather than a common evolution towards a singular type of informationally empowered patient, the reality is a multiplicity of patient types anchored in multiple attitudinal and behavioural factors representing very different patterns of information utilisation and engagement with professionals.
- *Internet as an informational space confronts patients with challenges as well as opportunities.* Access to the internet as a health resource is a complex pathway, with the balancing of these countervailing tensions reflecting the particular circumstances of the patient and determines their ability to exploit the internet as a space of extended choice.

- *Structure of the consultation requires to be rethought to reflect the diversity of patient behaviours and expectations.* Not simply in terms of the evolving patterns of engagement in the consultation, but rather in terms of the place of the consultation in the context of patients' undertaking self-directed self-service activities in parallel with the core face-to-face consultation.

Conclusions

Reflecting these overarching findings two key areas for further research and service development can be identified.

- Key challenge facing health care professionals and organisations is to handle the increasing diversity of patient expectations and behaviours in respect of information acquisition and use. Critical that effective, and usable, analytical frameworks are developed to provide health care organisations at the strategic level, and health professionals at the operational level with the ability to identify patient informational and encounter preferences and thereby personalise service provision.
- The self-care agenda within the NHS, particularly in respect of chronic conditions, needs to take account of the self-initiated and self-directed activities of patients facilitated by the internet. Such activities represent a potential resource to support patients in coping with the lived experience of their condition. However, integrating such activities into the delivery of care will require that prevailing professionally determined approaches to self-care anchored in bio-medical frameworks are rethought.

Underpinning these two overarching areas are multiple specific issues that require to be confronted by the NHS in managing the opportunities and challenges arising from patient access to internet based informational resources.

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Addendum

This document was published by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO) research programme, managed by the London School of Hygiene and Tropical Medicine.

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