



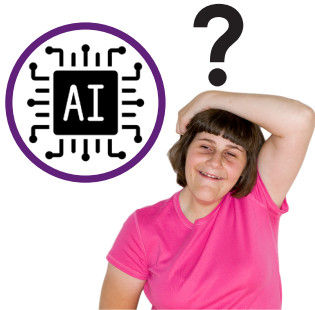
Good regulation for AI in healthcare

What people with learning disabilities, carers and young people told us





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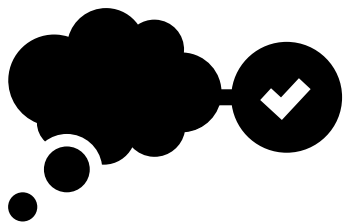
What is AI?



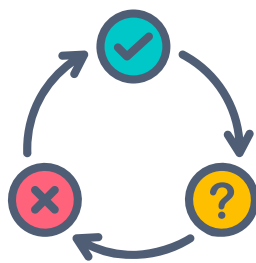
AI stands for artificial intelligence.



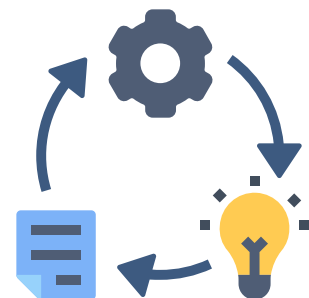
AI means computers and other technology can do complicated tasks that only people used to be able to do, such as:



Thinking things through



Making decisions



Solving problems



About this report



AI is being used more in health care.



New **regulations** are needed to make sure AI is being used the right way for everyone.

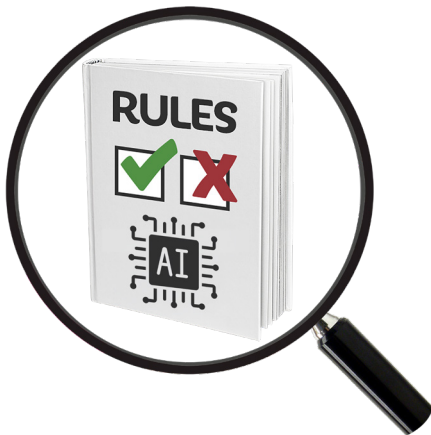


Regulations are rules that say how something should be done.

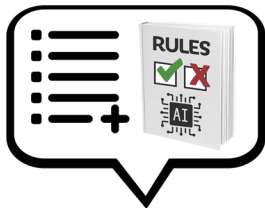


The UK government has set up a National Commission into the Regulation of AI in Healthcare.

This is a group of experts who will:



- Look at current rules on using AI in healthcare.



- Suggest new rules if needed so that AI is used safely.



The National Commission asked a lot of people what they think about using AI in healthcare.





Some groups of people were not heard from as much as other groups.

They included:



- Young people aged 16 to 25 years old.



- Unpaid carers, for example, family carer.



- People with a learning disability.



National Voices was asked to talk to these groups of people.



This report is about what rules they told us needed to be in place to make sure using AI in healthcare was:



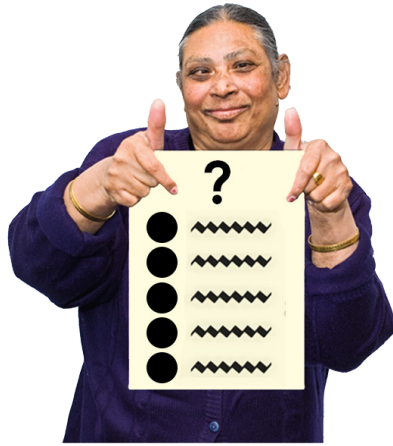
Safe



Trustworthy



Fair



What we did?



We worked with 3 partner organisations:



Learning Disability England



Carers UK





The Association for Young People's Health



Our 3 partner organisations helped us find people to talk to.



We ran 3 online workshops.



Online workshops made it easier for people to take part.



People did not need to spend time and money travelling to the workshop.



People could take part in a place they felt comfortable, like their home.



We gave people £55 as a thank you for taking part.



We talked to 11 young people aged 16 to 25 years in the first workshop.



We talked to 9 unpaid carers in the second workshop.



