Resources review

Patient information services: a strategic partnership approach

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Background

With a commitment to build health-care services around the needs of patients, the NHS Plan¹ for England signalled a radical shift in health-care strategy. To meet growing public demand for health and health-care information and to empower patients to participate in decisions about their treatment and health-care options, NHS Trusts needed to adapt and develop services to embrace patient information as a sphere of activity. *Information for Health*² and *Building the Information Core*³ emphasized the need to develop skills, access and infrastructure for health and patient information but did not specify how this might be achieved. In the absence of national guidance, NHS Trusts embedded the patient information function variously within the emerging PALS service, staff libraries, communications departments or as a discrete patient information function. Increasing numbers of producers and providers of patient information are taking up membership of the Patient Information Forum (PiF),⁴ an independent forum established in 1997 under the King's Fund to share good practice in the production and dissemination of consumer health information.

The new focus on patient information (hereinafter the term 'patient information' should be read to include 'health information') for NHS organizations has also influenced patient and consumer health information services provided by Government, local government, Government-funded organizations, the voluntary sector and the commercial sector. An emphasis on patient safety and managing risk,⁵ including informed consent,⁶ has required patient information providers to attend very closely to the content, scope and presentation of information and to develop systems and processes for validating and providing information to patients and the public. Disability, human rights, race relations and equality legislation⁷ also impact on patient information. At the same time, Department of Health core and developmental standards, assessed by the Health care Commission,⁸ require NHS Trusts to report on their performance with regard to patient information.

Patient information service responsibilities include:

- Strategic and operational planning, management and operation of local patient information services.
- Supporting clinical governance.
- Selecting high quality external sources of patient information.
- Developing, validating, cataloguing, publishing (including web-publishing), reviewing and archiving in-house leaflets.
- Organizing information for retrieval.

- Providing information to patients and the public: through an information centre, telephone helpline and/or the internet; indirectly through health-care staff.
- Developing and implementing operational systems, processes and guidelines.
- Training clinical staff in skills relating to selection and development of patient information.
- Procuring products and services.
- Auditing organizational compliance with national standards, policies and clinical guidelines that specifically require information to be provided to patients.
- Partnership working within the organization to provide patient information as an integral part of health-care services.
- Networking with other information providers to share good practice.
- Managing and developing interpreting services.

Services, health literacy and self-reliance

Development of organizational patient information services, in response to the NHS Plan, coincided with the withdrawal in 2001 of health authority funding for local health information services. Funding was diverted to NHS Direct to deliver a national triage and information service for patients and the public.

*Better Information, Better Choices, Better Health*⁹ emphasized that patient information should be at the heart of health care, not provided through a separate service. *Better Information* launched initiatives including information prescriptions, power questions and a pilot Patient Information Bank, developed by NHS Direct New Media to provide NHS Trusts with a web-based core collection of patient leaflets on elective treatments. A national framework contract for supply of leaflets through an Information Service for Patients (ISP) is currently in development.

National strategy for health promotion, treatment and care has converged with a focus on maintaining and restoring good health and supporting patients to manage their own long-term conditions.^{10–12} Underpinning this shift in strategy, the *Wanless Report*¹³ highlights the need to

improve health literacy within the population. The rationale is that providing people with supported access to high quality patient information will help them to maintain good health, reduce the need for treatment and care interventions, choose between treatment options and maximize compliance with agreed necessary treatments. Indicators of a shift towards patients taking charge of their own preventive care and health maintenance include renaming the National Institute for Health and Clinical Excellence to include 'Health', and expansion of its role, and developing a National Library for Public Health within the existing National Library for Health.¹⁴

A strategic framework?

Health services and patient information providers receive no government guidance on where patient information services should sit within NHS organizations, how they should be led, structured and managed or what information architecture to use to support information processes and publication. Department of Health guidance focuses on the content and presentation of information¹⁵ rather than on information systems and architecture and how to deliver services.

Furthermore, the guidance requires NHS Trusts to provide patient information^{16,17} but does not specify that this should be in written (or alternative) format rather than verbal. Provision of written information to patients is mandatory only where specific clinical guidelines and policies require this. Many guidelines and policies have no such requirement. Yet national assessments^{18,19} of the performance of patient information services require Trusts to provide evidence of comprehensive patient information systems, processes and services including provision of validated written patient information leaflets. Assessment needs to confirm not only that information is available to patients but also that it is provided or signposted at the clinician/patient interface to support individual patient decisions and consent. A planned code of practice for health professionals communicating with patients²⁰ may provide a benchmark against which provision of patient information

can be audited. It would also enable skills development through the Agenda for Change *Knowledge and Skills Framework*.

