Electronic Healthcare Records survey

Brief summary

Introduction

This is a summary report of a survey by the European Patients' Forum on the patients' perspective on electronic health records (EHRs). Having worked in the area of digital health for many years, we conducted the survey among its membership to further develop our positioning. We covered several key questions concerning access, use and understanding of current and potential uses for electronic health records.

The results of this survey will be used to help shape and develop EPF's policy advocacy and support us in providing a patient perspective to the various European initiatives that are taking place on the digital transformation in healthcare.

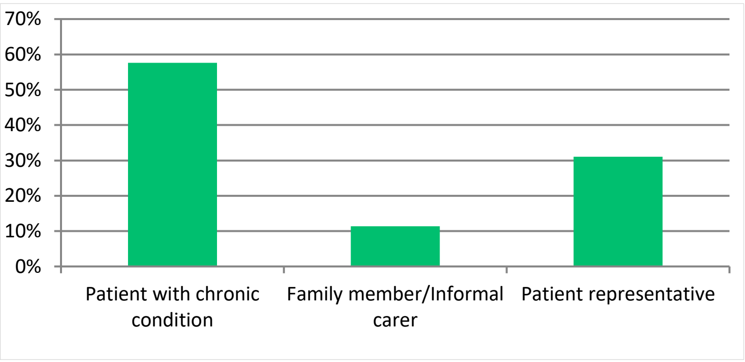
The survey ran for two months in November-December 2018 to give sufficient time for patient organisations and individual patients to reply. The questionnaire was co-developed with the EPF internal Digital Health Working Group and was disseminated to the entire EPF membership by email, distributed through the weekly members' newsletter and on social media.

In order to ensure that the survey could be answered by a wide range of individuals, it was translated into five languages in addition to the original English: Bulgarian, German, French, Spanish and Swedish. Languages were selected with the aim to ensure a balance of small and big countries, different types of healthcare systems, different levels of uptake of digital health,[1] different levels of digital literacy,[2] geographical spread around the EU, and trying to maximise the number of countries that we could reach with each language.

The survey received a total of 279 responses (199 to the English version, 23 to the French, 4 to the Spanish, 25 to the Swedish, 23 to the Bulgarian, and 4 to the German). Please note that the results presented in this summary are based only on the 199 responses to the English version of the survey.

Survey participants

Respondent categories



Just under half of the respondents were patient representatives. Slightly less than one third said they were themselves patients with chronic conditions, and around 10% said they were family members or informal carers. Respondents who selected the option "other" (17%) explained that they belong to more than one category.

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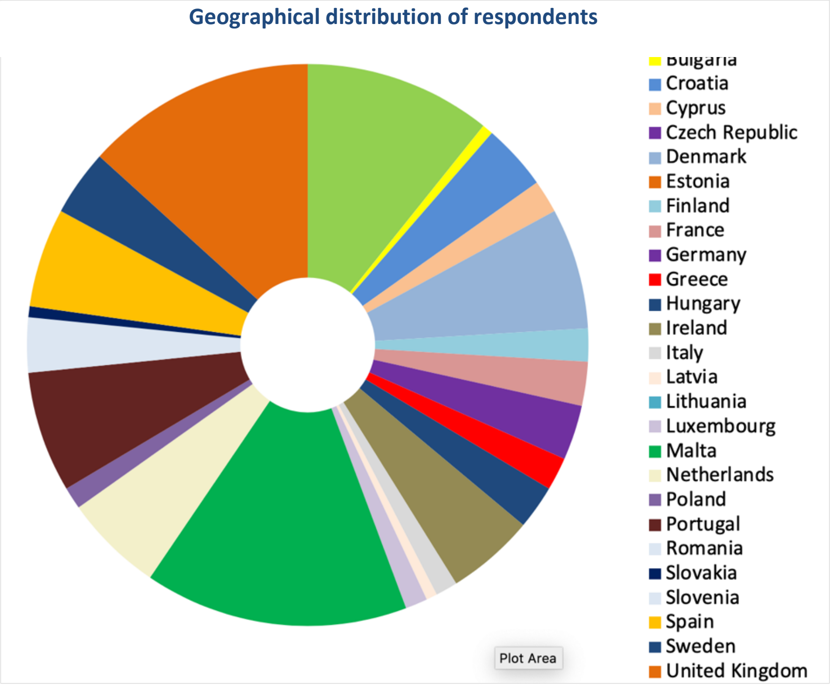
[1] http://www.euro.who.int/__data/assets/pdf_file/0012/302331/From-Innovation-to-Implementation-eHealth-Report-EU.pdf

