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'Quality signposting': the role of online information prescription in providing patient information

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Abstract

Background: Information prescriptions (IPs) are part of a Department of Health (DH) initiative to improve patient care. IPs aim to meet health information needs by providing personalised, high quality patient information about conditions and treatment.

Objectives: This paper identifies current online IP provision and evaluates a sample of IP websites against the original DH aims of IP provision; British Medical Association usability criteria; and information seeking vignettes.

Methods: Five UK and one international IP website were randomly selected as a sample. Two checklists designed to appraise the websites were used to review each IP provider. Two patient information seeking vignettes were developed to enable the websites to be assessed from a patient-centred perspective.

Results: Information prescriptions currently vary in content, accessibility and quality. National IP websites score more highly than local IP websites, which are often weak on content for specific conditions and poorly designed but strong on signposting to local services.

Conclusions: Guidelines for IP provision need to be improved to ensure higher quality, more easily accessible information is available. A synthesis of expertise included in national and local websites would improve usability for patients. IP websites should conform to standards of web design and accessibility.

Key Messages

Implications for Practice

- There is a need to link local and national information prescription (IP) websites to ensure high-quality condition-specific information and accurate, comprehensive local service information are provided.
- Information management skills, as well as condition-specific expertise, need to be utilised to ensure high-quality IP provision.
- Online information providers need to ensure that website design guidelines are followed to make IPs accessible.

Implications for Policy

- Information standards need wide dissemination to ensure best practice in information management.

Introduction

The concept of information prescription (IP) was first introduced into UK governmental policy in the 2004 paper, *Better Information, Better Choices, Better Health: Putting information at the centre of*

health.¹ In this white paper, IPs were defined as a method of 'raising the importance of information in consultations where time is often limited'.¹ The concept of using 'high quality information [to] empower people'¹ linked with a recognition of the need for increased patient awareness of treatments to ensure choice. It was also influenced by service providers' focus on increased responsibility for patients.²

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*Better Information, Better Choices, Better Health*¹ focused on the importance of putting information at the centre of health and set out a single national approach to information provision. It followed on from other policy documents including *Creating a Patient-led NHS*² which described the major changes underway in delivering patient-centred services, including patient choice, patient involvement and providing information for decision making. Subsequent reviews, including *High Quality Care for All: NHS next stage review*,³ *Choice Matters*,⁴ and *Our Health, Our Care, Our Say*⁵ have reinforced this focus on information provision as central to healthcare policy.

Information prescriptions are designed to guide people to relevant and reliable sources of information to allow them to be better able to manage their condition and maintain their independence. They include relevant information about conditions and treatments, care services, benefits and support groups. IPs are predominantly recommended for patients with long-term conditions, like asthma, chronic obstructive pulmonary disease and cancer. They aim to be relevant throughout progress along the care pathway. IPs also contain links or signposts to sources of information. They can be made available through a wide variety of sources, including the online provision on which this paper concentrates.

In the UK, an National Health Service (NHS)-based pilot project was undertaken on 20 sites in 2007, examining delivery approaches for IPs. The pilot focused on information provision for a variety of long-term medical conditions.⁶ It looked at both online and offline solutions, and piloted the use of IP for specific conditions or age groups, aiming to compare the effectiveness of different models of IP.⁷

While the pilot projects identified some issues, such as equity of delivery, IP provision was regarded overall as a success.⁷ An evaluation of the pilot schemes considered the impact IPs had on patients, carers and professionals; findings included improved confidence, and IPs compared well with other methods of information delivery.⁷ The pilot evaluation made recommendations which were taken forward into a national IP website, NHS Choices.⁸

Aside from the pilot project report,⁷ there is little current literature on IP. Papers tend to be

short, focusing on individual examples of project provision, or the benefits and drawbacks of implementing IP provision. Chamberlain, Heaps and Robert found few examples of literature explicitly concerned with IP in their survey of IP and bibliotherapy.⁹ There is thus a gap in the evidence base, with comparative studies of different IP provision neglected. This study examines the accessibility and usability of IP provision, unlike previous literature which has focused on the organisation or potential importance of IP.

