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Making and working of a new electronic resource for patients, carers and professionals: maxfacts.uk

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Abstract

Many maxillofacial patients have serious short, medium, or long-term problems, as well as having to make informed decisions about often life-changing interventions. Validated comprehensive information, at the right time and the right level for a diverse group of users (patients, carers, and professionals), is vital if patients are to make a serious contribution to their treatment. We describe the development of an online resource for this purpose. Maxfacts.uk aims to cover every aspect of oral and maxillofacial surgery and care, from neck dissection and ballistic wounds to physiotherapy and texture-modified foods.

The principles of design, and the multilayered structure, interface, and functions of such a multiuser website are outlined, including accessibility and engagement. The maxfacts model and design could easily be adapted for other users with similar, complex, long-term needs.

Keywords: Patient empowerment; oral surgery; maxillofacial surgery; maxfacts.uk

Introduction

Making patients partners in therapeutic decision making, particularly with respect to chronic conditions and life-changing events, has become an essential component of the doctor-patient relationship.[1]

Many oral and maxillofacial surgical patients, in particular those with head and neck cancer, and after major trauma, have serious short, medium, or long term issues to deal with. The need for appropriate information as and when required is great and varied. Problems that result from "selective listening" (in clinic or in hospital), misunderstandings (both deliberate and unintended), or lack of understanding and information overload, all make properly informed decisions about sometimes life-changing interventions extremely difficult.

Similarly, optimal ways to take back control of life after a major intervention and adapting to new circumstances require the knowledge and understanding of all involved. If giving patients some responsibility is a serious commitment, new and better ways of providing comprehensive and validated information are necessary.

There are small pockets of good and useful information, but the current online provision of information for this diverse group of users (patients, carers, and professionals) is wanting. General purpose leaflets for patients can be insufficiently informative for their specific needs. Web sources with clear commercial connections and interests are not the most suitable platform for unbiased and evidence-based information, and unmoderated online forums can end up as echo chambers for ill-informed views.

However, it seems wasteful not to exploit the power of electronic media for the provision of free, pertinent, high-

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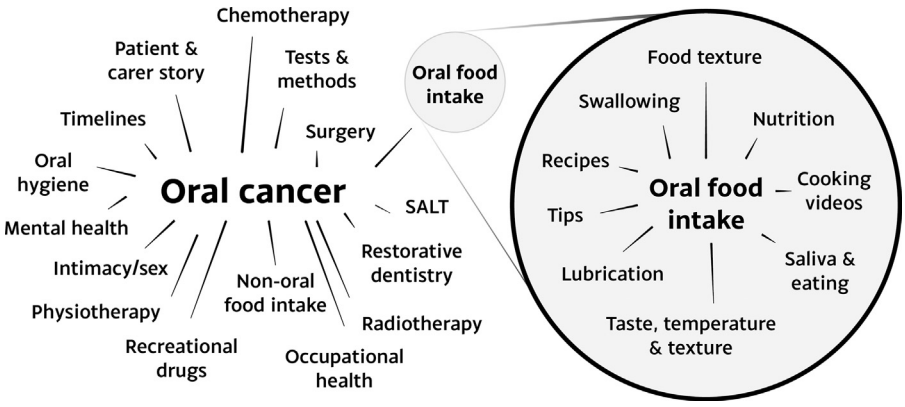

Fig. 1. The many complicated and multilayered connections of themes covered by maxfacts.uk, with "oral cancer" as an example.

quality (and updatable) comprehensive information, with no commercial bias. For such an electronic resource to function, it needs to be optimally designed for its various purposes. The next logical step is therefore to design and implement such an online tool for maxillofacial patients.

Here we outline the principles of the design and functions of such a website (maxfacts.uk) the β version (a pre-release version that is tested on a large group of subjects under normal conditions of use) of which is publicly accessible. We discuss the need for feedback and communal engagement during the design and implementation of this website.

Material and methods

The maxfacts.uk web-server is all coded in Java Script and is open source (https://github.com/laurenkt/maxfacts).[2] Maxfacts.uk is locally hosted by the University of York IT services (safe and secure, audited by University of York IT services) on a node web-server where it runs off a database. All content is modular for ease of maintenance and portability for other users.

Maxfacts.uk was inspired by the award-winning gov.uk website.[3,4] It is designed to work with all current and older browsers and to run on most hardware, as we specifically want to avoid limiting access to it. It makes the data as clear and easy to find as possible,[5–9] and does not use cookies or any other user-tracking or identifying tools. In addition to its optimised, public-facing user interface (available to the general public), maxfacts.uk also features a (confidential) interface for easy maintenance and updating of its content. Contributors can provide content as WORD documents.