[2] https://ec.europa.eu/eurostat/statistics-explained/index.php/Digital_economy_and_society_statistics_-_households_and_individuals

Participants were spread across age categories, with moderate peaks of respondents between 25 and 35 years old and between 55 and 63 years old. The gender balance of the respondents was about 70% women and 30% men.

Responses were unevenly spread between countries (though please note this summary includes only the results of the English-language survey). Belgium, the United Kingdom and Malta yielded 17, 24 and 21 responses, respectively. They are followed by Denmark and Portugal, with 11 responses each, Spain and the Netherlands with 9 each, and Ireland with 8. NO responses were received from Austria, the Czech Republic, Lithuania, Estonia or Slovenia.

Almost 80% of the respondents said they live in urban areas.



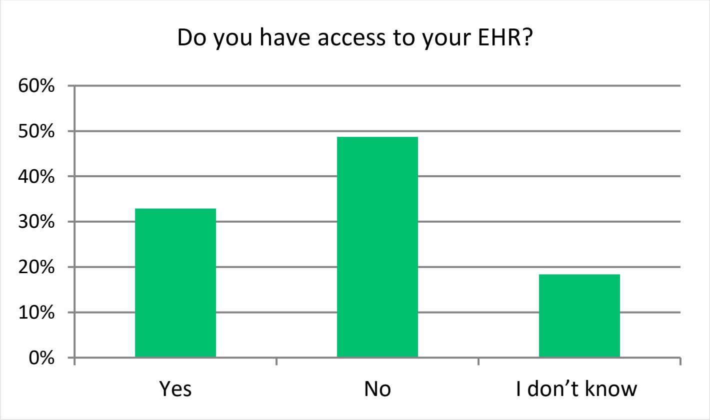
Main results and discussion

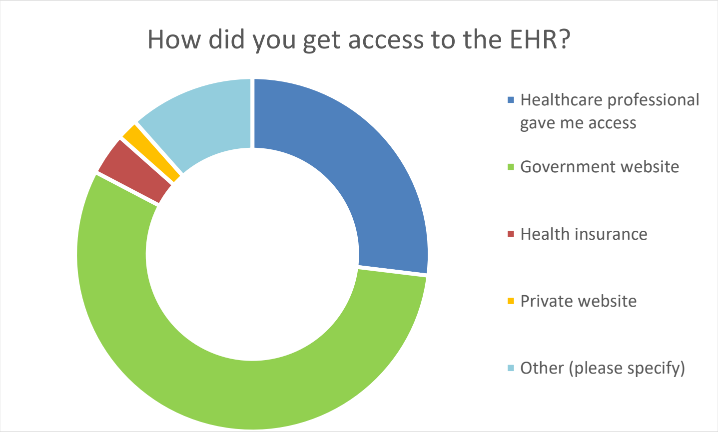
Our survey was divided into six main sections. Below, we present the summary results of each.

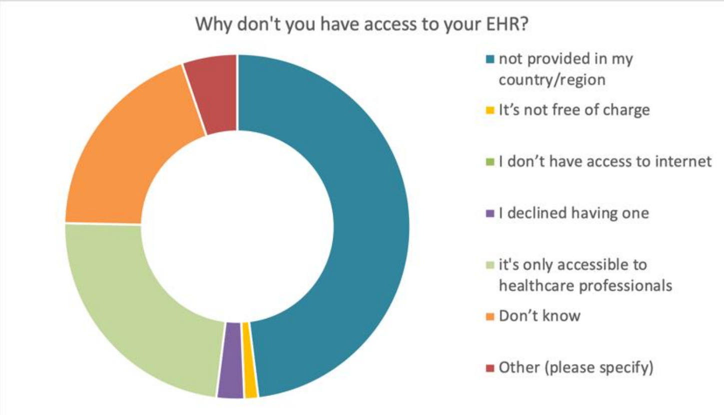
1. Patients' access to their own electronic health records

We first asked the respondents whether they have access to their Electronic Health Records.

