Data
Saves
Lives

Toolkit

Part Two:
AI: from science fiction
to science fact

Part **Two:**
AI: from science fiction to science fact

AI: FROM **SCIENCE FICTION** TO SCIENCE **FACT**

Introduction

Many people still think of Artificial Intelligence (AI) as being futuristic – something that belongs in a science fiction film. In reality, AI is already here and is firmly rooted in everyday life. Think of weather apps, digital assistants and chatbots, online banking and wearable devices such as fitness trackers so many of us use. All of these are examples of AI technology.

>> **FACT:** **Alan Turing, British mathematician and WWII code-breaker is widely credited as being one of the first people to come up with the idea of machines that 'think'. He created the *Turing test*, also known as the imitation game, which is still used as a benchmark to determine a machine's ability to 'think' like a human.** <<

AI has shown great potential in the field of healthcare. It is already transforming many aspects of the way we diagnose diseases, develop medicines, treat patients and monitor our own health. AI technology is developing at astonishing speed. It is likely that it will revolutionise other areas of healthcare over the coming years. We have barely begun to scratch the surface …

AI can be used to carry out some tasks normally performed by humans – but more rapidly, accurately and often at a lower cost. AI technology is already supporting radiologists in spotting malignant tumours, and guiding researchers in how to construct cohorts for costly clinical trials.

Some fear that AI will eventually replace healthcare professionals, but this is highly unlikely. AI has limitations and will never be able to consider the whole and holistic context of a patient or show emotion. What it can do is help reduce the chance of human error and free up the time of healthcare professionals so that they can focus on what they do best – spending time with patients.

What is the relationship between health data and AI?

There is a strong link between big data (large volume of data, different types of data and high speeds of data transmissions) and AI. AI tools need large volumes of data in order to operate and this inevitably raises issues of privacy and security, especially within the context of healthcare. Work is underway to develop appropriate regulations and a robust framework that is designed to protect the interests of all parties and to safeguard the security and privacy of patient data used in AI technology. (See Section 03 for further details).

As is often the case with anything new, some people are hesitant about embracing AI technology. Often this is due to misinformation or misunderstanding and this toolkit aims to dispel some of the myths surrounding the subject.

Why should you engage with AI?

Currently, there is limited involvement of clinicians and citizens in the design of AI healthcare tools – particularly in the initial stages of development. This means that some AI technology could potentially not meet the needs of the patients it has been designed for.

We believe this situation needs to change. We would like to see closer cooperation between AI developers and patient communities.

Developers working on apps and AI tools are usually experts in technology rather than healthcare. They may lack true insight into the needs of patients. Your communities are ideally placed to provide this real-life perspective. With your support, we can help to improve the quality and relevance of AI tools and develop AI technology that truly meets the needs of your members.

This section of the toolkit aims to give a simple explanation of what AI is and to highlight its potential benefits for the patient community, as well as some of the potential drawbacks. It will equip you with the information you need to talk confidently about the topic and to engage with the AI community in a constructive way.

WHAT IS AI AND HOW COULD IT BENEFIT PATIENT COMMUNITIES?

Let's take a brief look at what AI is, what it can and can't do, and how it offers exciting opportunities but also some potential downsides.

AI is a branch of computer science. It involves many different technologies working together to enable machines to sense, understand, act and 'learn' with human-like levels of intelligence.

FACT: AI is not new – the phrase 'artificial intelligence' was first used by computer scientist John McCarthy in 1956!

What it can do

- AI is assistive technology – it can help a healthcare professional reach a decision about a patient's diagnosis or treatment
- AI can improve productivity by analysing huge amounts of data quickly and accurately
- It can predict care needs
- AI can generate game-changing research
- It can reduce the risk of human error in certain settings

What it can't do

- AI cannot fully replace humans but it can support them
- It cannot generate original ideas or strategies (although content generation is original)
- AI cannot solve everything: some problems are too vague, ambiguous, or subjective for AI to handle or they require human judgment, intuition, or creativity
- It can't offer unique human skills such as emotion

Potential benefits

- Improving diagnostics by developing more sophisticated screening and diagnostic models
- Advancing treatment – helping to develop more targeted, personalised medicines and treatment plans
- Improving patient engagement
- Supporting administrative tasks freeing up healthcare professionals
- Improving prediction of disease outbreaks

Potential drawbacks

- Potential biases that could disadvantage some people
- Privacy and security issues
- Potential harm due to AI errors
- Misuse of medical AI tools and vulnerability to hacking
- Accountability issues – it could be difficult to know how AI technology has reached a decision
- Obstacles to implementation in real-world healthcare – lack of training or infrastructure

Potential healthcare applications	**Potential healthcare applications**
• Outbreak prediction	• Drug discovery
• Diagnosis of diseases	• Electronic health records (e.g. for data analysis and insights and clinical decision-making)
• Medical image analysis	• Medical robots
• Clinical trials (e.g. automating patient recruitment and data collection)	• Personalised medicine
• Optimisation of appointment scheduling	

Why is there potential bias?