Results/Discussion

The needs of the users and the type of content have been taken into account in the design and implementation of maxfacts.uk. The process of design starts with a list of essential and desirable functions. The content and its structure shape the architecture, and the heterogeneous nature of the users (patients, carers, and professionals) and their needs underpin the design of navigational techniques and interface of the website. Take, for example, the topic "oral cancer" (Fig. 1) and the many connections that it has with other topics, each of which is connected and related to many other topics.

Complicated connectivity maps of content obviously need to be mirrored by the design of the website, but must not compromise navigation. One way to ensure ease of navigation is a homepage (Fig. 2), which summarises the overall, high-level structure of the website at a glance without the need to scroll or navigate. The homepage displays the three main structural pillars of content (Diagnosis, Treatment, and Help and self-help) on one page; the horizontal arrangement is essentially a timeline (note that every effort has been made to discourage self-diagnosis: there is no pillar for "symptoms").[10,11]

All content needs to be produced by an expert and proof-read by an expert – essentially like peer review in conventional publishing. Crucially, from a governance perspective, as it can be construed to be a "medical advice site" the authors are both credited with, and are accountable for, the information given. Complexities arise in relation to the originating author and the proof-reading author in a way that is not found in conventional scientific and even medical publishing.

A website such as maxfacts.uk needs to be safe and secure, and the privacy of users must be ensured at all times. We do not collect data about users, and we do not use social media.

A minimalist page layout, in conjunction with collapsible menus, is the primary navigation route through and between the areas of content to ensure ease of use. Users can either find their target area from the menu, or from links in the introductory text that gives context for the menus (Fig. 3).

This design makes for a gently guided tour of information that may or may not be needed without the user being overwhelmed by overcrowded pages, or by having to navigate a complicated website.

Different people will require different depths and breadths of information, and a person will have different needs at different times. The design of the maxfacts.uk website takes such varied needs into account by presenting all content at different levels of technical detail, mostly in a three-level structure (Fig. 4).

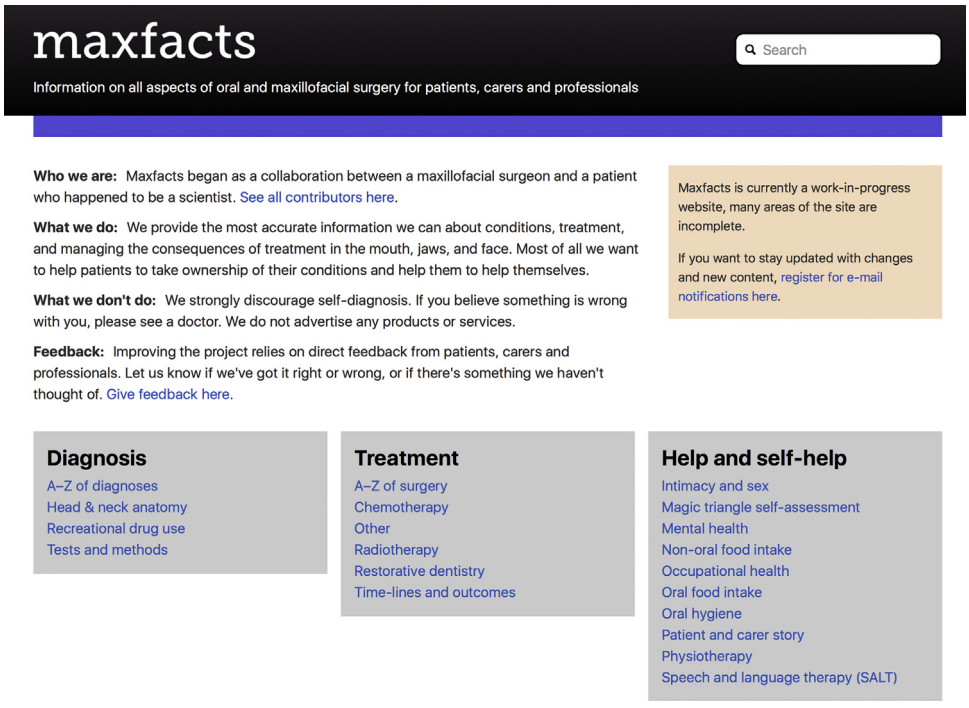

Fig. 2. The current homepage of maxfacts.uk.