Only a third of participants responded positively to this question (32,9%). The majority of respondents either do not have access (around 48,7%), did not know if they have access (around 18,4%).





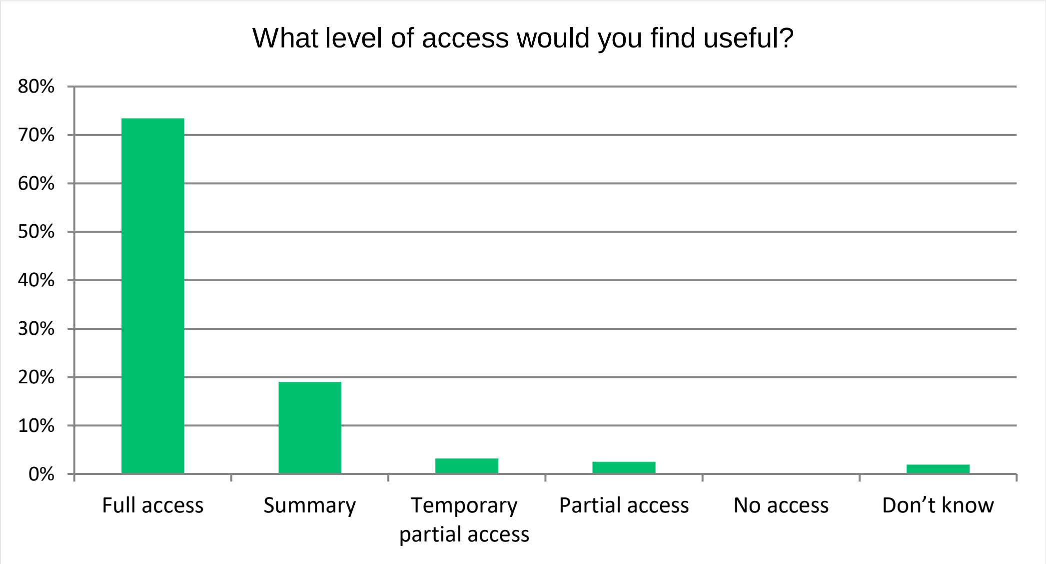


When asked how they got access to their EHRs, most respondents (55.8%) said it was possible through a government website. Some (26.9%) said they got access through healthcare professionals, and a minority through health insurance or a private company (3.8% and 1.9% respectively).

When asked about the **reasons why patients do not have access** to their EHRs, these were mainly connected to lack of EHR availability in their country or region (48%) or because access to these is not granted to patients (23.4%). In addition, 19.5% said that they did not know why they did not have access to their electronic records

Patients do want access to their electronic health records: 85.7% of the respondents answered in the affirmative with 7.8% saying they did not want access and 6.5% saying they did not know. This is a clear message to policymakers and needs to be taken further.

We asked patients what level of access they would prefer. Stating, "it is a patient's right to have full access to their EHR", we asked for preference between full access (same as the healthcare professionals); access to a summary (whose content would be agreed between patients and health professionals); temporary partial access (where the patient would not, for example, see the results of diagnostic tests until they had been formally informed); partial access (where professionals can mask some parts of the information), or no access.



A large majority of 73.4% wanted full access to their EHRs. 19% said they would agree to having access to a summary of the information, while a few respondents opted for partial access. No respondent said they did not want any access, whilst three said they did not know.

2. Patients' satisfaction with their electronic health records

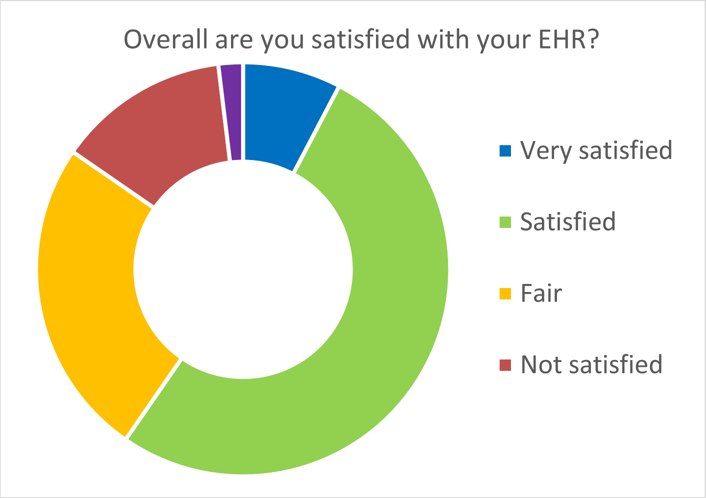
The following questions addressed those patients who do have access to their EHRs.

