



Royal College
of Nursing

Personal health records and information management

Helping patients, clients and
their parents / carers to make
the most of health information

Policy Briefing

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Royal College of Nursing
Policy & International Department
20 Cavendish Square
London
W1G 0RN

Telephone: 020 7647 3723
Fax: 020 7647 3498
Email: policycontacts@rcn.org.uk



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Introduction

Nursing is concerned with empowering people and helping them to achieve, maintain or recover independence (RCN 2007). Assisting patients and those who support them to obtain, understand and use information is a core element of person-centred nursing care. With good quality information, people are more able to understand their health situation, make decisions about their care and treatment and manage their own health. Governments have at last recognised that empowering people to play a greater and more active role in their health and self-care is 'critical to quality improvement and healthcare cost containment strategies' (Pagliari et al 2007a).

Information and communication technologies (ICT) such as the internet and mobile phones have transformed society and are rapidly changing all aspects of health care. People who manage their lives using information systems either mobile or wired are helping to drive the IT revolution in health care. They research their health condition on line, communicate with their consultant by email, access their electronic GP records, update their monitoring and test results and get help and support from peers.

So far, the number of people who actively manage their own health information in these ways is small. Lack of patient-centred systems, complex security arrangements, staff skills and knowledge and a lack of national standards are some of the barriers to wider patient control and use of health records and information.

The RCN believes that all people, including children and young people, should be supported to control and manage their own health information according to their preferences and needs.

This document summarises the RCN vision for personal health information management, how ICT can support this vision and what needs to be done to overcome barriers to achieve the changes required. It is intended to inform all aspects of records development, record standards development and nursing educational programmes. A glossary of terms is provided on page 9.

Person-centred requirements for health information¹

These requirements (from Goossen et al 2009) are framed in the first person to exemplify a person-centred approach.

If I am to manage my health, well-being or illness (and I wish to do), I should be able to:

¹ These requirements were developed at an international workshop following the 2009 Nursing Informatics conference - *Personal Health Information Management – Tools and Strategies for Citizens' Engagement*. The full report of the workshop can be downloaded at <http://www.uku.fi/vaitokset/2009/isbn978-951-27-1321-9.pdf>

- a) access and download health information from trusted sources;
- b) use information to make decisions about which services to access;
- c) access and download my health information that is held securely by providers and others;
- d) organise and manage my health information so it supports me to be proactive in managing my health / illness;
- e) manage a health related diary / schedule;
- f) maintain a personal health record;
- g) control access to and use of my health information (based on secure identity management);
- h) gather, view and make sense of data about my health status;
- i) send data to provider or other about my health status, treatment variance etc;
- j) communicate with providers and others, for example, to ask questions or request appointments;
- k) receive reminders, prompts, alerts and advice through a medium that I choose – including personalised health decision support.

Systems supporting people to manage their health

In 2003, Connecting for Health (Markel Foundation) defined the personal health record as:

...an electronic application through which individuals can access, manage, and share their (health) information, and that of others for whom they are authorized, in a private, secure, and confidential environment.

The phrases in this definition were used by Brennan (2009) to describe personal health information management systems (PHIMS) that could meet the person-centred requirements listed above.

Table 1: Personal health information management systems (Brennan 2009)

<i>...electronic application</i>	These computer tools can be accessed through a web-browser or some other computer system, but are also available on cell phone platforms, embedded within devices, or integrated with other emerging technologies. Ideally, PHIMS reside in a networked environment allowing seamless access to, and sharing of, personal data and health information through linked applications.
<i>...through which individuals</i>	PHIMS are designed for use by lay people, not health professionals, and therefore may share features with other consumer electronics, such as simple interfaces, ubiquity (accessible everywhere), and durability
<i>...access, manage and share their health information</i>	PHIMS enable individuals to acquire, read, or send health data. They support a wide range of information management services, including: <ul style="list-style-type: none"> • mechanisms to acquire health information from clinical records held by health providers; • databases for storage of health data on a local computer or in