AI can 'learn' from data and make predictions or recommendations based on patterns and probabilities, but it cannot guarantee that the data source is of good quality, accurate, complete, or representative. This means that AI can inherit or amplify the biases of the data sources, the algorithms, or the human designers. The AI developers can mitigate some biases by using more diverse and inclusive data sets, methods, and teams, but it is almost impossible to eliminate them completely.

KEY REGULATIONS/ GUIDELINES

> *"Our future is a race between the growing power of technology and the wisdom with which we use it. Let's make sure that wisdom wins."*
> **Professor Stephen Hawking, 2015**

AI technology is advancing at lightning speed and regulating such a fast-moving area is challenging. There is an urgent need to develop appropriate regulations to ensure that there is a strong framework to protect the interests of all parties and to increase trust.

FACT: Citizens of the US and Europe remain cautious about AI and how it is implemented. In a recent survey by the Centre for the Governance of AI, 91% of respondents agree that AI 'requires careful management'.

[Source: Preliminary Survey Results: US and European Publics Overwhelmingly and Increasingly Agree That AI Needs to Be Managed Carefully | GovAI Blog (governance.ai)]

Here are some of the key guidelines existing and in development, that are relevant to the development of AI technology.

The 2017/745 Medical Devices Regulation (MDR) and 2017/746 In vitro Diagnostic Medical Devices (IVDR) regulation

AI Regulations on medical devices produced by the EU co-legislators, the European Parliament and the Council of the European Union aim to ensure a high level of protection of health for patients and users by setting high standards of quality and safety for such devices.

Currently, medical devices that use AI technology are covered by these regulations. However, in 2017, when the Medical Devices regulations were agreed upon, AI healthcare technologies were still at the very early stage of development and the regulatory framework did not anticipate some of the aspects related to AI.

Ethics guidelines for Trustworthy AI

In 2019, the European Commission published the guidelines that set out requirements that AI systems should meet in order to be deemed trustworthy. According to the Guidelines, trustworthy AI should be: lawful, ethical and robust. The requirements cover 7 key areas:

- Human agency and oversight
- Technical robustness and safety
- Privacy and data governance
- Transparency
- Diversity
- Societal and environmental well-being
- Accountability

Ethics and governance of artificial intelligence for health

The 2021 WHO Guidance identifies the ethical challenges and risks with the use of artificial intelligence in health and sets out six consensus principles to ensure AI works to the public benefit of all countries. It also contains a set of recommendations that can ensure the governance of artificial intelligence for health maximizes the promise of the technology and holds all stakeholders – in the public and private sector – accountable and responsive to the healthcare workers who will rely on these technologies and the communities and individuals whose health will be affected by its use.

Artificial intelligence in healthcare: Applications, risks, and ethical and societal impacts

This study carried out by the European Parliament Think Tank provides an overview of how AI can benefit future healthcare, for example by increasing the efficiency of clinicians, improving medical diagnosis and treatment, optimising the allocation of human and technical resources. The report also highlights the main clinical, social and ethical risks posed by AI in healthcare: potential errors and patient harm; risk of bias and increased health inequalities; lack of transparency and trust; and vulnerability to hacking and data privacy breaches. The study proposes mitigation measures and policy options to minimise these risks and maximise the benefits of medical AI. These include multi-stakeholder engagement through the AI production lifetime; increased transparency and traceability; in-depth clinical validation of AI tools, and AI training and education for both clinicians and citizens.

The EU proposal on the regulatory framework for AI

The European Commission is proposing the first-ever legal framework on AI. The regulatory proposal aims to provide AI developers, deployers and users with clear requirements and obligations regarding specific uses of AI. The aim is to ensure that when an AI system goes 'live', safeguards are in place to ensure it complies with regulations and that action can be taken if this is not the case.

The Regulatory Framework will define 4 risk categories: minimal, limited, high and unacceptable. The negotiations are still underway, but the current positions suggest that all medical devices will most probably fall into the high-risk category which will be subject to specific stringent legal requirements.

