ENABLE Repository Delphi survey - study information letter

What is this study about?

Adherence to medication has been found to be suboptimal in numerous chronic conditions and to have a negative impact on chronic disease management, patient’s general health status, quality of life and working abilities as well as health care costs and waste. Numerous technologies exist to support medication adherence, yet few are implemented into practice. An online interactive repository of available technologies may facilitate their selection and adoption by different stakeholders. Developing such repository is among the main tasks of the ENABLE COST Action (CA19132), within the remit of Working Group 2. To meet this challenge the ENABLE Action includes a large interdisciplinary network of experts in medication adherence from 39 European countries and has initiated several activities towards these goals. A definition of medication adherence technologies and a framework of attributes were developed. The framework was structured into three domains (product and provider information, medication adherence descriptors and evaluation and implementation) branching in attribute groups, which branch further into sublevels with related labels and definitions.

What to expect from study participation?

The proposed definition and framework will be evaluated in a real-time online Delphi study by stakeholders from 39 countries with research, practice, policy, patient representation and technology development backgrounds. It is expected that you and other invited stakeholders evaluate the proposed the relevance, clarity and completeness of the definition and repository attributes. All participants have multiple opportunities to reconsider their evaluations based on aggregated feedback updated in real-time.

Participants are invited to rate the degree of relevance and clarity of the proposed definition of medication adherence technologies, and of each attribute group, by placing a dot on a 2D-grid; the position of the dot on the vertical axis indicates clarity (low to high = bottom to top), and its position on the horizontal axis indicates relevance (low to high = left to right). Participants are encouraged to provide their comments and suggestions (anonymously) on the comments section and engage with other participants’ comments.

We will stop the survey when a predefined number of participants will respond, and when stability of responses will be reached. We will summarize the results descriptively and compare evaluations across stakeholder groups and countries. We will quantify agreement among stakeholders on proposed attribute groups using the IPRAS analysis technique from RAND/UCLA Appropriateness Method.
How to participate?

Firstly, by this email we extended our invitation to you and are asking for authorization to use your email within the scope of this study. If after considering this information you agree to participate, please access directly the link provided in the email sent from the eDelphi.org. You will be formally asked about your consent to participate when you will access the survey after a brief introduction, and the questions will appear only once you will consent to this study.

How are data collected and stored?

For this study it is necessary to collect some personal data. This includes your name and email address, as well as your age, gender, field of work/expertise, country, education level and the role of your participation with years of experience in it (researcher/academic; healthcare practitioner; policy/decision maker; patient representation; eHealth/IT specialist). Your name and email address are not linked to other data you provide by answering the survey. The personal data will not be visible to other respondents. The personal data used for conducting this study will be stored until the end of the COST Action ENABLE (October 2024) and then erased.

Ethical and data protection approvals

This study obtained ethics approval from Malaga Regional Research Ethics Committee in April 2021. In addition, the Delphi protocol was determined as compliant regarding data protection and security by Data Protection Officer from University of Basel.

For more information about your rights on data processing, and further questions about the project please contact the ENABLE-R Delphi at wg2enablecost@gmail.com.

On behalf of the ENABLE WG2 Steering Committee,

Alex Dima and Urska Nabergoj Makovec