

PHCSG Annual Conference papers

Stimulating convergence of clinical and lifestyle perspectives on the web: asthma as an example

Jean Roberts BSc MHM MBCS CEng

Founding Fellow, Centre for Health Informatics Research and Development (CHIRAD), Winchester, UK

Karen Copeland Dip YMCA

Exercise Professional, Phoenix Fit for Purpose, Staffordshire, UK

ABSTRACT

The paper explores the quality issues and principles of presenting information, for both professional and lay audiences, in an area where there is also potential synergy in increased knowledge exchange between health and lifestyle professions whose current interworking is very limited. It requires an investment in dialogue, joint research and an understanding of the indicators of quality that relate to 'fitness for purpose' in this situation. Using the example scenario, information relating to exercise and

asthma, the paper concludes that decisions on what interventions are best for a specific individual based on cross-validated web-based information could then be made in a more informed way and bring about enhanced patient outcomes. This timely convergence is consistent with the strategic direction of European and NHS plans.

Keywords: informatics convergence, lifestyle, quality, web

Introduction

The exploration of clinical issues and topics through web means is now prevalent. Such investigations are carried out by both professionals and the lay citizen. The tone, language and content of sites that address clinical conditions are frequently targeted at either professionals or citizens but are accessible to both. There are dangers in this dichotomy.¹ In a piece being considered 'fit for purpose' by one cohort, it may create misunderstanding, confusion and anxiety, or be dismissed as bland, in the other. Where sites are open, the authors and content providers should recognise this and either take the additional steps necessary to address these potential problems or be very explicit in the sites' navigation and declaration.² Many groups are working on the detail of self-regulatory quality definition and maintenance; a summary review describes them.³

The choice of asthma as the sample condition to research was based on the premise that:

- it is a frequently occurring clinical condition

- there is considerable potential for patient/client intervention in improving their own condition
- there are demonstrable links between the condition and the effects of exercise, both positive and negative
- asthma can be both an underlying clinical issue, and induced or exacerbated by inappropriate exercise (as can other clinical conditions).

Findings

The research was carried out using a range of search engines and sites, all readily accessible to various professionals (for example Medline, *Bandolier*, The Sports Web, Health Zone) and to the general public (for example, material identified through www.google.com).^{4,5} The research was done by a health informatician, a fitness professional and a public Internet user.

In practice, for people with an asthmatic condition, the overlap between the domains of health and lifestyle professionals are typified by the two statements:

- The healthcare practitioner: 'If you take more exercise it may help your condition.'

- The lifestyle/fitness professional: 'If you have any concerns, then see your general practitioner before embarking on an exercise programme.'

Neither cohort appears to have much in-depth knowledge about the benefits and detailed aspects of each other's activities. Relevant websites can be identified by referring to the keywords 'asthma' and 'exercise' (qualified for this study by 'UK'). However, the cross-linkages found are of limited use, and most professional-targeted sites (from either perspective) revert to professional jargon that clouds the meaning for lay readers (and in part the other professional cohort). There are recognised interactions between exercise and asthma.⁶ The situation is compounded by the fact that an asthmatic condition can become more severe from inappropriate or excessive exercise.

Examples

Using keywords 'asthma', 'UK' and 'exercise' on a public search tool, Google (www.google.com), and professional vehicles (www.bmj.com, www.BIOME.ac.uk, www.netdoctor.co.uk and www.oclc.org/firstsearch/logon/ through the Open University) resulted in the identification of over 25 000 hits. A top-level analysis identified three main categories of subject:

- asthma induced by exercise
- medications
- exercise for health.

Approximately one-third of contributions that were easily accessible did not present a clear theme to their content for a layperson or for a non-specialist professional. This lack of clarity may result in considerable time spent on the acquisition of detailed content that is written in such clinical language as to present a risk to a lay audience in its current form. It could be argued that the sites and contributions were designed for a professional reader and as such should not be considered suitable for a lay group. However, for a condition such as asthma where self-management is an integral part of interventions, it is not surprising that sufferers wish to have as much information as possible about their condition. There could be considerable benefits in outcomes if the professional views were effectively communicated to a lay audience.

Analysis

There are a number of criteria for evaluation that could (and it is suggested should) be used to determine

the usefulness of a site addressing situations where considerable public interest and multiprofessional working is indicated:

- intended audience
- provenance of the authors and site contributors
- sponsorship of the site
- currency of the content
- effectiveness of the knowledge exchange.

Each of these criteria is considered in the context of the subject ('asthma', 'exercise' and 'UK'). A number of sites do highlight their context setting and intended audience, for example, 'since the site is aimed at the professional, there may be a high jargon count'.²

Intended audience

In scenarios where the client or patient can have a considerable impact on their condition by self-management and personal interventions, it is crucial that all readily accessible information sources are couched in terminology that will facilitate the positive involvement of the layperson. This will require different writing styles and additional investment to maximise knowledge transfer. Where a site is explicitly for particular professionals, then that fact should be clearly stated in the opening screen, whilst bearing in mind that it is impossible to exclude the determined investigator, unless the site is password protected in some way for a defined cohort. Increasingly, therapy, treatment, health maintenance and lifestyle management are team or at least multiprofessional initiatives, so the requirement is not solely for a review of language used from two perspectives.

