

Introduction

What is the survey about?

Artificial Intelligence (AI), together with big data, has the potential to transform care delivery, and change several aspects of the healthcare value chain: population health, healthcare operations and healthcare-related innovation. Reports and studies also highlight a number of key areas where AI may possibly have a direct impact on the patient: self-care, prevention and wellness, triage and early diagnosis, diagnostics, clinical decision. AI is also a key element of the recently released EU strategy for digital transformation '[Shaping Europe's digital future](#)' and in particular of the EU White Paper on AI (February 2020) and the related public consultation, to which EPF responded in [June 2020](#).

Given this rapid increase of interest in the importance of AI in healthcare and in view of upcoming policy activities, EPF has decided to reinforce its engagement on this matter to ensure that the patients' views will be adequately represented in the future discussion and EU-level debates, starting with this first EPF survey on AI.

Who is the survey for?

The survey includes one single core set of questions, addressed to both individual patients with chronic or long-term conditions, their family members or informal carers and patients' communities, and patients' organisations. You do not need in-depth knowledge on AI in healthcare to complete this survey, questions are primarily about your experience and perception, there are no wrong or right answers. However, to discover more about the topic and about EPF's recent views on it, we invite you to consult the recent EPF publications on AI (see section 'Background Documents').

How will the survey responses be used?

With the results of this survey, EPF intends to produce a report that will serve as additional evidence base for our policy and advocacy work and make recommendations towards EU institutions' policymakers, which we hope will ultimately inform the decisions that are taken at EU and national level.

Immediately, the results will be used to inform EPF's ad-hoc engagement activities on the topic of AI, including for example participation in events or informal exchanges with policymakers and stakeholders.

The survey report will be published and available for free on EPF website in the coming months.

How much time will it take?

This survey consists of around 15 questions, some of which have tick-box options. It should take around 10 - 15 minutes to complete. In our analysis we can only take into consideration completed surveys in order to have reliable and comparable results.

What is the deadline for completing the survey?

The survey is open until **25 October 2020**.

Will my identity be published?

The survey is anonymous and the results will be treated as strictly confidential. We only ask for information necessary to analysing the results, e.g., demographic and country information. No personal information will be published. By completing and submitting this survey, as a participant, you are providing your informed consent.

Background documents

Thank you for your interest and for filling out our survey. Below you will find a series of key background documents to help you in your feedback.

Clicking on the links below, you will be able to retrieve:

▣ **[EPF EU Policy Briefing on Big Data and Artificial Intelligence](#)**: in this document you can find an overview on current and future state of play on data and AI, including challenges, opportunities and the latest updates from policy at EU level (published in May 2020). **For a brief overview on AI, please consult pages 8 - 13 .**

▣ **[EPF Response - Public consultation on the White Paper on AI](#)**: in this document you can find our statement in response to the Public consultation on the European White Paper on Artificial Intelligence.

▣ **[Video - Artificial Intelligence meets the health sector](#)**: This European Commission's CONNECT University session explored the impact of Artificial Intelligence on the future of healthcare, presenting the major role that AI has in diagnosing and preventing diseases. Ethical issues in the application of AI to healthcare were also included in the discussion.

▣ **[EPF Response - Public consultation on the European strategy on data](#)**: in this document you can find our statement in response to the Public consultation on the European strategy on data.

For further details, more information about AI in healthcare and any kind of support needed to fill this survey, please do not hesitate to contact **michele.calabro@eu-patient.eu**

General information about you

* 1. I am responding on behalf of a:

- Patient organisation
- Individual patient/carer

Questionnaire for Patient Organisations

* 1. What is the geographical remit of your organisation?

- European
- National
- Regional
- Local
- Open question: if regional or local, please state location.

* 2. Your organisation is based in:

* 3. What disease area(s) does your organisation cover?

- cardiovascular
- neurological
- respiratory
- metabolic
- cancers
- neuromuscular
- rare
- autoimmune
- mental health
- all of the above
- Other (please specify)

Knowledge about AI implications in healthcare and use of AI-based services or applications

In this section, EPF would like to collect information about both your level of knowledge about AI and its implications in healthcare and, if applicable, about your experience with AI-based services or applications.