	<p>some public repository;</p> <ul style="list-style-type: none"> • electronic communication of personal health information to other parties such as family caregivers or clinicians. <p>'Next generation' PHIMS not only display relevant data but use innovative data integration and visualization approaches to provide meaningful, interpretation of the data, launch clinical alerts or make health behaviour recommendations. A significant challenge in personal health information management at the present time is the lack of common data and terminology standards that preclude integrating data from many sources into a single display.</p>
<i>...and that of others for whom they are authorized</i>	<p>PHIMS reflect and support real personal health information management behaviours. In many family situations, one member handles the health information for another, such as an adult child for a parent. Such sharing of health data has long been an informal practice, however, introducing an electronic tool to support such common family behaviours may make these arrangements more formal.</p>
<i>...in a private, secure, and confidential environment</i>	<p>PHIMS must provide a level of privacy and security that matches that desired by the individual about whom the information refers. Some people may prefer to keep all information strictly private; others may wish to share information with family caregivers, health professionals or emergency response workers. A hallmark of PHIMS is that the privacy management is under the user's control, and needs to be technically implemented in a way that is easily managed by lay people (Simons et al, cited in Brennan 2009).</p>

Benefits of people managing their health information

The idea of people managing their own health information is not new. Most people have paper-based systems such as loose-leaf binders or shoe boxes for keeping copies of letters, reports, immunisations and health histories in one place (Detmer et al 2008). Evidence from the many years of parent-held child health records, woman-held maternity records and patient-held records for people with cancer / chronic illness shared care records demonstrate the benefits of people sharing and controlling health information (Gysels et al 2007, NHS Quality Improvement Scotland 2006; Walton and Bedford 2007) They are recommended by consumer groups such as Diabetes UK www.diabetes.org.uk/About_us/Our_Views/Care_recommendations/ and the Patient Information Forum www.pifonline.org.uk/themes/pif-publications.

Today's technology allows us to move beyond simply holding records towards active information management, the goal of which is to ensure that relevant information is in the hands of those who need it, at the time they need it, and in a format that they can understand and use. There is growing evidence of the benefits of personal health information systems in three main areas (Tang et al 2006, Pagliari et al 2007b, Gaunt 2009), as below.

1. Improved access to personal data and health information

- Supports shared and more informed decision making between people and their clinicians.
- Improves people's confidence in self care by confirming advice given by clinicians
- Improves trust between person and clinician, enhancing the quality of care and communication.
- Reduces consultation time and therefore time waiting to be seen.
- Influences lifestyle improvements supporting improved health outcomes.
- Supports accurate record keeping improving patient safety.

2. Improved access to services for patients

- Reduces the need to attend healthcare premises to obtain prescriptions.
- Improves access to appointments at times convenient for people.
- Supports new ways of delivering services e.g. health assessments in accessible locations.
- Improves awareness of the services available to help people manage health problems.

3. Interactive communication

- Improves access to personal health advice with named clinician e.g. through email.
- Enables the delivery of personalised health recommendations and educational communication.
- Provides access to virtual self help groups and support.
- Supports self monitoring of long term conditions.
- Improves continuity of care through having a point of record integration

Overcoming barriers

Professional factors

Some people already manage their health information and actively direct or participate in treatment and care decisions. Others who might wish to do so have to first overcome a number of barriers including the knowledge, skills and attitudes of professionals – very few services have followed the example of the Haughton Thornely Medical Centres (www.htmc.co.uk/) where patients can access their primary care record, make appointments, order repeat prescriptions, find health information and use decision support tools. According to Hannan (2010) on-line access to GP records for patients and other information sharing must be based on a 'partnership of trust'.

Most provider organisations allow rather than encourage patients to access their health records and related information, although initiatives such as widespread copying of outpatient letters are beginning to make a difference (Treacy et al 2008, Lepping et al 2010). Nurses and other providers may feel uncomfortable with the required changes in the traditional provider-patient roles (Pagliari et al 2007b). Other concerns include patients overusing or abusing record access or email contact with clinicians and increased responsibilities and workload (Detmer et al 2008). Perceived

and real concerns about security and confidentiality are a further barrier, particularly in relation to vulnerable groups such as children and young people.

Equity and usability: ‘the digital divide’

The gap between those with and those without the ability to access and effectively use information technology is another significant barrier to personal health information management (Detmer et al 2008, Patel et al 2011) The potential for inequity also exists for those who choose not to actively engage in their own health management or participate in using IT. National health delivery and IT strategies are heavily focused on participation and self care. Equality and diversity assessment needs to be part of national and local planning for IT innovation with alternative strategies put in place to ensure that people are not disadvantaged. People may need to be offered education or support to access information technology, together with support to determine what information is relevant and how they might use it to take action to manage or improve their health. Research is needed to develop and validate assessment tools and outcome measures related to the use of technology that take account of those who are unable or choose not to use it.

