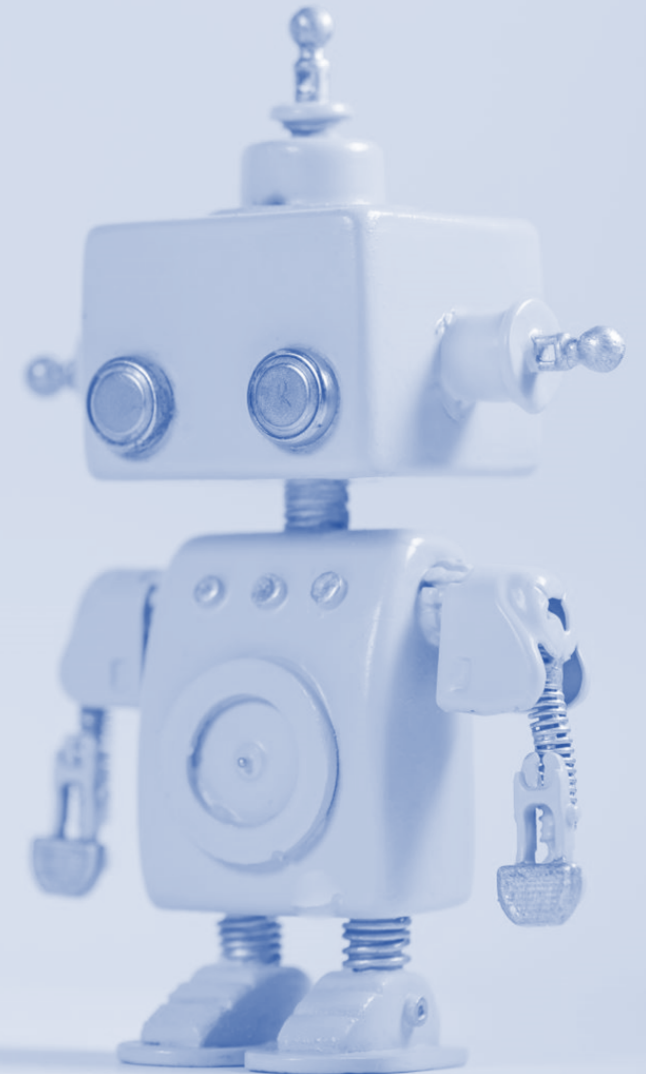RESULTS OF THE **EPF** European Patients Forum SURVEY FOR
PATIENT ORGANISATIONS AND INDIVIDUAL PATIENT ADVOCATES ON