The AI Act is designed to be future-proof, allowing rules to adapt to technological change.

The regulatory framework is expected to come into effect in 2025.

AI AT WORK: FROM PREVENTION TO REHABILITATION

AI is already integrated into a whole range of elements of healthcare and there is huge potential for it to play a role in a wide variety of other areas. Currently, AI tools can be grouped into four key areas: **clinical practice, biomedical research, public health and health administration.** Let's look at each of these in a little more detail.

Clinical practice	Biomedical research
AI TOOLS IN HEALTHCARE	
Public health	Health administration
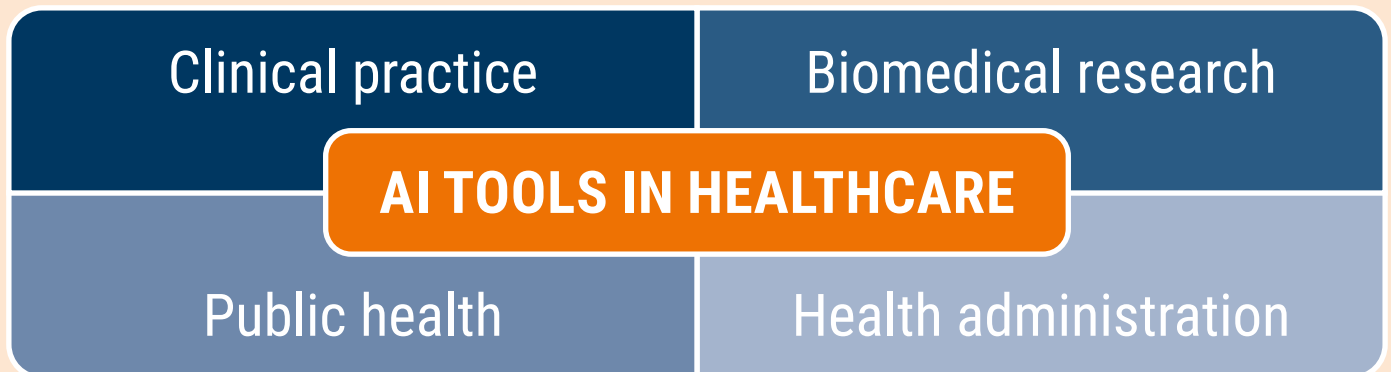
Clinical practice:

AI can provide support in a variety of areas, by speeding up the analysis of data, improving administrative systems, or supporting the decision-making process in terms of diagnosis and treatment. AI already plays a key role in the following areas:

- **Radiology:** analysis of X-ray images or scans – AI can detect clinically relevant features in imaging data that the human eye cannot perceive

- **Pathology:** analysis of images to support a diagnosis

- **Surgery:** use of robots to provide precise and minimally invasive surgery

AI **IN ACTION**

Analysis of CT scans in patients with suspected coronary heart disease

AI technology called HeartFlow is being used in the NHS in the UK and in many other healthcare settings. It analyses CT scans of patients who are suspected of having coronary heart disease. It creates a personalised 3D model of the heart that shows blood flow and highlights any blockages. HeartFlow is less costly and invasive than standard procedures such as angiograms.

[Source: https://www.heartflow.com/heartflow-ffrct-analysis/article/our-technology-core/]

AI **IN ACTION**

Diagnosis of skin cancer

A number of different forms of AI technology are available to assist in the diagnosis of melanoma and research has shown that a form of AI can actually out-perform experienced dermatologists at detecting skin cancer. Researchers in Germany, the USA and France 'trained' AI technology by showing it more than 100,000 images of malignant melanomas, as well as benign moles. They compared its performance with that of 58 international dermatologists and found that the AI technology missed fewer melanomas and misdiagnosed fewer benign moles less as being malignant. It is not envisaged that AI will replace dermatologists in the diagnosis of skin cancer but that it will act as a supportive tool.

