

2022

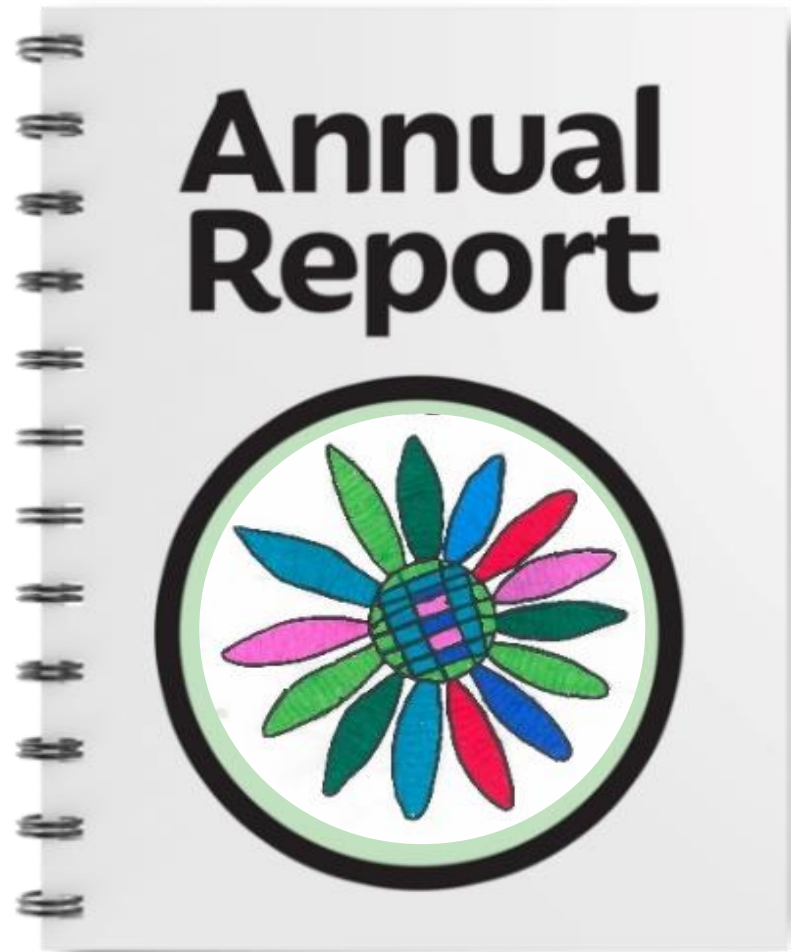
LeDeR

Learning from lives
and deaths:

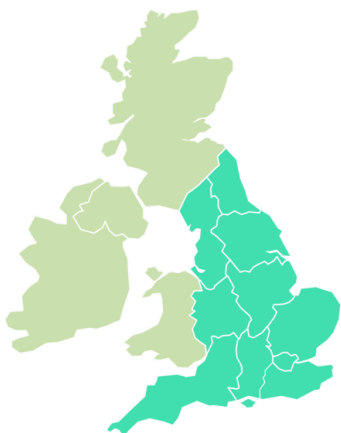
People with a
learning disability
and autistic
people



Made with
PhotoSymbols™



What can we say about the people with a learning disability who died in England in 2022?



This video has **7 parts**.
Each part has a **different colour**.



This is what is in each part...

1

2

3

4

5

6

7

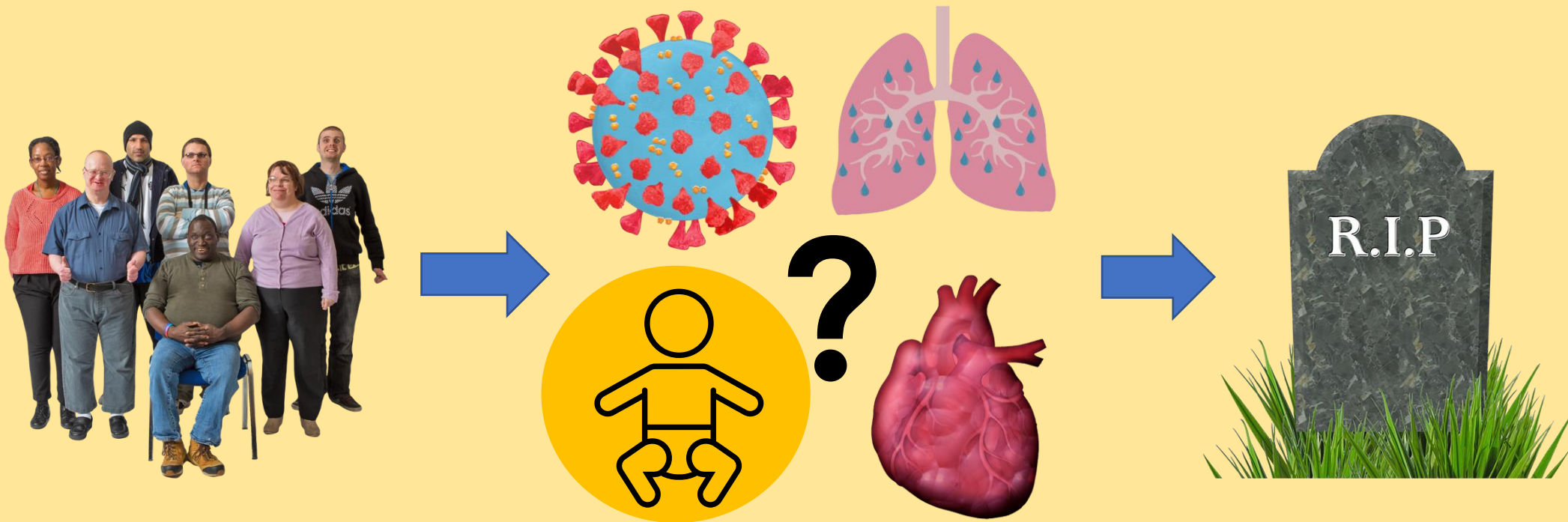
The grey part: Who died, and how old were they?





The yellow part

What did people with a learning disability die of in 2022?



The blue part:

How good was the care for the people with a learning disability who died?



The green part:

Which people with a learning disability were more likely to die younger?



The orange part:

Could more people with a learning disability have lived longer?



The pink part:

COVID-19 and heatwaves



The purple part: Autistic people who don't have a learning disability



Now we are going to look at each part.





The grey part Who died in 2022, and how old were they?

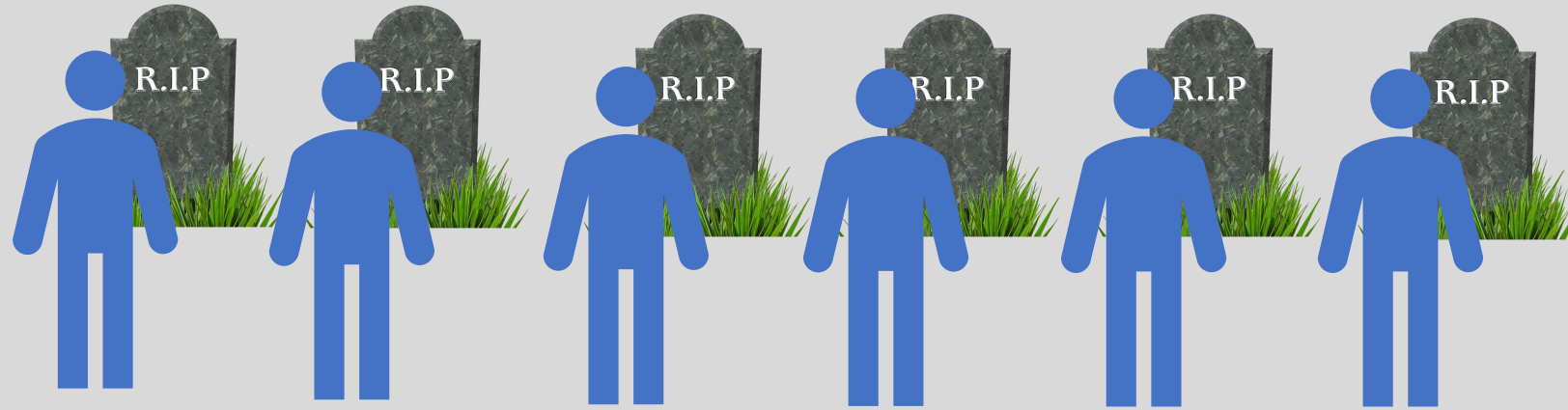


2022

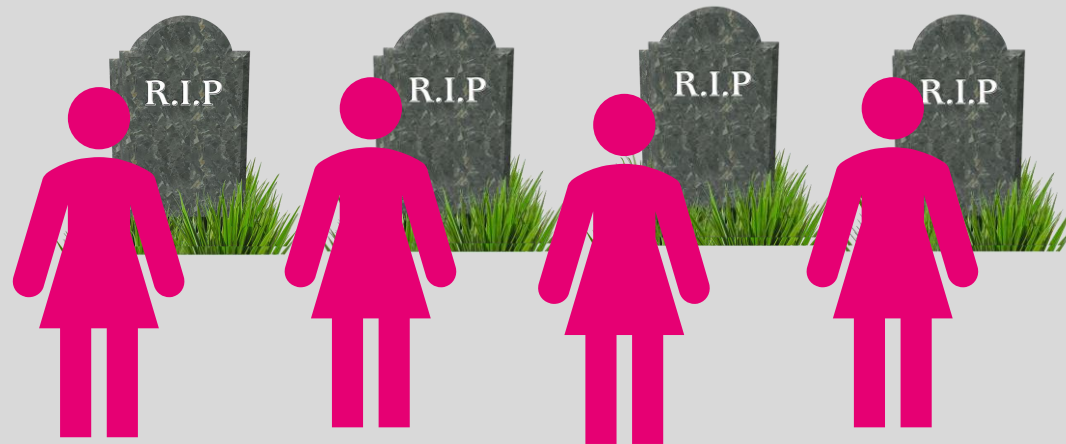
We heard about 3,648 people with a learning disability who died in 2022



