MyDiabet.es Pilot Research Project Results

CHRODIS
ADDRESSING CHRONIC DISEASES & HEALTHY AGEING ACROSS THE LIFE CYCLE

THIS REPORT ARISES FROM THE JOINT ACTION ADDRESSING CHRONIC DISEASES AND HEALTHY AGEING ACROSS THE LIFE CYCLE (JA-CHRODIS) WHICH HAS RECEIVED FUNDING FROM THE EUROPEAN UNION, UNDER THE FRAMEWORK OF THE HEALTH PROGRAMME (2008-2013).

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I. Background

Accessible, easy to understand and accurate information is a valuable tool to empower patients, caregivers and their families. Health information can be used to provide information on health conditions and medical needs to patients, caregivers and their families. People, who are health literate have lower mortality rates, are less likely to use healthcare services (shorter stays, fewer visits), engage in safer use of medicine and better manage their chronic conditions than are those with low health literacy.[i,ii,iii]

Health literacy remains a huge issue throughout the European Union (EU). The first European Health Literacy Survey in 2011 found, on average, 12% of people have insufficient and 47% had limited health literacy in the eight case countries (Austria, Bulgaria, Germany, Greece, Ireland, the Netherlands, Poland and Spain). Large discrepancies exist with regard to health literacy both within and across EU Member States with insufficient or limited health literacy rates varying between 29% and 62% of national populations. Certain groups notably low socioeconomic status, low education, low social status and older age, had disproportionately high levels of insufficient or limited health literacy.[iv]

Patients trust the information they receive from their healthcare providers.[v] Healthcare professionals can use targeted health information to educate and to support their patients, helping them manage their health and avoid potentially adverse outcomes. Information can act as a reminder, e.g. medication compliance, and can support information given during a consultation.[vi,vii] Thus, healthcare professionals are a vital resource for increasing patient health literacy. However, few studies exist that explore healthcare professionals understanding of health literacy and the barriers to patient access.[viii,ix]

As a result, this Pilot Project seeks to:

1. Assess the need for health literacy information; and
2. Obtain preliminary feedback on the information that should be included in an online tool in the future.

II. Methodology

MyDiabet.es is a Pilot Research Project that examines the need for the provision of accessible, easy-to-understand and accurate health information on medical conditions. In 2016, the MyDiabet.es Pilot Research Project conducted an extensive review of the available diabetes information. This information was then critiqued by a group of diabetes patients to ensure the content was comprehensive and met their information needs.

Diabetes has been selected as the case study for the Pilot Research Project in line with the JA-CHRODIS objectives. Diabetes is the fourth most common cause of death in Europe, affecting 32 million adults in 2013. Diabetes information was used as a case study to identify patient information and literacy needs and to provide the inputs to the website content for test purposes.

This research also examined the current methods and tools available to the various healthcare professionals and other stakeholders that interact with patients to prevent, manage and control their diabetes. The Project has identified the existing challenges, gaps and opportunities for improvement with regard to health information in order to ensure that health professionals have the appropriate tools to provide appropriate support to patients. Basic health literacy information has been compiled from the existing knowledge base and written in accessible language.

The prototype website is currently only in English with sets of basic texts covering the areas identified by interaction with a test group of diabetes patients. The Pilot serves as a needs assessment to help determine the requirements that potentially need to be included in the specification of tools designed to manage trusted information provision as a service. In the future model (potentially to be developed depending on the results of this Pilot Research Project), providers would be able to easily adjust the information to meet individual patient needs.

A survey was created in English using Survey Monkey. The prototype was reviewed and the survey completed by two groups of experts:

1. Participants from JA-CHRODIS; and
2. Healthcare professionals in Europe.

The experts were asked to assess the need for this type of tool and information. They also rated the prototype, including the existing topics and information. They were asked to identify gaps and make suggestions for improvements. User feedback is vital in order to determine and to meet the health information needs of patients, healthcare professionals and other stakeholders.

III. Results

Survey distribution began on February 16th, 2017 to healthcare professionals and JA-CHRODIS work package leaders (for distribution to relevant WP participants). The data was exported on February 25th, 2017. As of February 25th, 44 experts had responded. Respondents were allowed to skip questions in the survey when they saw fit.

The results have been disaggregated into three sub-categories:

i. Respondent Demographics;
ii. Health Literacy Information Needs Assessment; and
iii. MyDiabet.es Pilot Project Feedback. The central findings are summarised in this section.

The results indicate:

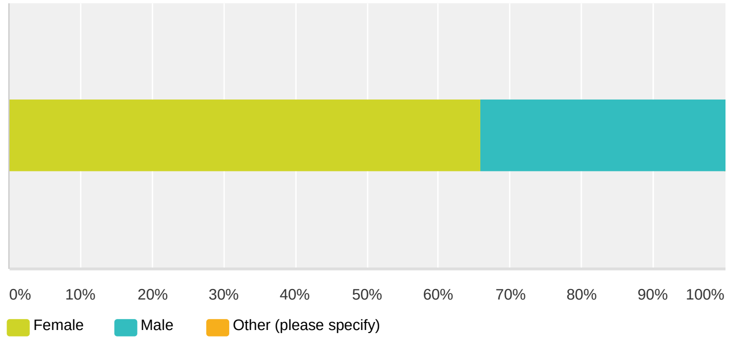
1. A significant perceived need for health literacy information; and
2. Preliminary predominantly positive feedback on the MyDiabet.es pilot website as a potential health literacy tool.

i. Respondent Demographics

All respondents identified their sex/gender in question 1 (Q1). Although the survey was distributed to roughly an equal number of women and men, the respondents were disproportionately female. This result is not entirely surprising; some academic studies have indicated that women respond at higher rates than do men.[x] Sex/gender factors should be factored into further studies and into project design. Future studies should also make concerted efforts to try to illicit roughly proportionate responses from men and women.