[Source: https://www.esmo.org/]

Biomedical research

AI is already widely used in clinical research and is helping to streamline the process of drug discovery. Key areas include:

- **Clinical research:** analysing large volumes of data
- **Drug discovery:** identifying potential candidates for drug development, significantly reducing traditional timescales
  - Some technology companies are now using AI to design experiments to discover new drugs and potential treatments.
    [source: https://www.exscientia.ai/our-mission]
- **Clinical trials:** ensuring patient diversity, improving retention rates patient selection and recruitment, randomising patients signed up for trials
  - Some tech companies are leveraging AI to improve clinical trials. For example, 'digital twins' (identical data sets) of patients can be created in clinical trials to design more efficient, ethical and reliable clinical studies
    [source: https://www.unlearn.ai/about]
- **Personalised medicine:** developing treatment plans based on individual patient data or personalised treatment such as immunotherapy

Public health

AI can support public health by analysing data more efficiently and facilitating the development of wearable technology to monitor health. Areas where AI is already being employed include:

- **Prevention:** AI can identify, track and monitor emerging health threats so that appropriate action can be taken
- **Global health:** identifying risks via accurate forecasting
- **Health facilities:** use of virtual wards, where patients can be assessed at home via remote monitoring tools
- **Resource allocation:** targeting treatment more effectively, improving efficiency and reducing costs

AI **IN ACTION**

Forecasting a patient's risk of stroke recurrence

A research team based at the Vall D'Hebron University in Barcelona has presented a study demonstrating how AI can be employed to accurately predict a patient's risk of stroke recurrence. AI technology was used to review non-modifiable risk factors (e.g. age and ethnicity) and modifiable factors such as body weight, smoking, blood pressure and physical activity levels. The technology was able to provide accurate and personalised risk profiles for patients at three months and one year.

[Source: https://www.healtheuropa.com/potential-risk-of-stroke-recurrence-predicted-with-artificial-intelligence/110697/]

AI **IN ACTION**

Assessing pain in people with dementia who cannot self-report

PainChek is a CE-marked pain assessment tool in the form of an App on personal mobile devices. It takes a 3-second video of a person's face and applies AI to identify facial micro-expressions indicative of pain. This information is combined with other pain indicators recorded by a carer to generate an overall pain score. Originally developed in Australia, PainChek is now used in many care homes in the UK.

[Source: https://transform.england.nhs.uk/ai-lab/explore-all-resources/understand-ai/assessing-pain-people-dementia-who-cannot-self-report/]

AI **IN ACTION**

The role of AI in COVID-19 treatment decisions

The use of an AI tool aiding personalised COVID-19 treatment decisions has been shown to lead to a 50% reduction in COVID-19 mortality rates. The tool was developed by researchers at Hospital Clinic Barcelona-IDIBAPS. It is capable of analysing, in real time, more than a trillion anonymised data points of patients, identifying clinical patterns and suggesting personalised treatments. The tool was able to predict, with 90% accuracy, the trajectory of the disease in individual patients to allow for timely and appropriate treatment.

[Source: https://www.healtheuropa.com/artificial-intelligence-covid-19-mortality-reduction/102053/]

Health administration

AI can support the healthcare administrative burden by streamlining a number of processes, including:

- Clinical coding
- Scheduling of appointments
- Patient flow management
- Healthcare audits

AI **IN ACTION**

Using AI to predict demand for hospital beds coming from A&E

Bed allocation in hospitals is a complex, constantly-changing matter. An artificial intelligence tool developed by researchers at University College Hospital in London is being used to predict how many patients coming through the emergency department will need to be admitted into the hospital, helping planners manage demand on beds. The AI technology assesses each patient's probability of being admitted to hospital from the emergency department, based on a range of data including age, how the patient arrived in hospital, test results and number of consultations.

[Source: https://www.ucl.ac.uk/news/2022/sep/ai-predicts-demand-hospital-beds-coming-ae#:~:text=An%20artificial%20intelligence%20tool%20developed,planners%20manage%20demand%20on%20beds]

COMMUNICATING ABOUT AI IN HEALTHCARE

Getting to know the stakeholders

Every type of stakeholder involved in the development and uptake of AI will have a different perspective, with their own specific priorities and viewpoint. Below we look at the key stakeholders and some of their drivers and perspectives.