The Perception of AI in Healthcare

Spring 2023

INITIAL CONSIDERATIONS

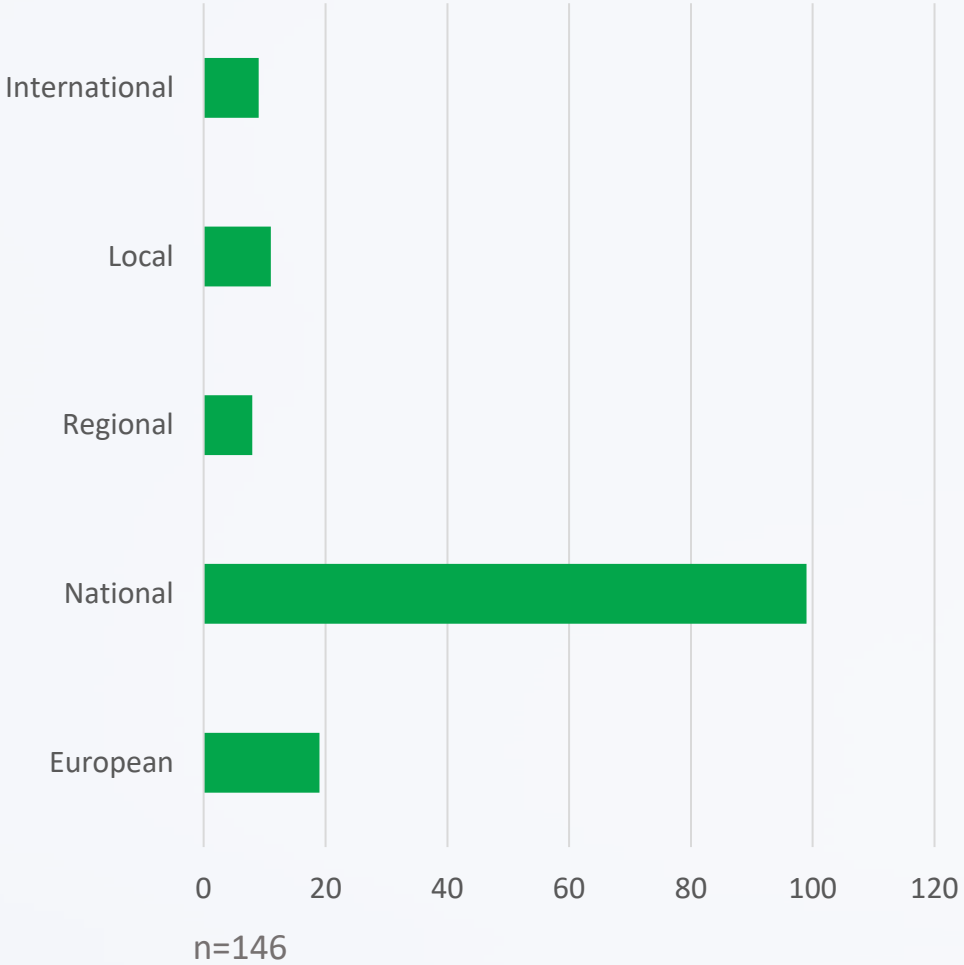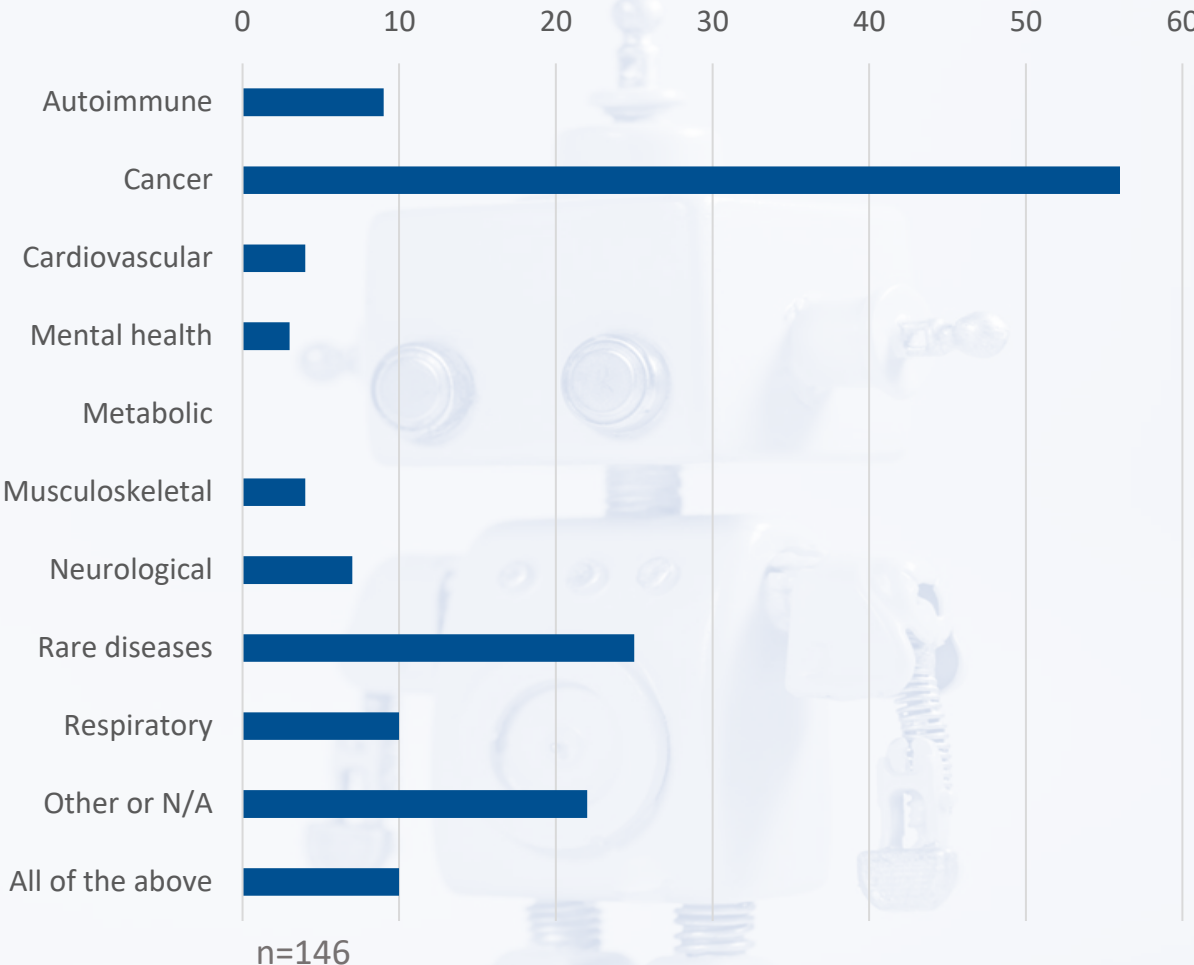o **146** respondents

o **12** languages

o Most represented disease area: **cancer**. Followed by **rare diseases**

o The majority of respondents (**53%**) has never actively engaged on AI in healthcare, **34%** of respondents are planning future activities and only **13%** have already engaged on the topic.