Of each
10 people with a learning disability
who died...



**6 were
men**



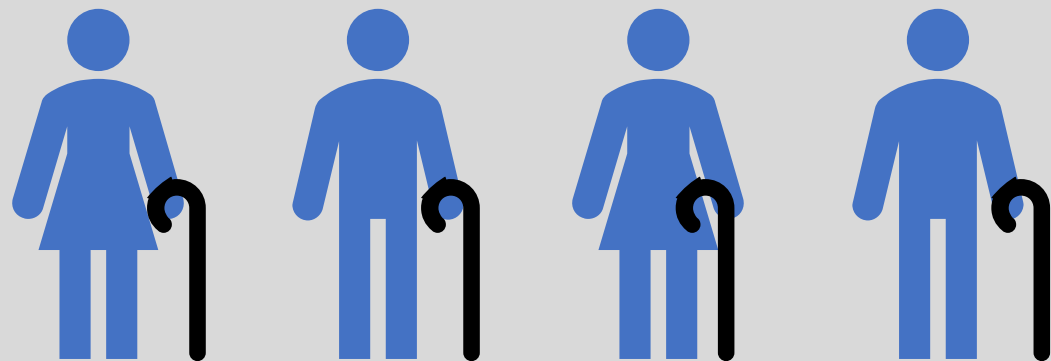
**4 were
women**

Of each
10 people with a learning disability



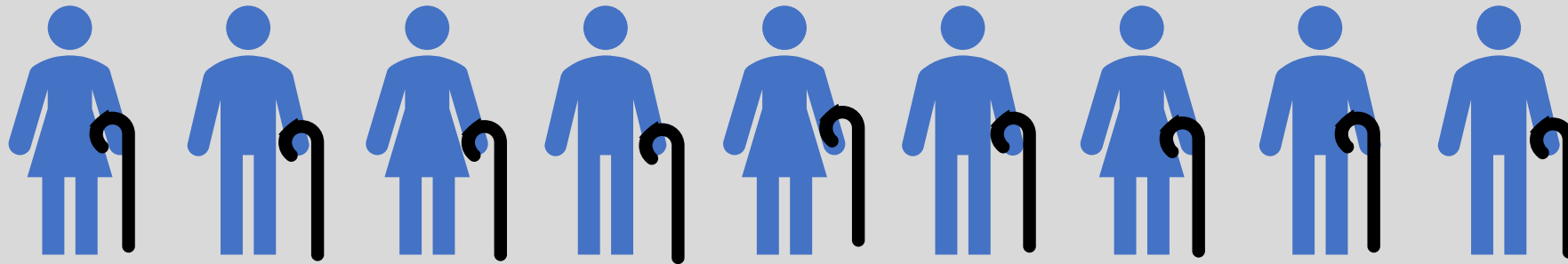


4 were still **alive** at the age of **65**





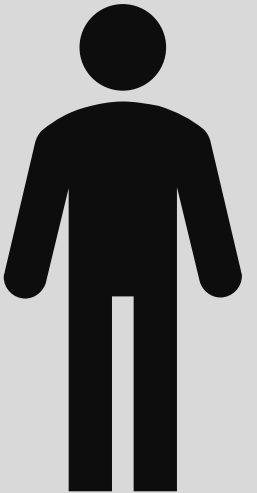
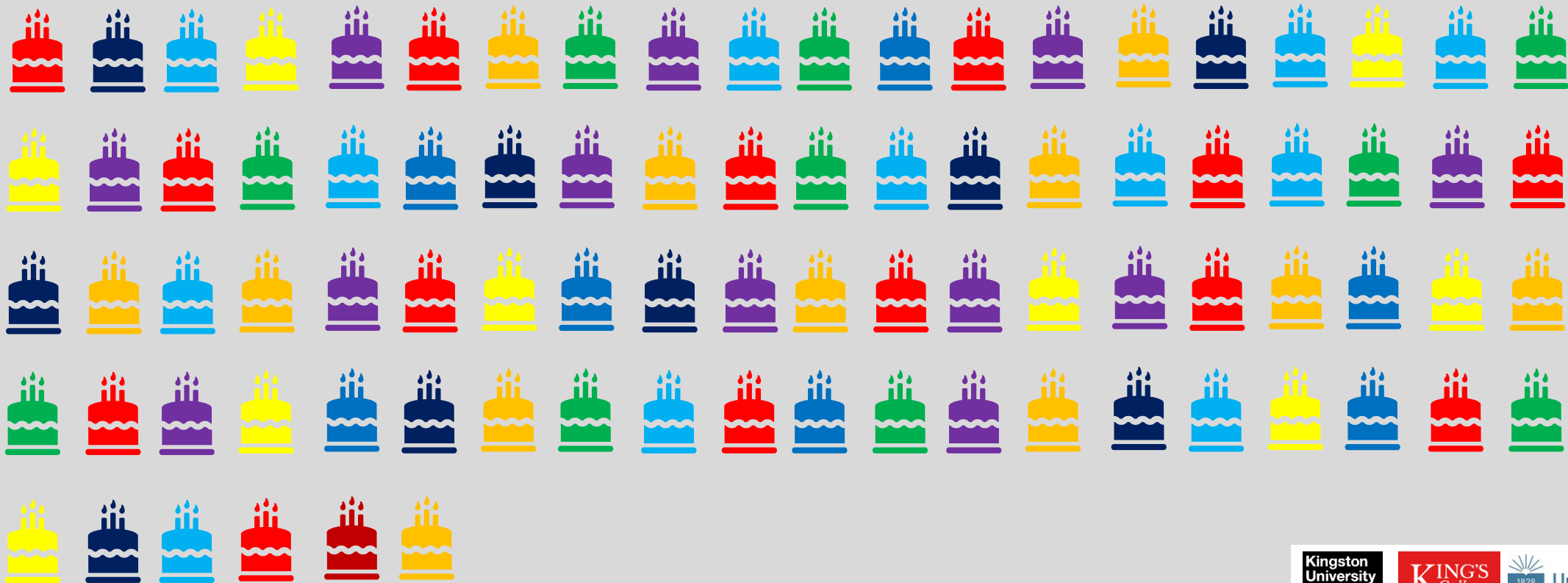
Of each **10** people who **don't have**
a learning disability,
9 were still alive at the age of **65**