DEVELOPERS

- Key driver is likely to be the success/viability of the AI tool rather than how it will benefit patients
- Likely to have technical rather than clinical expertise
- They may have minimal understanding of the disease area for which they are developing AI technology and low awareness of the true needs of patients
- They may place greater emphasis on 'tech' elements of an AI tool rather than usability and accessibility factors that make it easy to use – this can affect adoption of the technology
- They may lack insight into factors affecting the uptake of the tool, such as training of users
- They may be less or entirely unaware of the ethical implications of their products

Opportunities for engagement

- Emphasise that you can offer valuable insight into the needs of patients via the lived experience of your community and that you can help to identify where there are gaps that AI technology could fill
- Offer advice on practical aspects of AI technology that are likely to improve usability and increase uptake
- Suggest that your community could be involved at the development stage, for example by taking part in advisory or focus groups, and in testing early versions of AI technology
- Explain that your community can offer 'real life' feedback on the AI technology and the important ethical values that might be at stake
- Offer guidance on training materials for patients
- Offer to act as a point of contact for information on the new technology and how it is being used

HEALTHCARE PROFESSIONALS

- Key driver is likely to be how AI can improve efficiencies and benefit HCPs and patients
- Key questions/concerns are likely to be:
  - What are the benefits to me and/or my patients? Cost?
  - How well will the technology integrate with existing systems?
  - What resources will be needed to implement the technology?
  - Will my staff be offered appropriate training?
  - Will this impact on the relationship I have with my patients?
  - Am I responsible and accountable for possible unforeseen and undetectable mistakes of the AI-system?
  - Will using AI technology disrupt current care pathways?

Opportunities for engagement

- Emphasise that you can offer insight into how the new AI technology might benefit your members and why there is a need for it
- Offer to act as an interface between healthcare professionals and your community
- Offer to act as a point of contact for patients who need additional information on the new technology

PATIENT COMMUNITIES

- Key driver is likely to be whether the technology will have a positive impact on the patient communities
- Key questions are likely to be:
  - Will the technology benefit me?
  - Will I have less opportunity for face-to-face contact with my doctor?
  - Will my privacy be safeguarded? And if so, how?
  - How will my data be used?
  - Will the AI technology be biased and could this affect me negatively?

Opportunities for engagement

- Act as a point of liaison between patients and the AI technology developer – forwarding questions from users and sharing patient feedback
- Offer to act as a point of contact for patients who need additional information on the new technology
- Ensure that you have the information you need to deal with enquiries about privacy and security

TELLING THE STORY OF **AI**

AI is a complex, often controversial topic. Many people have misconceptions about how the technology is being used in healthcare or concerns about what may happen in the future. You can contribute positively by providing clear, balanced information in a way that is accessible to your community. Some of you will feel confident about doing this but others may be less relaxed about tackling the subject. This factsheet provides general guidance on how to talk about complex subject matters along with some useful statements on AI that can be incorporated into any materials you produce.

Please also refer to part one of the toolkit, which has additional information on communicating effectively with your community.

GENERAL TIPS ON COMMUNICATING COMPLEX SUBJECTS

- Use clear everyday language

- You will inevitably need to use some technical terminology when talking about AI, but explain any terms in simple language

- If you are producing something with a lot of technical terms, it can be useful to include a glossary (list of terms with short explanations) at the end of the item. There is an example of a glossary in section 12 of this toolkit

- Don't try to communicate too much at once – it is better to give an overview of the key points of a subject with links to sources of further information

- Good layout is important – use short paragraphs and break text up with graphics, quotes, fact boxes and images where possible

- Many people are not wholly familiar with the subject of AI. If possible, include examples of how AI is already being used in healthcare – there are some examples in section 04 of this document

Data Saves Lives

Template statements that can be used when communicating about AI in healthcare

What is AI?

- AI is a branch of computer science. It involves many different technologies that can work together to enable machines to sense, interpret, act and 'learn' with human-like intelligence
- Weather apps, digital assistants, online banking and wearable devices such as fitness trackers are all examples of AI technology in common use
- AI is already being used in numerous healthcare settings. AI tools can be grouped into four key areas: clinical practice, biomedical research, public health and health administration

AI in healthcare

AI has the potential to transform healthcare. There are already a number of research studies suggesting that AI can perform as well as or better than humans at key healthcare tasks, such as diagnosing disease. Today, algorithms are already supporting radiologists at spotting malignant tumours, and guiding researchers in how to construct cohorts for costly clinical trials
[Source: Future Healthcare Journal https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6616181/]

- AI is not designed to fully replace medical professionals. It is assistive technology that is designed to support them, allowing them to use their time more profitably. In theory, freeing clinicians from routine or time-consuming tasks will allow them to spend more face-to-face time with patients
- AI cannot offer uniquely human skills such as emotion
- AI is already transforming healthcare in a number of ways. Key areas include:
    - improving diagnostics by allowing faster and more sophisticated screening and diagnostic models
    - advancing treatment by streamlining the process of drug discovery and helping to develop personalised treatment plans
    - improving patient well-being and engagement through the use of wearable or remote devices that allow patients to be monitored away from the clinical setting
    - supporting the design and recruitment of patients into clinical trials

