

# 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. © 2017 The Authors. Published by Elsevier Ltd on behalf of The British Association of Oral and Maxillofacial Surgeons. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

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## 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.<sup>1</sup>

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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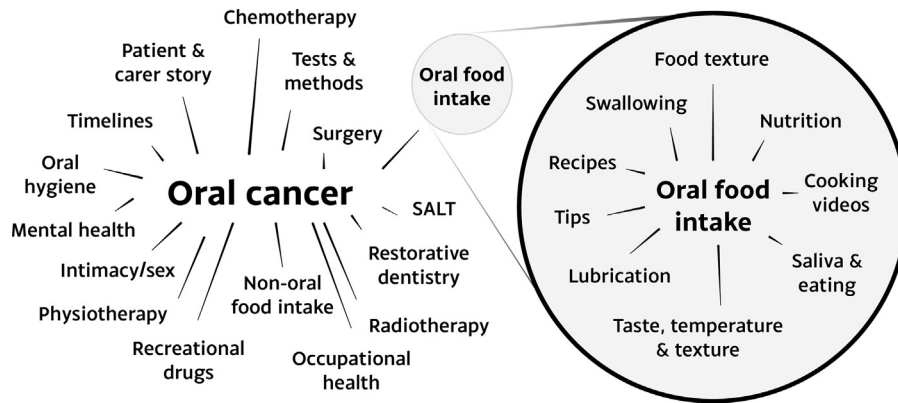


Fig. 1. The many complicated and multilayered connections of themes covered by maxfacts.uk, with “oral cancer” as an example.

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  $\beta$  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>).<sup>2</sup> 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.<sup>3,4</sup> 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,<sup>5–9</sup> 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”).<sup>10,11</sup>

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).

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