Q1 What is your sex/gender?

Answered: 44 Skipped: 0

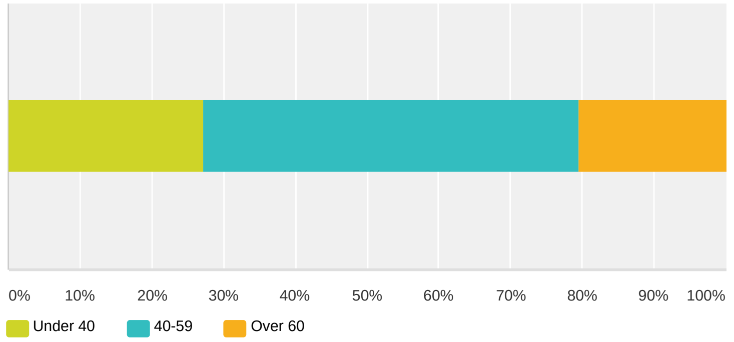


Answer Choices	Responses	
Female	**65.91%**	29
Male	**34.09%**	15
Other (please specify)	**0.00%**	0
Total		**44**

All respondents noted their age in Q2. More than half of respondents were between the ages of 40 and 59. About a quarter of respondents were over the age of 60. The remainder of responses was from those under the age of 40. Further studies should further explore the opinions of those healthcare professionals under the age of 40, because training and education offers an opportunity to educate healthcare professionals on health literacy and technology.[xi]

Q2 What is your age?

Answered: 44 Skipped: 0

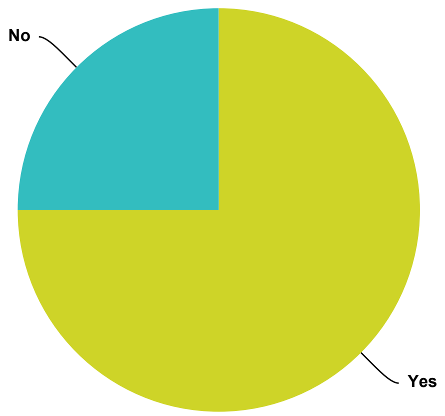


Answer Choices	Responses	
Under 40	**27.27%**	12
40-59	**52.27%**	23
Over 60	**20.45%**	9
Total		**44**

Most respondents are healthcare professionals based on the findings of Q3. They were also the target audience for the pilot research project. A quarter of respondents are not healthcare professionals. The survey was also distributed to various JA-CHRODIS partners, which likely accounts for the non-healthcare professional audiences. Non-healthcare professionals also are a valuable audience, offering potential insight from a patient, caregiver and/or public perspective.

Q3 Are you a healthcare professional?

