

LETTER TO THE EDITOR

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Guiametabolica.org: empowerment through internet tools in inherited metabolic diseases

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Abstract

Web-based interventions are effective on the patient empowerment. *Guiametabolica.org* constitutes an interface for people involved in inherited metabolic diseases, trying to facilitate access to information and contact with professionals and other patients, offering a platform to develop support groups. *Guiametabolica.org* is widely considered for Spanish-speaking patients and caregivers with inherited metabolic diseases. Preliminary evaluations show changes in their habits, decrease in their senses of isolation and improvement regarding self-efficacy. Specific inherited metabolic diseases websites, especially participative websites, should be considered as a complement to more traditional clinical approaches. Their contribution lies in patient's general well-being, without interfering with traditional care.

Keywords: Dietary treatment, E-patient, Inborn errors of metabolism, Inherited metabolic diseases, Patient empowerment

Findings

Inherited metabolic diseases (IMD) are a very heterogeneous group of more than 500 rare diseases that mainly appear during childhood. The effectiveness of Web-based interventions on the patient empowerment, which is essential for patients with rare diseases for various reasons, has recently been proven [1-3]. *Guiametabolica.org* is a frequently-updated website in Spanish for people involved in IMD that facilitates access to information and contact with professionals and other similar patients, and offers a platform for developing support groups.

Guiametabolica.org offers (Figure 1): scientific information in easy jargon about clinical features, biochemical traits, genetics, treatment and prognosis of 56 IMD, translated abstracts of more than 300 articles, more than 100 tips and recommendations for daily life, 32 geolocated-resources, 172 specific recipes for controlled diets in proteins, carbohydrates and fat, and 6

stories for children in which IMD patients are the leading characters.

Through the comment field, *Guiametabolica.org* offers a chance to pose medical/nutritional questions to our clinical team, and to share experiences among families. The target population is estimated at about 62,000 people around the world, considering Spanish speaking people involved in IMD.

Aiming to evaluate our platform and to analyse the effect of the social network initiative in a public hospital setting and focalized in different rare diseases, we elaborated a questionnaire. E-patients and e-caregivers' feelings and self-perceptions, as well as their developed skills and abilities, were analyzed as a measure of their empowerment process.

Guiametabolica.org in the internet

In 22 months we registered 243,305 visits and 663,497 page views, from more than 100 countries, and with average time on the site of 2:45 minutes (Figure 2). Near 70% of the visitors came from Latin America (Figure 3). *Guiametabolica.org* registered 886 comments that have been handled by the nutritional/medical staff (Table 1). There is equilibrium between those comments regarding

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Regístrate | Accesibilidad | Mapa web | Buscar:

guía metabólica SANT JOAN DE DÉU HOSPITAL UNIVERSITARI DE BARCELONA

ECM | CONSEJOS | LA CUINETA | APRENDER JUGANDO | INFORMACIÓN | ¿QUIENES SOMOS?

/ ECM
Guía metabólica dispone de información, consejos y recursos de casi 60 **Errores Conocidos del Metabolismo**.

/ NUESTRAS RECETAS
En La Cuineta tenemos sabrosas recetas adaptadas para la alimentación restringida en **proteínas, grasas o glúcidos**, y también puedes enviarnos tus propias recetas para compartirlas.

/ CONSEJOS
A partir de las experiencias de padres y profesionales incluímos **recomendaciones útiles** que pueden ayudar en el día a día de las familias, en la escuela, en los deportes o en la alimentación.