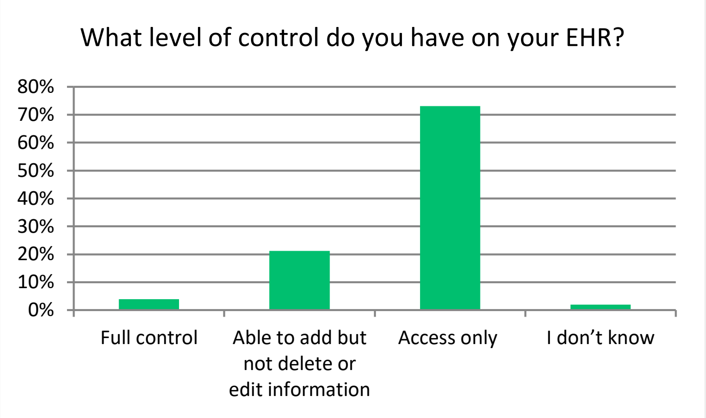
We patients **how satisfied they were with their EHRs**. The majority seem to be fairly satisfied (25%) or very satisfied (50%) with what they are provided with. There is however still room for improvement: around 15% of the participants shared negative comments regarding their EHRs.

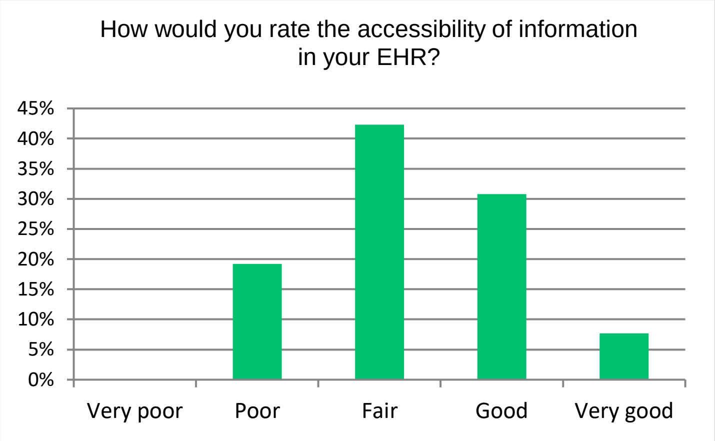
With regards **to modes of access and levels of control**, most respondents (73%) said they can only access their EHR but not edit the information. Some 21% said they could add information but not edit or delete; and two respondents (3.9%) said they had full control.

It should be noted, however, that the answers to this question varied significantly for respondents from the same country. Reasons for these variations should be further investigated.

We then asked respondents to rate the **accessibility of information** in their EHRs. Accessibility in this survey meant whether information in the EHR is presented in a way that is understandable, is easy to find, and is tailored to the individual patient's needs. A bit over a third rated the accessibility of their EHRs as good (30.8%) or very good (7.7%). Most respondents (42.3%) said it was fair, but a significant number (19.2%) said it was poor.



