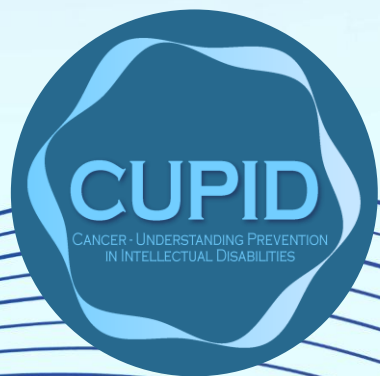


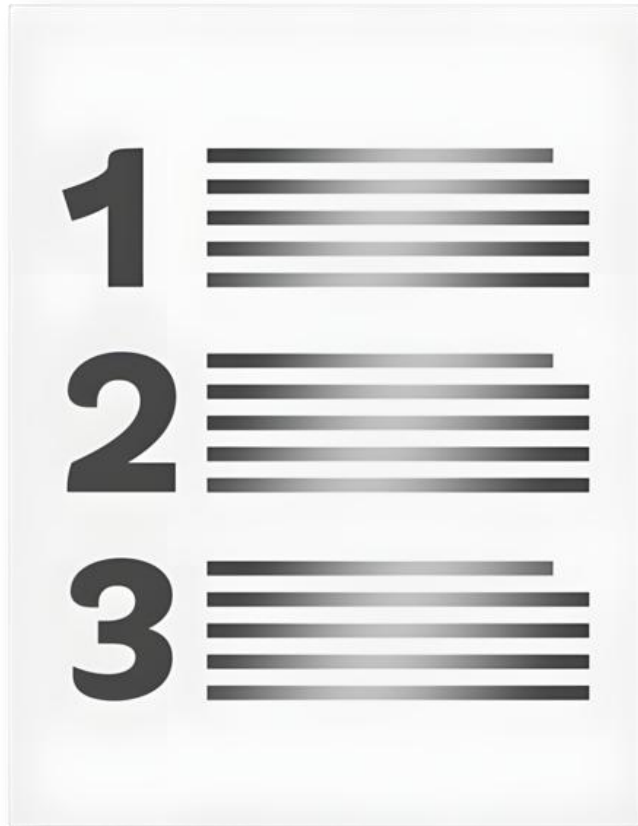
# Cancer- Screening and Prevention for People with Intellectual Disability - Lunch & Learn - Webinar Series

## Why it matters: The case for cancer screening and prevention



Dr Kate Sykes and Mr Simon Milner

# Session Plan



1. Housekeeping
2. Introductions
3. What is cancer?
4. What does screening and prevention mean?
5. Why it matters for people with an intellectual disability?
6. Take away messages and questions



- Please mute your microphone.
- Put questions in the chat or you can ask them at the end.
- We have tried to make this presentation in plain English. If there is something you do not understand please ask.