If you want to have more information about AI in healthcare before responding to this survey, please have a look at our 'background documents', listed in our introduction page.

* 4. As a patient organisation representative, how would you rate your members' knowledge about Artificial Intelligence and its application in the healthcare field?

- They have never heard of AI
- They have heard of AI but I they not know how it could apply in healthcare
- They have a very basic knowledge of possible AI applications in healthcare
- They have a good knowledge of possible AI applications in healthcare, including possible risks, challenges and opportunities, but no technical understanding on how it works.
- They have a solid knowledge of possible AI applications in healthcare, including possible risks, challenges and opportunities, and sufficient technical understanding on how it works.
- Not applicable/prefer not to answer

* 5. To your knowledge, how would you rate the use of AI-based services or applications among the patient community you represent?

- Our community do not use AI-based services or applications
- Our community seldomly use AI-based services or applications
- Our community regularly use AI-based services or applications
- Not applicable/prefer not to answer/I am not sure

Please elaborate on your answer (e.g.If yes, what kind of AI-based services or applications?)

Challenges and opportunities

In this section, EPF would like to collect your views on challenges and opportunities of using AI in health.

* 6. As a patient organisation representative, what are the most interesting positive aspects of using AI in health? You can select up to 3 answers from the list below.

- Improve the accuracy of diagnosis
- Improve quality and efficiency of research and innovation in healthcare (e.g. better products)
- Support healthcare professionals in delivering more personalised care to patients
- Facilitate access to care (e.g. AI supported hospital management systems)
- Improve and facilitate self-care or adherence to treatments
- Facilitate better prevention and improve people's well-being
- Better prediction of public health threats (e.g. emerging pandemics)
- Support health systems efficiency and improve organisation and delivery of care
- Provide information and support to patients and carers (e.g. through chat bots)
- Not applicable/prefer not to answer
- Other (please elaborate in the text box below)

Please elaborate on your answer(s) (e.g. providing examples or data specific to your disease area or local context adding, if desired, references to surveys, papers or documents)

* 7. As a patient organisation representative, what are your organisation/patient community main worries concerning the development of AI solutions? You can select up to 3 answers from the list below.

- Unauthorised use of or access to the data used to train a machine learning model
- Concerns over the quality of the data used to train a machine learning model (e.g. biased or insufficient data)
- Lack of transparency on how algorithms are made and work
- Lack of collaboration with healthcare professionals and patients in the co-design of AI solutions
- Not applicable/prefer not to answer
- Other (please elaborate in the text box below)

Please elaborate on your answer(s) (e.g. providing examples or data specific to your disease area or local context adding, if desired, references to surveys, papers or documents)

* 8. As a patient organisation representative, what are your organisation/patient community main worries concerning AI application in healthcare? You can select up to 3 answers from the list below.

- Less human interactions with healthcare professionals
- Potential risks of overdiagnosis
- Potential risks of incorrect diagnosis
- Unauthorised use of or access to AI outputs with potential impact on patients' lives (e.g. health insurance)
- Limited clarity on liability (e.g. who should respond in case of AI errors?)
- Barrier-free access to all AI applications in healthcare and barrier-free access to the underlying data and decisions - in particular in the patient health records
- Not applicable/prefer not to answer
- Other (please elaborate in the text box below)

Please elaborate on your answer(s) (e.g. providing examples or data specific to your disease area or local context adding, if desired, references to surveys, papers or documents)

Trust and regulations

In this section EPF would like to collect information about current level of trust in AI application in healthcare and knowledge on AI regulations

* 9. As a patient organisation representative, how much would you rate your members' trust AI-based or supported healthcare services or tools?