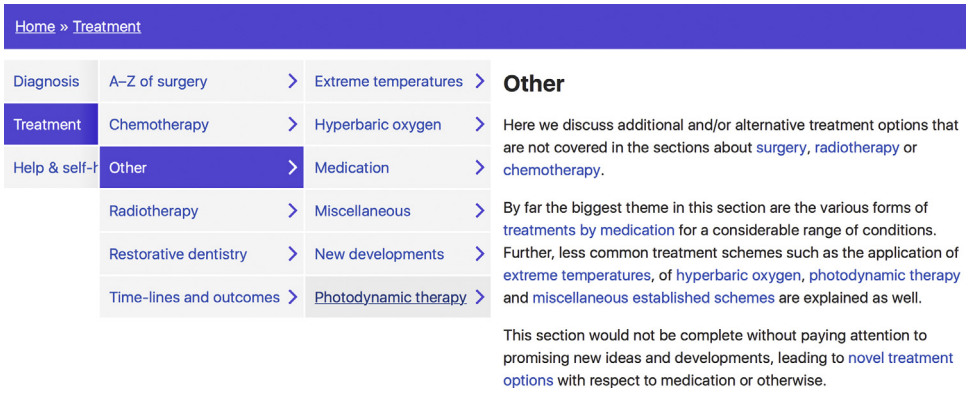

Fig. 3. Maxfacts.uk, illustrating navigation either by the collapsible menu or by links in the introductory text.

Fig. 4. Illustration of the vertical navigation of depth and breadth of information, and corresponding design and layout of a page, next to the horizontal navigation to the topic of choice.

The content progresses from "Getting started" (basic information in plain language) through "Getting to know more" (slightly more detailed information, introducing and explaining some technical terms) to "detailed information" (more or less expert, professional terms). Most detailed information is accessible only through the previous, less detailed sections so that nobody will be frustrated by sudden exposure to off-putting, frightening, or incomprehensible content. Each level of depth/breadth of information is associated with a distinct design and layout (Fig. 4). The distinct layouts of the different levels of content, together with a simple and clear screen arrangement of collapsible menu lists (Fig. 3) enable easy and clear horizontal and vertical navigation of the website. It needs to be accessible for users with a wide range of computer literacy. Ease of navigation is a major criterion for the design of such a website, given that there is a lot of information that needs to cater for a wide range of users and aims to be inclusive and engaging.

An electronic resource such as maxfacts.uk can take full advantage of all the numerous media that can be embedded

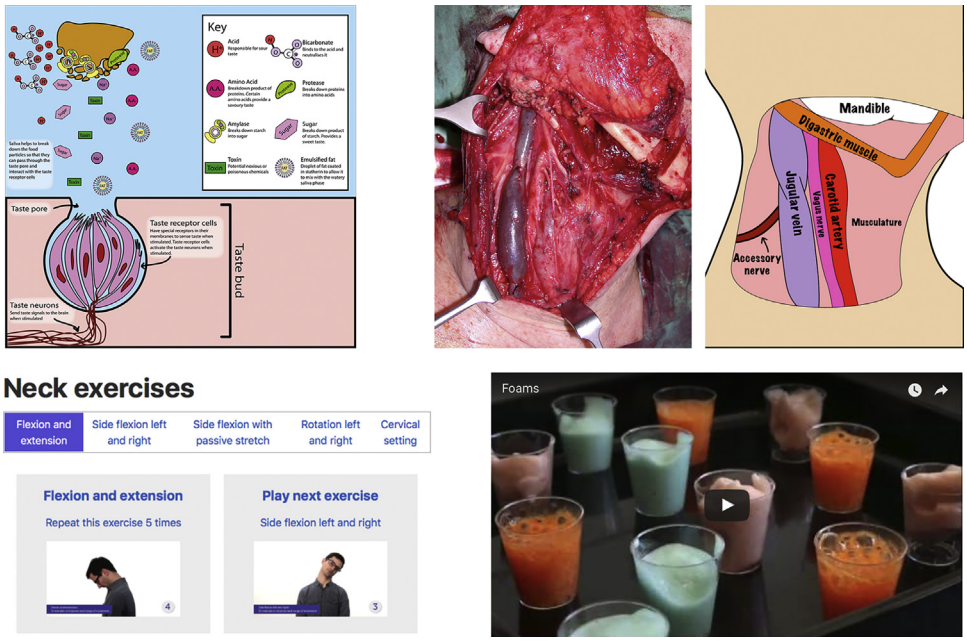

Fig. 5. A collection of examples of non-textual media embedded in text. *Top left*: A diagram of the biochemistry of taste. *Top right:* Neck dissection illustrated by a clinical photograph and a diagram, depending on context. *Bottom left:* Physiotherapy video of neck exercises. *Bottom right:* Video of preparation of unconventional (and conventional) foods.

in a website. This is a major advantage and permits optimal presentation and explanation of its content. Combined use of text, in different ways, plus a lot of non-textual media (graphics, photographs, videos, and animated graphics) allow for communication of pertinent knowledge while minimising the danger of patronising presentations and deliberately dumbed-down content, neither of which would be appropriate or helpful.