o **8** respondents were not at all familiar with the term artificial intelligence.
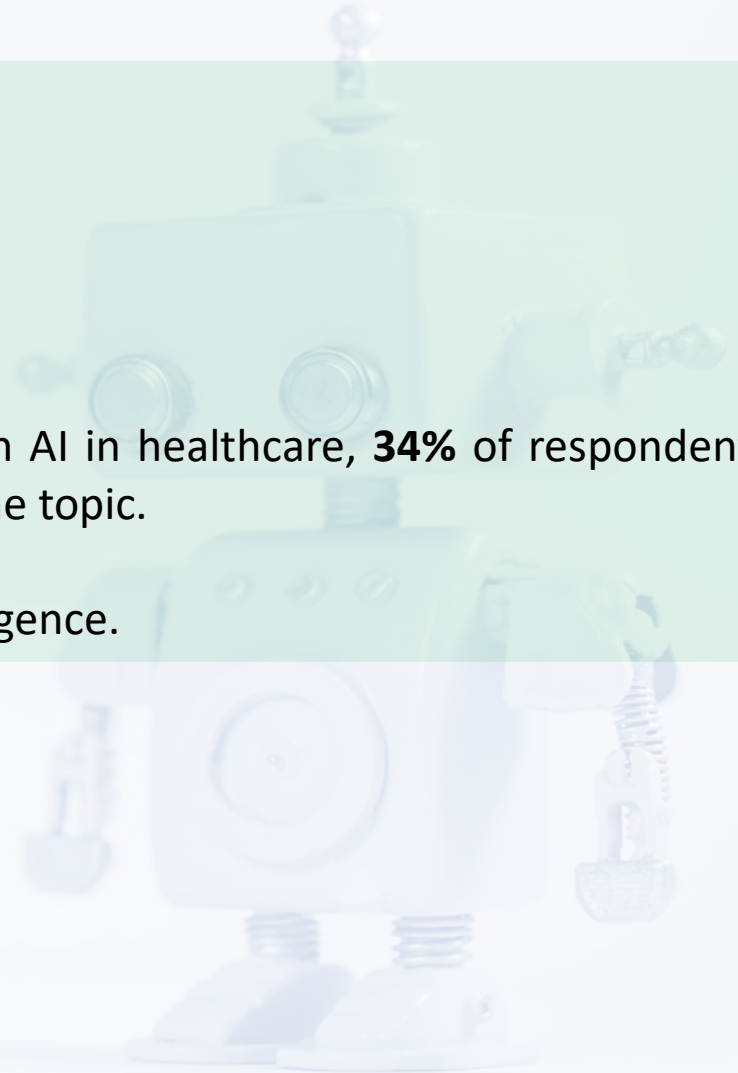
What is the geographical remit of your organisation/patient advocacy activity?

Geographical remit	Value
International	~9
Local	~12
Regional	~8
National	~99
European	~19

n=146

What disease-area(s) does your organisation/patient advocacy activity cover?

Disease area	Value
Autoimmune	~9
Cancer	~57
Cardiovascular	~4
Mental health	~3
Metabolic	0
Musculoskeletal	~4
Neurological	~7
Rare diseases	~25
Respiratory	~10
Other or N/A	~22
All of the above	~10

n=146

Where is your patient organisation/activity based?

n=146
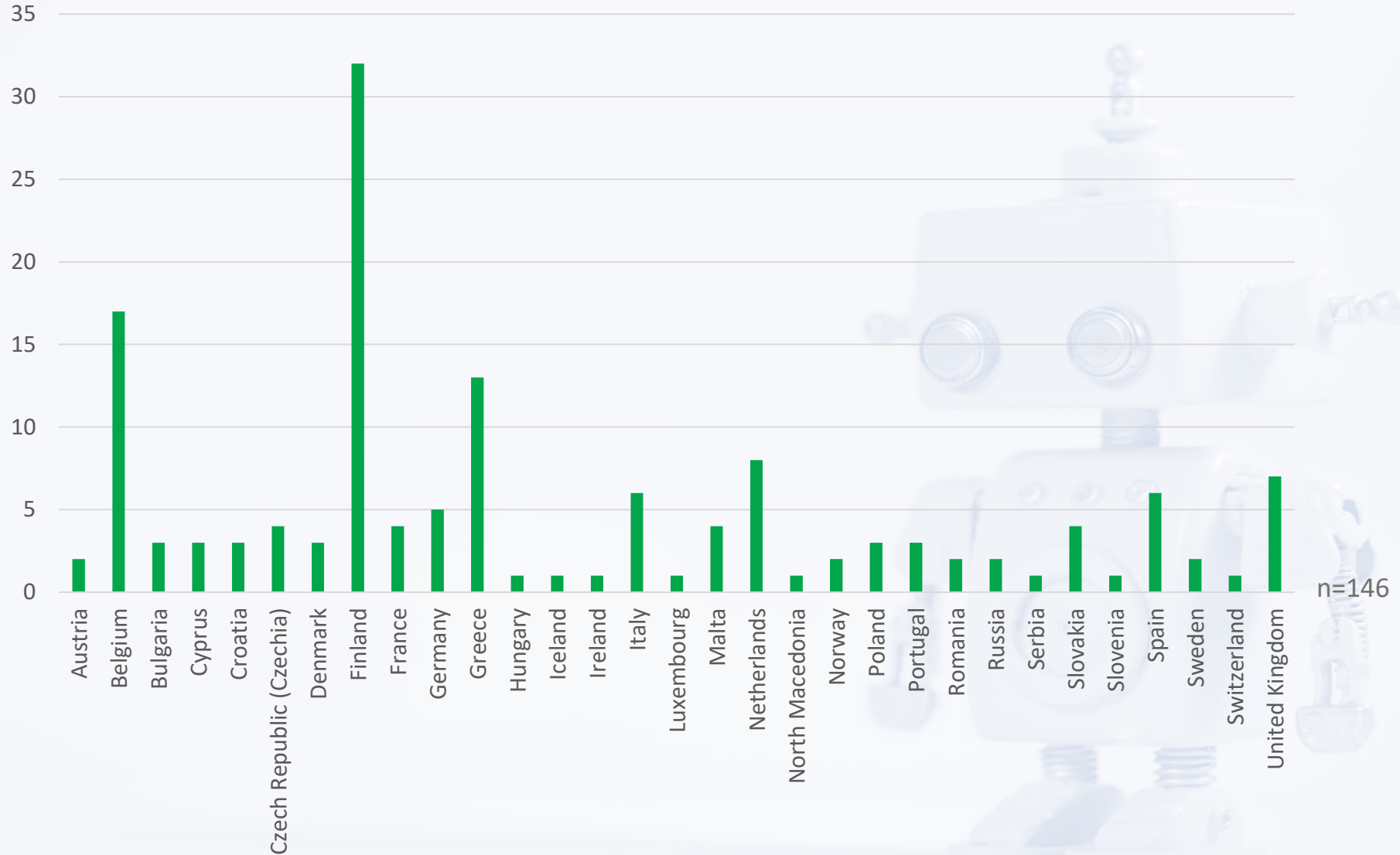
How would you rate your organisation's knowledge about AI in healthcare?