INICIO DE SESIÓN
Usuario:
Contraseña:
INICIAR SESIÓN
[Crear nueva cuenta](#)
[Solicitar una nueva contraseña](#)

Comentarios recientes
HSJD Dra. M Serrano en **Tirocinemia tipo 1**
HSJD Nàtalia Egea en **Aciduria metabólica**
HSJD Dra. M Serrano en **Aciduria glutárica tipo 1**
fanfrúcula en **Aciduria glutárica tipo 1**
marce-mazo en **Aciduria metabólica**

/ Información médica
El yogur, producto de las bacterias
18/01/2012
Uno de los productos alimentarios elaborado por el ser humano más antiguo es el yogur, que surgió por casualidad cuando los nómadas de Oriente intentaban conservar la leche de sus animales en contenedores hechos con la piel de éstos, que contenían bacterias.
Actualidad médica alimento del mes yogur **Actualidad**

El Síndrome de Lowe, incorporamos este ECM a Guía metabólica
11/01/2012
El síndrome de Lowe es una enfermedad metabólica hereditaria multisistémica (afecta a la función renal, el metabolismo óseo, el sistema nervioso, la vista...), causada por una alteración en la **enzima Fosfatidilinositol (4,5) bifenolato 5-fosfatasa**.
Actualidad médica fosfatidilinositol (4,5) bifenolato 5-fosfatasa membrana celular PIP2 síndrome de Lowe síndrome oculo-cerebro-renal **Actualidad**

Quiénes está en línea
Actualmente hay **2 usuarios** y **9 invitados** en línea.
Usuarios en línea
- Jordi
- HSJD Dra.MAVilaseca

/ Eventos
Celebra con Guía metabólica el Día de las Enfermedades Raras
29/02/2012
El 29 de febrero es un día muy especial para los **Errores Conocidos del Metabolismo**, se celebra el **Día de las Enfermedades Raras**, coordinado a nivel internacional por **EURORDIS**. En Guía metabólica queremos celebrarlo de una forma muy especial, para lo que os pedimos vuestra colaboración.
Eventos Día Mundial de las Enfermedades Raras ECM **Actualidad**

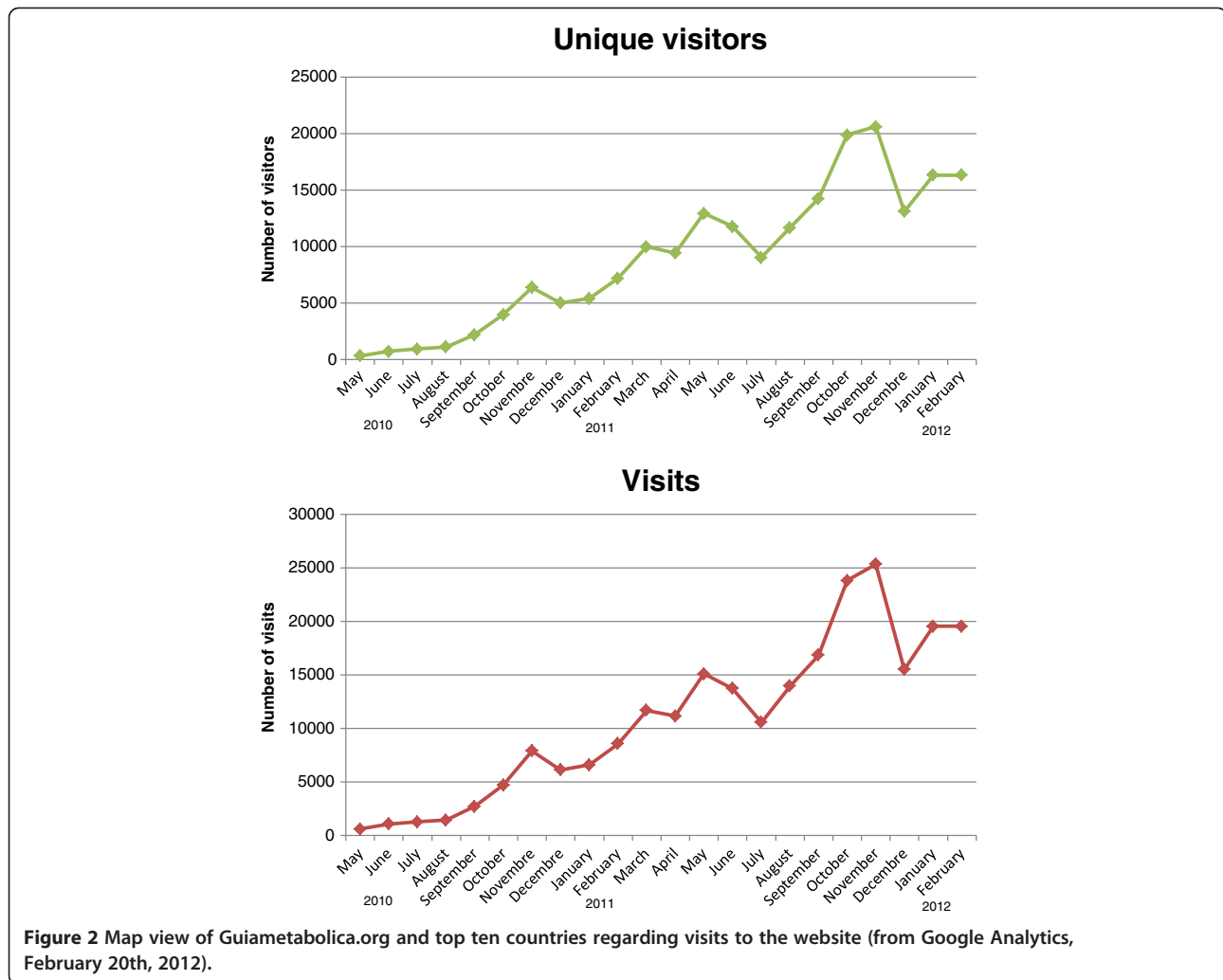
/ Buscador de recetas
Dieta controlada en:
 Proteínas Glúcidos Grasas
Platos:
 1º plato 2º plato Postre
 Aperitivo Salsas Panes Masas Fiesta
Ingrediente:
BUSCAR