The ethics of AI

- AI is relatively new technology and it is important to ensure that adequate legislation is in place
- There are concerns over data privacy and data protection
- There are concerns over potential biases that could lead to unreliable results or disadvantage some people
- Transparency is another area of potential concern. AI technology is based on algorithms and in some cases, it could be difficult to know how a decision regarding patient diagnosis or treatment has been reached
- Establishing a clear line of accountability is crucial. This entails defining responsibilities in case of errors and outlining available options for redress

The need for transparency in AI

- In the past, healthcare decisions were taken almost exclusively by humans. The use of AI technology to make or assist such decisions raises issues of accountability, transparency, permission and privacy

- It is important for all stakeholders to clearly understand how an AI system works and how it makes decisions and processes data. This will help to build trust in AI and will ensure that AI systems are fair and ethical

- AI developers should clearly explain the processes involved in decision-making so that it is clear how a decision was reached. This will help to reduce the risk of potential bias

- All stakeholders need to be open and transparent about how personal data will be used and what type of procedures are in place to safeguard privacy and security. Moreover, any applicable consent mechanisms need to be fully respected.

- Specific regulations are being drawn up to help ensure that AI technology is transparent, trustworthy and explainable

How your community can be part of the conversation around AI in healthcare

- AI developers are skilled in technology but some lack medical expertise or insight into the disease area for which they are developing AI technology. Therefore, it is important for the patient community to be involved from the initial concept stages and throughout the development process

- Patient communities can provide real life expertise on what it is like to live with a specific condition and highlight the areas in which AI technology could be useful. They can also provide valuable feedback during testing phases of development

- Co-operating with AI developers can increase the likelihood of developing tools that are relevant, user-friendly and fulfil a useful function

- Engaging with AI developers will help to build trust in the new technology

HOW TO COMMUNICATE WITH DIFFERENT AUDIENCES

Below we have developed a series of outline content for presentations on AI that can be adapted to suit different audiences.

FOR YOUR COMMUNITY

SLIDE 1: About your organisation	• When you were founded and by whom • Introduction to team members • Membership details • Geographical location
SLIDE 2: Aims	• Aims and objectives of group • Why the group was founded
SLIDE 3: Support	• Services/materials provided by your group (helpline, patient materials, forums, webinars etc.)
SLIDE 4: Successes	• Details of any key initiatives and how they have improved the situation for your community
SLIDE 5: Current benefits of AI for your community	• Examples of AI how technology is already improving the lives of your community
SLIDE 6: Potential areas of AI development	• Examples of circumstances where appropriate AI technology could improve the lives of your community
SLIDE 7: Safeguards	• Importance of robust systems to safeguard privacy and security • Examples of systems already in place
SLIDE 8: Why should your community engage with AI?	• Importance of involving patients in the early stages of AI technology development • Potential to develop more targeted and personalised tools and to improve numerous stages of the healthcare journey
SLIDE 9: How you can get involved	• Ways in which your community can get involved, either in the development of AI tools or their testing

FOR POTENTIAL FUNDERS/INVESTORS

SLIDE 1: **About your organisation**	• When you were founded and by whom • Introduction to team members • Membership details • Geographical location
SLIDE 2: **Aims**	• Aims and objectives of group • Why the group was founded
SLIDE 3: **Support**	• Services/materials provided by your group (helpline, patient materials, forums, webinars etc.)
SLIDE 4: **Successes**	• Details of any key initiatives and how they have improved the situation for your community
SLIDE 5: **Current benefits of AI for your community**	• Examples of AI how technology is already improving the lives of your community
SLIDE 6: **How could AI tools/ funding support your community?**	• Current challenges facing your community • Examples of circumstances where appropriate AI technology could improve the lives of your community
SLIDE 7: **Why should we work together?**	• Importance of involving patients in the early stages of AI technology development • Potential to develop more targeted and personalised tools that truly meet patient needs • Increases likelihood of good uptake of AI tools
SLIDE 8: **How could we work together?**	• Stages at which your community could become involved – initial concept, development, testing and assessment, training of clinicians, ongoing feedback

Data Saves Lives

TEMPLATE QUESTIONS
FOR DEVELOPERS

Before considering any involvement with an AI developer, it is vital to understand what is being proposed – what the technology aims to do, how it could impact on your patient community and exactly what is being asked of you.