Advanced knowledge (I know about possible applications of AI in healthcare as well as risks, challenges andopportunities and am aware of the complex interplay between these).

Solid knowledge (I know about possible applications of AI in healthcare as well as risks, challenges and opportunities in general, but not tailored to particular healthcare context nor to the different subtypes of AI techniques)

Basic knowledge (Some knowledge of possible applications of AI in healthcare)

No or limited knowledge (I don't know or have just heard about how AI could be applied in healthcare)

0   10   20   30   40   50   60   70

n=125

What are the main barriers for effective patient advocacy in your experience?

- Lack of knowledge
- Lack of personnel / workload
- Lack of collaboration with other stakeholders
- Lack of funding
- Lack of awareness at a decision-making level of the organisation
- N/A
- Other (please explain)

Other:
"Lack of training for advocates"

30%
31%
19%
14%
5%
1% 1%

n=108
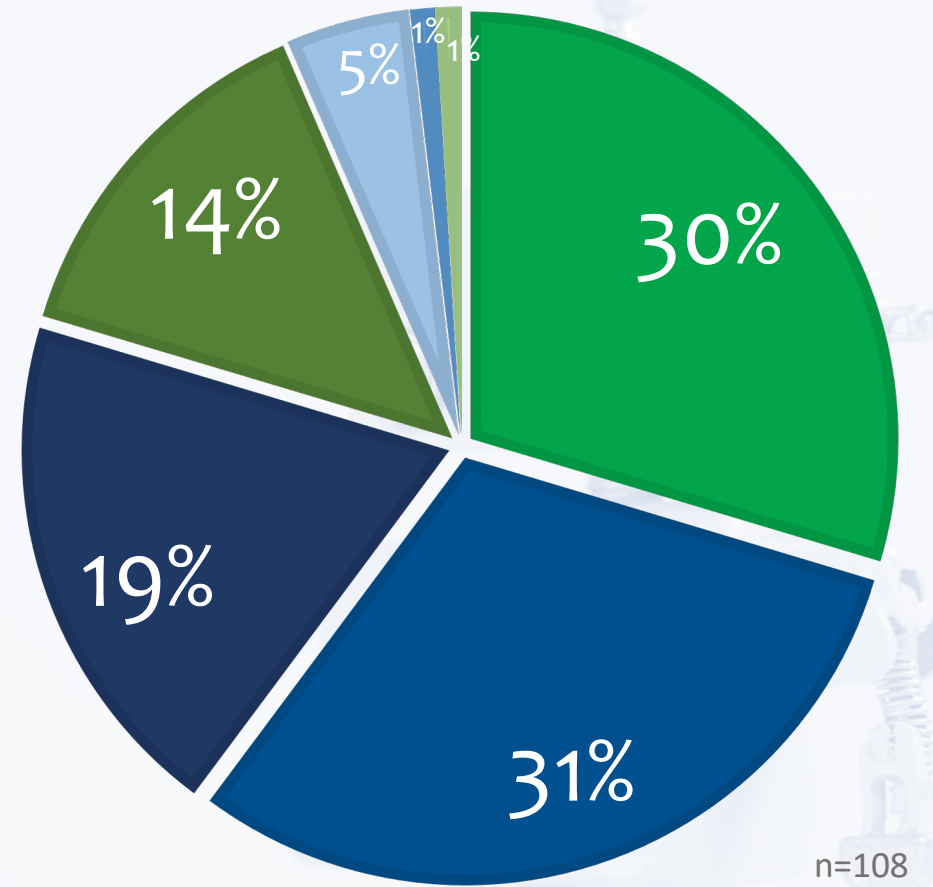
To your knowledge, are there AI-based healthcare services or applications being used in your country or disease-area?
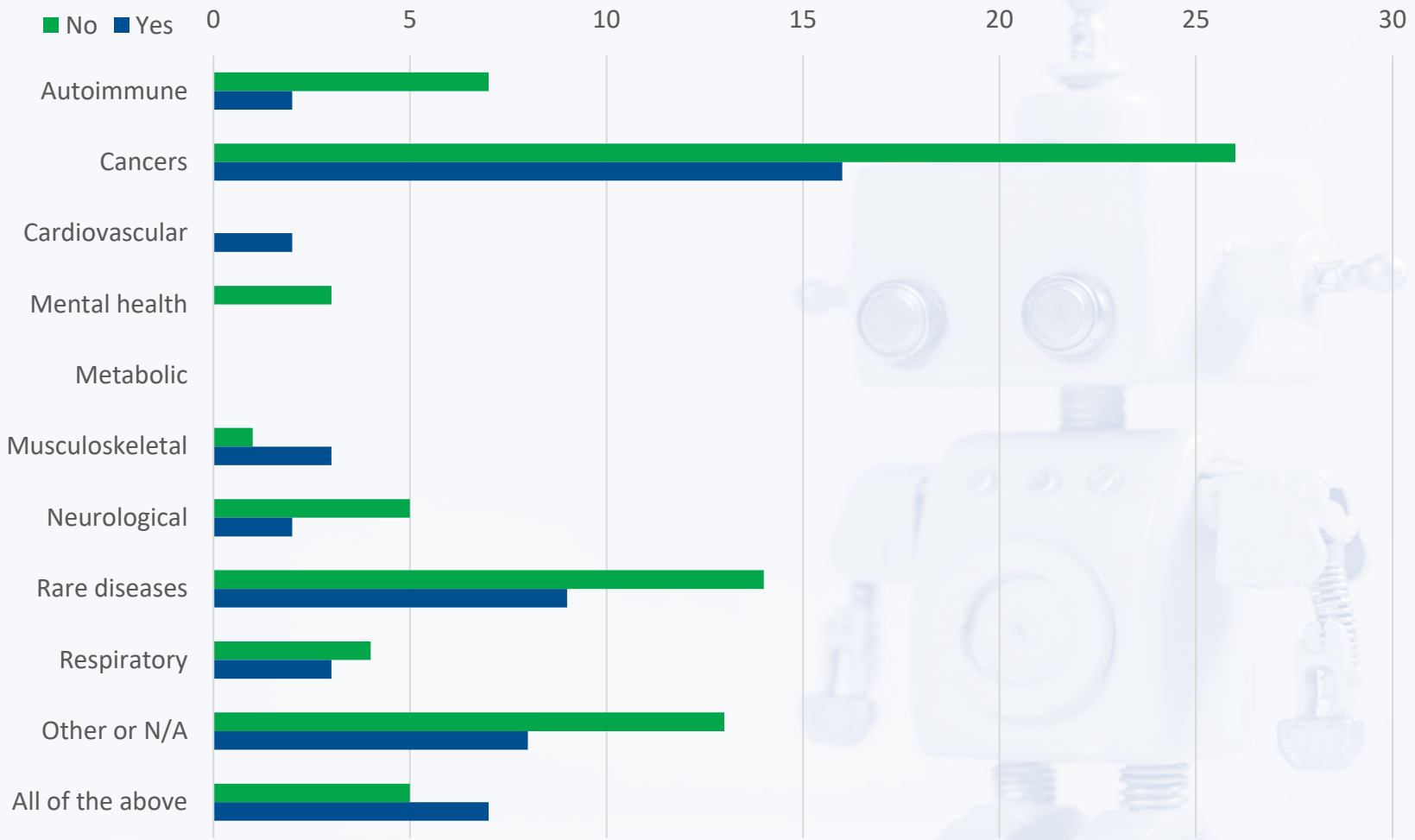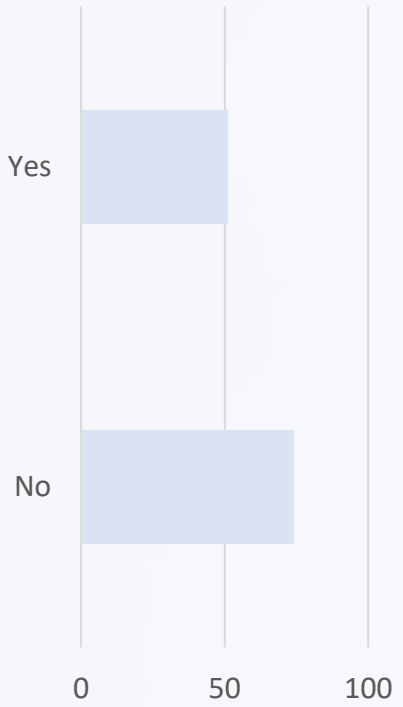
n=125
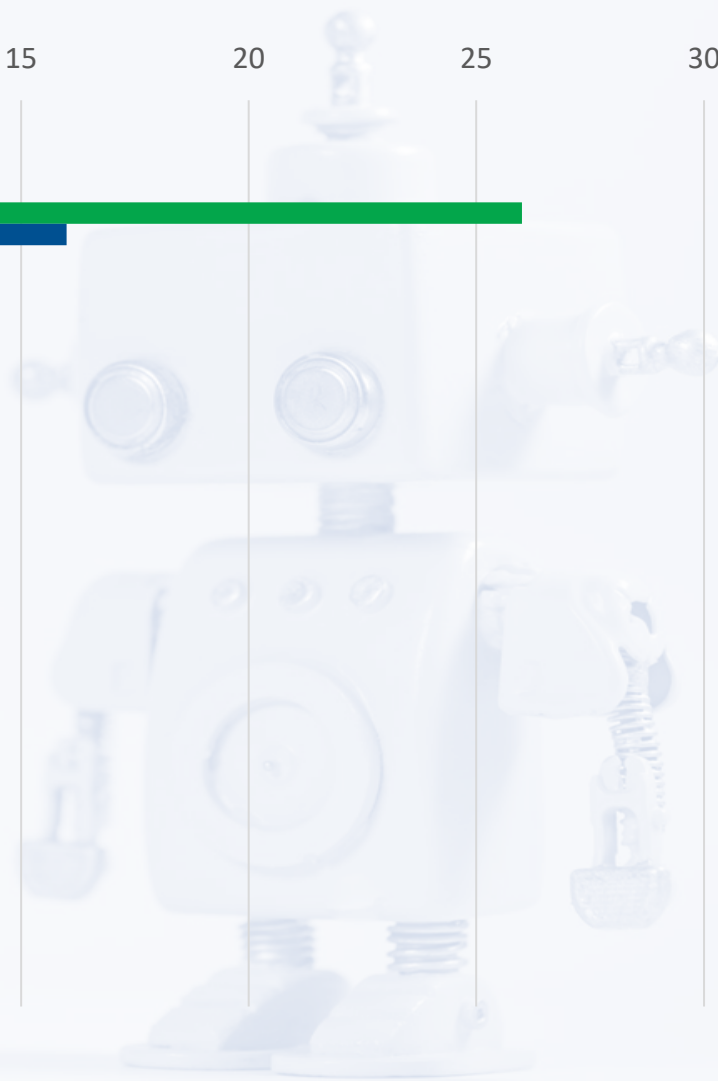
EXAMPLES OF APPLICATIONS AT THE NATIONAL LEVEL