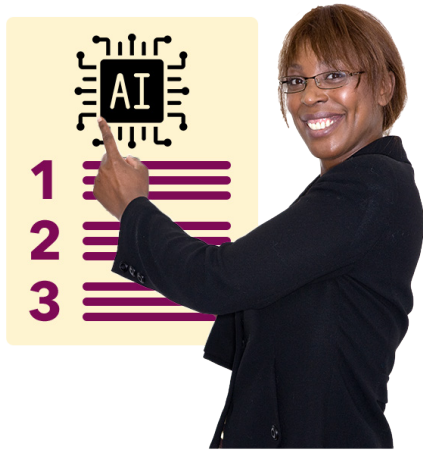
We talked to 6 people with a learning disability in the third workshop.



We worked with our 3 partner organisations to make sure the workshops were right for people.



For example, the workshop for people with a learning disability had less text and more time for talking.

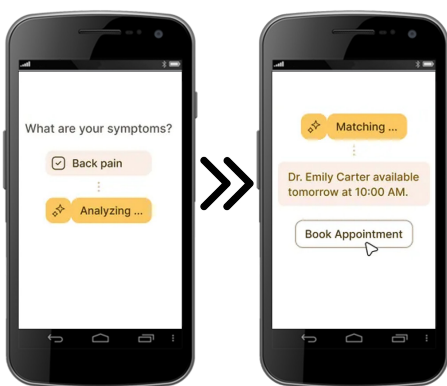


In the workshop we talked about 3 types of AI tools.



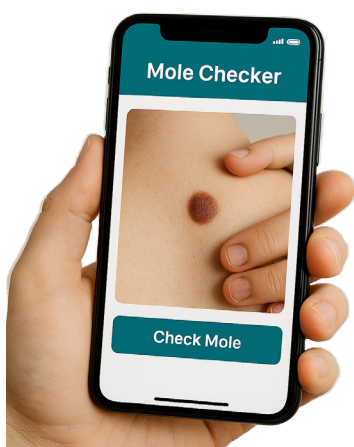
1. AI note writing tool

The AI listens during the appointment and writes the notes automatically.



2. AI booking appointment tool

The AI asks the patient some questions, then decides and books the appointment.



3. AI mole checking tool

A person takes a photo of a mole using a mobile phone app, and the AI gives simple advice on what to do next.



What we found out?



1. People said, **real people must be involved in their care**



- They did not want AI to replace real people.



- AI must only be used to help staff.



- There must always be a way for you to talk to a real person.



- It should be easy to tell a real person any worries you have.



2. People said, **trust depends on proof, not promises**



- People said they will only trust AI if it is shown to be safe.



- They want clear rules and protections when they are using AI tools.



- People cared more about having clear information on safety and choice over knowing how AI worked.



3. People said, **be open and get real consent**



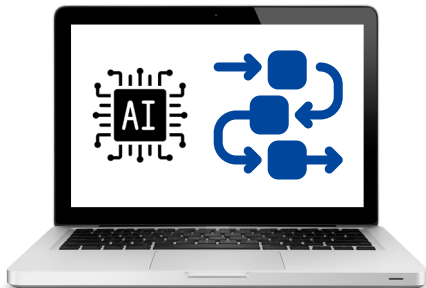
People expect to be told when AI is used.



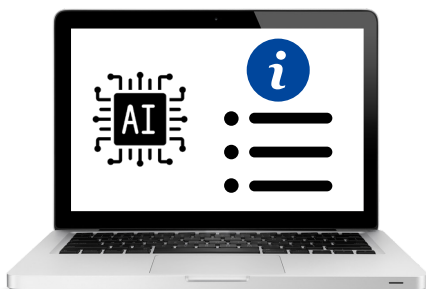
Information must be clear and easy to understand.



Before they use AI tools, people need to know:



- What the AI does?



- What information it uses?



- What choices they have if they don't want to use AI tools?



4. People were **worried about how information collected by AI is used**



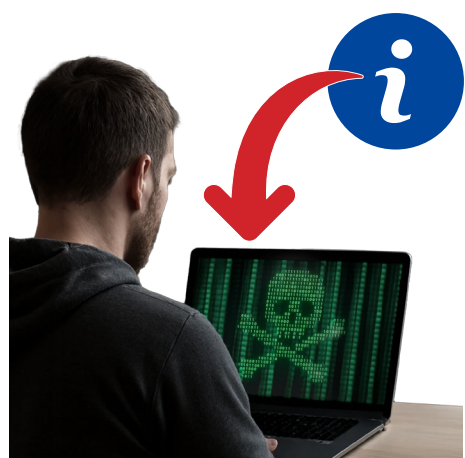
People were worried about:



- Other companies looking at and using their information



- Their information being used for something they didn't agree to



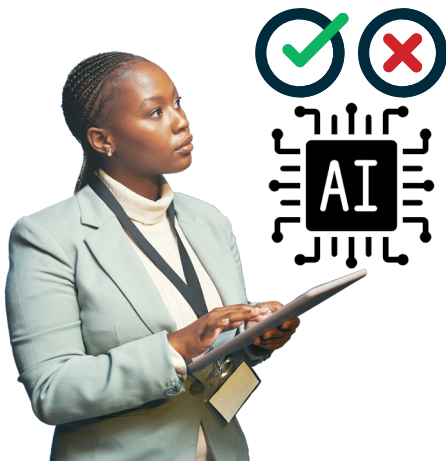
- Their personal information being stolen by hackers



- People were only willing to accept their information being used if stronger protections were put in place.