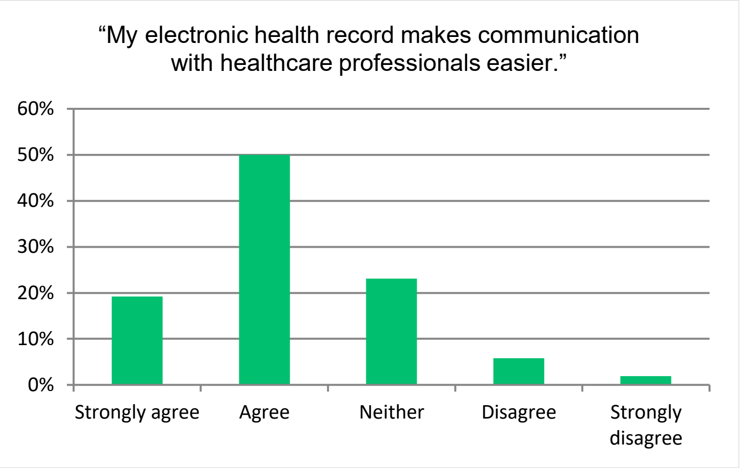


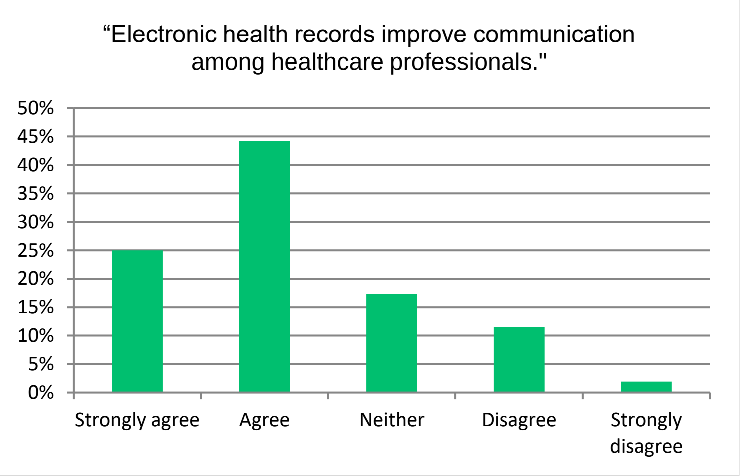


Moreover, **when asked whether the information in their EHRs was up to date and accurate** – whether it reflected the patient's health status/condition(s) – almost a third (26.9%) of respondents said it was not. This raises questions that warrant to be investigated further.

EPF has always called for easily understandable lay-language information for patients. This is particularly vital when it comes to the patient's own health information, given that access to one's own information is a cornerstone of patient empowerment. From the responses to the above question, it appears that many patients do not think their own EHRs are presented in an accessible way. More effort needs to be made across Europe to ensure that this is the case. The EHR should not only facilitate collaboration between healthcare professionals, but also enable patients and carers to understand their own health status and become active participants in their care.

3. Added value of EHRs perceived by patients



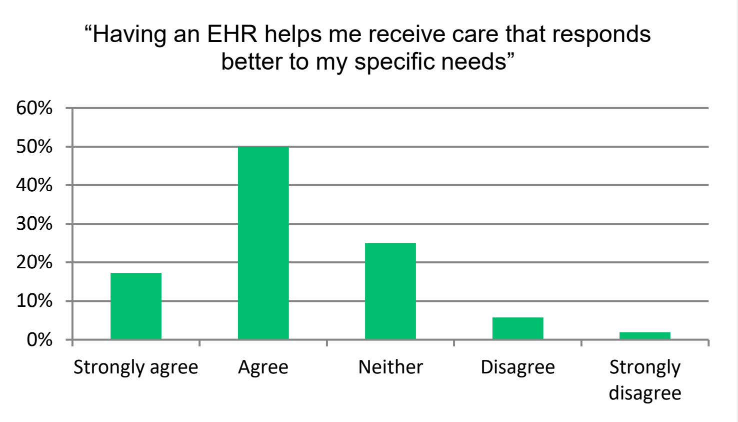


The majority of **patients recognise the important added value of the EHR when it comes to enhancing communication.** These benefits are seen to apply to communication between patients and healthcare professionals, but also between healthcare professionals and, for example, different care organisations. Just over 69% agreed EHRs ease communication with healthcare professionals (though just under 8% disagreed).

