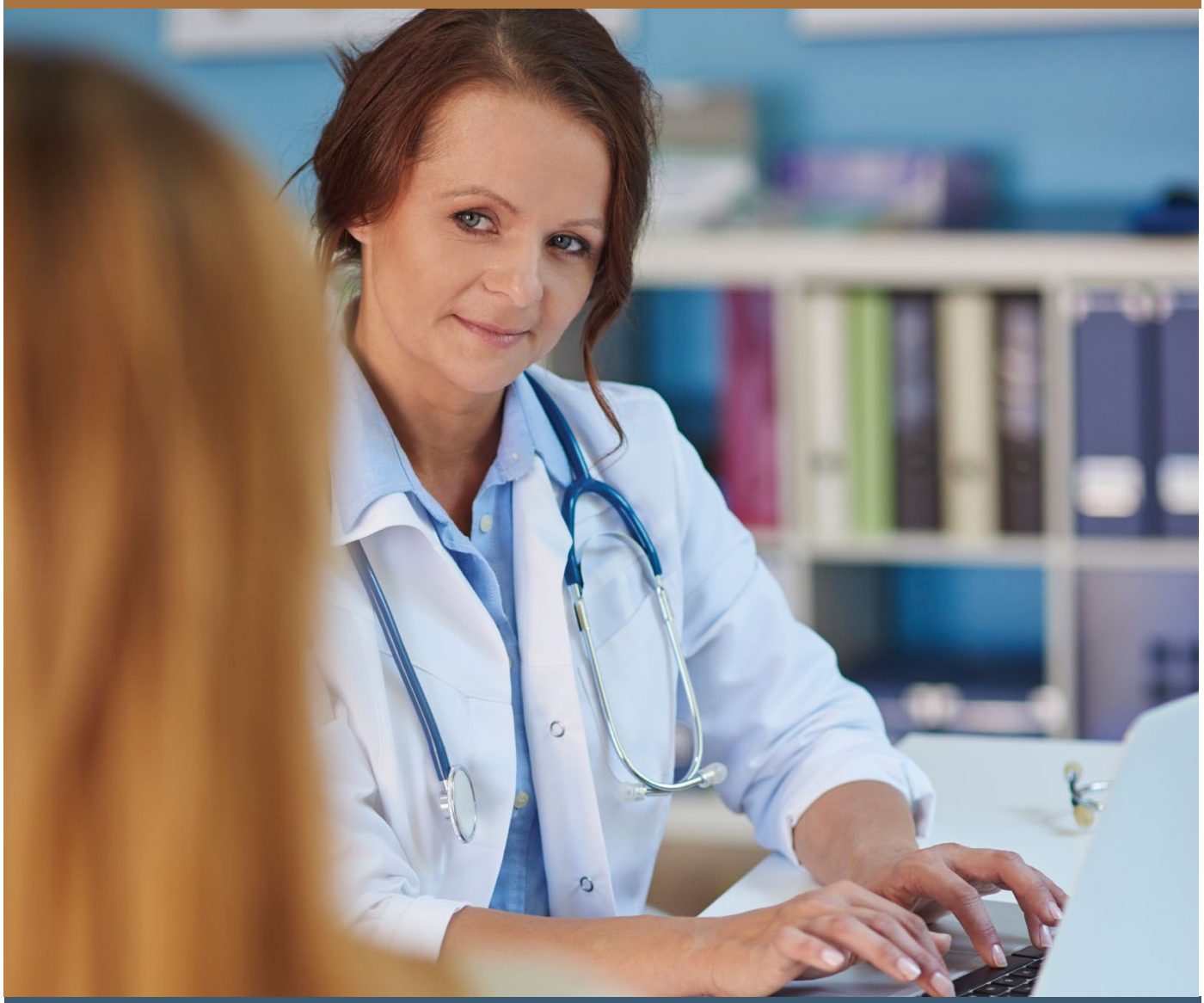
Localizing a disease management system



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The localization of a disease management software system poses unique challenges. In addition to the problems inherent in translating any complex, public-facing software, special attention must be paid to the particular medical standards and cultural norms of the target country. Medical codes differ from country to country and there may be no standard way to translate a particular medical term in the target country. While people around the world are happy to talk about their health to some degree, some subjects remain taboo or are considered inappropriate in certain countries. The use of measurements in other countries can have unexpected effects on translation. All these factors — in addition to the problems associated with translating any software package — can make the localization of a disease management or healthcare system particularly challenging.