Please also refer to Health Data 101 (Part one) for
Supporting health data initiatives: should you engage? **which includes relevant information on engaging in digital healthcare design.**

Product/technology

In terms of the technology itself, make sure you understand what the tool is intended to do, how it will work and how you will be involved. Potential questions include:

- **What** problem are you trying to solve and how will AI support this? How will this new technology offer advantages over current technology?
- **How** will the technology work on a practical basis and what results do you anticipate?
- **What** stage of development has the project reached? Are you being involved in the development of a new AI tool or are you being asked to test an existing AI tool?
- **What** input do you expect from us? How much time is likely to be incurred?
- **Will** you provide adequate training/support materials for patients and/or healthcare professionals to ensure that the AI technology can be used successfully?
- **(For fully developed tools) Does** the product meet regulatory standards? Is it safe?
- **(For fully developed tools) Was** the AI-system trained on a dataset representing my patient group?
- **(For fully developed tools) Does** the product/technology perform in line with the manufacturer's claims and what evidence is available to support this?

Security and privacy

Security is a particular concern with newer tools that have not been tried and tested. Again, make sure you understand how patient data will be collected, stored and used. Potential questions include:

- **How** will you comply with individual rights requests?
- **How** will you mitigate security risks?
- **How** will you ensure transparency?
- **Where** will patient data go and will it be shared with any other parties?
- **Are** you the controller, joint controller or processor of the data?

If the AI developer you are engaging with is not able to answer your questions fully or you feel uncomfortable with any aspect that is being asked of you, it may be wiser not to proceed or to take some time to consider your options. Do not feel pressurised into going ahead.

GATHERING **INSIGHTS**

It is helpful to understand how AI is currently being used in your patient communities.

As a starting point, we have prepared a short survey to share with practising clinicians in your disease area. This can be adapted to take account of local infrastructure.

- **How** is AI currently being used in the treatment pathway, from screening and diagnosis to ongoing management?

- **What** is your attitude to using AI – do you feel comfortable, neutral or uncomfortable about using AI in the treatment pathway?

- **How** would you rate the current accuracy of the AI?

- **Have** you experienced any issues using AI technology? If so, what are they?

- **Are** your patients aware that AI is being used in their treatment pathway? If yes, how do they feel about it?

- **Do** you believe that AI helps to eliminate human bias from decision-making?

- **How** does AI influence decision-making?

- **Are** patients aware of the use of AI in their treatment decision-making?

- **How** have patients responded to the use of AI technology? Please give examples of positive and negative responses if relevant

- **Are** there aspects of your clinical practice where you believe AI technology would be beneficial? If so, what are they?

- **Are** there any other therapy areas that you plan to use AI for?

TIPS FOR FINDING FUNDING OPPORTUNITIES

The question of how to secure EU project funding in today's fiercely competitive market is a common one. It's important to recognise that the process of securing funding isn't always a straightforward path. It calls for meticulous planning, relationship building, and above all, a healthy dose of patience.

In the following section, we provide ten practical tips on how to find, approach and ultimately secure funding:

1. **Plan ahead:** Before contacting potential funders, ensure you have your project concept note and budget ready. This will help you establish a clear strategy, define goals, outline a communication plan and identify necessary tools.

2. **Align on missions:** Look for funders whose mission aligns with yours. Prioritise those who are key stakeholders and partners, as you never want to compromise your reputation for funding!

3. **Stay informed:** If you cannot find suitable opportunities online, sign up to the newsletter of the target funders, as that is often where they publish funding opportunities, particularly in the not-for-profit sector

4. **Diversify funding sources:** Strive for funding diversity from various sources like not-for-profit entities, for-profit organizations, private donors, and public sectors

5. **Build sustainable partnerships:** Seek long-term, sustainable and transparent funding partnerships

6. **Play the long game:** Prioritise establishing a genuine relationship before discussing funding matters

7. **Leverage networks:** Delve into your existing network and their contacts to identify potential funders

8. **Initiate Contact:** Reach out to funders to arrange a meeting where you can introduce your organisation. This initial step will lay the foundation for a future relationship and potential funding opportunities

9. **Apply early:** Submit funding applications well in advance of your project's start date. This ensures compliance with funders' budget deadlines and allows for any necessary preparations. Depending on the organisation, submitting your application a quarter before the activity starts might be prudent due to potential compliance delays

10. **Honour commitments:** Be aware and respectful of reporting and contractual requirements. Remember that funders need to demonstrate value to their stakeholders too!