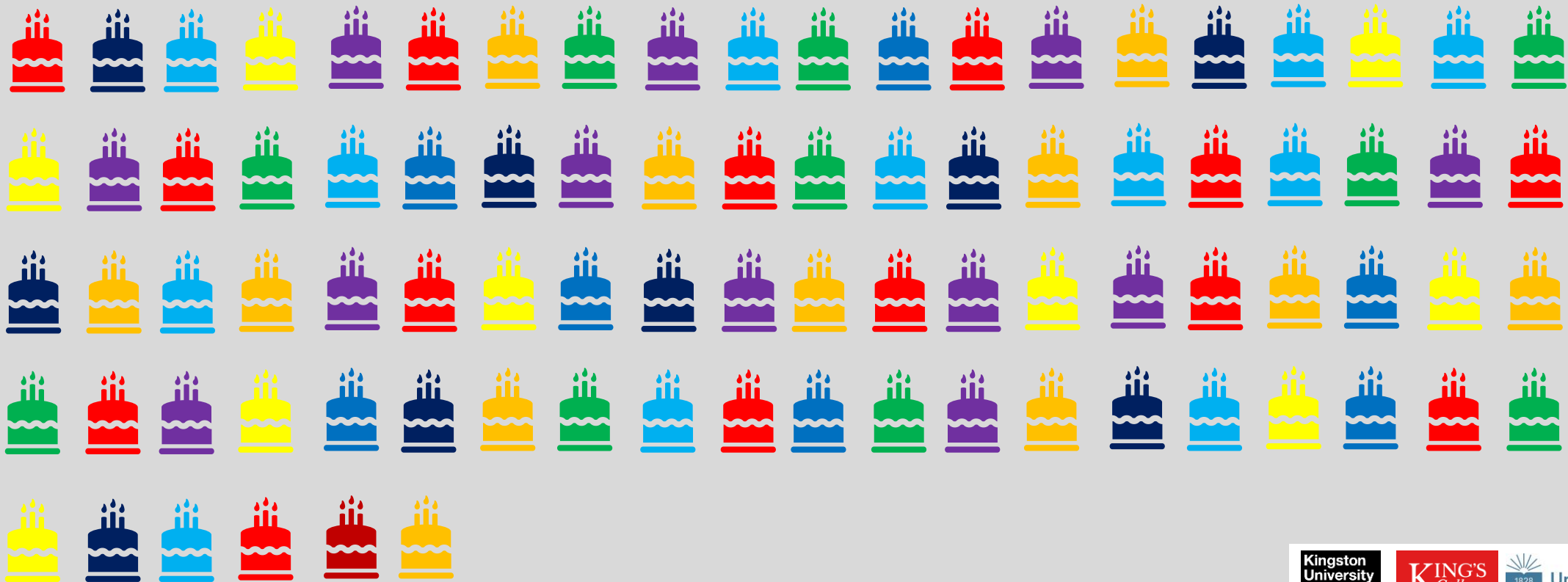
It means that people
who have a learning disability
don't live as long as people
who don't have a learning disability



Men with a learning disability usually died **20 years earlier**



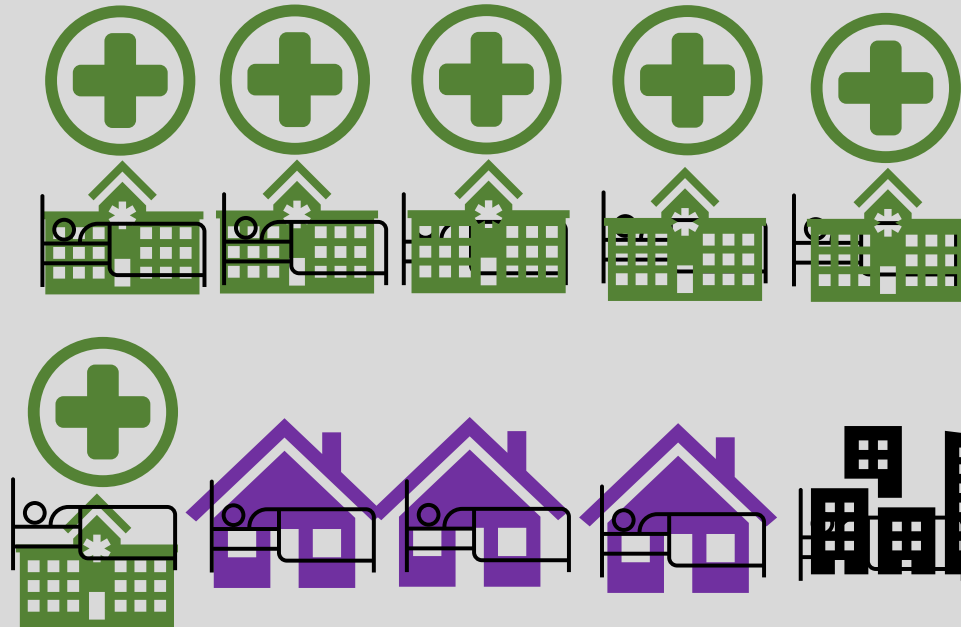
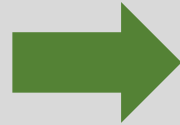
Women with a learning disability usually died 23 years earlier





Of each
10 people with a learning disability
who died...

6 died in
hospital



1 died
somewhere
else

3 died
at their home



Most people we heard about, who died,
were **white**.



We need to learn more about the people from
minority ethnic backgrounds who died.

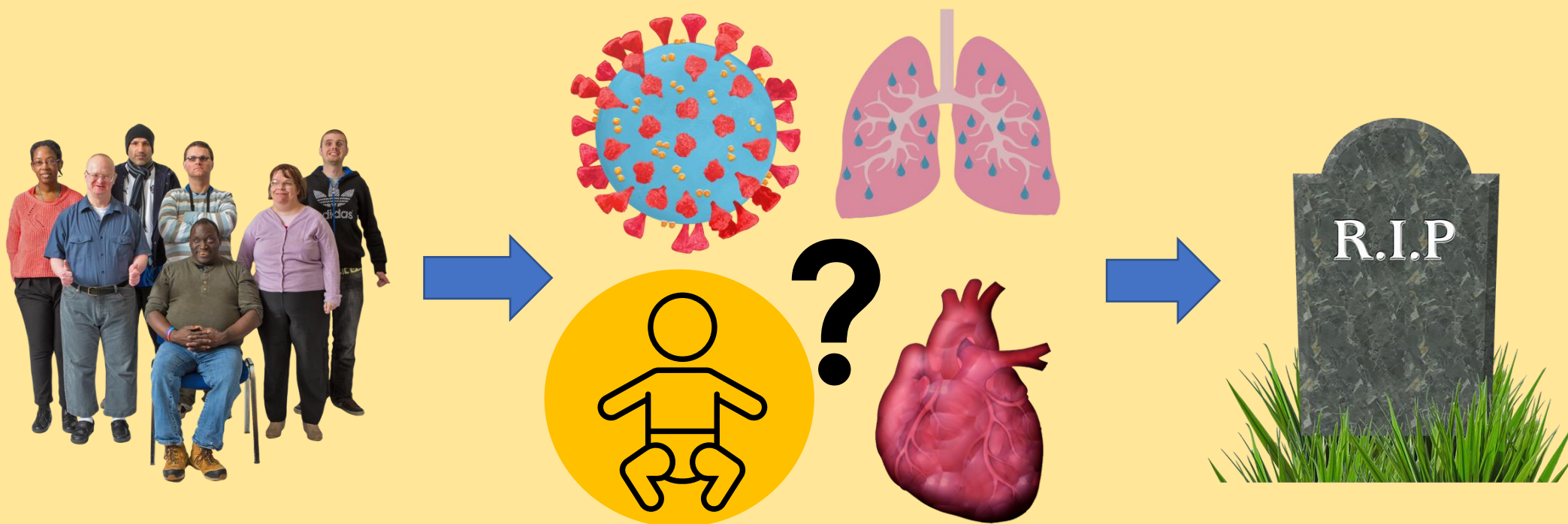


Black people
Asian people
People from mixed backgrounds
Other people who are **not white**.





The yellow part What did people with a learning disability die of in 2022?



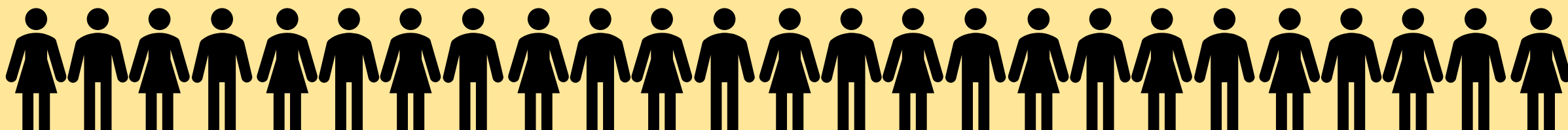
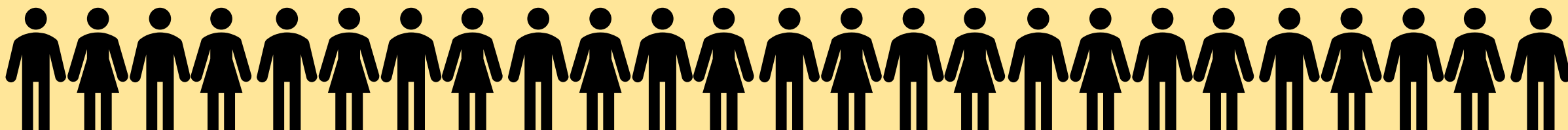
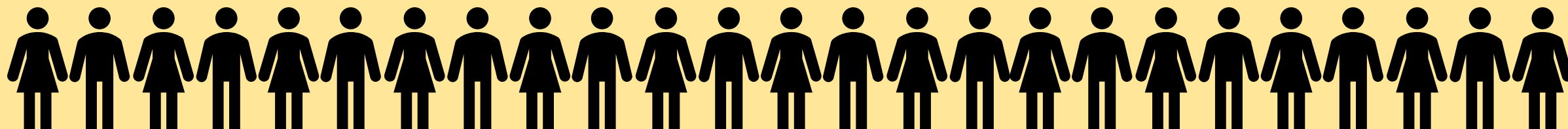
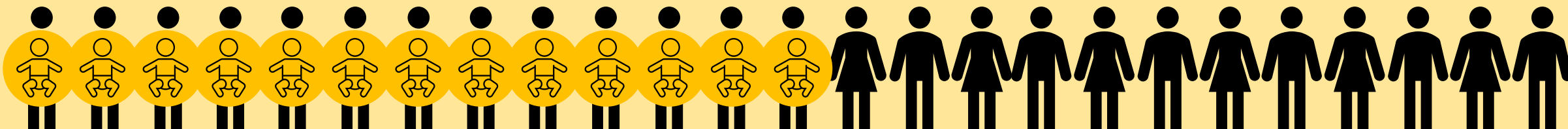


Of each
100 people with a learning disability
who died in 2022...