Finland
- Robotics in surgery
- Chatbots
- Laboratory (ex. *Silo.AI*)
- Administration (ex. *Digital Workforce*)
- Use of AI in biobanks and patient registries

France
- Health apps (ex. *Moovcare*)
- Imaging diagnostic assistance software
- Drug interaction detection software
- IVF (ex. *Im-Vitro*)

UK
- DNA analysis

Croatia
- Cancer screening programs

Belgium
- Radiology
- Detection of chronic obstructive pulmonary disease (COPD)
- Laboratory
- Prediction models (ex. when to discharge the patient)

Denmark
- Blood testing

Portugal
- Detection/diagnosis of skin diseases

Netherlands
- Digital nose (electronic nose technology to detect diseases)
- Data collections

In your opinion, what are the most interesting applications for AI in health?

Category	Value
Improve the accuracy of diagnosis	84
Improve the quality and efficiency of research and innovation in healthcare, leading to better treatments	77
Support healthcare professionals in delivering more personalised care to patients	68
Support patients' self-management and adherence to treatments	55
Support health systems efficiency and improve the organisation and delivery of healthcare (e.g. identifying and eliminating fraud or waste, scheduling...	53
Provide information and support to patients and carers, for example through online chat bots	48
Improve access to care	42
Support better prevention and people's well-being (e.g. assessing the likelihood of individuals experiencing a specific health condition or outcomes)	37
Improve the prediction of public health threats, for example emerging pandemics	30
Other	3
N/A	1

n=114

For your organisation, what are the main worries concerning AI in healthcare?

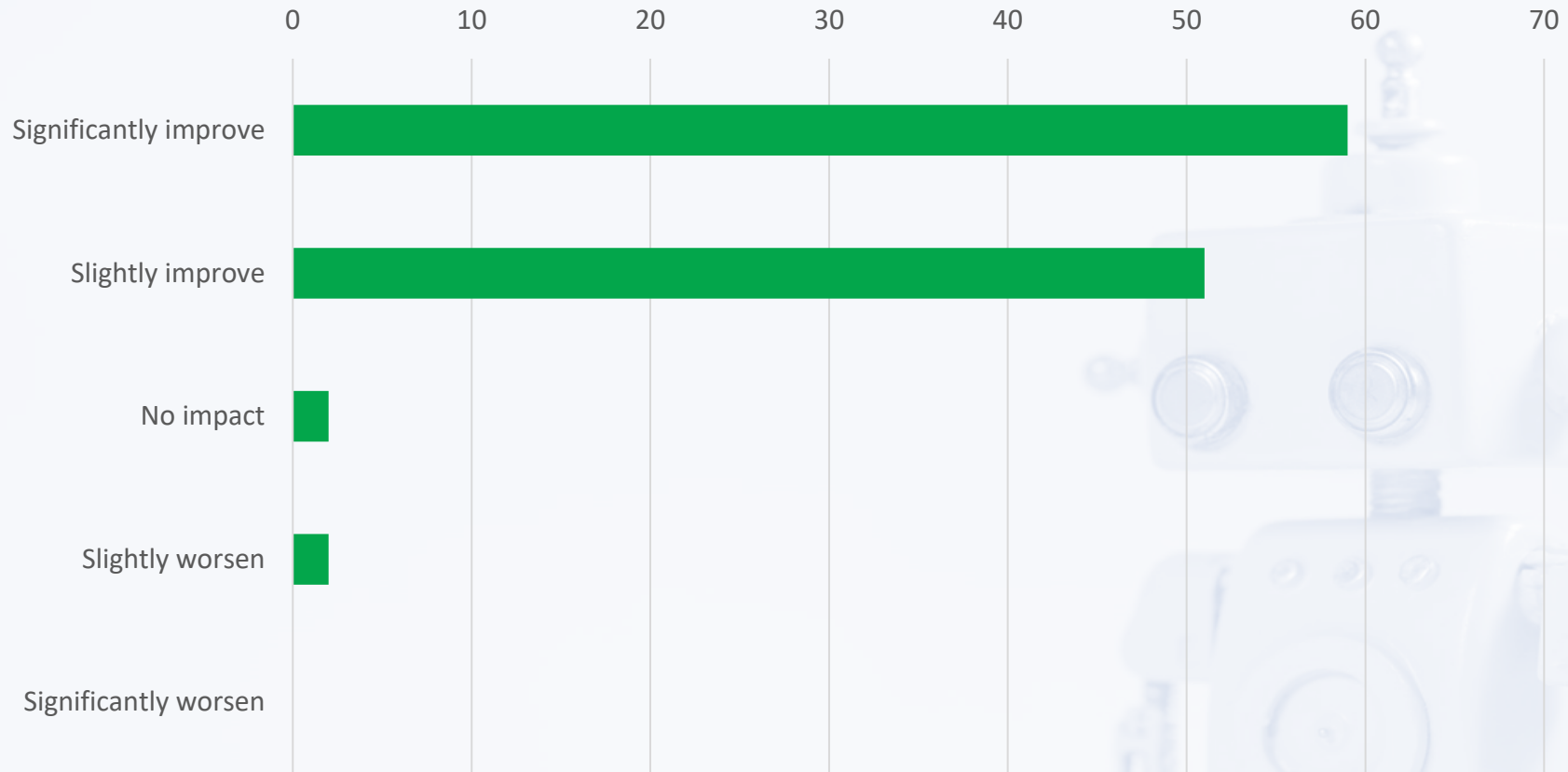| Worry	Value
Data used to train AI can be biased or not representative of all groups of patients	52
Lack of involvement of patients in design of AI solutions	49
Safety issues due to low quality and unvalidated AI systems	47
Lack of transparency on how algorithms work	45
Patients not being informed about the use of AI in their healthcare	38
Patients not having equal access to AI-supported systems (risk of perpetuating…	35
Incorrect usage of AI tools by patients due to lack of awareness and literacy	35
Lack of clear liability in case AI-supported system makes a mistake	34
Risk of overdiagnosis, missed or incorrect diagnosis by AI-supported systems	34
Incorrect usage of AI tools by healthcare professionals due to lack of awareness…	31
Inappropriate use of AI-generated results (e.g. by excluding some patients from…	29
Lack of data privacy, confidentiality and protection	25
Potential alterations in the doctor-patient relationship (e.g. diminished human…	25
I do not know	4
Other	1