5. People said, **safety and keeping an eye on AI tools was important**



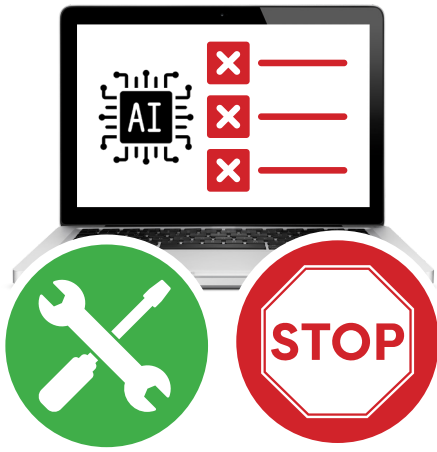
- AI tools must be tested before use.



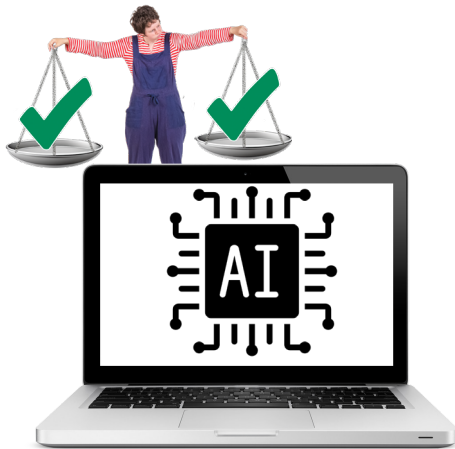
- Someone must keep an eye on AI tools.



- This is to make sure they are working well.



- If AI tools are not working well, there must be ways to quickly fix or stop them.



6. People said, **equity must be built into AI tools from the start**



- Equity means people are given the tools and support to allow them to access AI tools.



Tools can be equipment such as computers, or resources such as information and training.



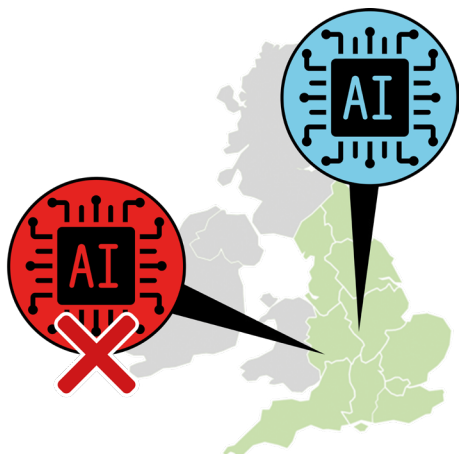
- People said some groups of people may need more help when using AI tools.



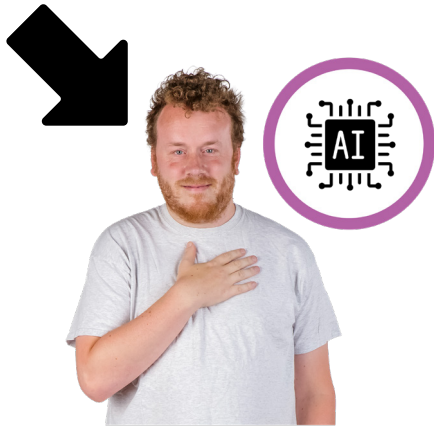
- For example, people may need support if they cannot use computers or mobile phones.



- AI tools must be accessible and work for people with different needs.



- If some areas of the UK got AI tools before other areas of the UK it will not be fair.



7. People said, **accountability must be clear**



- **Accountability** means a person or a group of people are responsible and put things right if something goes wrong.



- People want to know who is responsible for the AI tools.



- More than one organisation should be responsible for the AI tools.



- Sharing responsibility means more people are making sure AI tools are working well.



- It should be easy to know who to go to if something goes wrong to get it sorted.



8. Different groups have different worries



Young people said:



- They were worried about how their information would be used.



- They did not trust businesses with their information.