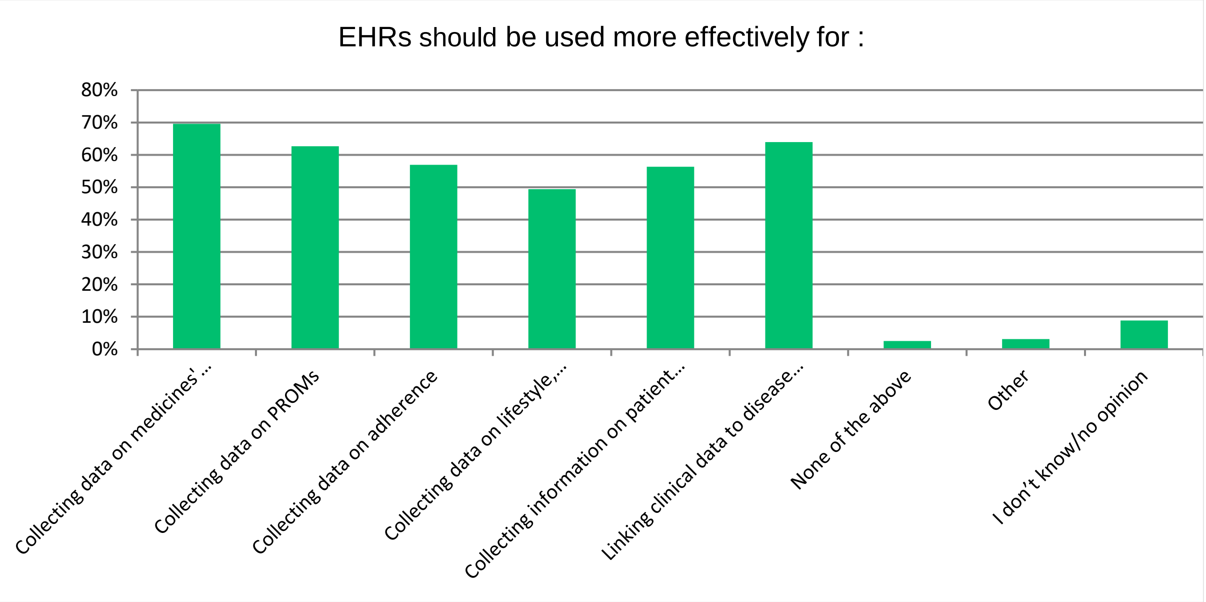
Regarding communication between healthcare professionals, including between different organisations such as hospitals, over 67% agreed whilst around 13.5% disagreed and some remained neutral.

Realising the communication benefits of EHRs will require interoperable and connected systems that allow data to be drawn from all kinds of healthcare institutions that treat a patient and enable treating health professionals to compile one coherent overview of all the information available around a person – with that person's consent as to how information can be used and who can access it.

In terms of **more personalised care**, more than half of the respondents agreed that having an EHR helps them to receive are that responds better to their specific needs: 50% agreed and 17.3% strongly agreed. Nevertheless, 25% took a neutral view and a few respondents disagreed. It would be interesting to explore in more depth what lies behind these perceptions.



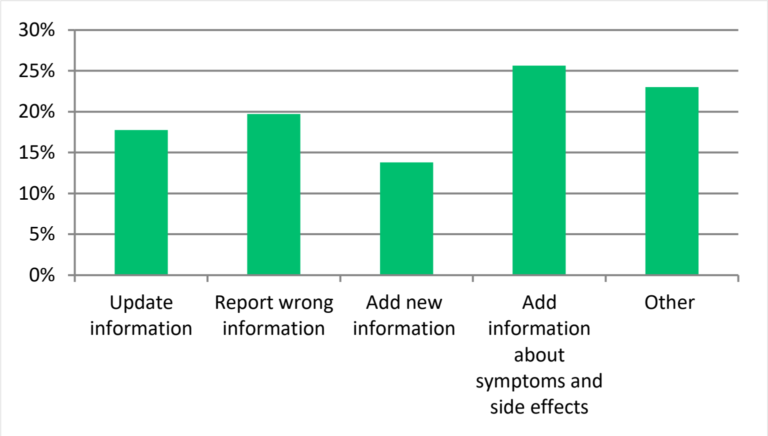
Most respondents agreed that **EHRs should be used more effectively**. Respondents saw the benefit in particular of collecting real-world data for various purposes: to assess specific medicines' safety and efficacy after authorisation; to collect patient-reported outcome measures (PROMs); adherence to treatment; lifestyle and demographic information; and collecting information on the patient journey to develop patient experience measures (PREMs). They also agreed with linking patients' clinical data to registries for more information on specific diseases for research.