Answered: 44 Skipped: 0

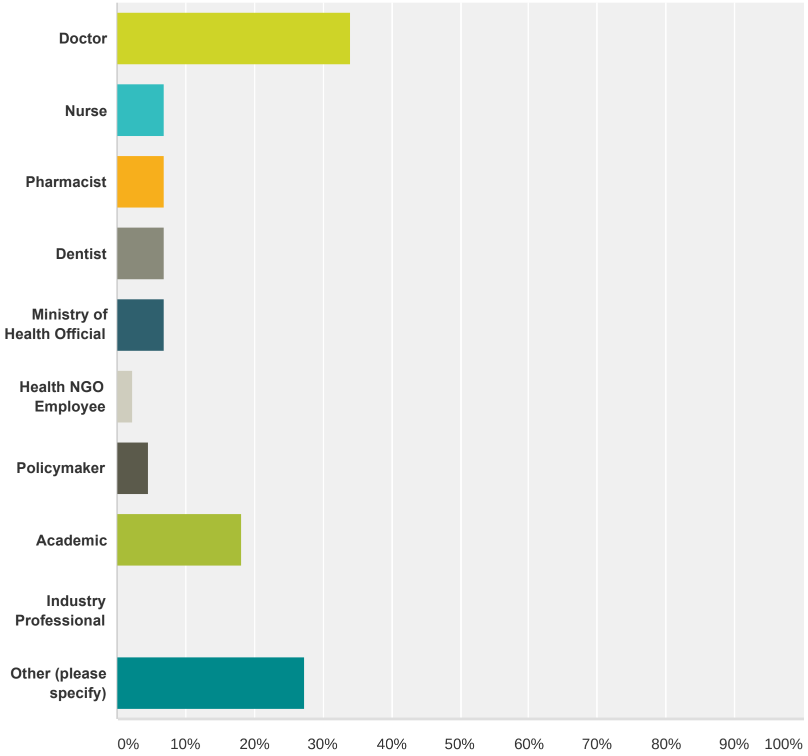


Answer Choices	Responses	
Yes	75.00%	33
No	25.00%	11
Total		44

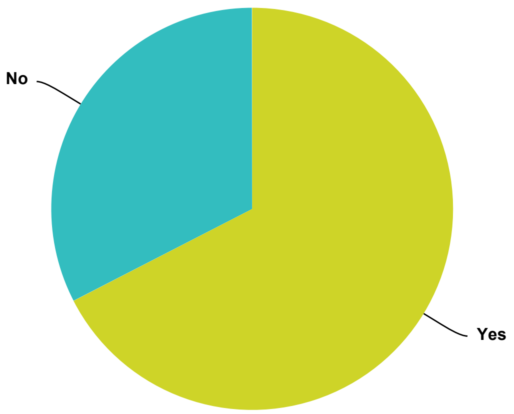
The respondents covered various professions in the healthcare sector. Doctors comprised the largest single professional group. The “Other” category is primarily comprised of those identifying as researchers. It also included other professionals, such as nurse practitioner, optometrist, scientific officer, and patient advocate. Further surveys should include a larger number of respondents from the various professional groups and should disaggregate based on the profession in order to be customise the tool development to provider needs. Based on the current sample size, variation between types of healthcare professionals cannot be reliably tested.

Q4 What is your profession?

Answered: 44 Skipped: 0



Answer Choices	Responses	
Doctor	34.09%	15
Nurse	6.82%	3
Pharmacist	6.82%	3
Dentist	6.82%	3
Ministry of Health Official	6.82%	3
Health NGO Employee	2.27%	1
Policymaker	4.55%	2
Academic	18.18%	8
Industry Professional	0.00%	0
Other (please specify)	27.27%	12
Total Respondents: 44		



Q5 Do you work as part of a multidisciplinary team?

Answered: 43 Skipped: 1

Answer Choices	Responses	
Yes	**67.44%**	29
No	**32.56%**	14
Total		**43**

The pilot survey was distributed to a diverse group of healthcare stakeholders from a variety of ages and Member States in February 2017. 27 of the respondents identified their nationality: Belgium (1), Bulgaria (1) Czech Republic (1), Germany (2), Ireland (2), Italy (6), Lithuania (2), Netherlands (3), Portugal (2), Spain (1), Sweden (1) UK (2) and Other (2). Concerted efforts in the future should be taken to ensure a representative sampling across all EU Member States. If the tool is to be further developed, some countries could potentially be selected as case studies.

Overall, some gaps and potential biases possibility exist, which is expected in a preliminary survey with 44 responses. Further surveys should representatively sample large groups of healthcare professionals across Member States in order to establish more generalised conclusions and ones that account for cultural differences. Nonetheless, the results indicate that there is a large perceived need for more health literacy information, which the next section explores.

ii. Health Literacy Information Needs Assessment

After answering basic demographic questions, the participants were asked an open-ended question, “What is your interest in health information?” in Q6. The 35 responses are listed below and indicate a range of answers.

Q6 What is your interest in health information?

CVD, gender dimension, pregnancy complications

Diabetic retinopathy

Evidence Based Medicine, Technology

Expand knowledge

For proper patient education

Great interest

Health information technologies

Health information/education is the foundation to solid personal healthcare

I provide it to patients

I used to be a healthcare professional. Also have cared for seriously ill family members

I'm interested in health information because I need it for making decisions in my ordinary day

I'm working for a guideline developing organization. We provide patient information based on evidence.

If it is gender sensitive in content, presentation and intention

Implementation of diabetes self-management support projects

Knowledge transfer to professionals

Making best health evidence accessible to all

Management of patients

Medical imaging

My interest is in Safety and Compliance

Not sure

Physical activity, diet, alcohol

Preconception healthcare, prevention

Professional

Professional interest

Providing information to the public

Research

Research interest

Research, patient has to get evidence-based information for shared decision making

Scientific evidences

To empower patients in managing their chronic diseases

To increase patients' knowledge and attendance to exams

To inform patients according to their age and sex

To raise awareness of health or clinical conditions

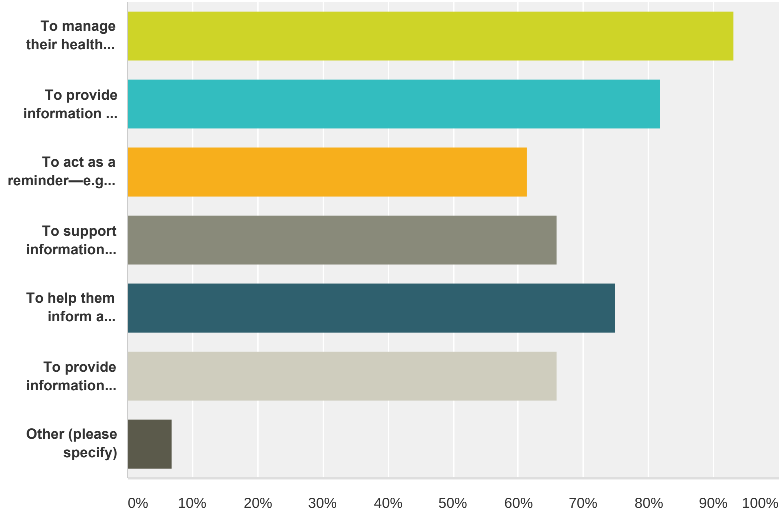
Trying to improve it

Unbiased evidence based information

Following the inquiry into their general interest in health literacy information, respondents were asked about the health information needs of patients in Q7. Overwhelmingly, participants perceived a patient need for health literacy information for multiple reasons, most notably for managing health conditions (93%) and providing information on conditions (82%).