Identified potential barriers to IP: initial findings from the literature review

O'Connor examines the use of IP in the context of cancer treatment, noting that there are a number of barriers to accessing IP, including literacy skills; accessibility in different languages and in different formats; conditions including dyslexia which can affect reading and comprehension and health information literacies.¹⁰ He also comments that sometimes patients may not want to have more information about their condition, citing the need to return to normal life as influential on information seeking behaviour following diagnosis. Similar barriers are also identified by Leisey and Shipman in their work on American IPs, though medical professionals' perceptions of these barriers were a key determinant in the effectiveness of prescription.¹¹

Corner, again exploring notions of IP from the perspective of cancer care service providers, offers similar concerns that there needs to be more information about the nature of IP to ensure quality.¹² In her view 'IPs should meet, not only patients' clinical information needs, but also their emotional, practical and financial needs'. Nevertheless, Corner's preliminary exploration of IP provision for cancer sufferers is supportive of the potential offered by the schemes for patients to access information at any point of need. This contrasts with Dodson, Bisnauth and James' work, which noted that clinician-directed IP was more successful than independent online provision. IPs in this context were delivered in a variety of formats, but initial access was via a healthcare consultation.¹³

One concern raised by stakeholders identified in Hand, Greenwell *et al.*'s IP development for

people with Parkinson's disease and their carers was that online information could vary in accessibility and quality.¹⁴ This led their IP provision to focus on directed IP provision via telephone, which proved popular for this condition. Their conclusion that 'it will be essential to engage the support of voluntary organisations where they have quality-assured resources, and ideally, user-led information support systems' emphasises the need to involve all stakeholders in IP provision. This was also reinforced in Wheeler and Nicholson's work.¹⁵ This work also examined the role of traditional information providers, including public libraries, in the administration of new IP schemes.

A recent review of consumer health information provision in the UK noted that information providers needed to face a number of issues related to health information literacy issues as well as ensuring that new technologies were harnessed to provide information in formats acceptable to patients¹⁶ and this applies in the case of online IP.

Objectives

The objectives of the research were:

- To identify websites from the pilot scheme that are still accessible and being utilised, as well as national and international examples of IP.
- To assess a sample of online IPs against the five components defined by the Department of Health (DH) as integral to successful IP.
- To apply information seeking vignettes and usability criteria to an evaluation of a sample of IP sites.

Methods

A sample of five UK IP sites and one international IP site were identified and assessed against a number of guidelines. The research utilised a checklist based on the original guidelines for IP provision⁷ (Appendix A, available online) to evaluate the websites, as well as an independent checklist designed using the British Medical Association (BMA) Patient Information Award criteria for websites (Appendices B and C, available online).¹⁷

The original integral components of an IP were identified by the DH⁷ are:

1. Information content – or the identification of reliable and relevant sources of information
2. Directories, defined as repositories of information that link to individualised IPs
3. Personalised process, identified in this instance as whether the patient can find information that is specific to a condition, place and point on the care pathway
4. Issuing or prescribing, to assess if the patient can access a personalised IP by collecting information to meet their needs
5. Access and outreach – or the channels that are used to make information available to users.

Two patient information seeking vignettes (Appendix D, available online) were also devised and the website reviewers assessed the IP provision against the needs of these patients. Each website was assessed twice using the IP provision checklist, once focusing on its information provision for depression, and once for dementia. A maximum possible score of 124 was available for each website.

The use of vignettes was inspired by Jorm *et al.*'s work,¹⁸ and the checklists and vignettes were written and agreed through peer discussion. The aim of providing vignettes was to ensure that patient-centred, personalised care was being provided, rather than more general health information. This means that the websites were specifically assessed for the quality of their information on the treatment of depression; local information on support groups for depression; the prognosis for people with dementia; and support groups for people who care for people with dementia. The ages and genders of the patients seeking information and an indication of time since diagnosis were also given in the vignettes.

The HONCode guide for health websites¹⁹ and DISCERN tool²⁰ were also considered as guide for checking quality, but it was decided that the BMA guidelines¹⁷ were more appropriate in this instance as they included considerations of usability such as the use of language – focused on the use of Plain English – interactive features, design and accessibility in line with current W3C guideline criteria.²¹ While the HONCode and DISCERN tools examine criteria such as authority, confidentiality, reliability and transparency, it was felt that there needed to be a greater focus on usability in this study. This was considered important in light of the concentration on patient-centred information provision.