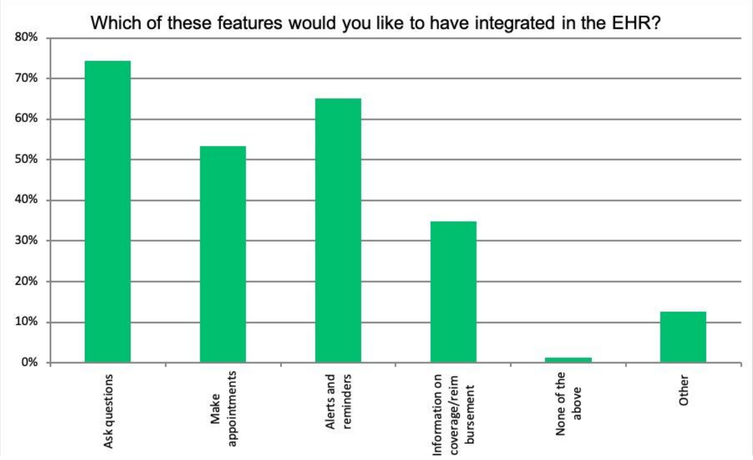
4. Interactive shared patient records

The next section asked patients if they would like to be able to contribute to their own EHRs in addition to having access to the information therein. The answer was a strong “yes” with 86.7% affirmative (though 9% said no). Responses imply that giving patients full access to their EHRs and the option to contribute their own observations can lead to safer care, better inclusion of patients’ preferences, patient-reported outcomes, and quality of life information.

In terms of **the patient’s contribution to the EHR**, respondents said they would be particularly interested in having the possibility to update their information (17.8%), report wrong information (19.8%), add new information such as details of family and personal medical history or wellness information (13.8%), and provide more details about their symptoms and side effects, such as new side effects (25.6%). In addition, many respondents commented that they would like to be able to do all of these things.



The respondents clearly indicated their interest in having more than mere access to a basic EHR: they **would like to have access to a comprehensive electronic system**, such as a patient portal, that would facilitate their interaction with healthcare professionals, healthcare provider organisations and the national health system, through which they could make appointments, receive alerts and reminders, and get information about their coverage and reimbursement entitlements. EPF’s previous work has shown that patients find the health and social care system difficult to navigate, and many experience having to “fight the system” just to get information about their rights and access to the services they are entitled to. This experience is confirmed by European surveys.[3]



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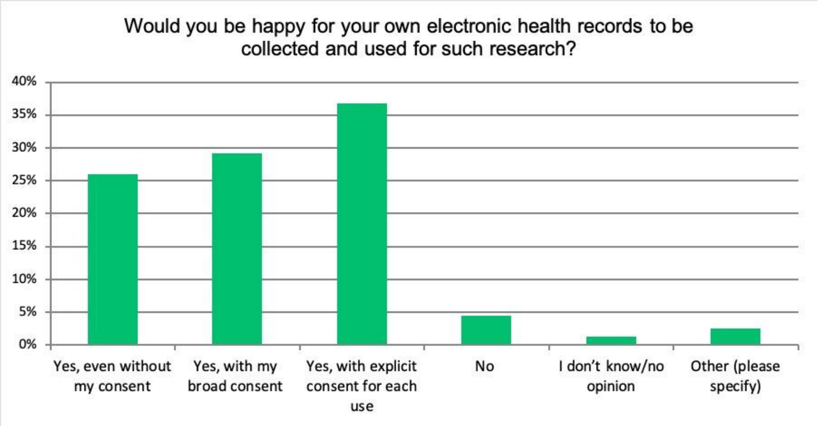
[3] Special Eurobarometer 425 “Patients’ rights in cross-border healthcare in the European Union”, 2015, page 15. Only about half of the respondents to the Eurobarometer said they were well-informed about the right to be reimbursed for healthcare in their own country.