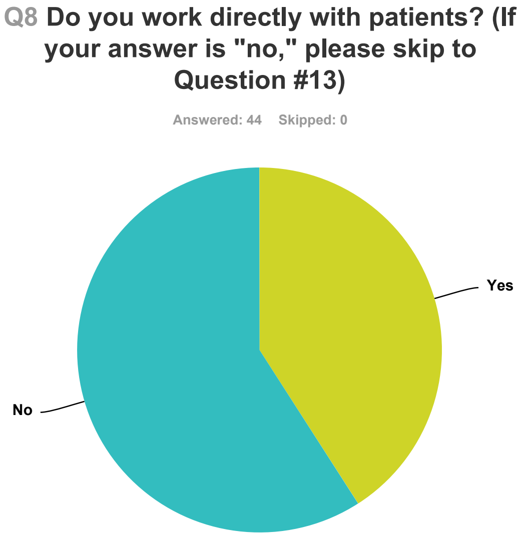
Q7 Do you perceive a need for health-related information for patients? If so, their information needs are (please check all that apply):

Answered: 44 Skipped: 0

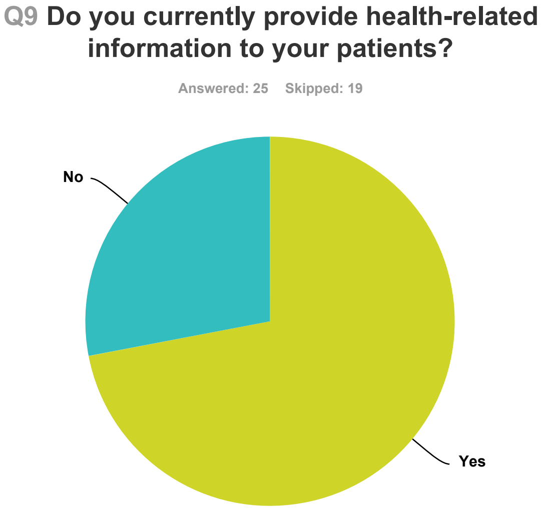


Answer Choices	Responses	
To manage their health and avoid a potentially adverse health condition or outcome.	93.18%	41
To provide information on a health or medical condition.	81.82%	36
To act as a reminder—e.g. medication compliance.	61.36%	27
To support information that you gave during a consultation.	65.91%	29
To help them inform a partner, family member or carer about their condition and/or needs.	75.00%	33
To provide information about available services.	65.91%	29
Other (please specify)	6.82%	3
Total Respondents: 44		

Although the survey participants are in the health sector, not all respondents work directly with patients . About 41% of respondents work directly with patients, as illustrated in Q8.

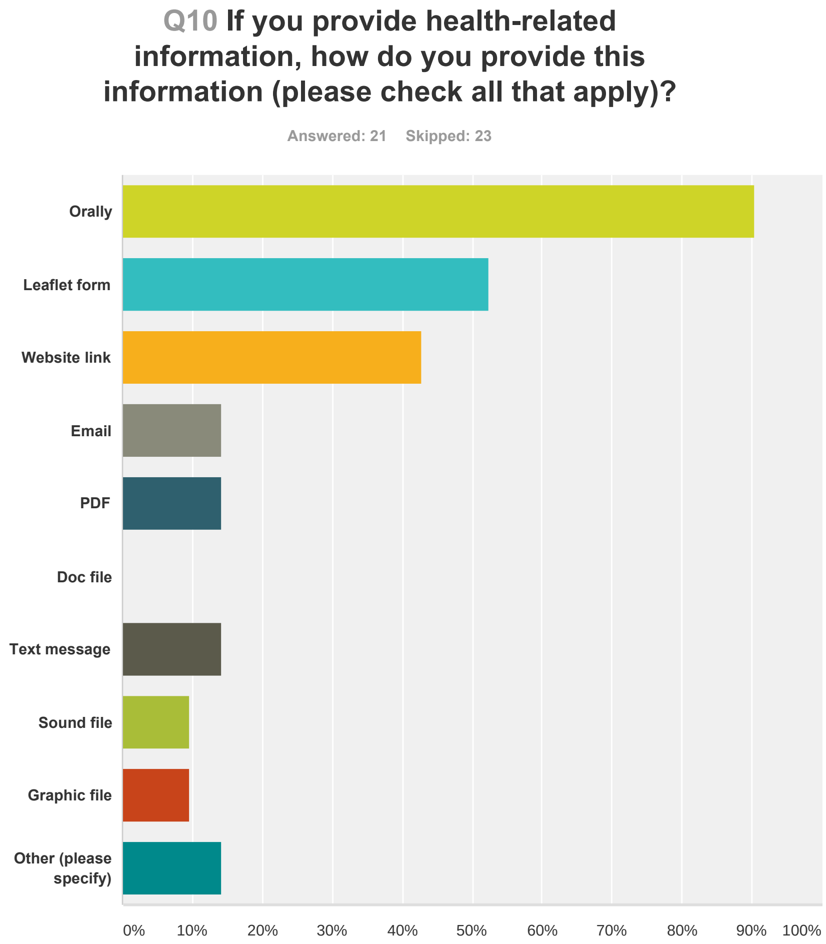


Answer Choices	Responses	
Yes	40.91%	18
No	59.09%	26
Total		44



Answer Choices	Responses	
Yes	72.00%	18
No	28.00%	7
Total		25

Respondents who provide health-related information do so in various forms, as indicated in the results from Q10. Oral provision of information is the most common form of provision of health-related information (90%), followed by leaflets (52%) and websites (43%). Other electronic forms are less common (email, PDF, text and file). In “Other,” radiology reports, EHR Portal and trustworthy health applications were also noted as sources.