Even when the technology is available, it may not be useful or useable: an evaluation of one national initiative identifies the need for personal electronic health records to align with people's attitudes, their self management practices and information needs, and with the wider care package, including organisational routines (Greenhalgh et al 2010).

Preventing unintended consequences

As Strachan et al (2009) identified, changes to the way information is managed can introduce unintended consequences but if these are anticipated, they can be managed to ensure that any risks are outweighed by benefits. Unintended consequences of people managing their own health information include:

- Information overload as a consequence of increased information availability.
- Misinterpreting information creating anxiety or confusion, or misleading patients.
- Increased responsibility for people, and expectations from providers.
- Concerns over accuracy of information entered by the people.
- Increased risk of litigation against providers.
- Security and confidentiality concerns, including access by family members.
- Changes in relationships between people and their clinicians.
- Changes in provider to provider communication.
- Increase in clinical workload.

(Pagliari et al 2007b, Gaunt 2009, Strachan et al 2009).

Public engagement, along with equity and diversity impact assessment and privacy impact assessment are required to support the design of systems that benefit people and reduce the risk of undesirable unintended consequences.

Creating the right environment

Changes that are needed to support more people to manage their own health information include:

- **Changes to health service finance models** Innovative projects do not get picked up partly because change is challenging in general but more importantly because NHS funding models do not yet encourage use of ICT to reduce costs and improve patient experiences. This is beginning to change as the benefits are demonstrated, for example, home monitoring for elderly and chronically ill people. However, resources may need to be transferred from acute to community services if these kinds of innovations are to spread.
- **Adoption of standards** –including: technical standards for consumer health IT (Goossen et al 2009); information governance standards such as authentication and access controls; and professional standards for integrating consumer health IT into nursing practice. Lessons learnt from research and from pilot projects need to be converted into standards, guidance and quality measures so that further improvements can be made. There is an urgent need to develop audit tools that address the safety and equality aspects of personal health information management.
- **Improved leadership** - Strong policy advocates and clinical leaders are needed to guide a flexible and regularly reviewed eHealth Strategy and to support change management (Strachan et al 2009). Joint messages from service leads, clinical leaders and professional organisations can help to reduce organisational barriers as well as changing attitudes and practices of professionals.
- **New competences** - Nurses and other clinicians may need to develop new skills and adopt new working practices to support changes in relationships with patients and the public. Clinicians also need to consider how they present information in the person's record to ensure it is in understandable language. The role of the nurse in helping people access, understand and use health information has already been recognised (RCN 2010). Other skills that are required include competence in assessing the preferences and needs of individuals related to using IT in health care and in monitoring outcomes related to people who manage their own health information. Professional nursing competences include using up to date information and communication technologies (NMC 2010) but more emphasis is necessary in nursing education curricula on working with people to manage their own health information, including using ICT.

Quality improvement and cost containment seem to be the main political drivers for widespread adoption of ICT to support people's active engagement in health care. Reducing costs is a desirable goal, but nurses need to work with patients, clients and parents'/carers to help ensure that the use of ICT remains consistent with people's own health goals and contributes to quality outcomes.

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Appendix 1: Glossary of Terms

Term	Acronym	Definition
Carer		Person who spends a significant proportion of their time providing unpaid support to a relative, partner or friend (HM Government 2008). Also referred to as 'informal carer' or 'caregiver'
Information Technology (also referred to as Information and Communication Technology)	IT ICT	Hardware (computers, personal digital assistants, mobile phones and other devices) and the software (the information systems) that enable information to be manipulated and transmitted from one place to another (RCN 2010)
eHealth		All uses of information and communication technology (ICT) in health and health care. - for example, telemedicine, telehealth, telecare, decision support systems, electronic patient records (RCN 2010)
Person / people		All recipients of health and social care services in all settings i.e. including children, young people, those with learning difficulties, resident in care homes etc.
Personal health record	PHR	A PHR of an individual is a representation of information regarding, or relevant to, the health, including wellness, development and welfare of that individual, which may be stand-alone or may integrate health information from multiple sources, and for which the individual, or the representative to whom the individual delegated his or her rights, manages and controls the PHR content and grants permissions for access by, and/or sharing with, other parties (International Standards Organization 2012)