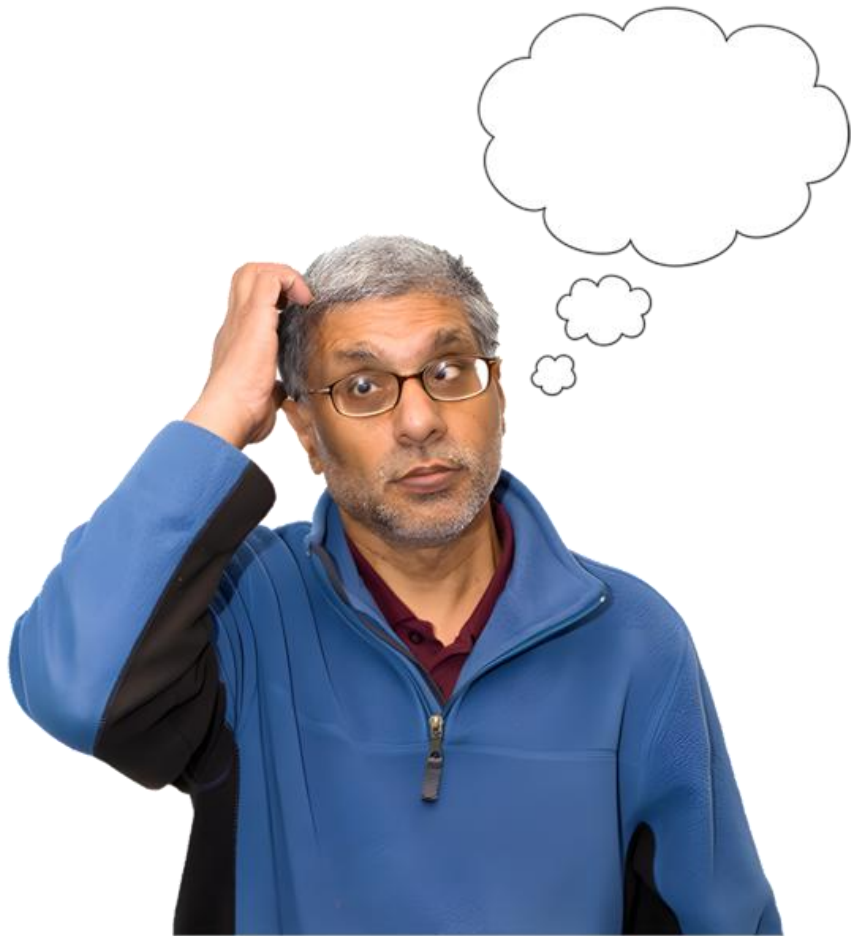
# Introductions



Dr Kate Sykes



Simon Milner



# What is cancer?

# What Simon had to say about cancer...

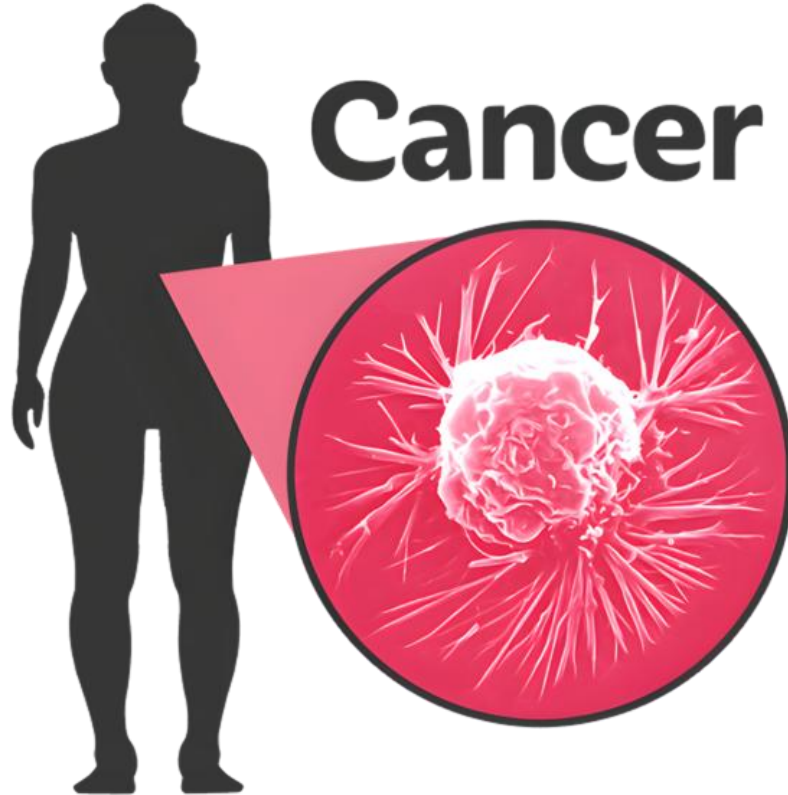
I had a lump that didn't go, it didn't hurt. I had a cough that didn't go. That was it really.

One cell goes "awol", it replicates and then the other cells go bad. It multiplies by the millions. It kills off the other cells in the body.

If you have a lump, even if painless, it could be something. It could be cancer.




# What is cancer?



- Cancer is a condition where cells in the body grow in an uncontrolled way.
- Some tumours are benign (they are not cancer), some are malignant (this means they are cancerous).
- Cancer cells can spread to other parts of the body.