- Extremely low
- Generally low, but depends on the nature of the decision that AI was being used for (e.g. use of AI for diagnosis or use of AI to better interpret public health statistics)
- Generally sufficient, but depends on the nature of the decision that AI was being used for
- Sufficient, but only if clearly suggested by healthcare professionals
- Very high
- Not applicable/prefer not to answer

If you want, please elaborate on your answer (e.g. What kind of AI use would you be incline to trust more and which one would be less trustworthy? Why do you trust/not trust AI in healthcare? What would improve your level of trust? Do you think that current AI regulations provide enough protection to patients)

* 10. Would you be able to identify who regulates AI in healthcare in Europe?

- The European Union
- Individual member states
- Industry
- A combination of the options above
- There is no active AI regulation in Europe
- Not applicable/prefer not to answer

If you wish, please elaborate on your answer(s)

Additional questions

In this section, EPF would like to collect any additional views and experiences about AI in healthcare, including desired knowledge on this topic but also prospective AI challenges, active projects, studies or interesting applications.

* 11. As a patient organisation representative, what kind of knowledge would you/your membership need to better engage with AI in healthcare. You can select up to 3 answers from the list below.

- Knowing about its potential risks
- Knowing about the AI regulations
- Basic knowledge on how AI works in healthcare
- Knowing your rights in case of errors (e.g. overdiagnosis or incorrect diagnosis) and how to exercise them
- Knowing your rights in case of unauthorised use of or access to the data used to train a machine learning model or AI outputs
- Knowing how algorithms are made and what data is used to train them?
- Knowing how the AI outputs are used
- Barrier-free access to knowledge about AI
- Not applicable/prefer not to answer
- Other (please elaborate below)

If you wish or your selected 'Other', please elaborate on your answer

12. With regards to your organisation disease area and/or geographical context please feel free to share with us any additional views you may have on the application of AI, including challenges or potential interesting applications.

13. Please feel free to share with us any relevant project or current AI applications that you may be aware of, indicating, where possible, the impact on patients. Please provide references/links to websites or documents.

14. If you agree to either be contacted further, for example for an interview, or if you agree to be quoted, please provide contact details (name of your organisation and email address) below

Name of your organisation

Email address



Questionnaire for individual patients and communities

* 1. Are you:

- A patient with chronic or long term condition(s)
- A parent/family member/informal carer
- A patient and informal carer

* 2. Your country of residence is:

* 3. What age group are you? (or the patient you are responding on behalf of)

- 0-15
- 16-30
- 31-45
- 46-60
- 61-75
- 76 and above

* 4. What is your gender?

- Male
- Female
- Other
- Prefer not to say

* 5. What disease area(s) does your condition(s) fall under?

- cardiovascular
- neurological
- respiratory
- metabolic
- cancers
- neuromuscular
- rare
- mental health
- autoimmune
- Other (please specify)

Knowledge about AI implications in healthcare and use of AI-based services or applications

In this section, EPF would like to collect information about both your level of knowledge about AI and its implications in healthcare and, if applicable, about your experience with AI-based services or applications.

If you want to have more information about AI in healthcare before responding to this survey, please have a look at our 'background documents', listed in our introduction page

* 6. How would you rate your knowledge about Artificial Intelligence and its application in the healthcare field?

- Never heard of AI
- I have heard of AI but I do not know how it could apply in healthcare
- I have a very basic knowledge of possible AI applications in healthcare
- I have a good knowledge of possible AI applications in healthcare, including possible risks, challenges and opportunities, but no technical understanding on how it works.
- I have a solid knowledge of possible AI applications in healthcare, including possible risks, challenges and opportunities, and sufficient technical understanding on how it works.
- Not applicable/prefer not to answer

* 7. To your knowledge, have you already used AI-based services or applications?

- Yes
- No
- I am not sure
- Not applicable/prefer not to answer

Please elaborate on your answer (e.g. If yes, what kind of AI-based services or applications?)

Challenges and opportunities

In this section, EPF would like to collect your views on challenges and opportunities of using AI in health.

* 8. In your opinion, what are the most interesting positive aspects of using AI in health? You can select up to 3 answers from the list below.