- They want AI to be tested across different groups of people to make sure that it works for everyone



People with a learning disability said:



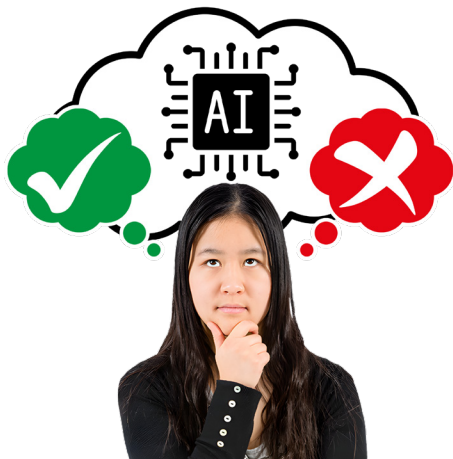
People with a learning disability were the most worried using AI tools.



They said it is very important that:



- AI tools are accessible and easy to use



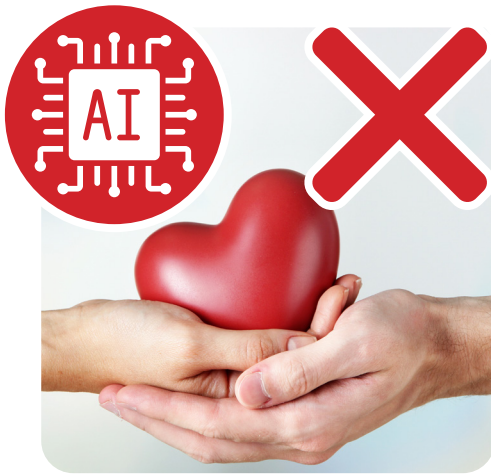
- People can make their own choices whether to use AI tools



- People can get information and education on the benefits of AI and how it is being used



- There are still real people involved in their care



They were worried that AI won't have the same compassion as a real person.



Unpaid carers said:



- They were worried this could create a two-tier system.



This means people who cannot use digital services, or who have additional needs, could be unfairly affected.



- They wanted to keep other ways for people to access services.



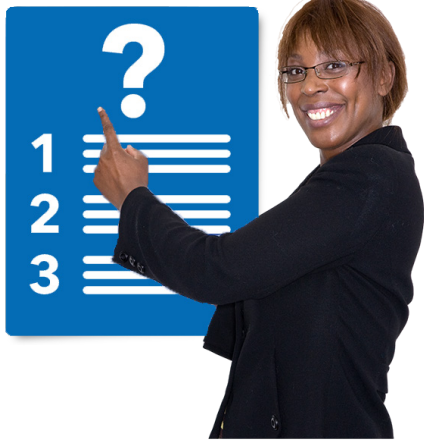
- They want to know who is responsible for AI tools



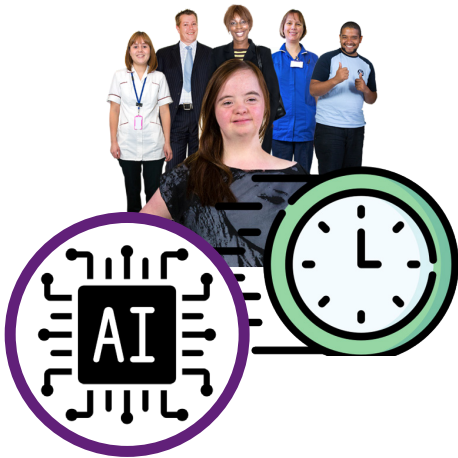
- They want people to keep a close eye on AI tools to make sure they are working well



- They want ways to stop problems with AI tools.



10. Our conclusion



AI tools can help healthcare services work faster.



But people may trust AI less and may be treated more unfairly when getting healthcare if:



- AI does not have clear ways to keep people safe.



- It is not clear who is responsible for the AI tool.



- AI does not have easy ways to get support from a person.



Key considerations



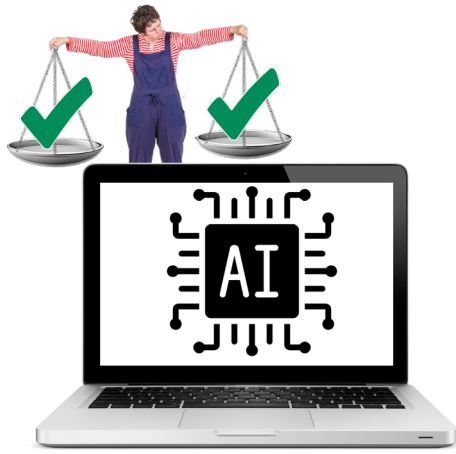
Considerations are things to think about carefully before deciding something or taking action.