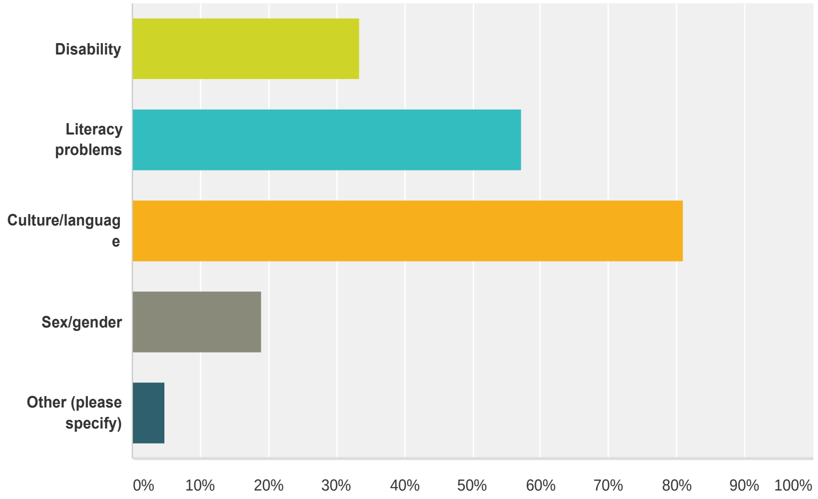


Answer Choices	Responses	
Orally	**90.48%**	19
Leaflet form	**52.38%**	11
Website link	**42.86%**	9
Email	**14.29%**	3
PDF	**14.29%**	3
Doc file	**0.00%**	0
Text message	**14.29%**	3
Sound file	**9.52%**	2
Graphic file	**9.52%**	2
Other (please specify)	**14.29%**	3

Healthcare professionals indicate that most have had to deal with patient with information access issues in their responses to Q11. The top obstacle is culture and language (81%) followed by literacy problems (57%). Disability (33%) and sex/gender (19%) are not as prominent; this finding possibility warrants further investigation to determine whether this finding is due to the prevalence of the issue or a lack of awareness on the topic. Not knowing where to get additional information is listed under “Other.” The findings indicate that information access issues are an important factor to consider with regard to health literacy.

Q11 Have you dealt with patients who have issues with accessing information due to any of the following (please check all that apply)?

Answered: 21 Skipped: 23

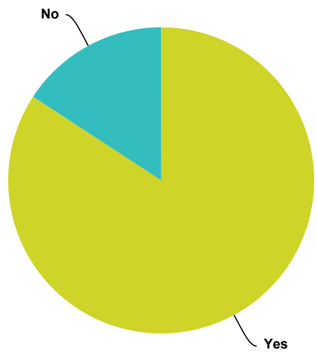


Answer Choices	Responses	
Disability	**33.33%**	7
Literacy problems	**57.14%**	12
Culture/language	**80.95%**	17
Sex/gender	**19.05%**	4
Other (please specify)	**4.76%**	1
Total Respondents: 21		

Moreover, the majority (84%) of respondents would provide personalised/individualised information and/or detailed directions for treatment to their patients if they have the appropriate information tools and support.

Q12 If you currently do not provide personalised/individualised information and/or detailed directions for treatment, would you consider doing so if you had the appropriate informational support /tools?

Answered: 19 Skipped: 25



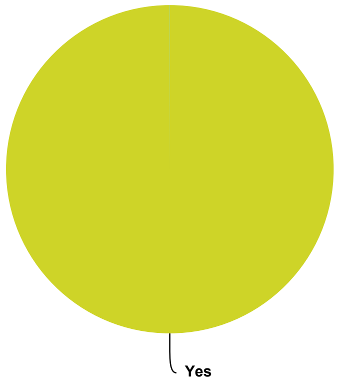
Answer Choices	Responses	
Yes	84.21%	16
No	15.79%	3
Total		19

One of the strongest findings of the survey is the ubiquitous perceived need for more personalised/individualised approach to provide information to meet the needs of patients, family members and/or caregivers. **Every** (all 44) respondent perceives a need for personalised health literacy information. This result strongly indicates a need for further studies on the topic and possibly the development of an intervention to correct this issue.