Both reviewers were information professionals, which can be said to conflict with the typical identity of an information-seeking patient. However, for the purposes of this review, the provision of the vignettes enabled the reviewers to focus on the information needs of specific patients. Professional skills were also appropriate when considering some aspects of the checklists, such as the application of W3C standards.²¹

As information-seeking practices are highly individual, it was considered appropriate that some aspects of the checklists required subjective judgments, e.g. the navigability of the website. These subjective measures were supplemented with more objective ones, including the presence of the last date of update. The reviewers scored each website independently, then scores were assessed for agreement, and discussed. However, as the reviewers subscribe to Savolainen's recent work on Everyday Life Information Seeking (ELIS),²² which states that information seeking behaviour/information practices depend on socio-cultural contexts, it was not considered appropriate to revise these scores to provide a consensus.

Sampling

The characteristics of all 20 pilot sites⁶ were noted and considered for inclusion in this project. A full list of the pilots, noting their suitability for inclusion in this study, is available online in Appendix E. As the research in this paper focuses on the quality and accessibility of current online provision, IPs could only be included in the study if they were available online; covered a number of long-term conditions; were aimed specifically at adults (as opposed to subgroups such as the elderly, or young people); and were still operational in August 2009, as some IP sites had been discontinued following the pilot. Five of the pilot IP sites met these criteria, and a random sample of three of these suitable sites was chosen for manageability for this exploratory study.

The sample, as presented in Table 1 thus comprises:

- Three of the online pilot IP websites.
- One local site developed after the initial pilot programme, meeting the same sample criteria as above. This was included, following random selection from a list of other UK IP sites, to

examine the impact of the evaluation report in influencing local provision.

- The national NHS Choices IP site.
- One American IP website, MedlinePlus.

The purpose of the inclusion of an international site was to provide a comparison, which could be utilised for benchmarking UK provision. There is some provision of IPs internationally, with projects in the USA, Australia and New Zealand identified in a detailed internet search. However, because of the private sector, insurance-based nature of healthcare provision in the USA, some of these websites were unavailable for evaluation as they provided cost-based information. Some IPs were also linked to specific healthcare providers, and required a password log-in to access. This limited the number of international IPs available for evaluation. A further limitation was the restriction to the evaluation of English-language IP websites only. For this reason, only MedlinePlus, an open-access IP scheme addressing a number of long term conditions was included.

Results

As discussed in the introduction, a number of online IP sites were identified from the pilot

Table 1 Information prescription (IP) websites evaluated

Website	Focus
Darlington Healthclick ²³	General long-term conditions IP in pilot scheme
Derbyshire IP ²⁴	Developed after original pilot scheme, covers various long term conditions
Isle of Wight Onelink ²⁵	Dementia and depression IP in pilot scheme, expanded to cover further long term conditions in 2008
MedlinePlus* ²⁶	National American site, includes a variety of long term conditions
MyManchester ²⁷	General long term conditions IP in pilot scheme, expanded to cover further long term conditions in 2008
NHS Choices* ²⁸	National UK site includes a variety of long term conditions

NHS, National Health Service.

*IP websites with a national focus.

studies conducted by the NHS. NHS Choices, NHS Direct Wales and a number of independent charities such as the Stroke Association also provide access to online IPs in the UK. Primary Care Trusts not involved in the original pilot project have also added IP provision to their services, sometimes in association with the local public library. Internationally, as stated, many IP sites are linked to local healthcare providers. There is not scope within this review to discuss this in more detail. A broad, varied pattern of IP was thus identified, and a sample was selected for evaluation of quality and usability.

Initial results show mixed rates of success in delivering all the required components effectively. The overall score for each website is presented in Table 2. The top scoring website, with 102 out of 124, was the NHS Choices website. Both reviewers thought it was very professional and had a good range of information and services. It was also very easy to use, and would be easily navigable for those with limited computer skills. The lowest scoring website was Derbyshire IP, with 40. It had a limited range of information on very few conditions and no mechanisms for personalisation. Overall, national IP sites scored more highly than local ones.

Table 2 also presents scores for usability based on BMA criteria. This shows that the American MedlinePlus provided the most user-friendly accessible source of IP. Despite not aiming to conform to the original NHS criteria, MedlinePlus still scored highly when compared to local IP provision in the UK. NHS Choices consistently provided the highest quality information for both conditions in the study, meeting the criteria for IP in almost every aspect. Further comments from the reviewers are organised by themes emerging from the analysis in the following sections.