n=114

To what extent do you believe healthcare stakeholders (patients, doctors, nurses..) should be involved in some aspects of the development and deployment of AI-powered tools and technologies that are to be used directly in patient care?
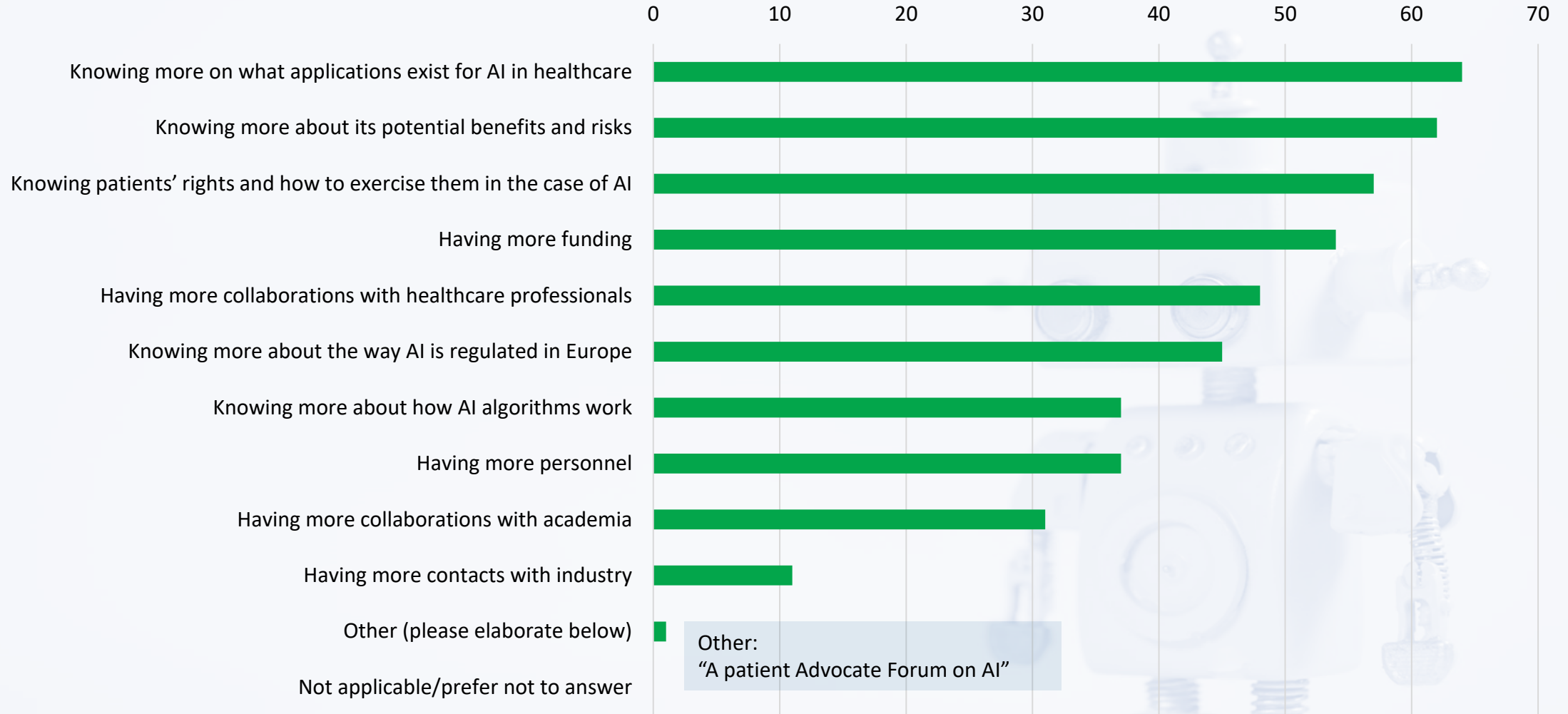
n=114

# To what extent do you believe AI can improve patient outcomes in the coming years?

n=114

What would help you better engage with AI in healthcare?