Provenance of the authors and site contributors

Titles and locations will provide a proxy to aid evaluation of the likely content. However Internet-based content is transnational and the general reader will not necessarily have the background knowledge to determine whether the XYZ Clinic is a major unit, an alternative therapy specialist provider or a small service location with no distinction in a particular field. Lifestyle information could be made available by an individual unqualified participant or a qualified professional, individually or through the website of the club or facility in which they are based. Similarly, sites may represent personal views, present a selective focused perspective, or not state the evidence base of their content. Therefore sites need to be clearly declared for what they are.

Sponsorship of the site

A variation on the theme of *caveat lector* (reader beware) should be applied to sites that have declared or virtual supporting organisations. For example, a site with an address like 'ABC Pharma' or 'ANO Health Club' telegraphs its origins, and the discerning reader will not expect to find exhaustive unbiased content on all the alternative available health technologies and exercise regimes. The site described as 'LMN User Group' may contain subjective material, and also may be financially supported by sympathetic organisations with their own agendas. Detailed work on codes of ethics are addressing how such collaborations should be expressed.⁷ Personal sites, put up by individuals with the best of motives, may suggest eclectic interventions that are supported by little formal evidence other than 'it worked for me'. All are useful if their agenda and background are clearly declared.

Currency of the content

There have been many sea changes in the (clinical) wisdom and evidence base of various processes, procedures, potions and protocols over the years. These revelations are now more widely and more quickly available through the Internet. Care must be taken to state when a site was last updated, what is the chronology of contributions and when the material is to be reviewed. There is a danger that, in ignorance, a site user may find and apply guidance that is out of date. Taking the decision to make information available through the web implies a responsibility to maintain that information for as long as it remains accessible. Again, this takes considerable investment, especially with a publicly accessible site, as the content presented is constantly 'under question' by other media such as press, TV and radio which communicate messages in a different way. For example, the UK Department of Health felt it necessary to introduce a fast response service in 2000 called 'Hitting the Headlines' to underpin stories appearing in the general press with clarification from the evidence base.⁸

Effectiveness of the knowledge exchange

A fully informed population and range of professionals can enhance the likelihood of understanding of a clinical condition or intervention. The Internet is an emerging vehicle for more effective communication if utilised wisely. Little research has yet been

carried out into the *quantification* of the effects of knowledge exchange through web channels; only the anecdotal 'I challenged my doctor with the information I had got from the Internet and he said why had I done that, did I not believe him?' or 'After nothing else worked, I put an enquiry on the Internet and received lots of suggestions for alternative therapies, one of which proved to have a positive effect.'

Increased improved knowledge exchange is indicated as potentially beneficial where a condition can be affected by the inputs of a range of professionals – in the case of asthma, clinical and lifestyle professionals.

Conclusions

A clinical condition such as asthma has well-known evidence-based indicators of the (positive and negative) interactions between clinical (medication) and lifestyle interventions. Information is now widely available through the Internet, hosted by both professionals and sufferers. There can be benefits to the layperson from the contributors to such sites sharing their knowledge. There is synergy between the actions of both professional cohorts (clinical and lifestyle) in creating a successful outcome for the individual. It requires an investment in dialogue, joint research and an understanding of the indicators of quality that relate to 'fitness for purpose' in this situation. The benefits of such interprofessional synergistic working will only be realised when both the clinical and lifestyle professionals understand more about the possible contributions of each other. The different perspectives on the overlapping issues regarding the same condition can then be expressed, *through consistent messages*, in a language that is appropriate for a lay audience and has a value to professionals additionally. Clear enunciation of the effects of exercise on, for example, an asthmatic condition, can benefit the individual and generate cost-benefits to both professional cohorts. Decisions on what interventions are best for a specific individual, based on cross-validated web-based information, can then be made in a more informed way.

REFERENCES

- 1 Roberts JM and Copeland KL (2001) Clinical websites are currently dangerous to health. *International Journal of Medical Informatics* 62: 181–7.
- 2 Scottish Health on the Web: www.show.scot.nhs.uk
- 3 Risk A and Dzenowagis J (2001) Review of Internet information quality initiatives. *Journal of Medical Internet Research* 3 (4): e28.

- 4 *Bandolier*: www.jr2.ox.ac.uk/bandolier/
- 5 The Sports Web, Health Zone: www.leisurejobs.com/healthzone/index.html
- 6 Browne D (1994) Prescribing exercise in general practice. Encourage active community life. *British Medical Journal* **309**: 872–3.
- 7 International Medical Informatics Association: Working Group 2 (Consumer Health Informatics) and Working Group 4 (Data Protection in Health Information Systems): www.imia.org
- 8 Hitting the Headlines: www.nelh.nhs.uk/hth/archive.asp

ADDRESS FOR CORRESPONDENCE

Jean Roberts
CHIRAD
King Alfred's College
Winchester SO22 4NR
UK
Tel/fax: +44 (0)1538 266944
Email: jean@hcjean.demon.co.uk

Accepted July 2002