Over the last three years, we have participated in the localization of a disease management system and a related wellness portal. These efforts required some process retooling as detailed in the July/August 2017 issue of *MultiLingual* and some inventive use of XML editing tools as described in the April 2016 issue. Just as importantly, they required in-depth collaboration with the customer and in-country experts to bring the localization of these products to a successful conclusion.

What exactly is disease management?

Before proceeding further, you might need to know what exactly is meant by disease management. In its broadest sense, disease management refers to a process of treating a patient with an ongoing medical condition. Patients with chronic conditions such as heart disease, emphysema or diabetes typically need years of regular medical visits, tests and medications. Disease management software, of course, refers to the computerized systems that make treating a patient with a chronic condition more effective and, it is hoped, more economical, obviating the need for time-consuming hospital stays.

Disease management software overlaps with and is sometimes referred to as telemedicine. Telemedicine refers to any kind of medical intervention undertaken at a distance, usually by telephone. Disease management software systems, including the one that we adapted for overseas customers, incorporate telemedicine but are focused on improving the outcomes of patients suffering from chronic illnesses and not just performing a remote diagnosis.

chat version

Disease management software must take into account the cultural norms of the target country.

The good news

In the course of treating a patient — particularly one with a chronic condition — it is often useful to have recourse to documents about the disease. These documents are intended for the layman who wants to make a certain effort to understand the causes and effects of a particular ailment. The English language version of our disease management product has this kind of collateral. When indicated for a patient, one or more documents are sent electronically or by postal mail to the concerned parties.

Fortunately, we usually do not need to translate most of these documents. In every developed country and in many developing ones, there are organizations that have already written patient facing documents on chronic diseases. In our case, it was basically a matter of obtaining permission to use these documents and to make certain small changes to the database tables where we loaded them.

Another bit of good news was that the translation of many of the features in the user interface was straightforward. The audience of the translated administration functionality, for example, consisted of software professionals. Since the technical terms to be translated had well-established equivalents in the target languages, this part of the localization effort was concluded rapidly.

The not-so-good news

Nontrivial problems begin to appear with the adaptation of medical condition codes. These ISO codes are used to identify the conditions that afflict a patient. While there is a general consensus on what characterizes a particular condition, there are nuances that vary between countries or more specifically between companies in different countries. One customer, a South American insurance company, for example, used some ICD-9 codes in its billing software that were not used in the English disease management product. It also did not use other codes that were.

In the same way and for the same reasons, the medical procedure codes used by overseas customers did not correspond exactly to those used in the American product. While mapping the additional or missing procedure codes to existing ones was not too complicated, the underlying changes

to the database, testing, review and customer approval took time, in some cases weeks. Translation of the names of any missing procedures or conditions, on the other hand, took only minutes and was provided through public sources.

The bad news

Missing or extra codes did contribute to a larger problem, that of adapting clinical rules to a foreign culture. The clinical rules are at the heart of the disease management engine. In response to changes in the patient record — changes such as a newly diagnosed medical condition or a recent medical procedure — one or more clinical rules may be invoked and a medical provider, a caregiver or the patient might be obligated to perform a health-related action of some kind.

As you can probably guess, the new or missing procedure and condition codes necessitated changes in these clinical rules. Hundreds of clinical rules needed to be reviewed and several dozen modified, tested and validated.

While this localization task was time-consuming, the real problems began with the translation of the diagnostic questionnaires and of their responses. The responses — whether entered by the patient online or by a nurse speaking by telephone with a patient — are evaluated by the clinical rules in the same way that a new condition or procedure entered into the patient record is. Unlike codes, the responses provide much more individualized information that the system can use to profile accurately a patient's health needs.