Co-funded by the Health Programme of the European Union

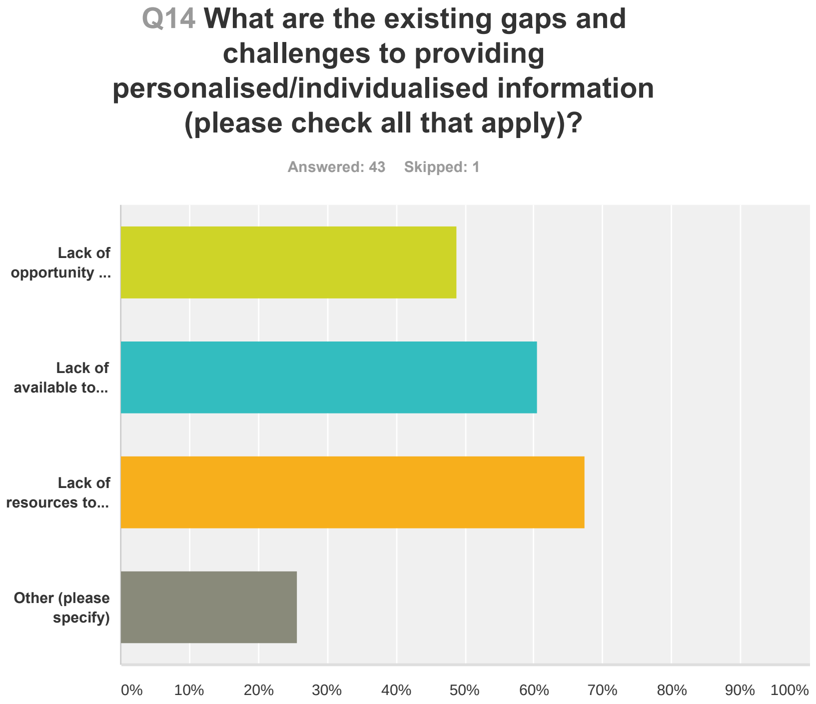
Q13 Do you see a need for a more personalised/individualised approach to providing information to meet the needs of patients, family members and/or caregivers?

Answered: 44   Skipped: 0



Answer Choices	Responses	
Yes	100.00%	44
No	0.00%	0
Total		**44**

The results from Q14 indicate a perceived need from healthcare professional to have more tools, resources and opportunities to personalise information for patients. Respondents noted a lack of resources to provide detailed information (67%) and a lack of tools to personalise information for patients (60%) are the top gaps and challenges.


Q14 What are the existing gaps and challenges to providing personalised/individualised information (please check all that apply)?

Answered: 43 Skipped: 1

Answer Choices	Responses	
Lack of opportunity to personalise information for patients.	48.84%	21
Lack of available tools to personalise information for patients.	60.47%	26
Lack of resources to provide suitably detailed information.	67.44%	29
Other (please specify)	25.58%	11
Total Respondents: 43		

Overall, results from the survey indicate a large need for a more personalised and accessible approach to provide healthcare information to patients. Thus, the preliminary survey findings support the need for the development of tools to provide accessible and customised information to patients. Barriers, including culture/language, must be incorporated into the tools. Preliminary results suggest much support in the health community for improved health literacy information. The final section of the survey explores the respondents' feedback on the Pilot Research Project in order to work to develop a tool that meets the existing gaps and challenges with regard to patient health literacy information established by the survey.

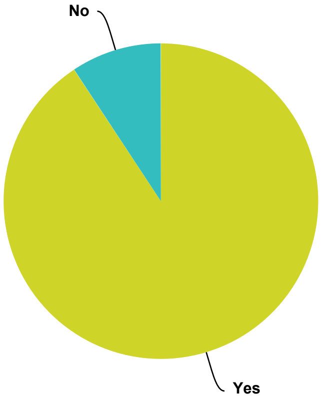
iii. MyDiabet.es Pilot Research Project Feedback

The survey provides strong preliminary evidence for perceived health literacy gaps and barriers in the health sector, particularly amongst healthcare professionals working with patients. There is a lack of tools for healthcare professionals to provide accessible and personalised health literacy information.

Another aim of the MyDiabet.es Pilot Research Project is to provide information on diabetes in order to design a tool to provide health information to help fill the gap and to address unmet needs. The results from Q15 illustrate that 91% of the respondents believe that http://mydiabet.es website could provide the basis for addressing the existing health literacy challenges to provide health information to patients.

Q15 Using the model, do you think that http://mydiabet.es pilot website could provide a basis for providing health information to patients?

Answered: 43 Skipped: 1

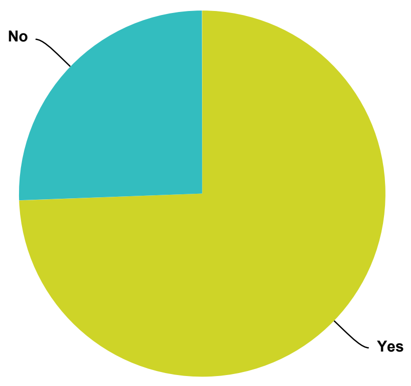


Answer Choices	Responses	
Yes	90.70%	39
No	9.30%	4
Total		43

The majority of respondents (74%) like the existing structure of the pilot as summarised in Q16, indicating that the basic design of the Pilot offers some promise for providing health literacy information.

Q16 Do you like the existing structure of the pilot?