Themes

Information provision and personalisation

As is evident from Table 2, some websites scored more highly for one condition than the other. Typically, the information on dementia was found to be more relevant, useful and high quality than resources for depression. This may relate to the

Table 2 Total scores for each IP website

Scheme assessed	Darlington PCT Healthclick	Derbyshire IP	Isle of Wight Onelink	MedlinePlus*	MyManchester	NHS Choices*
Criteria Reviewer	1	2	1	2	1	2
BMA criteria total (out of 34)	22	13	21	28	24	26
IP depression criteria total (out of 14)	8	1	3	12	11	12
IP dementia criteria total (out of 14)	3	3	9	12	12	12
Total score (out of 62)	33	41	33	44	47	50
Total score (for both reviewers, out of 124)	74	40	78	96	81	102

BMA, British Medical Association; IP, information prescription; NHS, National Health Service.

*IP websites with a national focus.

nature of the conditions themselves, but there is not scope within this article to discuss this finding in more detail. In the case of information regarding local groups, this may reflect the provision of such groups in the areas sampled. Interactive features to personalise information ensured the relevant and appropriateness of the information. Derbyshire IPs contained no mechanisms to personalise the information. This meant that the information provided was often irrelevant, as the patient information seeking vignettes included specific information seeking requirements.

Three of the websites allowed the IP service user to specify whether they were a patient, carer or medical professional, which also enabled more relevant information to be accessed, especially in terms of support groups. Reviewers thought that this was a positive development, enabling less confident information seekers to identify appropriate resources without suffering from information overload.

Evidence base, attribution and authorship

The website reviewers found few problems with the accuracy of the information available the IP websites. However, there was little evidence to demonstrate that this information came from reliable sources. The provenance of the information was not clearly attributed to appropriate medical professionals, though the reviewers chose to assume – where there was an association with the NHS – that this was the case. NHS Choices provides a link to its editorial policy, which provides further information on the process through which its content is provided. While IPs are designed to provide information in a simple, accessible format, there were no references or links to the evidence base supporting the information given to enable IP service users to assess the quality of information provided.

Accessibility and design

W3C accessibility guidelines²¹ were used to ensure that international standards for web content were adhered to. All websites met most, or all, of the guidelines. Design varied throughout the websites. Darlington Healthclick utilised a simple free text search box to enable the creation of an IP. Isle of

Wight Onelink had a front page described by reviewers as ‘cluttered’. MedlinePlus and NHS Choices were both considered to be well designed. There were some problems loading Portable Document Formats (PDFs) and pictures in the Derbyshire IP website.

Language

As the UK is a multicultural society, with many community languages, the website reviewers examined both the provision of information in Plain English,¹⁷ and the opportunity to access information in community languages. All IP providers scored highly on providing information in Plain English, meeting 6–9 criteria of the Plain English campaign’s standards for medical information. Text on the Isle of Wight OneLink site contained spelling errors. Only MedlinePlus provided information in languages other than English. This is because of the large Hispanic population of the USA, which makes up a higher proportion of the community in some areas than comparable Black and Minority Ethnic communities in the UK. Since the initial survey was conducted, NHS Choices now provides translation options including Arabic, French, Polish and Urdu.

Date, codes of conduct and consumer involvement

While all of the IP websites provided evidence of the date they had last been updated, it was not always obvious if this was within the last 6 months, as sites only provided reference to the year. It was difficult to note if there had been any evidence of service user involvement in service design, as no IP provider referred to the inclusion of consumers. Only MedlinePlus linked to its quality statement, though NHS Choices did provide an editorial policy statement, performing a similar function.

Navigability

There were significant issues with navigability of the IP websites. Firstly, much of the IP provision was difficult to find within wider website content. Internal website search engines needed to be used

Table 3 Strengths of national and local information prescription (IP) websites

Strengths of national IP websites	Strengths of local IP websites
<ul style="list-style-type: none"> • Well-designed • Good overall information content • Information specific to a point on the care pathway • Good functionality • Broad range of topics covered • Range of outputs, including different languages • Good mechanisms for feedback on appropriateness of information content • Clear outline to aid user expectations and signposting to other sites 	<ul style="list-style-type: none"> • Good signposting to local services information • Can provide a better range of options for appropriate local services

to locate the appropriate page. This means that IPs could only be located if the person seeking health information was already aware that an IP would fulfil their needs.