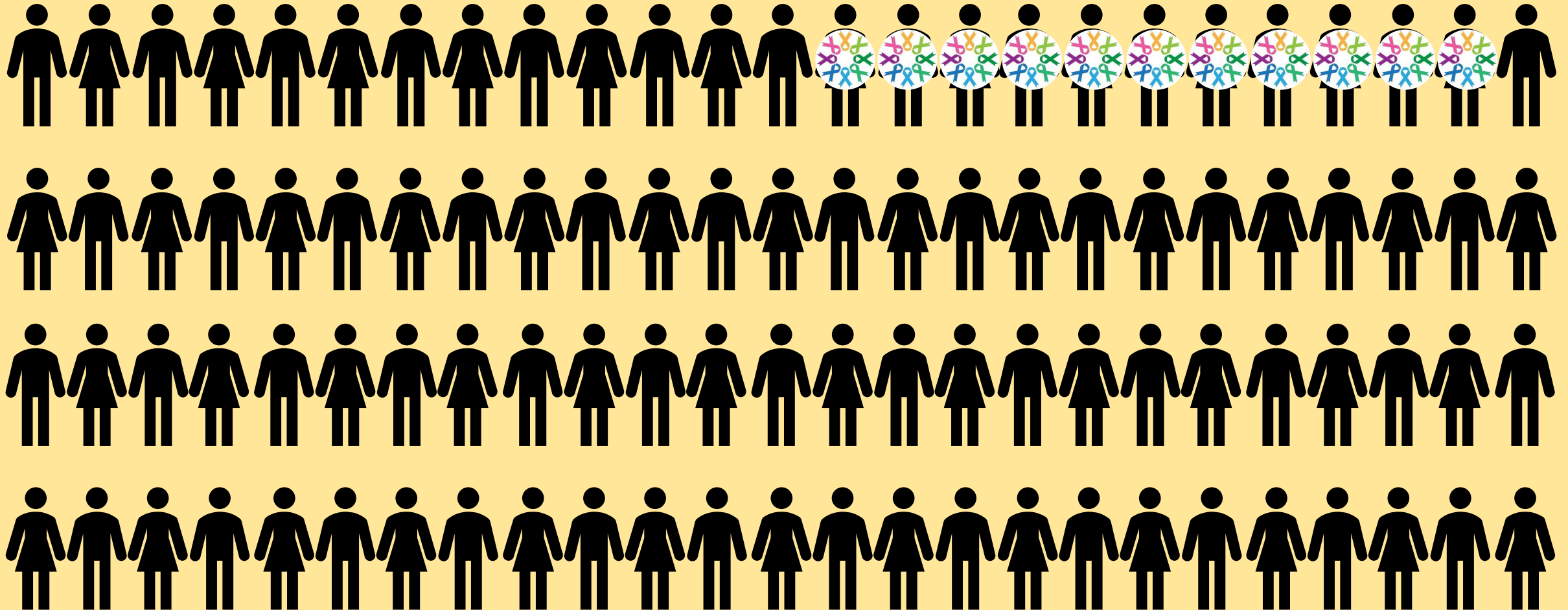


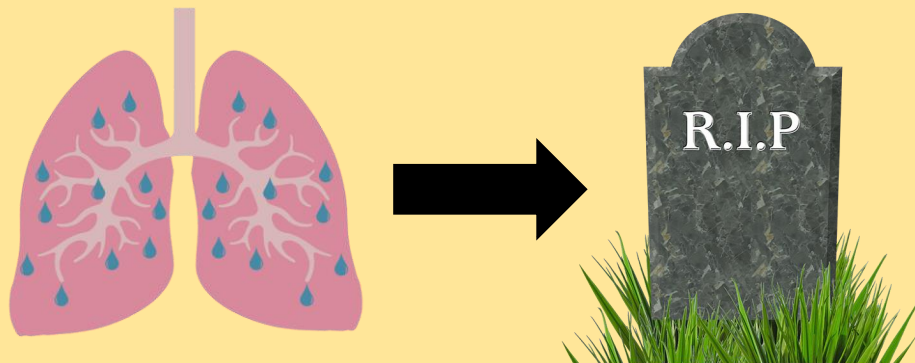
13 died of health problems
that they have had all their lives, from
when they were babies



