

Innovation in health informatics: much is underpinned by eHealth and better information for patients

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ABSTRACT

Health informatics is a relatively young discipline, bringing together professionals with a range of backgrounds, including management professionals, computer specialists and health care professionals. A lot of focus has been on developing systems such as medical records and information sharing, and it also has the potential to span the boundaries between health care professionals and patients. This is especially true for people living with a long-term condition.

Keywords: consumer health informatics, eHealth, participatory health care

INNOVATIONS IN HEALTH INFORMATICS SHOULD CONNECT WITH PATIENTS

Health informatics is a concept whose time has finally come. Alongside considerable long-term investment in health information technology (IT), there has been a parallel growth in eHealth, especially the use of information by patients. Whilst the history of IT in the UK National Health Service (NHS) is chequered to say the least, the underpinning aims and intentions and repeated introduction of innovative technologies have been consistent since at least the start of this millennium, although they have possibly lacked sufficient patient focus.

SUCCESSIVE WAVES OF INFORMATION TECHNOLOGY INTRODUCTION

Information for health¹ – the strategy that took us into the new millennium was published just two years before the end of the last century and had dual aims of providing health care professionals with the technology and the information necessary to support their work and ensuring that patients had the information they needed to participate in their care:

Information technology can undoubtedly improve NHS professionals' use of information in day-to-day patient care. There must be an equally strong focus, however, on the practical use of information and technology to provide direct benefits to patients in their use of NHS services (p14)

The strategy also aims to ensure that patients, carers and the public have the information necessary to make decisions about their own treatment and care (p9).

Significantly, the strategy document talked about information rather than information technology.

Slow progress on implementing information for health was followed four years later by the launch of the national strategic programme [National Programme for Information Technology (NPfIT)],² which focused more on the technology, aiming to centralize:

specification procurement ..resource management.. performance management and delivery of the information and IT agenda.

Any success was limited, and the programme quickly became unpopular, beset with problems,^{3–5} and ultimately failed with one report concluding that 98% of the benefit anticipated at the launch had not been realised when the programme closed.⁶

As the focus of NPfIT turned to the infrastructure, the importance given to how information and technology benefited patients and care had a lower profile than system developments. Alongside IT policies, other developments were driving the need for patient-focused information; the rights of patients to have access to information about treatment choices and risks were reinforced⁷ and models of care that promoted the importance of self care, especially for people living with long-term conditions, were being promoted.^{8,9}

However, it is in these areas that arguably there has been more success. How much of that success can be attributed to the NHS strategy and how much to outside factors is less clear.

PARALLEL DEVELOPMENT OF eHEALTH AND PATIENT INFORMATION

In 1998, when Information for Health was launched, the Internet was not the pervasive technology that it is today. In the UK, 9% of households had home Internet access,¹⁰ which was generally through slow and expensive dial up accounts. In 2014, 87% of the population were Internet users, with over three-quarters of the population (76%) using the Internet daily.¹¹ Access is no longer restricted to home computers, with people increasingly connecting through wireless devices and smartphones, meaning that the resources available are on hand whenever and wherever needed. In the USA, the Pew Research Centre¹² reports that in 2000, 25% of American adults had used the Internet to look for health information and by 2009, this had increased to 61%. The Internet has also enabled the development of a new paradigm, that of peer-to-peer health care,¹³ a model that has the potential for changing the relationship between patients and health care professionals.¹⁴

The availability of the Internet has been a significant factor in the increased access patients have to health information. People living with long-term conditions are developing their own systems of sharing information, for example in online forums.¹⁵ This combination of health, the Internet and technology has become known as eHealth¹⁶ or Digital Health;¹⁷ both terms are fluid but include telehealth and telecare, mobile apps and online support for self management and

teleconsultation,¹⁸ and are accepted as being part of the health informatics field.^{19–21}

AN INNOVATIVE DISCIPLINE NEEDS A GREATER PATIENT FOCUS

In 2002, this journal carried an editorial by Hayes,²² where he asserted that health informatics was a young discipline, attracting people from a variety of backgrounds including management professionals, computer scientists and clinicians. Over the intervening years, the discipline has matured, but is still not located within any one discrete career path. Hayes also espoused a set of principles that should be applied to health information system strategy. The first four of these are about the importance of patient centredness.²³

1. The patient must be at the centre of all information systems
2. The provision of patient-level operational data should form the foundation – avoiding the dataset mentality
3. Store health data as close to the patient as possible
4. Enable the patient to take a more active role with their health data within a trusted doctor–patient relationship.

In a recent editorial, discussing the decision to rename the journal, de Lusignan²⁴ describes informatics as a boundary-spanning, science-based discipline:

Informatics is the scientific study of the use and processing of data, information and knowledge

He also argued that it provides the scope to innovate as well as automate, drawing on examples of how routinely recorded health data can be used for research and surveillance. This is undoubtedly true, but this places the emphasis on the use of information by professionals.

CONCLUSIONS

Health informatics has the potential to span the boundaries between health care professionals and patients. This is especially true for people living with a long-term condition. Health informatics innovations in the area of eHealth are as important as those in management science, computing and information technology.

Carol Bond is a member of the editorial team for Journal of Innovation in Health Informatics (JoliHi) and is the editor with responsibility for eHealth. Her goal is to ensure that this important area continues to be developed and that JoliHi becomes the journal of choice for eHealth articles. Her professional background is as a nurse, with over 20 years' experience in health information. She moved into academia in 2001 and is currently Principal Academic Digital Health at Bournemouth University. Carol is also a chartered fellow of BCS, The Chartered Institute for IT.

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