/ Recetas
 Glúcidos Proteínas Grasas
Quiche de calabacines
Usuario: magali
Trinchado de olivas negras
Usuario: Familia Moreno Riquelme
Ensalada de patata, pimiento y bacalao
HSJDBCN

/ Envía tu receta
¿Tienes alguna receta deliciosa que quieres compartir?
[Inicia sesión](#) o [regístrate](#), envíanosla y nuestro equipo médico valorará su publicación en La cuineta.

Un proyecto de: **SANT JOAN DE DÉU** **Associació Catalana PKU-ATM** **WEB de médicos acreditados**
Con el apoyo de: **GOBIERNO DE ESPAÑA** **PLAN AVANZA L333** **ER ciberes**
Núm. Ref.: TSI-070100-2009-134
Sobre el web: [Aviso legal](#) y [Condiciones de uso](#) [Política de protección de datos](#)
Desarrollado por:

Figure 1 Home page of www.guiametabolica.org.



educational issues and those related to *Guiametabolica.org* function as a support group (Table 2).

Helpfulness of the different categories of contents is represented in Table 3. Concerning educational issues, 93.6% of questionnaire responders discovered new information or increased their knowledge. Regarding changes in daily life, 50.1% changed or developed at least one new habit. Regarding feelings of solitude, 75.4% of the visitors acknowledged that they felt less lonely and 72.4% realized that they were doing well when getting in touch with others in the same situation.

Conclusions

To the best of our knowledge, this is the first interactive website focused on IMD in Spanish providing plain language information about a large number of IMDs and offering online consultations with medical/nutritional staff.

There is probably an excess of health information on the Internet [4], especially true for prevalent diseases.

However, regarding rare diseases there is a lack of information, particularly easy-to-understand information. *Guiametabolica.org* offers relevant and up-to-date information in easy jargon that is, in fact, considered one of the most useful contents by our visitors. A sense of personal empowerment is often achieved by acquiring relevant information and knowledge, especially when information is acquired through direct access to relevant sources [5,6]. Moreover, successful communication may be especially important for patients with chronic clinical conditions, such as IMD patients [7].

We believe that *Guiametabolica.org* role in some of the developing countries of Latin America, has to do with the limited resources that they have for health, particularly for rare diseases. We think that *Guiametabolica.org* can contribute to overcome the “health digital divide” providing users and professionals of developing countries useful information and tools to manage IMD diseases.