In contrast to patient information services, NHS staff libraries have the benefit of strong links with Strategic Health Authorities and Workforce Development Corporations, operate within an NLH national framework²¹ (previously regional²²), and funding is linked to annual assessment. The Library and Knowledge Development Network (LKDN)²³ leads the strategic development and assessment of NHS staff libraries, whilst Strategic Health Authorities (SHAs) have commissioning and service management responsibilities, providing a supportive link between the Department of Health and local Trusts. Patient information services lack this framework and support, commonly having developed independently or having been set up *ad hoc* in response to the NHS Plan; anecdotal evidence suggests that they are poorly supported both strategically and financially.

Patient information services would benefit from strategic and financial links with LKDN, SHAs, workforce development confederations and Primary Care Trusts (PCT) to negotiate service specifications and a performance/funding link.

Patient-focused information services

Information needs

At the point of delivery, patients and the public need, and should have, access to the same knowledge resources that are available to health-care staff, through the provision of sign-posted web-based resources, printed information and alternative formats. Essential elements are national and local patient information leaflets, clinical guidelines and clinical evidence or knowledge summaries²⁴ based on systematic reviews. All of these resources should be fully referenced, with online links to full-text reference sources.

National Library for Health

The National Library for Health (NLH), steered by the National Knowledge Service, has

expanded its target user group to include patients and the public. The NLH Strategy for 2005–2008²⁵ aims to ‘...extend NHS library services to patients and the public for the first time’. The new NLH Single Search Engine (SSE)²⁶ cross-searches nationally held patient information, clinical knowledge summaries and guidelines and evidence from research (for example journal articles that may or may not have been critically appraised for the quality and rigour of the research that they describe). NLH Single Search follows the example of Knowledge4health (now to become a local layer of NLH), a patient information/library partnership initiative at North Bristol NHS Trust.^{27,28} Through this model, patients, the public and NHS staff can access information leaflets and explore topics in greater depth. NLH is developing a Map of Medicine, including a version for patients, to provide a common software platform for the delivery of health knowledge services.²⁹

The NLH draft National Service Framework³⁰ proposes library service standards for health-care professionals providing information resources to patients and the public, to complement services from NHS Direct. However, NLH and NHS Direct continue to develop information architecture and content largely in parallel rather than in partnership, suggesting a conceptual distinction between information for patients and information for health-care staff. Knowledge resources for staff and patients are not yet joined up.

Partnership initiatives

The NLH National Service Framework mentions a need for partnership working with ‘Patient Information Officers’, but does not acknowledge that, within some NHS Trusts, patient information managers have strategic responsibility for information and library management with regard to patient information.

Public libraries³¹ and NHS Direct have a commitment to work with local health-care providers to support the delivery of health and patient information to the public. At a local level

there are examples of partnership working between information sectors and providers. However, without a national steer and NHS infrastructure, partnership initiatives may remain localized or discontinue after the pilot phase.

Nationally and locally, consumer health/patient information services and staff/public library and information services are left wondering who is responsible for what. Who should lead the strategic development of patient information services and what should they be doing? Who should coordinate knowledge services for staff and patients? Defined boundaries of responsibility, and areas of overlap, will influence the activities of individual sectors and organizations, the use made of resources, the basis of any partnership working and, ultimately, impact on patient health choices and outcomes.

Service users

Audience

Patient information services and library and information services have different but overlapping target audiences. Health-care staff and students are at the same time members of the public and may also be patients. Patients and the public need information about their health and health-care options and the risks and benefits of each option; health-care staff and students need information to support their education, research, professional development and clinical practice. Individual patient preferences/values and information literacy are independent variables that influence the breadth and depth of knowledge to which patients and members of the public aspire. Based on their individual preferences and values, some patients want only basic health and health-care information; others want broader and/or more in-depth information.

Health literacy

Levels of health literacy vary within the population, including amongst those who want broader and/or more in-depth information than

is provided in many patient information leaflets. All patients should be offered timely written information that is relevant to the service they are accessing and to their condition and treatment and care options. Many patients will want to find out more.