Derbyshire IP was noted as a particular example of a website with a circular structure, which was difficult to navigate. It also contained a number of links which did not link to the content listed. One reviewer felt that MyManchester was difficult to navigate, with a structure based on a large number of drop-down menus. One major concern with navigability was that most links to the home page returned the information seeker to the main website home page, rather than the IP provision home page.

Discussion

The main problems identified with the online IP sites sampled were information overload and a lack of personalisation. Several websites had better information on one condition than the other. Design was a problem in many cases, often reflected in the navigability of the website.

In general, it was noted that good IPs contained a variety of information, with some local services and some general condition information. These prescriptions also had a range of outputs, and opportunities for personalisation and selection of information. It was noted that there were differences between local and national IP websites, presented in Table 3.

There are some limitations to the current project. Restricting the health information sites to those

available in English meant that both reviewers could access the content, but this meant that the provision of information in other languages could be checked, but not assessed. For example, the availability of MedlinePlus in Spanish was a significant feature of the website, but for the purposes of this review, the quality of the information could not be considered. This also meant that the identification of the provision of IP websites internationally was limited to the English speaking world.

The use of two independent reviewers with different information seeking behaviours, as well as the quantifiable checklists, helped to prevent a biased account of the quality of the websites. However, both reviewers found that some categories (e.g. consumer involvement in website design) were difficult to ascertain, and so websites tended to have lower scores for these criteria as there was little evidence on which to base the rating. The information seeking vignettes also presumed a degree of computer literacy on the part of those seeking information.

Conclusions

The BMA and IP checklists highlighted a number of key themes, important for considerations of the appropriateness of online IP for patients. IPs offer great opportunities to provide patients with helpful information, personalised to their health information needs. Good IPs contain evidence-based information on symptoms, treatments and support, combined with signposting to useful local services. However, there are still some issues, expanded below.

Variations in quality of website design

While NHS Choices and MedlinePlus were well designed and easy to navigate, local IP sites were often difficult to navigate. This meant that reviewers had concerns about accessing the IPs if health information literacy was low. IP providers need to ensure that IPs are simple to use, with a clear layout, instructions for use and a facility for reporting problems to service providers.

Variation in quality of information content

Improvements need to be made in the organisation and selection of patient information. Options for personalisation also needed to be improved to ensure that the search for information provided relevant results. There were differences between local websites, which provided high quality information about local services, and national sites, which supplied high quality, condition-specific information. While this condition-specific content was useful for patients, it was clear that there was a need for skilled information management professionals to ensure that this content was organised in an accessible manner.

Lack of evidence of use of information standards

Information prescription websites did not contain evidence of adherence to information standards. However, in the UK, this may change with the introduction of the DH's Information Standard initiative, following pilot testing in Summer 2009.²⁹ It is the intention of the DH that 'ultimately, all sources of information on IPs will be quality assured through the information accreditation scheme.'³⁰

Considerations of a patient-centred approach

As previously stated, there was no evidence of patient involvement in IP design. An introduction of patient review for these sites, or application of patient information seeking vignettes like the ones utilised in this study would aid IP providers in identifying weaknesses in their IPs. While the information is usually accessible, the personalisation process often required a higher degree of accuracy.

Allowing patients to specify age, gender and length of time since diagnosis would ensure information was accurately targeted to the patient.

Recommendations for practice and future research

There is an argument for linking national and local IPs as both have strengths. There should be some support and guidance for local IP websites on content – preferably from patients noting information seeking preferences – and on design from IT professionals, as accessibility issues were particularly bad on some local IP sites. Sites would also benefit from the introduction of some guidelines about what patients can expect from an IP, and the best way to utilise them. Improvements made to local IP sites could include the introduction of information in community languages.

In terms of further research, it would be appropriate to repeat this evaluation when the new DH Information Standard criteria have been finalised, see if the websites meet the standards or assess changes required to ensure that these standards are met. There should be an evaluation of any future partnerships between local and national schemes, to ascertain if this improved services as theorised.

Conflict of interest

No conflicts of interest have been declared.

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Supporting Information

Additional Supporting Information may be found in the online version of this article:

Appendix A. Scoring checklist for Information Prescription based on DH guidelines.

Appendix B. BMA checklist criteria.

Appendix C. Scoring checklist for information prescriptions based on BMA criteria.

Appendix D. Patient information vignettes.

Appendix E. NHS information prescription pilot projects, discussing reasons for inclusion in current evaluation.

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