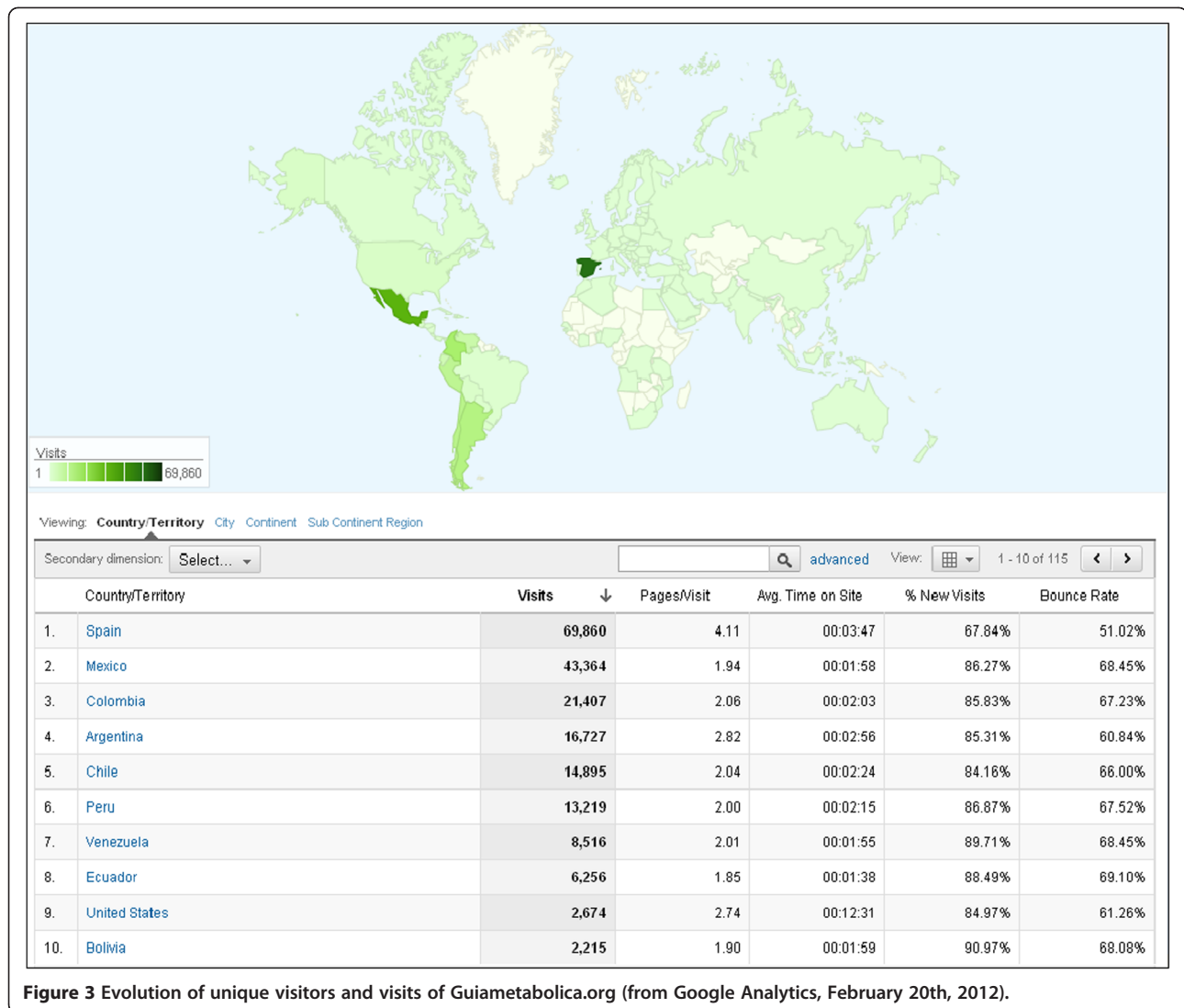


Figure 3 Evolution of unique visitors and visits of Guiametabolica.org (from Google Analytics, February 20th, 2012).