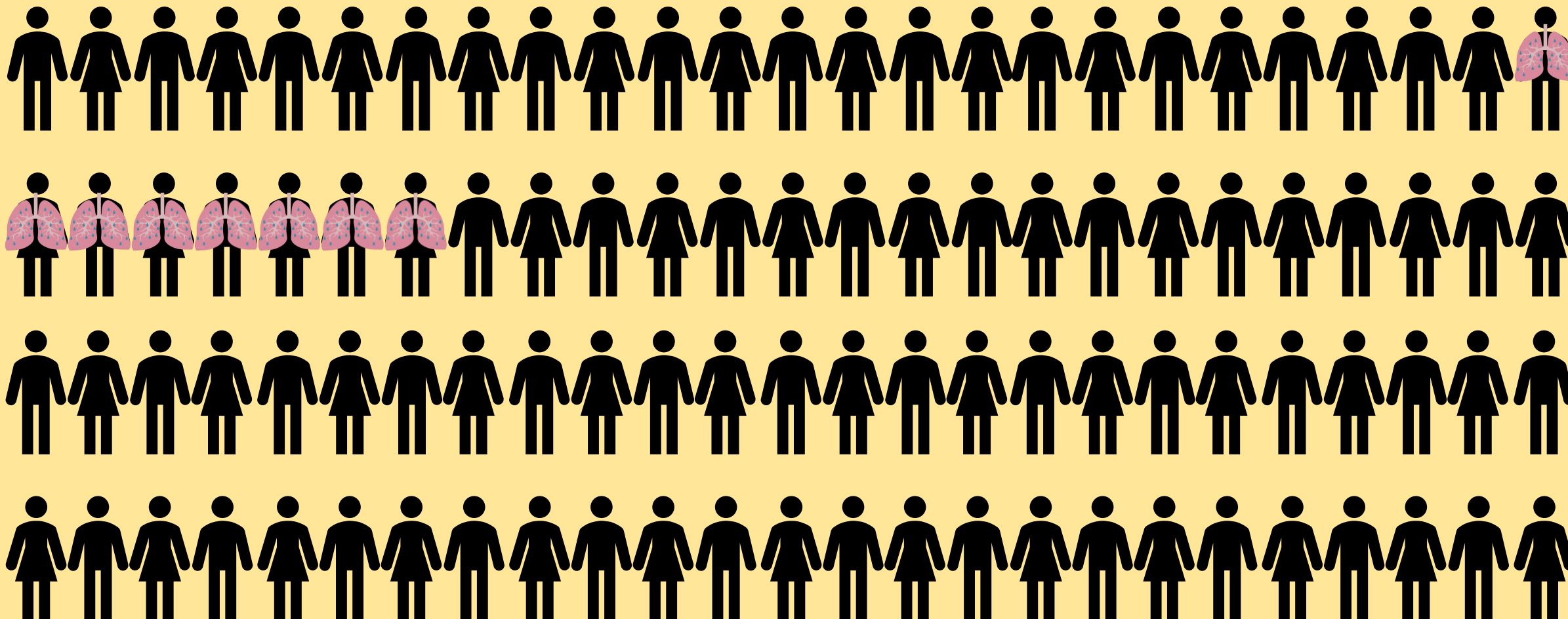


11 died of cancer



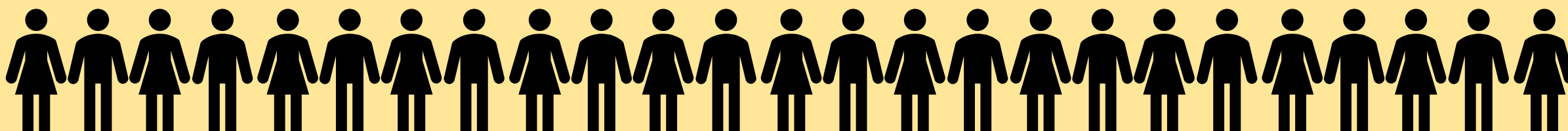
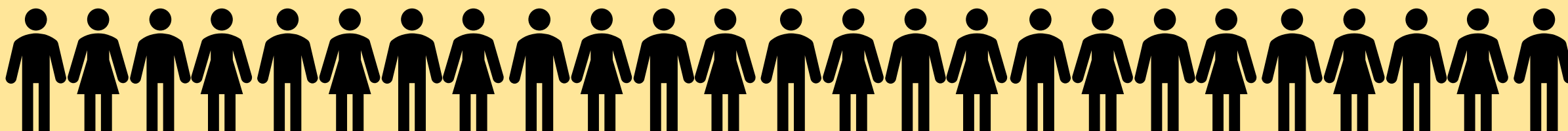
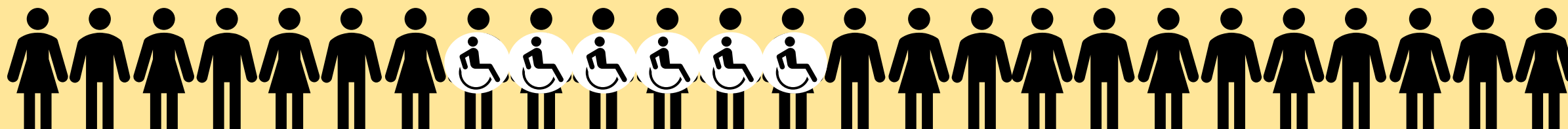
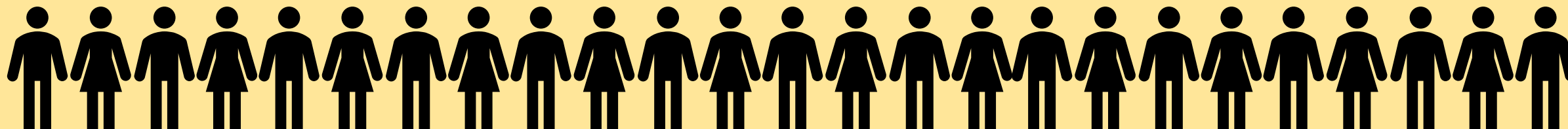


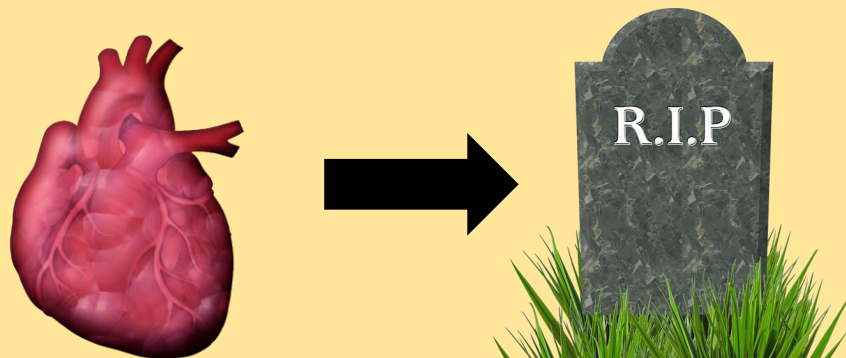
8 died of **flu** and **lung infections**
(pneumonia)



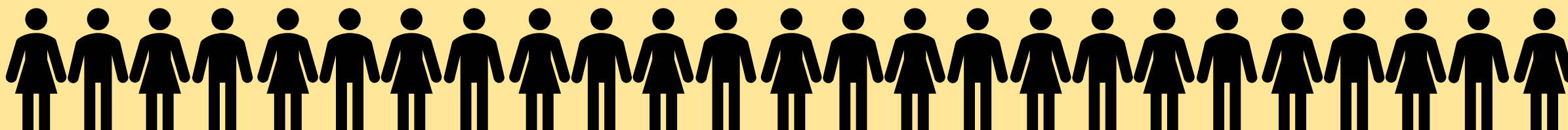
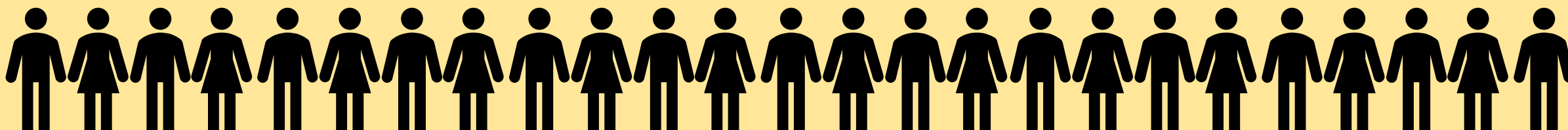
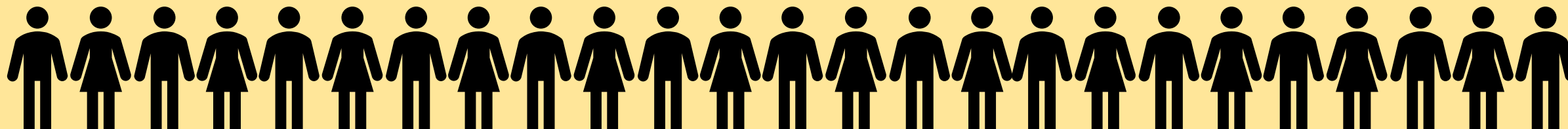


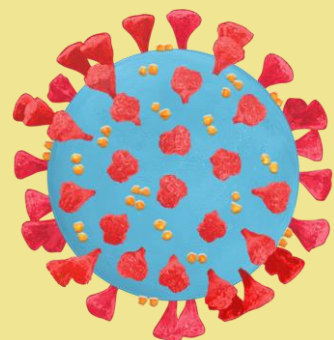
6 died of **cerebral palsy**
and **paralysis**





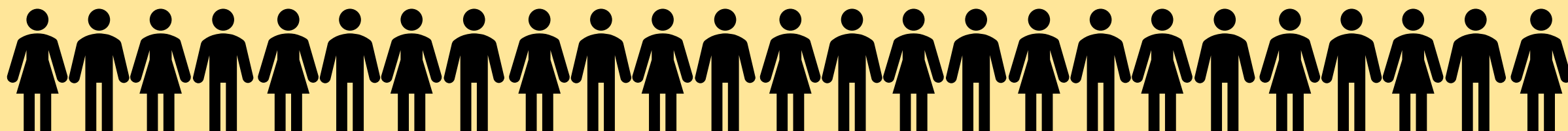
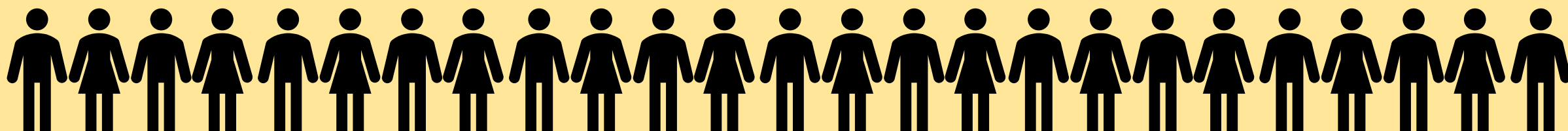
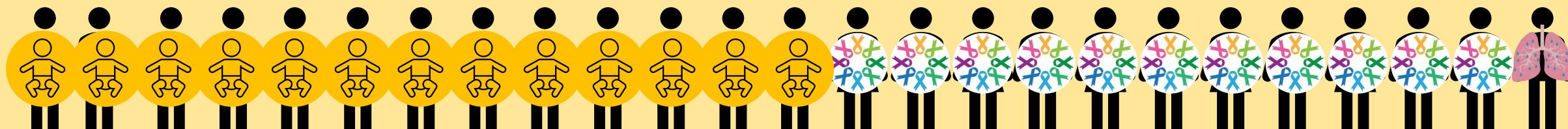
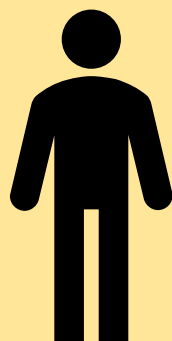
6 died of heart problems