- Improve the accuracy of diagnosis
- Improve quality and efficiency of research and innovation in healthcare (e.g. better products)
- Support healthcare professionals in delivering more personalised care to patients
- Facilitate access to care (e.g. AI supported hospital management systems)
- Improve and facilitate self-care or adherence to treatments
- Facilitate better prevention and improve people's well-being
- Better prediction of public health threats (e.g. emerging pandemics)
- Support health systems efficiency and improve organisation and delivery of care
- Provide information and support to patients and carers (e.g. through chat bots)
- Not applicable/prefer not to answer
- Other (please elaborate in the text box below)

Please elaborate on your answer(s) (e.g. providing examples or data specific to your disease area or local context adding, if desired, references to surveys, papers or documents)

* 9. What are your main worries concerning the development of AI solutions? You can select up to 3 answers from the list below.

- Unauthorised use of or access to the data used to train a machine learning model
- Concerns over the quality of the data used to train a machine learning model (e.g. biased or insufficient data)
- Lack of transparency on how algorithms are made and work
- Lack of collaboration with healthcare professionals and patients in the co-design of AI solutions
- Not applicable/prefer not to answer
- Other (please elaborate in the text box below)

Please elaborate on your answer(s) (e.g. providing examples or data specific to your disease area or local context adding, if desired, references to surveys, papers or documents)

* 10. What are your main worries concerning AI applications in healthcare? You can select up to 3 answers from the list below.

- Less human interactions with healthcare professionals
- Potential risks of overdiagnosis
- Potential risks of incorrect diagnosis
- Unauthorised use of or access to AI outputs with potential impact on patients' lives (e.g. health insurance)
- Limited clarity on liability (e.g. who should respond in case of AI errors?)
- Barrier-free access to all AI applications in healthcare and barrier-free access to the underlying data and decisions - in particular in the patient health records
- Not applicable/prefer not to answer
- Other (please elaborate in the text box below)

Please elaborate on your answer(s) (e.g. providing examples or data specific to your disease area or local context adding, if desired, references to surveys, papers or documents)

Trust and regulations

In this section EPF would like to collect information about current level of trust in AI application in healthcare and knowledge on AI regulations

* 11. How much would you trust AI-based or supported healthcare services or tools?

- Not at all
- Generally no, but depends on the nature of the decision that AI was being used for (e.g. use of AI for diagnosis or use of AI to better interpret public health statistics)
- Generally yes, but depends on the nature of the decision that AI was being used for
- Only if clearly suggested by my doctor
- Entirely
- Not applicable/prefer not to answer

If you want, please elaborate on your answer (e.g. What kind of AI use would you be inclined to trust more and which one would be less trustworthy? Why do you trust/not trust AI in healthcare? What would improve your level of trust? Do you think that current AI regulations provide enough protection to patients)

* 12. Would you be able to identify who regulates AI in healthcare in Europe?

- The European Union
- Individual member states
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- A combination of the options above
- There is no active AI regulation in Europe
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If you wish, please elaborate on your answer(s)

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- Knowing how algorithms are made and what data is used to train them?
- Knowing how the AI outputs are used
- Barrier-free access to knowledge about AI
- Not applicable/prefer not to answer
- Other (please elaborate below)

If you wish or your selected 'Other', please elaborate on your answer

14. With regards to your disease area and/or geographical context please feel free to share with us any additional views you may have on the application of AI, including challenges or potential interesting applications.

15. Please feel free to share with us any relevant project or current AI applications that you may be aware of, indicating, where possible, the impact on patients. Please provide references/links to websites or documents.

16. If you agree to either be contacted further, for example for an interview, or if you agree to be quoted on a first name and country basis (e.g. "Michael with multiple sclerosis from Denmark") please provide your contact details (full name and email address) below

Full name

Email address

Thank you for completing our survey!

If you have not already done so, please share this survey with your network by using this link: <https://www.surveymonkey.com/r/AIEPF>

The deadline to complete the survey is **25 October**.

The survey report will be published and available for free on EPF website in the coming months.

For any questions or queries, please contact: **michele.calabro@eu-patient.eu**