While translating these questions and responses is straightforward, the localization effort is far more difficult. Levels of sensitivity to health-related inquiries vary from country to country. Some of these are based on what services the government provides, what practices it bans and what it forbids. In most European countries, for example, a medical practitioner would not ask for the percentage of time a seat belt is worn, since it is mandated by law. In India, however, asking about a seat belt would be irrelevant because they are not commonly used. In addition, there is a wide range of sensitivities to materials that ask questions about one's ethnicity, income, social responsibility within a community or access to clean drinking water. Questions on these topics are commonly asked of Americans in health questionnaires.

For example, Figure 1 shows a screenshot of one questionnaire in English. Note that there is a question on seat belt use.

Figure 2 shows a screenshot of the health screen adapted for use in France. A question on seat belt use does not appear.

While the simple elimination of a culturally inappropriate question may not seem important, it means that one or more underlying clinical rules also have to be adapted in order to generate a culturally appropriate health profile for the patient. Consultation with in-country and in-culture specialists is required to reassign weights to different responses and to modify the overall questionnaire scoring. This cycle of revision, review and approval of any underlying rules takes time.

Odds and ends

We encountered other unexpected issues when localizing supplemental health material. We knew

Quick Screen	
In general how would you describe your current health?	○ Excellent ○ Very Good ○ Good ○ Fair ○ Poor ○ Not applicable: patient currently hospitalized
Hospitalizations	○ Currently in the hospital ○ Hospitalized within the last 30 days ○ No hospitalization within the last 30 days
Do you wear a seat belt at all times?	○ Yes ○ No
Do you smoke?	○ Yes ○ No

Figure 1: Health evaluation screen used in the United States.

Évaluation Rapide	
Comment est votre état de santé en général?	○ Très bon ○ Bon ○ Assez bon ○ Mauvais ○ Très mauvais ○ N/A: adhérent actuellement hospitalisé
Hospitalisations?	○ Adhérent actuellement hospitalisé ○ Adhérent ayant été hopitalisé dans les 30 derniers jours ○ Pas d'hospitalisation dans les 30 derniers jours
Fumez-vous?	○ Oui ○ Non

Figure 2: Health evaluation screen adapted for France.

that different units of measurement would be required when translating food-related information. We did not know, however, that the number of calories in standard items also varies across countries. A whole raw fresh egg, for example, can range in calorie count depending on which size is used as the standard in a particular country. Each size increment adds an additional ten calories, and can range from 54 calories in a small egg to 90 in a jumbo egg.

Related to this, translating materials about healthy eating can be tricky because nations that belong to the EU use both kilojoules and kilocalories when labeling food, while American documents only track "calories," the commonly used term for kilocalories or more precisely a "kilogram calorie." In Australia, there is a generation gap where older people still refer to "kilojoules" and the younger generation talks about "calories." The use of calories rather than kilojoules is a preference, and it warranted the use of both units of measure in material on nutrition. When discussing healthy eating in France, on the other hand, calories were not mentioned at all in comparable translations, since it would seem strange to do so in discussions concerning food.

One simple expression can become a stumbling block — and perhaps a political football — and can impede localization efforts. Finding the correct translation for *medical practitioner* is one example. Should it be the translated equivalent for doctor, general practitioner, primary care physician or clinician? This one is particularly difficult to get agreement on because it may vary by region, network, medical qualifications needed to practice in a country and by personal preference. When in discordant situations like this, it is useful to designate a local prechosen translation "referee" to pick a word that will be used across all materials in order to prevent wasted time in endless discussions about which word is best.

As is the case with any localization project, materials have to be created in the context of culturally acceptable colors, graphics and pictures. It is helpful to have style guidelines prior to beginning translation/localization in a new country or to look up visual color symbolism by culture. Graphics that are non-offensive in one culture can be very offensive in another and do not assume that seemingly generic photographs can be used across cultures. It can be helpful to contract with a local marketing firm to review materials before showing them to a client as it can prevent many embarrassing mistakes.

Localizing healthcare software products poses some unique challenges. When localizing disease management systems, the issues go beyond mere localization and may require modification of the underlying clinical rules and a remapping of ICD codes stored in the database. A reworking of questionnaires may also be required. The translation of more generic health related software may also present unexpected surprises. In all cases, it is essential to have local enterprises participate in review and approval of patient-facing software. [M]