

## S1 Image. Screenshot of the platform for co-creation activities

### IC-Health Community Platform



Welcome to the Platform for IC-Health Communities of Practice developed within the framework of the IC-Health project – Improving digital health literacy in Europe, funded by the H2020 programme of the European Commission.

IC-Health is a project to develop a series of Massive Open Online Courses (MOOCs) to help improve digital health literacy levels of European citizens. The project brings together representatives from five specific population cohorts:

- children (aged from 10 to 13 years)
- adolescents (aged from 14 to 18 years)
- pregnant and lactating women (PLW)
- elderly (aged over 60)
- citizens affected or susceptible to be affected by diabetes (type 1 and 2)

IC-Health population cohorts will work alongside researchers, healthcare professionals and web designers in a series of Communities of Practice (CoPs) to co-create the MOOCs. CoPs are a spontaneous phenomenon among people who share common interests and passion and who meet to learn from each other. CoPs will have several online meeting opportunities; moreover they will also interact on this platform to provide further feedback on MOOC structure and content.

The Platform is composed of different 'rooms', each one dedicated to a specific CoP, divided per country. Communities of Practice are moderated by appointed national coordinators from the IC-Health Consortium. In addition to CoP rooms, there is also an extra room called 'Europe' devoted to the exchange of knowledge and information on digital health literacy at EU level and to support the creation of a wider network of interest around the work of the IC-Health project.

If you are interested in taking part in the online co-creation of IC-Health CoPs and/or in joining the EU Platform for Digital Health Literacy, please go to 'Register' to create your own free account.

Before you dive in the IC-Health co-creation process, you might like a brief general explanation of platform's features and structure. You can read the guidelines by clicking here: [Guidelines for users](#).

Forum	Topics	Posts	Freshness
IEUI Europe EU Platform for Digital Health Literacy (15, 27)	15	42	1 year, 10 months ago Michelle Calabro
IBEI Belgium Enfants (de 10 à 13 ans) (5, 2), Adolescents (de 14 à 18 ans) (4, 2), Femmes enceintes et allaitantes (5, 2), Personnes âgées (plus de 60 ans) (5, 7), Patients atteints de diabète (type 1 ou 2) (8, 25)	27	64	2 years, 3 months ago Jessica
IDAI Denmark Børn (10-13 år) (0, 0), Teenagere (14-18 år) (8, 4), Gravide eller ammende kvinder (8, 6), Seniorer (ældre) 60+ (0, 0), Diabetespatient (type 1 eller 2) (8, 0)	24	34	2 years, 6 months ago Christianagaz
IDEI Germany Kinder (10-13 Jahre alt) (0, 0), Jugendliche (14-18 Jahre alt) (0, 0), Schwangere und stillende Frauen (0, 0), Ältere Menschen (> 60) (25, 38), Patienten mit Diabetes (Typ 1 und 2) (0, 0)	26	64	1 year, 11 months ago UU, TK
IITI Italy Bambini (10-13 anni) (7, 12), Adolescenti (14-18 anni) (6, 35), Donne incinta e lattanti (9, 23), Adulti sopra i 60 anni (10, 24), Pazienti con diabete (tipo 1 e tipo 2) (2, 3)	34	299	2 years ago Marco Polotto
INLI Netherlands Kinderen (0, 0), Adolescenten (0, 0), Zwangere en zogende vrouwen (0, 0), Ouderen (> 60) (9, 31), Patienten met diabetes (type 1 en 2) (0, 0)	9	40	2 years, 3 months ago Alfabeto Sejdor
IESI Spain Diabetes tipo 2 (18, 32), Niños (10-13 años) (4, 0), Adolescentes (14-18 años) (4, 0), Mujeres embarazadas y lactantes (11, 137), Adultos mayores de 60 años (18, 26), Diabetes tipo 1 (4, 13)	57	383	2 years ago Alexandra
ISEI Sweden Barn (10-13 år) (8, 11), Ungdomar (14-18 år gamla) (6, 9), Gravida och ammande kvinnor (6, 11), Personer med diabetes (typ 1 och 2) (6, 15)	24	70	2 years ago Linus Ersson
IUKI United Kingdom Older people (>60) (10, 7)	10	17	2 years, 7 months ago Asinobi Okunwade



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**S2 Table. Illustrative quotes from Focus Groups**