Table 1 Typology of contributions

Number	Kind of contribution
	Comments/Questions/Answers
257	Medical/nutritional questions
324	Medical/nutritional answers from nutritional/medical staff
73	Medical/nutritional answers from other users
69	Requests to contact other patients/caregivers
163	Other kinds of intervention
	Recipes
133	Guiametabolica staff
40	Users/ Fundación Alicia/ Consumer Eroski
	Geolocated Resources
22	Guiametabolica staff
10	Users

Users of *Guiametabolica.org* are very participative, probably due to the particular profile of our users; rather than e-patients, they are mainly e-caregivers (more than 80%). They are normally parents with a young child suffering an IMD, and then they are 30-to-50 years old, increasing their likelihood of being digital natives [8].

Furthermore, parents acting as e-caregivers could be more active and participative for two powerful reasons. The first one is related to strong filial affection, and the second one is due to the disconcerting situation of a child suffering a chronic illness. Caring for a child with chronic situation can become burdensome and can impact upon the physical and psychological health and, ultimately, the well-being of the caregivers [9]. In the case of rare diseases, this situation may lead to uneasiness and usually generates numerous questions that

Table 2 Analysis of users' questions (20th December 2011)

Comments/questions' topics	Percentage	Comments
Comments related to <i>Guiametabolica.org</i> function as a support group		
Requests to contact other patients/caregivers	17.5%	Frequent situation: a family with a young child suffering an IMD with plenty of uncertainties about future, demanding contact with older patients or parents
Patients' experiences and reflections, tips or recommendations.	13.0%	All of them with a positive point of view
Questions about practical issues of the daily life	5.8%	They include help for travelling, shopping, offers of special foods not needed anymore, information about government aids for chronic patients. . .
Messages exclusively to thank and express feelings	14.8%	Messages of gratitude and feelings are also incorporated in the vast majority of comments
Comments regarding educational issues		
Information about their IMD	22.1%	
		Doubts about diagnostic process 5.8%
		Doubts about treatments 5.4%
		Biochemical and pathophysiological doubts 4.0%
		Questions about clinical manifestations and evolution of disease 3.3%
		Therapeutic options under investigation 2.2%
		Questions about clinical/biochemical follow-up 1.4%
Doubts about other transitory or concomitant situations and their treatment	10.2%	
Doubts about dietary treatments and specific recipes.	16.6%	

need responses, making the e-caregiver more participative, involved and committed [10].

Our preliminary data show a decrease in feelings of loneliness among our users, as well as a reduced level of self-criticism; taken together, those results probably mean that the web is having an impact in the psychological and emotional health of the users.

We believe that specific IMD websites, especially online support groups, should be considered as a complement to more traditional clinical approaches. *Guiametabolica.org* contribution lies in the effect that it has on people's general well-being while not interfering with traditional care.

Table 3 Users' evaluation: Usefulness of contents

Content	Mean* (Standard Deviation)	No response
Specific recipes	3.42 (0.8)	14/81
Scientific/medical information	3.37 (0.9)	5/81
Medical/nutritional responses to comments	3.34 (1.1)	8/81
Tips and recommendations	3.28 (0.9)	6/81
News	3.16 (0.9)	10/81
Comments from other users	3.07 (1.0)	11/81
Tales and games	3.01 (1.0)	10/81
Geolocated resources	2.78 (1.1)	26/81

*Helpfulness of the different categories of contents was scored in a 1-to-4 Guttman scale (1 = strongly disagree, 4 = strongly agree) by the users.

Competing interests

The authors declare no financial or non-financial competing interest.

Authors' contribution

MA, MAV, JJF and MS contributed to the conception, design, organization and execution of the research project, and to the drafting of the manuscript. JC, MG, NG, MP and BGZ contributed to the acquisition of data, analysis and interpretation, and to the review and critique of the manuscript. FP, JPP and RA contributed to the review and critique of the manuscript. All authors reviewed and accepted the final version of the manuscript. The corresponding author is responsible for ensuring that author contributions and full disclosures appear on the submitted, revised, and final accepted manuscript.

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