Answered: 43 Skipped: 1

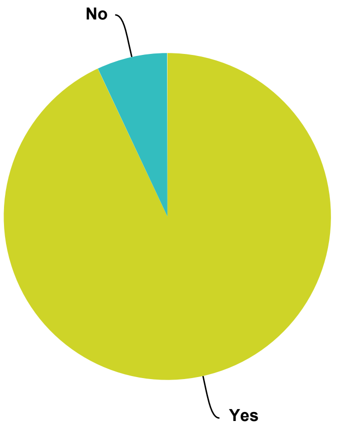


Answer Choices	Responses	
Yes	74.42%	32
No	25.58%	11
Total		43

Moreover, Q17 indicated that most respondents (93%) like the existing topics covered by the Pilot. Thus, reviewing the existing information and summarising it provides a strong basis for the development of healthcare information.

Q17 Do you like the existing topics covered by the pilot?

Answered: 43 Skipped: 1



Answer Choices	Responses	
Yes	93.02%	40
No	6.98%	3
Total		43

However, the results from Q18 indicate that not all topics have been fully covered. Therefore, expert review will be essential to developing health literacy information tools. A few respondents suggest providing additional information on services, for example. There are also suggestions to improve the visuals of the Pilot by employing graphics. The design and layout also should be improved. Gaps, such as the lack of information targeted at caregivers, are also pointed out. The majority respondents were positive about the Pilot and provided much constructive feedback to improve the Pilot in the future with regard to information covered, functionality and layout.

Q18 Using the model, can you suggest how http://mydiabet.es be improved? What topics and tools should be included?

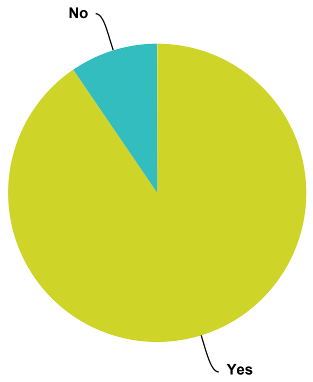
sex and gender differences; e.g. Whereas men predominantly feature impaired fasting glucose, women often show impaired glucose tolerance
It is a lot of information. The presentation can be more appealing. Please see www.thuisarts.nl as an example (sorry, only available in Dutch)
a personalized page showing only info relating to a particular patient, not topics that don't apply
Customizing the information to local resources
No
Information on local pharmacy, doctors and medical services
Give sliding scale examples and show how to use. Show how to count carbs and worksheets. Show how to rotate injection sites. More pictures. People like to see examples
General information should be the first thing you see when on the homepage (i.e. definitions). More topics on the links between diabetes and periodontal disease in the mouth
More visuals, less text, more organization, it appears too lengthy, tools for patients who speak other languages. Most of this information is available already in EHRs or on existing websites.
It depends on the National/local organization of care
It should work well as a reliable repository of information, but I think it lacks the capacity to really engage patients.
Should this website be improved in the future I would recommend considering a more user-friendly layout/design. Currently it might be difficult to find exactly what you need as a patient. Also a topic spefically for the carers such as parents of diabetic children or elderly patient would add a value to the overall project. Otherwise - a great tool.
There is not a section: The Prevention of the Diabetes
Adding a section for family carers
Information on safety of Diabetes drugs in pregnancy
expert patients programme, use of ICT tools, schools of patients...
Better presentation, e.g. through tags; info about common myths; info about roles of professionals and quality of care
Look at Mayoclinic.org/diabetes
Prevention, comorbidities
sex and gender, changing wording (cases - individual patient information contradictory), life

context is missing, risk communication is not available, commanding tone; health information should present options for individuals, differently for women and men, for their informed health decisions.
Dislipidemia, insulin delivery systems, CGM, mutually agreed written care plans, access to patients' notes and correspondence, annual reviews, a named nurse specialist coordinating personal care
Outreach to locations / trusted information portals so that patients and professionals can easily find information. Adapt the messaging to the mindset of the end user not the researcher / academic
I think it is a good start, that needs improvement regarding accessibility, structure, and layout. The idea, however, is good and bears a lot of potential, in particular if the work is extended to other areas.
novel technologies for home glucose monitoring
Less text, more graphic
glucose tolerance test and selftest

Preliminary results in Q19 indicate a strong consensus (90%) on the need to customise the website for national guidelines, recommendations and organisation of services further in the website's development.

Q19 Should this resource be adapted for the local context by including information on national guidelines/recommendations and the organisation of care/services?

Answered: 42 Skipped: 2

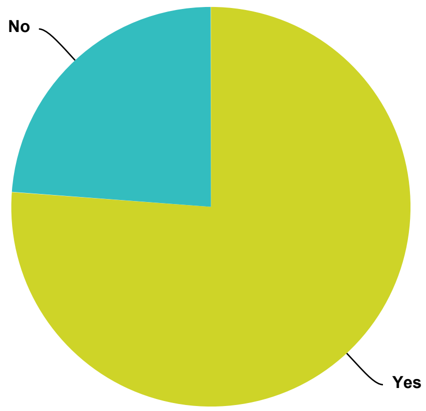


Answer Choices	Responses	
Yes	90.48%	38
No	9.52%	4
Total		42

Most respondents (76%) felt that the Pilot website could be a valuable tool in their countries. This result is promising and indicates that the Pilot site warrants further study and development.

Q20 Do you think that this pilot website could be a valuable tool in your country?