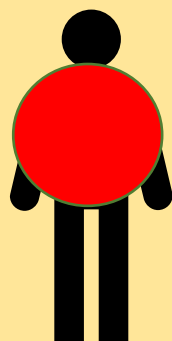




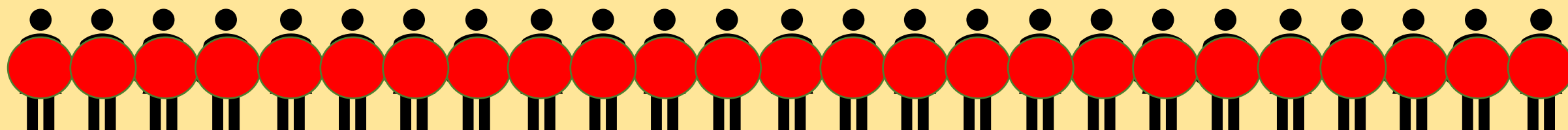
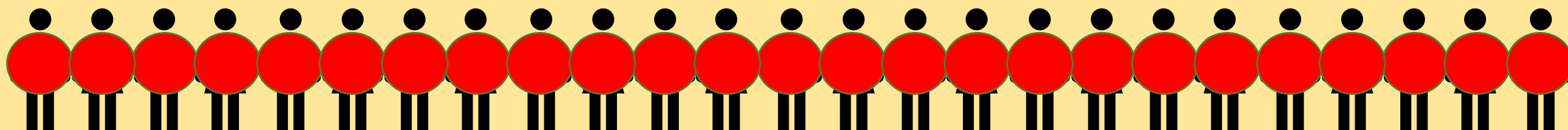
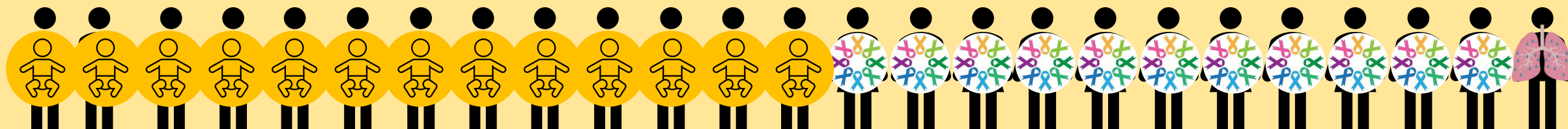
6 died of COVID-19







The others died of
all sorts of other things



The blue part

How good was the care for the people with a learning disability who died?

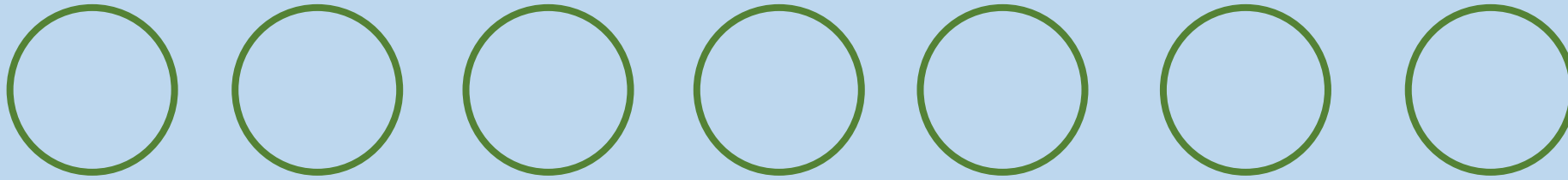


Most people with a learning disability
(9 out of 10)
had some care which was **good**.

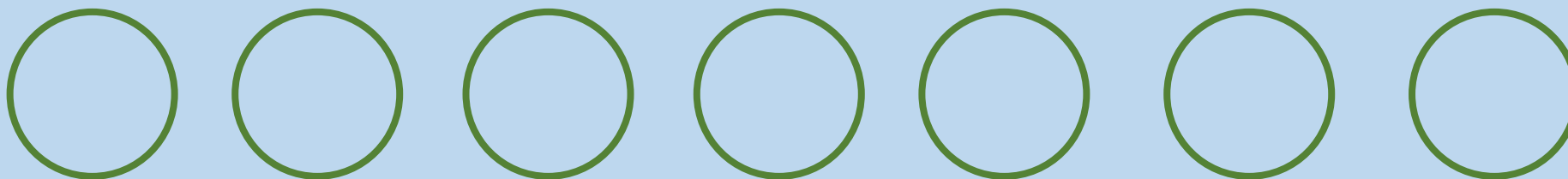


This doesn't mean that **all** their care was good, but at least some of it was good.

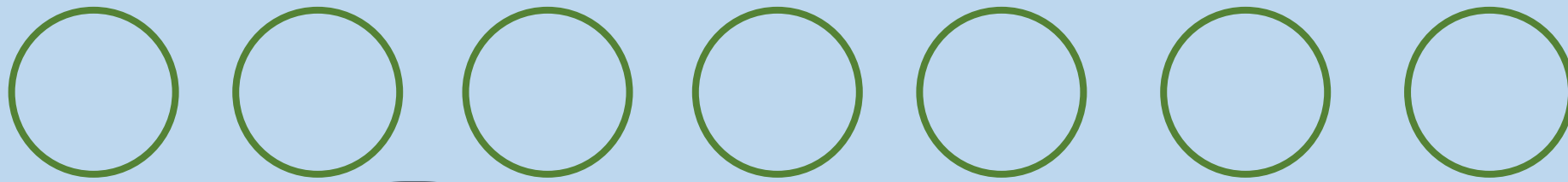
But some people
(1 out of 10)
did **not** have **any** good care.



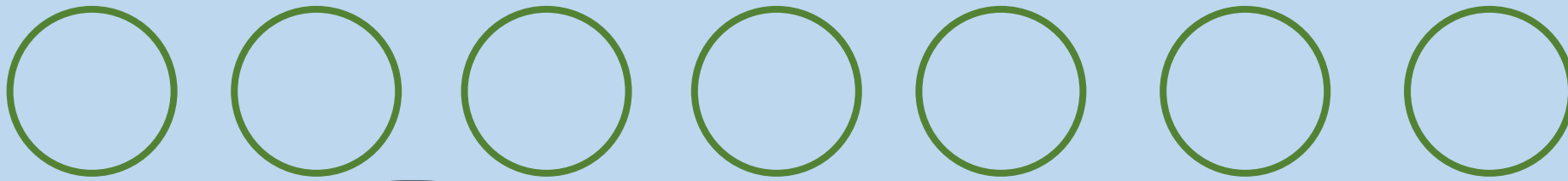
We spot a difference here!



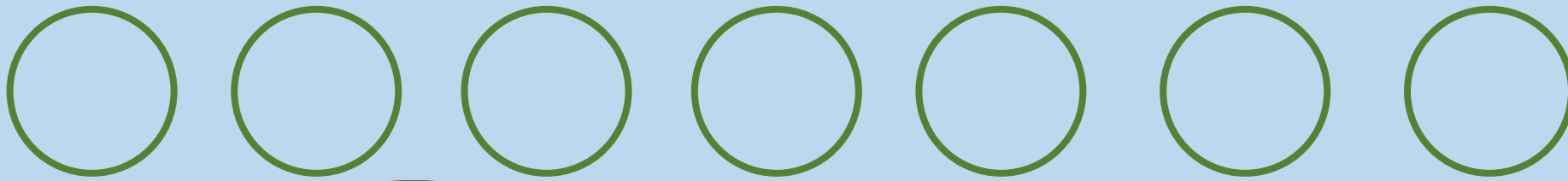
Last year **3 out of 10** people did not
have any good care



This year it is **1 out of 10**



This year it is **1 out of 10**



But it is still **1 too many**



What was good about people's care?



Reasonable adjustments helped people get good care



What are **reasonable adjustments**?

Changes staff can make to help people cope with their care and treatment.

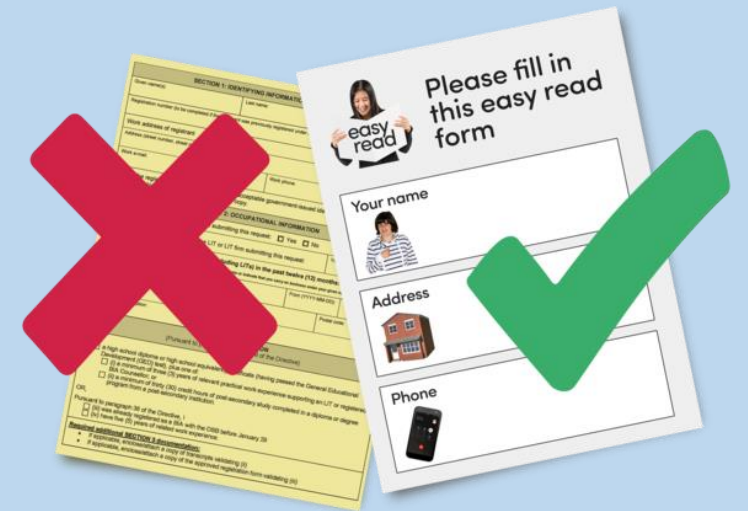
For example:



More time



A calm place to wait



Easy-to-understand information



**Staff working together
and working with families**
helped people get good care



What problems were there about people's care?