Experience/general opinion using internet for health and illness issues
<p>All mothers agreed that internet has never or hardly ever been the only or first source of information they consulted to get health-related information during pregnancy or after delivery. In most cases, they used internet because of failure in the communication with health professionals.</p> <ul style="list-style-type: none"> <li>– <i>“When doctors are not available or when the human touch is missing, internet can compensate this lack of empathy by health personnel”.</i></li> <li>– <i>“Doctors quite often have different opinions about health issues. How to treat disease, how to behave, etc. So, internet can help to compare these views and take a decision”.</i></li> <li>– <i>“If doctors talk too technical, I don’t understand”.</i></li> <li>– <i>“When I was seven-months pregnant I went the Emergency Room very upset because I had some contractions, and the midwives really treated me badly, screaming at me... So, which is patients’ reaction in these cases? They go home and the next time, rather than going back to the hospital, look on the web”.</i></li> </ul> <p>In the case of lactating women, they consider it can be beneficial when it is difficult to move from home, for example in the postpartum period when it is difficult to move around with a small baby. The most relevant benefit is the chance to find information and knowledge which can empower the person and know what is available and have things done the way one prefers. In fact, some say they have made changes thanks to the information they found on the Internet.</p> <ul style="list-style-type: none"> <li>– <i>“Empower yourself. Because the only way to change things is that patients get empowered and that when you reach there, they cannot do whatever they want, and this we have to change it”.</i></li> </ul> <p>Finding other people experiences is another of the benefits participants recall, it is a relief if you find other people who have something like you.</p>
Participants’ needs and expectations of the use of Internet as source of information on health and illness issues
<p>Participants expressed different and varied informational needs, including:</p> <ul style="list-style-type: none"> <li>• Information on pregnancy in general (e.g., phases) and more specific information about the aim and type of periodical texts/exams pregnant mothers are due to throughout pregnancy</li> <li>• Information on delivery, to get prepared to it</li> <li>• Information on how to donate milk or umbilical cord after delivery</li> <li>• Information about the possibility/process/opportunities of freezing of stem cells after delivery</li> <li>• Vaccine/vaccination</li> <li>• Drugs leaflets and side-effects</li> <li>• Availability of alternative care</li> <li>• Information on weaning and feeding induction, with focus on self-managed weaning</li> <li>• Information on diseases/illnesses/conditions they had never heard about before or they are not familiar with</li> </ul>
Participants’ trust on internet as source of information on health and illness issues
<p>Most participants could not clearly identify situations/topics for which they would not trust internet as source of information. Only one mother clearly stated she never consulted internet (and will ever do it) about vaccines/vaccination.</p> <ul style="list-style-type: none"> <li>– <i>“I refused to look on the internet about vaccines. I know the web is full of fake news about it and I simply didn’t want to assist or take part to that debate”.</i></li> </ul> <p>Another mother stressed on the poor utility of internet when the required information is more ‘emotional’ and entails a great deal of empathy (e.g., information on bodily changes during pregnancy).</p> <ul style="list-style-type: none"> <li>– <i>“Issues like ante-natal courses and preparation to delivery cannot be fully understood if read... you need sharing views with other peers, to listen to midwives’ indications, to make questions... maybe a webinar can help, but certainly websites are not enough”.</i></li> </ul> <p>Most mothers considered information on health/illness found on the internet trustful when:</p> <ul style="list-style-type: none"> <li>• The source of information is known and authoritative (e.g., scientific sources or health professionals’ opinion)</li> <li>• Multiple sites confirm/report it</li> <li>• The information found on internet was shared, discussed and confirmed also by experts / health professionals</li> </ul> <ul style="list-style-type: none"> <li>– <i>“I trusted that website since information was provided by a registered and referenced midwife, not anonymous, with full credentials disclosed”.</i></li> </ul>

- *“I tend to verify the source of information... I look for sites linked to health institutions, health professionals’ orders, research centres. I don’t link not science-based sites”.*
- *“When I look for information on the internet, I always try to compare information retrieved from different sites and I check the nature of the website... for example when the site is sponsored by a commercial brand, I am more cautious than when it is linked to scientific bodies”.*

#### **Perception of the use of internet as source of information on health and illness issues by other people**

In general, participants would not recommend to their peers the use of internet as source for information on health, due to the combination of widespread poor-quality information (e.g., on vaccines and vaccination) and most people’s lack of capacities to properly distinguish between reliable and not reliable sources. In case internet is used, they would recommend paying attention to the source of information (e.g., sites which may aim is to promote/sell products are not recommended) and to compare different sources, paying attention to their authority.

Also, many participants would encourage medical doctors to consider internet not only as a threat to their authority but as a possible ally in informing or educating patients/mothers, by recommending the consultation of reliable websites.