To exploit health and health-care knowledge independently and effectively, both patients/the public and health-care staff need the following skills, or supported access through a person who has these skills:

- Online search skills.
- Knowledge of the range of available classes of information (knowledge summaries of clinical evidence/knowledge from practice, knowledge from research, guidelines, patient information).
- Critical appraisal skills.
- Information literacy.

Joined-up knowledge resources for all

One set of information and knowledge resources, appropriately organized and signposted, can meet the needs of all service users (see Fig. 1). An open access policy and a single web knowledge portal will remove the artificial distinction between 'information for patients' and 'information for professionals'. Restricted classes of information which might be configured as portal targets include individual patient health records, accessible by secure login authentication. People without internet access and/or skills will need mediated access or provision of resources in printed or alternative format.

The optimal web interface will support end users to locate the type, breadth and depth of knowledge appropriate to their information need.

Web-based resources can support effective partnership working across and within sectors. Sectors may cooperate to develop, select, host, link, provide navigation to and promote web-based resources, including alternative formats on demand. Sectors include NHS, commercial, voluntary sector and government, local government (public libraries) or government-related patient information services and staff libraries.

Knowledge mapping

Figure 1 Knowledge mapping.

The People's Network: *Discover*

The Museums Libraries and Archives Council (MLA) is hosting a new information service, incorporating *Discover*³² and *Enquire*,³³ as part of the public library *People's Network* in partnership with the ITforMe Consortium and Sheffield University Information Studies Department. *Discover* has benefited from a *Big Lottery Fund* grant and currently hosts three headings for health information, though as yet no resources.

Partnerships to support access for all

Web-based resources provide an opportunity for partnership working to streamline access to high quality health and patient information, including in-depth resources provided through NLH, information from NHS Direct and potential accredited information partners. Knowledge resources should include, through a 'local layer', locally developed NHS service, policy, condition and treatment information where none is available nationally or where local circumstances

require this. A partnership between MLA, NLH and NHS Direct Online could link NHS-accredited and hosted health knowledge resources through the *People's Network*.³⁴ Supported by trained public library staff, end users could request information through the public library service and potentially place requests through a People's Network e-journal contract (perhaps within an NHS/Higher Education/Public Library contract) for resources restricted by licence and not immediately available to the public. This initiative would link with current research at Aberystwyth into e-content procurement for Higher Education and the NHS.

Service alignment: a role for CILIP

Patient information services need to be strategically positioned to champion the needs of patients and the public. They also need to be aligned with staff and public libraries to provide staff users, patients and the public with access to the same comprehensive and high quality health information and knowledge resources. The Chartered Institute of Library and Information Professionals (CILIP) recognizes the diversity and value of the information services within which its members operate³⁵ and can advise on professional and service issues.

Developing a strategic framework

Practical steps towards positioning patient information at the centre of health care must begin with a realignment of services:

- Define required service outcomes for patients, the public and health-care staff: to take account of consumer expectations and needs, technical and practical opportunities and constraints and current Government policy and guidance including *Better Information, Better Choices, Better Health*.³⁶
- Develop a national health knowledge strategy, service models and guidance for delivery, taking into account:
 - What is the current scope of responsibility for information services?

- Amongst potential stakeholders, who develops, makes available or provides patient information nationally and locally?
- What are the specialist and professional knowledge and skills of staff and how are they mobilized?
- What will be their role and responsibilities within a new integrated health knowledge service?
- When should they operate independently?
- When and how should they operate in partnership with other services?
- What financial resources are available or could be mobilized, and from what source?
- What impact will the new service model have on other services/projects and on overall patient and public health outcomes (cost/benefit analysis)?
- What changes to organizational and management structure will be needed to accommodate the new service model?
- How and by whom will service standards (within clinical practice and knowledge services) be set and assessed?

Delivery: a plan for national action

Strategic

- Initiate discussions between key stakeholders to develop a national health knowledge strategy which will clarify direction, roles and responsibilities for workplace health libraries (including NHS staff library and information services), public libraries, patient information services, and for individual health-care staff. A working party could include representation from: Department of Health, Patient Information forum, Patients Association, CILIP, British Medical Association, Royal College of Nursing, National Knowledge Service, Library and Knowledge Development Network and Museums, Libraries and Archives Council.
- Propose Department of Health guidance for national and local patient information services. This should include partnership responsibilities; development of information

architecture, systems, processes and search functionality (including use of meta-data, classification schemes and subject indexing to enhance information retrieval) and mechanisms to enable web-publishing of local Trust patient information catalogues and full-text leaflets.