People were waiting too long to get tests and treatments



Doctors and nurses were not doing
mental capacity assessments properly



What is a Mental Capacity Assessment?



A **Mental Capacity Assessment** is when they check to see what you understand.

What is a Mental Capacity Assessment?



It is **to see if you can help make decisions** about your own care and treatment.

The green part
**Which people with a learning disability
were more likely to die younger?**

2022



People who didn't get good
care and treatment



People who didn't get good
care and treatment



For example:
They didn't get a
COVID vaccine

People who didn't get good
care and treatment



For example,
they didn't get a
COVID vaccine

They were more likely to die younger

People from **minority ethnic backgrounds** were more likely to die younger.

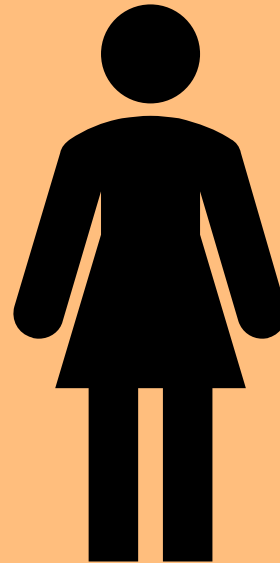


This means that many **white people with a learning disability** lived longer than people that were black, Asian or mixed backgrounds.

People with epilepsy were more likely to die younger.



The orange part Could more people with a learning disability have lived longer?



Some people died before their time.



Perhaps they could have lived longer if they had got better treatment and support.



For example, by:



Treating an infection



Managing epilepsy well

Or perhaps they needn't have got ill
in the first place.



For example, by:



Getting a vaccine



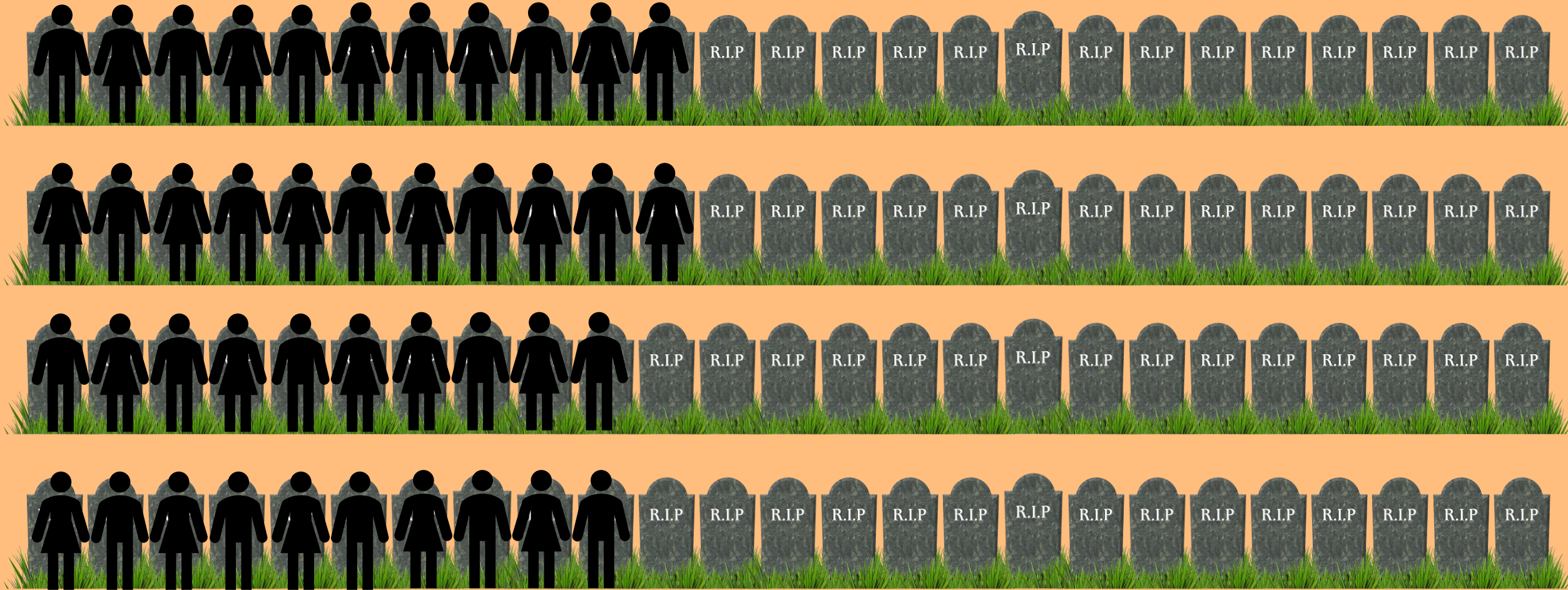
Checking for illnesses

This is called **avoidable death**.

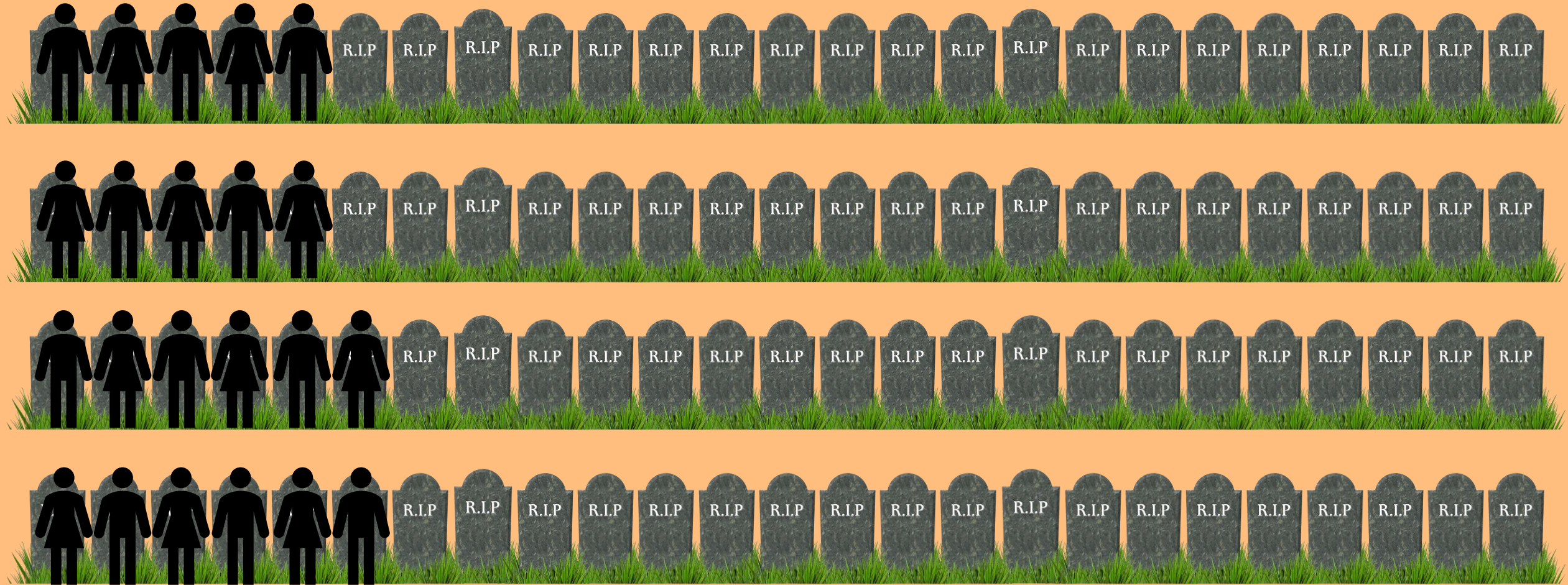


It means: dying of something that nowadays, you shouldn't have died of.

Almost half of all the people with a learning disability who died, died an **avoidable death**.



But of all the people **without** a learning disability who died, **less than a quarter** died an **avoidable death**.



This means that people
with a learning disability are
twice as likely
to die before their time.



The pink part: COVID-19 and heatwaves



This is a **spot the difference** chapter



because it is different from last year

COVID-19



In 2021, lots of people died of COVID



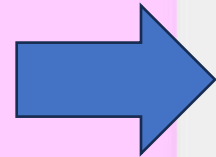
In 2022, fewer people with a learning disability died of COVID



But people with a learning disability
are still **more likely to die of COVID**
than people without a learning disability



So, we still need to be at the
top of the list
for vaccines



 **Priority List**

<u>1</u>	<u>6</u>
<u>2</u>	<u>7</u>
<u>3</u>	<u>8</u>
<u>4</u>	<u>9</u>
<u>5</u>	



The vial is labeled with a blue coronavirus icon, 'COVID-19', 'Coronavirus Vaccine', and 'Injection Only'.