Fig. 5 shows several examples of embedding non-textual media in the written content. Taste and changes to the sense of taste are relevant for a number of potential viewers of maxfacts.uk, and understanding the underlying biochemistry and physiology helps in several ways. The graphical summary of the ways in which saliva enables taste (top left, Fig. 5) is an example of how technically correct information can be translated into a representation that is more inclusive than 50 pages of text in a biochemistry textbook. Different amounts of detail in the content call for different ways to explain facts, including different ways of illustrating, for instance, anatomical facts (top right, Fig. 5). At a more basic level, it helps to illustrate neck dissection by a diagram, whereas in a more detailed description of content it is appropriate to use clinical photographs.

Many of the topics in the "Help and self-help" section of the website aim to engage people and to encourage them to look after themselves (or friends and relatives). For example, demonstrations of general physiotherapy exercises in little video clips using conventionally proportioned and dressed subjects (bottom left, Fig. 5) would be harder to engage with if they were scantily-clad extremely athletic actors.

Similarly, oral food intake is obviously a major issue for a number of maxillofacial patients, and an area in need of improvements in understanding and care. In addition to explaining textures and temperatures of food and providing suitable recipes, video demonstrations of some (basic) cooking techniques (bottom right, Fig. 5) in an appetising way should lower the barriers to preparing optimal food at home. Another encouraging feature is to present recipes as a small searchable database that is structured according to textures and temperature of foods. For example, anybody searching for "liquid" will find a long list of options, which we hope will carry the implicit message that a liquid diet is not restricted to survival based on banana milkshakes or power drinks.

The optimal representation of different topics at different levels of technical detail varies greatly and further functions of a website can help. Of course there is the obvious tool of direct links to other parts of the website, which ensures that the website faithfully reflects the interconnected and multilayered content. In addition, there are more sophisticated ways to exploit the functions of the links: we use so-called "commented" links (where the user is encouraged to read up in more detail on specific topics on pages with more detailed content). These are set apart from normal text and links embedded in the text.

Some topics also benefit from additional information beyond the technical detail of the "Detailed information" pages. Such additional information and content can be accessed only through commented links in so called "spin-off pages" that do not feature in the directory or menus of the website (for example, it is not technically necessary to know about the properties of the many different gelling agents

available to modify the textures of food, but people may find such information interesting, so we make it available without distracting from the overall flow and structure of the content).

In each subsection throughout the website we encourage feedback: maxfacts.uk is a living project and can only gain from comments from users, be they patients, carers, or professionals. However, care must be taken to avoid the spread of unchecked external input. Where applicable, however, we want to incorporate feedback from users into the website. The fundamental problem of sustainable expertise has not yet been fully addressed.

From a (theoretical), systems-thinking-oriented, point of view it is necessary to take an interactive and iterative approach because technically speaking we are dealing with a 'wicked system',[12–14] a system that is simultaneously complicated (the website) and complex (at least), if not wicked (a problem that is difficult or impossible to solve because of incomplete, contradictory, and changing requirements that are often difficult to recognise). A wicked system, therefore, cannot be developed and its behaviour predicted – so, the only way forward is to share an incomplete β version of maxfacts.uk. The standard methods of evaluation of human-computer interaction involve interviews with users (here, the patients and carers). This is what we would like to do for maxfacts.uk, but we need clinicians to collaborate with us.

Conclusion and outlook

Something like maxfacts.uk could not be created in book form, not even by writing three different books about the topic. Our maxfacts project is an example of a project that can work only with genuine interdisciplinary work, and that requires patience throughout the processes of coming together, thinking together, and finally working together. We note in passing the numerous similarities between teaching university students and the requirements for giving patients influence by sharing knowledge.

Please have a look at the current, highly incomplete, state of maxfacts.uk, and give us feedback – or perhaps volunteer to contribute to the content. We do not ask for contributions, feedback, and comments as an opportunistic gesture but stress that communication is at the heart of developing and optimising such a project.

Ethics statement/confirmation of patients' permission

Ethics approval was not required. No patients were involved so no consent required.

Conflict of interest

We have no conflicts of interest.

Acknowledgements

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