- Approach SHA knowledge leads through LKDN to agree a service specification and influence service development and funding for NHS patient and health information services for the public.
- Work with Department of Health and NICE to ensure that patient information outcomes link with key targets and specific funding.
- Seek clarification from NLH and NHS Direct Online, in liaison with the National Knowledge Service, on development of joined up and comprehensive information services for patients and the public, including marketing to staff, patients and the public through a single NHS knowledge portal. Search functionality could be improved by adding the NHS Direct Online patient-friendly subject terms to the clinician-focused National Library of Medicine *MeSH* subject headings within NLH Single Search.
- Seek NHS Direct Online and NLH support for the proposed Department of Health information provider accreditation scheme in identifying key national and local patient information resource providers including validated voluntary and commercial sector providers for inclusion as national and local target resources for a Department of Health/NLH/NHS Direct Online portal partnership. This would complement the NHS Direct New Media *Information Service for Patients*. The portal should provide patient, public and staff access to local patient information catalogues through an NHS knowledge portal. This workstream would include development and supply to NHS, commercial and voluntary sector health information services of ready to use databases to support patient information approval, cataloguing, publication and review processes.
- Develop a link between the NHS Care Record Service, Choose and Book and a single NHS health knowledge portal to enable patients to access a single portal to search their own health record, national and local condition and treatment information, clinical knowledge summaries and guidelines, as well as information about hospitals, consultant specialisms and waiting times.

Professional standards

- Use CILIP online membership directory, identify members working in patient information, staff and public library services to:
 - (i) recruit PiF members from all health information and library sectors
 - (ii) seek practical support to promote strategic and operational partnership working.
- Create reciprocal links between the CILIP and PiF websites.
- Develop relevant CILIP-accredited degree courses.
- Coordinating a register of interest and encourage qualified and experienced PiF members to offer relevant teaching sessions on CILIP-accredited degree programmes and other patient information related courses.
- Seek to comment on the proposed Department of Health Code of Practice and training programme for clinicians communicating with patients and set a Knowledge and Skills benchmark.
- Consult with CILIP on an accreditation scheme for patient information services.

Partnerships

- Contact the Museums, Libraries and Archives Council to:
- Facilitate access to an NHS accredited health knowledge portal (currently NLH and NHS Direct Online) through the People's Network *Discovery* service, to include validated local health knowledge resources and patient information.

- Develop a health specialist post within every public library area team. PiF Regional Coordinators could be matched to their local library authority to provide induction training to the health specialist public librarians and to develop resources and events in local libraries and other locations. Alternatively, patient information professionals could be seconded to these posts for 1 day per week. The initiative may qualify for a New Opportunities Fund (NOF) *Advice Plus* or *Well-being* grant.³⁷ A first step will be to meet with MLA with a view to producing a project plan and a joint NHS/MLA application for NOF funding.
- Develop the Information Prescription model in partnership with the People's Network *Discover* and *Enquire* services and through public libraries.
- Approach the Joint Information Services Council (JISC), Department of Health and Museums, Libraries and Archives Council to discuss the feasibility of including public libraries in the proposed NHS-HE e-content procurement. This will enable patients and the public to access licensed e-content through the public libraries *Discover* portal, the *Enquire* service or through public library staff.

Implementation

The first step towards supporting the health information needs of patients and the public is to involve key stakeholders in a radical reappraisal of required outcomes and a cross-sector review of national health information strategy. This will include mapping available resources – including skills and knowledge – mobilizing additional resources and developing an information strategy, implementation plan and guidance to partner organizations. Successful cross-sector partnership working can only be possible if the roles and responsibilities of key stakeholders are clearly defined, understood and agreed, and dynamic leadership and financial resources are put in place to support implementation.

Working through the Patient Information Forum, a version of this paper has been submitted to the Department of Health Information Taskforce with the aim of stimulating discussion and debate and identifying national leadership and resources to drive forward this strategic review and implementation.

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