- *“Once I spoke with my gyn about googoling health information, she told doctors are fully aware of this practice among patients and think this habit affects their work”.*

S3 Image. Screenshot of general appearance of the Spanish MOOCs updated version

Inicio   Curso   Discusión   Wiki   Progreso   Instructor

Curso > ULL IC-HEALTH-05 Uso de Internet para la salud en mujeres embarazadas y lactantes. Nivel 2 > Comienza el curso > Menú

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The diagram features a central pink circle with the text "IC-Health+ Improving digital health literacy in Europe". Surrounding this central circle are six units, each represented by a circular icon and a text label:

- Unidad 0. Introducción al curso** (Icon: Home)
- Unidad 1 - Alfabetización Digital en Salud** (Icon: Person with a plus sign)
- Unidad 2 - Búsqueda de información de salud disponible en Internet** (Icon: Magnifying glass over a heart)
- Unidad 3 - Comprender la información de salud disponible en Internet** (Icon: DNA helix)
- Unidad 4 - Evaluar la información de salud disponible en Internet** (Icon: Document with a plus sign)
- Unidad 5 - Aplicar la información de salud disponible en Internet** (Icon: Heart with a pulse line)

IC-Health+ Improving digital health literacy in Europe

Este es un proyecto ha recibido financiación del programa de investigación e innovación H2020 de la Unión Europea bajo el acuerdo de subvención Nº 727474


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   **Gobierno de Canarias**

## S4 Image. Screenshot of an example of the content of the unit "Find" of the Spanish MOOCs updated version


Inicio Curso **Discusión** Wiki Progreso Instructor

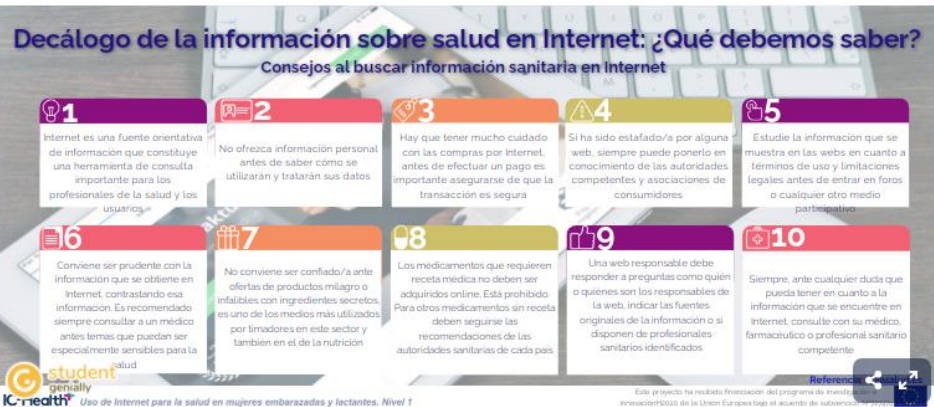
Curso > ULL IC-HEALTH-04 Uso de Internet para la salud en mujeres embarazadas y lactantes. Nivel 1 > Comienza el curso > Menú

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comenzamos por una serie de consejos generales que debemos conocer al buscar información sanitaria en Internet:



Si deseas ampliar la siguiente **infografía**, dirígete a la esquina inferior derecha, y dale al icono que se muestra así 



**Decálogo de la información sobre salud en Internet: ¿Qué debemos saber?**  
Consejos al buscar información sanitaria en Internet

- Internet es una fuente orientativa de información que constituye una herramienta de consulta importante para los profesionales de la salud y los usuarios.
- No ofrezca información personal antes de saber cómo se utilizarán y tratarán sus datos.
- Hay que tener mucho cuidado con las compras por Internet, antes de efectuar un pago es importante asegurarse de que la transacción es segura.
- Si ha sido estafado/a por alguna web, siempre puede ponerlo en conocimiento de las autoridades competentes y asociaciones de consumidores.
- Estudie la información que se muestra en las webs en cuanto a términos de uso y limitaciones legales antes de entrar en foros o cualquier otro medio participativo.
- Conviene ser prudente con la información que se obtiene en Internet, contrastando esa información. Es recomendado siempre consultar a un médico antes temas que puedan ser especialmente sensibles para la salud.
- No conviene ser confiado/a ante ofertas de productos milagro o infalibles con ingredientes secretos, es uno de los medios más utilizados por timadores en este sector y también en el de la nutrición.
- Los medicamentos que requieren receta médica no deben ser adquiridos online. Está prohibido. Para otros medicamentos sin receta deben seguirse las recomendaciones de las autoridades sanitarias de cada país.
- Una web responsable debe responder a preguntas como quién o quiénes son los responsables de la web, indicar las fuentes originales de la información o si disponen de profesionales sanitarios identificados.
- Siempre, ante cualquier duda que pueda tener en cuanto a la información que se encuentre en Internet, consulte con su médico, farmacéutico o profesional sanitario competente.

 **student**  
 **IC-reality** Uso de Internet para la salud en mujeres embarazadas y lactantes. Nivel 1

Referencia  

Este proyecto ha recibido financiación del programa de investigación e innovación digital de la Unión Europea bajo el acuerdo de subvención 101017993.

Si lo deseas, puedes descargar este recurso siguiendo [este enlace](#).