LOCALISING
DATA SAVES LIVES

Are you interested in setting up a national version of Data Saves Lives to raise awareness of the value of responsible health data sharing in your country? The idea might be daunting but in fact, it has already been successfully done in Germany and we are aware of other countries who are actively considering the possibility. This section explains what a local version of Data Saves Lives looks like in practice and outlines some of the considerations.

Re-use and recycle!

We understand that resources are limited so it makes sense to maximise the use of existing materials – there is no need to re-invent the wheel! Think about:

- **Using the #DataSavesLives hashtag –** this is free for anyone to use
- **Translating** some or all of the materials from the Data Saves Lives website, adapting them to your own country where relevant
- **Using the visuals** from our website for continued brand awareness
- **Taking inspiration from our communication channels –** consider using social media or organising webinars or training workshops

Data Saves Lives Germany

Launched at the end of 2022, Data Saves Lives Germany is the first local variant of the initiative. It is headed up by patient expert Birgit Bauer, who has been part of the advisory group for Data Saves Lives from the outset. It offers:

- **A fully translated website**
- **Local blogs in German**
- **A dedicated hub to access translated information and materials**
- **Dedicated Data Saves Lives DE social media channels, including Twitter**

Funding has been gained from the German Ministry of Health and from industry sponsors.

Key considerations

Before you embark on a localised version of Data Saves Lives, it can be helpful to consider a few key questions:

- **Why** do we need a local version – what benefits will it bring?
- **Is** there an appetite to keep local momentum around DSL alive through regular activities and communications?
- **What** specific elements would be useful?
- **How** can it be made relevant to your local community?
- **What** financial resources will be needed?
- **Will** additional funding be needed?
- **Who** will head up the project?
- **Do** you have the capacity to undertake this project – will you need to involve other people?
- **How** much time will the project involve?

Step by step guide

1. **Define** your goals and get in touch - contact the Data Saves Lives Secretariat to request the logo and data files
2. **Choose** which materials to translate
3. **Decide** whether or not you want to clone the website – the website is created on Wordpress and is easy to replicate
4. **Once** you have developed the relevant resources, you're good to go. Start communicating!

Timescale: allow approximately 6–8 weeks to launch the website, from the time you start the translation process.

We are also happy to share our experiences of setting up the Data Saves Lives project so if you have any questions, get in touch!

KEY TERMINOLOGY

Below is a glossary of key terms in the subject of AI.

AI	AI is the use of digital technology to mimic human intelligence to 'learn' how to perform a given task by analysing big data (See also **Machine Learning** and **Deep Learning**). AI helps computers to identify patterns, make predictions, solve problems and even learn from their own mistakes
Algorithm	A process or set of instructions that can be used by a human or a computer to solve a problem or perform an activity
Big data	In the healthcare setting, Big Data is used to describe the extensive healthcare databases (like electronic health record systems) or networks of interconnected healthcare databases (called 'linked' databases) coming from multiple organisations. See also **The Three Vs**
Consent	To give permission for something to happen or agreement to do something. This can be given verbally or in writing. Usually, medical staff do not need your permission to record information about a patient as it is important for their care (**implied consent**). If a patient's confidential information is used for purposes beyond their individual care, their **explicit consent** will be needed. However, under GDPR, certain exceptions exist for using health data for specific secondary purposes, such as research, where patient consent might not be required.
Deep Learning	A subset of **Machine Learning** that uses large **Neural Networks** and big data to better solve complex problems. It creates an adaptive system to allow computers to 'learn' from their mistakes
EHDS	**European Health Data Space:** an EU initiative designed to offer patients access to their own health data in electronic format immediately and at no cost, with the ability to share data with health professionals within the EU and cross-border (primary use) & facilitate the use of such data for research and innovation purposes
Federated data	Federated datasets allow data to stay in the place they are produced to avoid unsafe transferral to other areas
FAIRified data	**FAIRification** is based on the concept of data being Findable, Accessible, **Interoperable** and Reusable to allow data to be used in a **Federated** manner
Homomorphic encryption	An encryption technology designed to enhance privacy
Interoperability	Issuing information in a common format so it can be easily exchanged and made use of
Machine learning	A subset of AI that involves machines 'learning' from patterns of data or previous tasks and improving their performance
Neural network	A type of machine learning process that uses interconnected nodes to teach computers to process data in a way that is inspired by the human brain
The Three Vs (in the context of big data)	**Volume, velocity and variety:** these are seen as a way to define and measure big data and to understand how it differs from 'old-fashioned' data