Answered: 42 Skipped: 2



Answer Choices	Responses	
Yes	76.19%	32
No	23.81%	10
Total		42

Overall, the feedback was supportive and positive, indicating that there is not only a need for a new resource, but also that the Pilot may serve as a good base for addressing the unmet needs moving forward. The diabetes information requires more development, including the addition of other topics, the inclusion of graphics, contextualised for local services and eventual translation into other languages beyond English.

Please provide other comments/feedback about health literacy information, the survey and/or the pilot website.

Needs to differentiate itself from other compendiums of health information (healthwise, etc).
I'm an ophthalmologist, in my opinion a wider and more detailed discussion of visual symptoms should be provided, as well as information about guidelines-related exam scheduling, and the need of retinal screening diffusion, sometimes a way to discover an unknown diabetes.
Need this info in all languages
I personally think videos would be a good advancement in health information, especially those who cannot read, do not have access to internet, could be viewed in a waiting room,

or on a mobile device.
The proposal is interesting, but the content cannot be simply translated, it has to be adapted to the National guidelines/recommendations, and to the specific organization of care, and it has to be harmonized with other National materials/tool. Translation and adaptation of the content would require long time and strong efforts.
As is, the pilot seems to overlap with other existing sources of information. It lacks a practical feel to it and indeed at times it reads as a medical journal!
Overall a great pilot - as practitioner I would strongly recommend such tool for the patients. As for something to consider - maybe a more "attractive" form of information supply should be considered - not only through regular website but also mobile application. Also a place for discussion where patients could share their experiences and thoughts would be a nice touch.
COMPLIMENTS
Suggestion for website: information in levels - e.g. 3 : basic, more detailed and related to other topics. I will address more target groups (according education, health literacy etc.)
the information would have to be updated on a regular basis
1. Accurateness is questionable because the content is too sloppy: incomplete in terms of available information, missing explanations of the problems and solutions that are offered, without references to the sources. 2. More attention should be paid to the motivational value of the information and presentation. 3. The language must be tested on the future consumers, taking into account possible differences in gender, age and health literacy. 4. The advices must be fine-tuned for the country and health system involved. 5. The lay-out of the pages is not adequate: logo dominates content header f.i. .6. The accessibility of the site is hindered by the lack of a possibility to return immediately to the index (and not at the bottom of a page).
Local or national adaptation and complementary information related to a specific context could be useful; language issues should be taken into account
Pilot website: as an individual with diabetes, i will come to the conclusion to have/to be a problem, to be a risk/life is full of risks, the future offers only dark prospects, deterioration.
I am academic but your questiosn aer mainly related to practitioners, so I am not the right person and do not feel convenient with ersponding, as the topic is important it deserves more expert knowledge from practitioners than I could provide andit makes little sensehe
Good luck it is a great idea
Simplify, use imagery, graphics that go beyond words to explain the management of the condition. Give clear calls to action. End users will use qualtity sources of information. I cannot see (yet) where the site gives more value than a simple google search. This subscription based site could be an interesting benchmark http://www.uptodate.com/home
Usefulness in various countries: I think the information provided already differes very much from one country to the other. So, I guess, it can be really useful, in particular if extended to a one-stop-shop for information on diseases, but can be considered not necessary in other countries.
Figures and tables would improve readibility
at least there so many websites in sweden with information, but of course collected one and multilanguage would be of interest;

IV. Summary and Conclusions

The survey results support the concept that accessible, easy to understand and accurate health literacy is a valuable tool to empower patients, caregivers, their families and healthcare professionals. Much misinformation is available online, so it is important to have a reputable online tool to healthcare services. The preliminary findings show that those in the health sector, particularly healthcare providers, value providing health literacy information to patients, families and caregivers.

The survey illustrates that healthcare professionals perceive a need to access a range of health information and to have the ability to edit, store and disseminate the information to patients, their families, caregivers and others. The majority of respondents do not feel there are sufficient tools and resources to provide this type of information to their patients. As a result, most professionals currently provide information to their patients orally or with a brochure. However, they indicate they would use an online tool if it were available. Health professionals could also benefit from having access to a community of their peers online where they could share information, co-produce results and have access to experts to show them better or best ways of developing the necessary results.

The preliminary survey results indicate the Pilot Research Project, MyDiabet.es, has potential, and its development should be explored. The respondents' feedback indicates support for the Pilot. The Pilot, if developed, has the potential to provide accessible, easy to understand and accurate health literacy on medical conditions to healthcare professionals, patients, caregivers, family members and the general public to reduce inequities both within and across Member States. The survey findings also indicate that there is a need for a reliable online resource that is accessible, accurate, free and available in various EU languages. Some Member States provide similar information, though there is no multilingual repository at present.

The survey highlighted various considerations that must be taken into account when moving forward. If the Pilot is pursued in the future, it must be properly developed to ensure that the information is comprehensive, accurate and customised for local needs and services. A large gap currently exists with regard to tools and resources to provide personalised health literacy information. However, the website in its current form does not allow for customisation. In addition, similar surveys conducted with patients, caregivers and families in the future as they will be future recipients and users of the information.

In summary, the Pilot Research Project illustrates that there are outstanding needs for health literacy information, notably in personalised informational resources. In addition, the preliminary feedback on MyDiabet.es shows support for the initiative and provides guidance on how to more effectively move forward.

V. References

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