Heatwaves

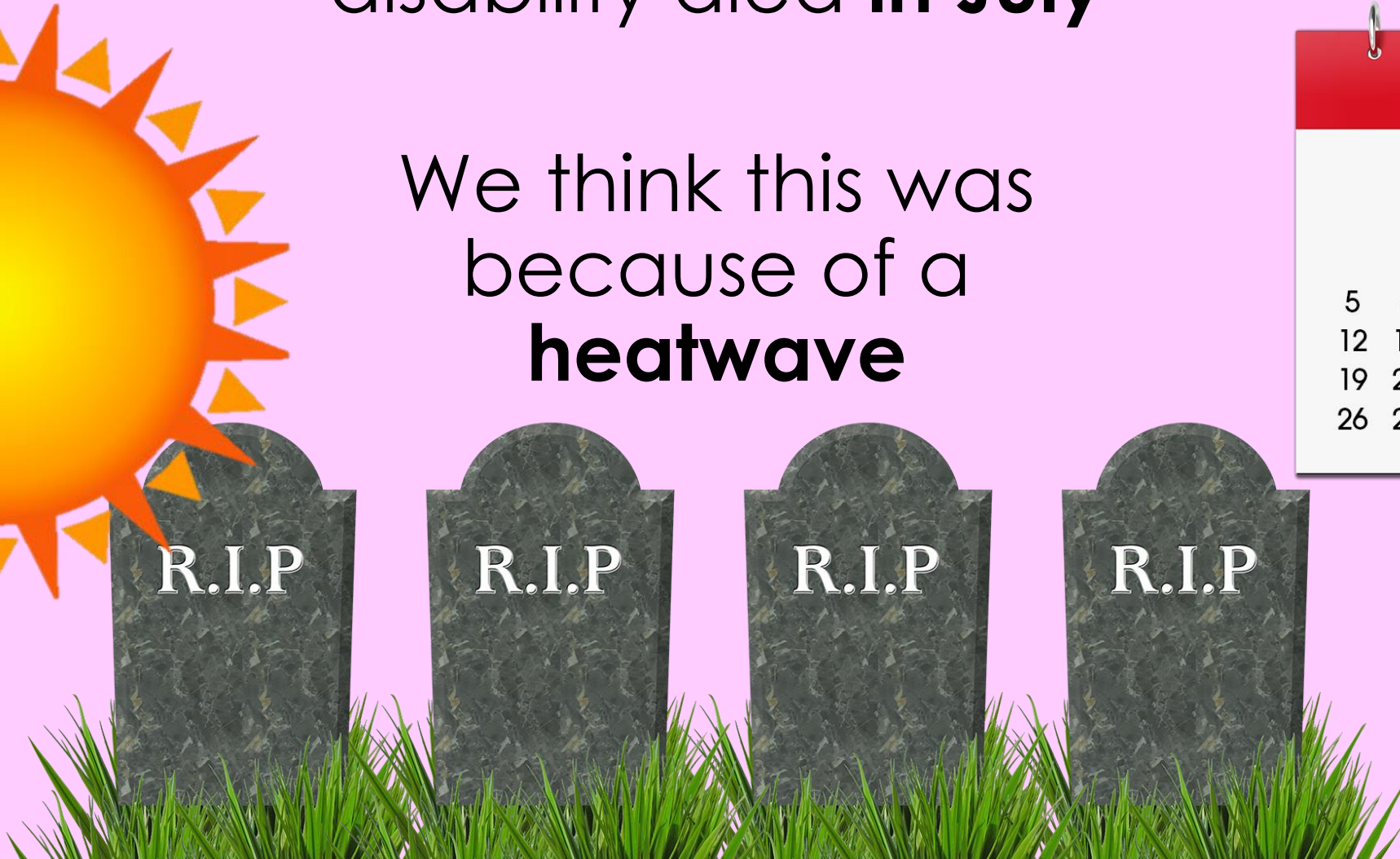


Lots of extra people with a learning disability died **in July**



Lots of extra people with a learning disability died **in July**

We think this was
because of a
heatwave



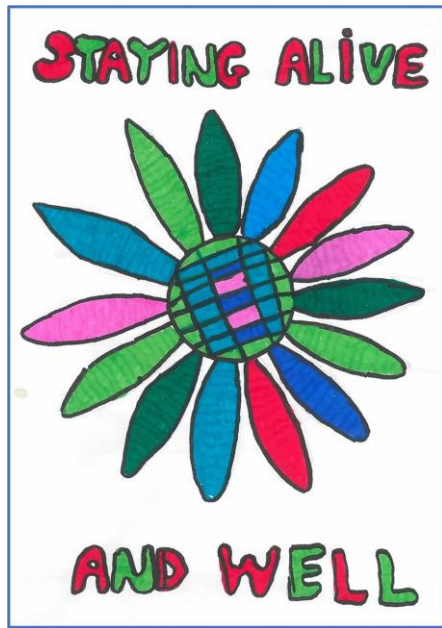
This means people with a learning disability
need extra **protection from the heat**



All autistic people can now be
reported to LeDeR



even if they **don't** have a learning disability



This video was produced by the **Staying Alive and Well Group**.

We are a group of people who have a learning disability or who are autistic, meeting at Kingston University London:

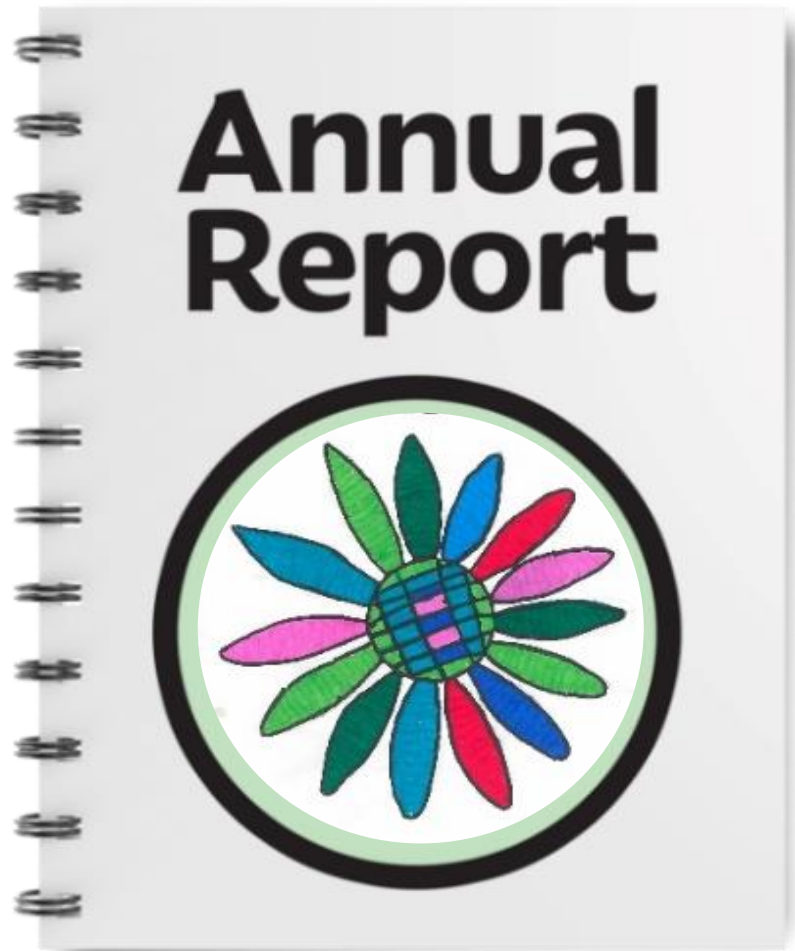
Richard Keagan-Bull, Maggie Brennan, Amanda Cresswell, Frankie Cutri, Joanne Kennedy, Andrew Meyer, Lee Scott, Mark Shackleton, Sonia Reed, Wayne McGregor, Caroline Ogundeji, Sunny Sokhal.

We were supported by:

Irene Tuffrey-Wijne, Jonathon Ding and Natasha Marsland (Kingston University), Janice Wycherly and Dene Donalds (Pathways Associates), David Mahon (Foundation for People with Learning Disabilities), Ruwani Ampegama (Estia Centre) and Jeanette Gallivan-Young (Learning Disability Partnership Board - East Sussex).



The Staying Alive and Well group is a co-production partnership. They are part of a collaboration led by King's College London, supporting the NHS England. Gary is not a real person. He was made up to help explain the purple part.



- This is a video introduction to the full 2022 Annual Report for LeDeR: *Learning from Lives and Deaths – People with a Learning Disability and Autistic People*.

The following versions of this report are freely available here:

www.kcl.ac.uk/research/leder

The **full** 2022 Annual Report

An easy-read **video** version

An **easy-read pdf** version

This video can be freely used, but must remain unaltered.