We have come up with some considerations from what people told us in the workshops.



Our considerations will be looked at when the UK government make new rules for using AI in healthcare.



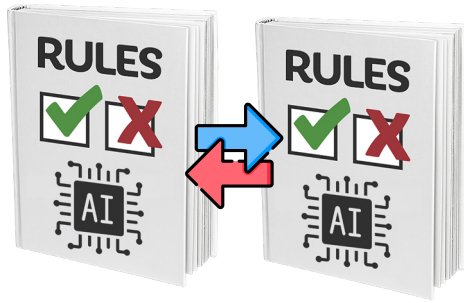
Make equity a condition for approval



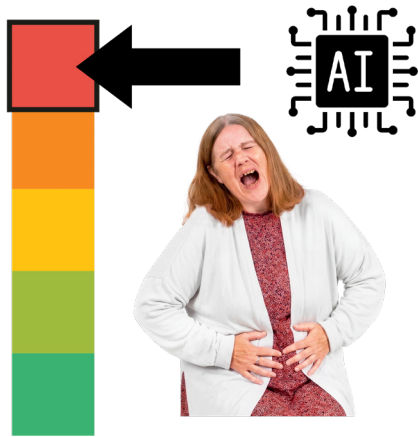
This means checking that the AI tools work well for different people so no group is left out or harmed.



Do not allow tools that could create unfair services.



Use different rules based on what AI is used for



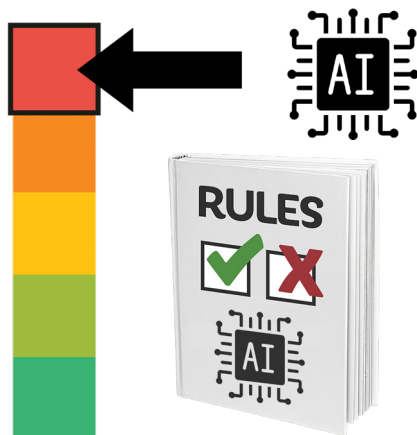
- Some AI tools are high risk.

This means if they go wrong there is a high chance it can cause harm to patients.



An example is **diagnosing AI tools**.

It asks you questions and makes decisions on your health.



High risk AI tools must be checked more and have stronger rules.



Doctors and other professionals must be involved in decisions.



Tell people and ask permission



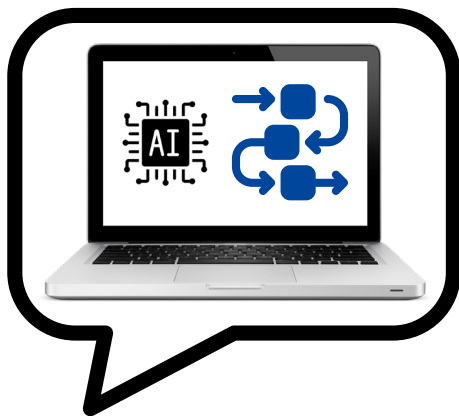
- People must be told when AI is used.



- You must give clear permission to say you are ok with AI tools being used.



Be open about how information is used and shared



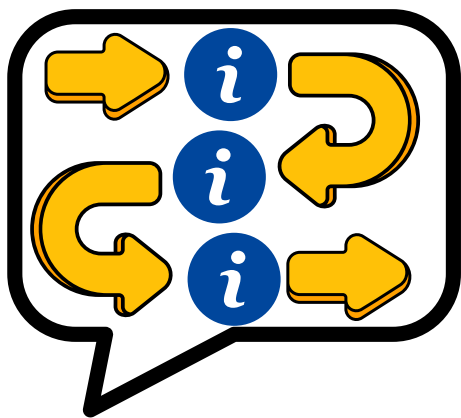
- Explain how AI works in a clear and simple way.



- Explain how your information will be used and stored.



- Explain who can see the information you put into AI and why they can see it.



Explain how the information moves through the system in simple terms.



Make sure people understand risks so they can give informed consent.



Always have other ways to get healthcare



- Make sure people can still access healthcare services if AI does not work for them.



- Always offer ways to get healthcare from real people.



- Provide clear ways to get help or speak to a person when needed.



Be clear who is responsible at each step



- Make it clear who is responsible if something goes wrong with AI tools.



- Show what each person or organisation must do at every step.



Act quickly when something goes wrong



- Provide easy ways to report problems with AI tools.



- Offer help and clear ways to fix problems with AI tools.



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