Category	Value
Knowing more on what applications exist for AI in healthcare	~64
Knowing more about its potential benefits and risks	~62
Knowing patients' rights and how to exercise them in the case of AI	~57
Having more funding	~54
Having more collaborations with healthcare professionals	~48
Knowing more about the way AI is regulated in Europe	~45
Knowing more about how AI algorithms work	~37
Having more personnel	~37
Having more collaborations with academia	~31
Having more contacts with industry	~11
Other (please elaborate below)	~1
Not applicable/prefer not to answer	0

Other:
"A patient Advocate Forum on AI"

n=107

Are you aware of any ongoing or upcoming EU policies or guidelines dealing with the use of AI in healthcare?

26%

74%

■ Yes ■ No
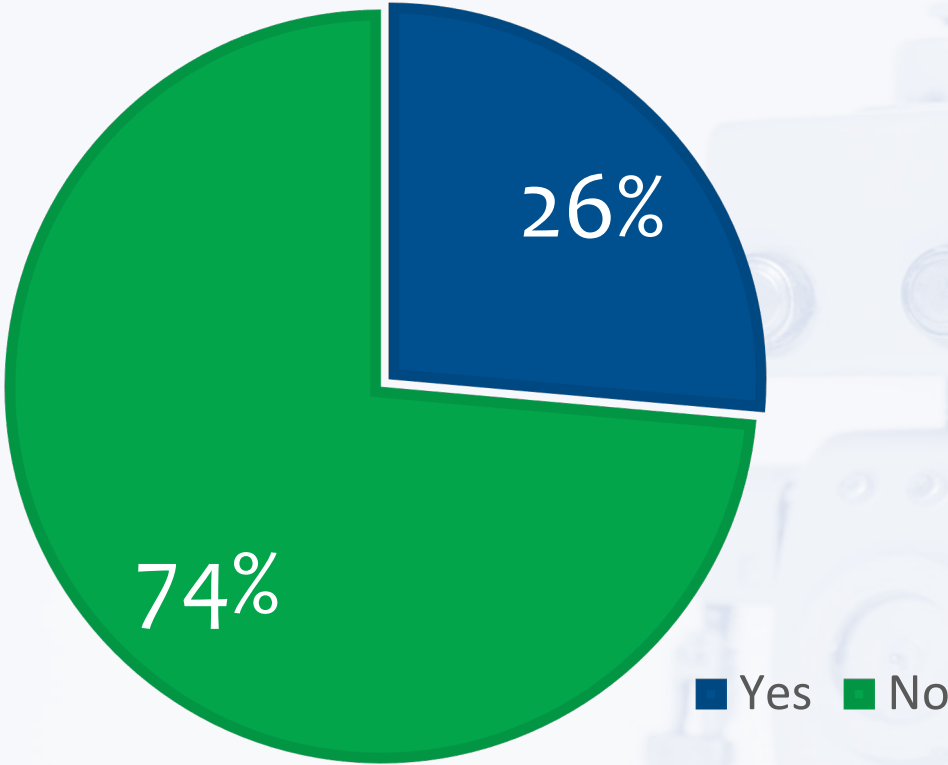
CONCLUSIONS (1/2)

o **67% respondents represented national patient organisations**. This could explain why 74% of respondents were not aware of any ongoing or upcoming <u>European</u> policies or guidelines dealing with the use of AI in healthcare.

o **Two thirds of respondents believed that their organisation's knowledge of AI in healthcare was basic or nonexistent**, while 19% believed it was solid.

o **Almost all respondents believed that AI would/could significantly improve or slightly improve patient outcomes**, while none of the respondents believed these could be significantly worsened.

o Among **the most interesting applications of AI in healthcare**, the respondents chose: improve the accuracy of diagnosis, improve the quality and efficiency of research and innovation in healthcare, lead to better treatments, support healthcare professionals in delivering more personalised care to patients and support patients' self-management and adherence to treatments.

CONCLUSIONS (2/2)

o The respondents believed that **lack of personnel and lack of knowledge were the main barriers for effective patient advocacy concerning AI in healthcare.**

o **Concerns about AI highlighted by respondents** relate to potential biased and non representative data used to train AI, lack of involvement of patients in design of AI solutions, safety issues due to low quality and unvalidated AI systems, lack of transparency on how algorithms work, and patients not being informed that AI has been used in the provision of healthcare/detection of disease.

o **82% of respondents believed that healthcare stakeholders (patients, healthcare professionals, nurses..) should be significantly involved in some aspects of the development and deployment of AI-powered tools and technologies**, while only 2% believed that they should be minimally involved.

o **59% of respondents did not know if AI was being used in their disease area/country**, especially in the area of cancer.