5. Views on privacy and sharing of data

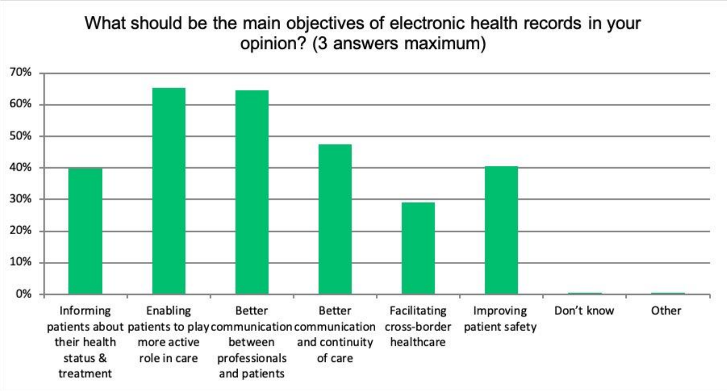
We then went on to ask respondents about their views on privacy and EHRs. When asked **whether patients should be able to decide which health professional can access their records**, 28.5% said the patients should always decide. An equal number, however, considered that an exception should be made in cases of medical emergency when the patient's life is in danger and they are not capable of giving consent. Some (8.2%) thought the patient should be able to decide on sensitive information, such as matters of sexual health, substance abuse, mental health or termination of pregnancy.



For research building to the options mentioned above, **participants would mostly agree with sharing their data**. Slightly more were in favour of explicit consent for each separate use (36.7%) than broad consent such as authorising use for any studies in a certain area or type of research (29.1%) or those who would be happy for their data to be used even without their consent (25.9%), but there is a close balance between those options.

When asked **what factors might influence their decision regarding the use of their data**, the following concerns were frequently mentioned: staying anonymous or unidentifiable, having reassurance of the effective protection of the data and the patient's confidentiality; knowing who is doing the research and for what purposes (some commentators made a difference between non-profit and for-profit entities); that the data should be used for the stated research purpose only; ethical oversight; worries that the data might be inappropriately shared with third parties, such as insurance companies or non-medical technology companies; that the data should be used for research purposes that bring actual benefit to patients. Mention was also made of knowing what happens to the data afterwards, being able to delete it, and having information about the results of the research.

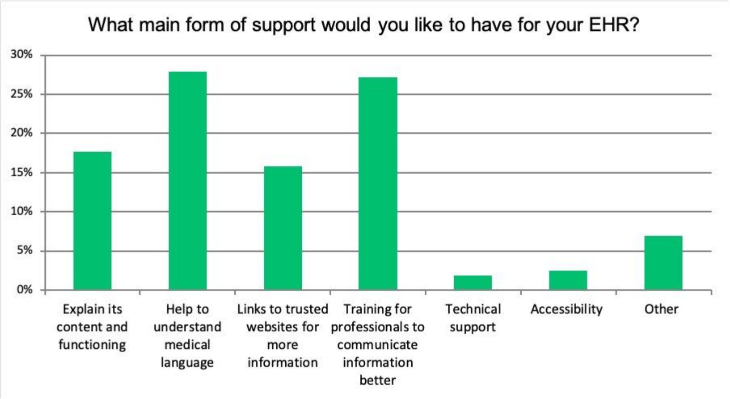
6. Expectations of EHRs and support needs of patients



Regarding **patients' expectations of EHRs**, respondents said the main objectives of EHRs should be to enable patients to play a more active role in managing their health and chronic or condition and ensuring better communication between healthcare professionals and patients, followed by better communication within healthcare teams and continuity of care, and informing patients about their health status and treatment. Improving safety by, for example, enabling better information flow about how to take medicines and reporting of side effects, and facilitating cross-border healthcare were also mentioned.

The final part of the survey asked participants what kind of **training and support** they would welcome for using EHRs effectively.

Almost a third (27.8%) said they would like support to understand the medical language in the EHRs, and virtually the same number (27.2%) said healthcare professionals should be trained to communicate information in the EHR in a patient-friendly way. This is in line with the patients' perception that the information in the EHR is not presented in a way that is easily understandable for patients and actually enables them to take more control of their own health and wellbeing. Respondents also mentioned support to explain the content and functioning of the EHR (17.7%) and 15.8% said they would like to have links to trusted websites providing more information. Accessibility for different abilities and technical support were also mentioned.



Conclusion

Despite the limitations of this survey, we can gain interesting insights from the responses, some of which should be further investigated. Overall, participants saw the EHR as an important tool for patients to play a more active role in the management of chronic health conditions, to facilitate communication with healthcare professionals, and to improve the safety and quality of care. However, clearly there is much more effort needed to ensure that all patients who wish to access their EHRs can do so easily and freely, that the availability and interoperability of such systems is improved across Europe and within countries, and that the contents of the EHRs are co-created with patients to ensure they are understandable and thus contribute to greater patient empowerment.