# What Simon had to say about cancer prevention...



Eating healthy will prevent it. If you don't eat healthy it will increase the chance of you getting cancer.

Prevention is making sure you are getting regular check up. Go to the doctors.

Go to get things checked. Some cancers are harder to trace.

# What is cancer prevention?



# What is cancer prevention?



It is important to:


- Know the signs and symptoms of cancer.
- Know what is normal for you.
- What your body looks like.

This can help you seek help if you notice any changes.



What is cancer and screening workshops at Camphill Village Trust.

# What Simon had to say about knowing signs and symptoms...




One week I didn't have a lump. Then I realised I had a lump the size of an orange under my arm.

I knew that was not normal for me. When I found the lump, I thought it was cancer, even before I got it checked.

I went to get it checked.

# What Simon had to say about cancer screening...



You have to send a poo sample off, if you have blood in your poo for bowel cancer.

Women get their breasts looked at for lumps. They get the cervical screening as well.

Sometimes cells are taken and checked.

I don't think there is a screening for testicular cancer.

# What is cancer screening?



- Screening can help to detect cancer at an early stage.
- Cancer screening is for people with no symptoms.
- This is because screening tests can spot possible signs of cancer before symptoms appear.
- There isn't a screening programme for every cancer.

# Common cancer screening programmes




# Cervical screening



- The cervix is the opening to the womb from the vagina.
- Everyone with a cervix should be offered screening.
- A small sample of cells will be taken from your cervix.
- The sample is checked for certain types of human papillomavirus (HPV).

# What Simon had to say about cervical screening...



Some people die from cervical cancer before they are invited.

Are they reducing the age?

# Breast cancer screening



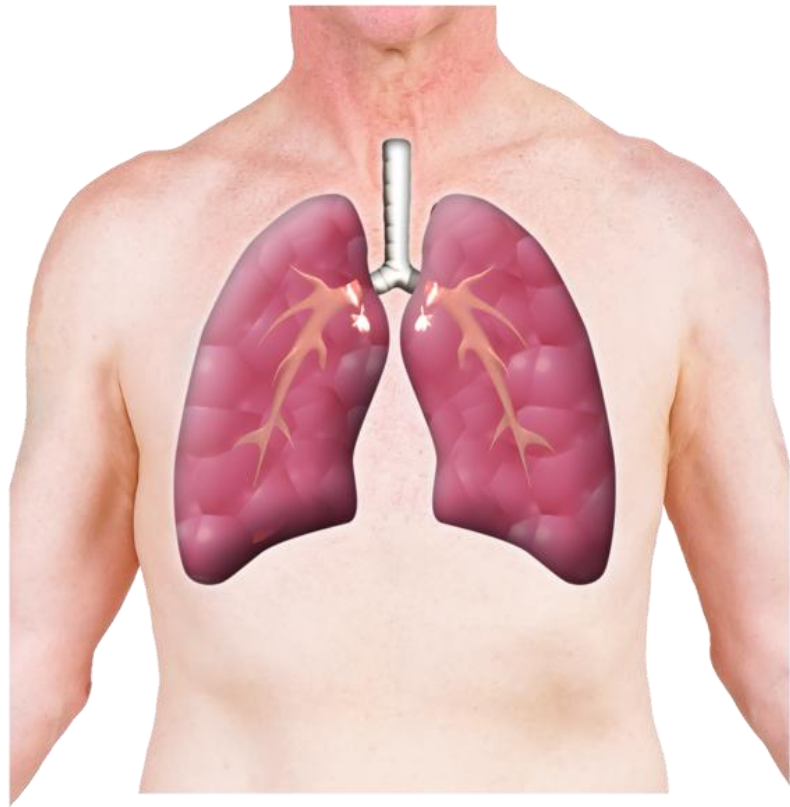
- Registered as a female – automatically invited.
- Images of the breast tissue are taken (Xrays). This is called a mammogram.
- The machine flattens the breast to see what is inside the breasts.
- The images are reviewed to see if there is anything that needs checking.

# Bowel cancer screening

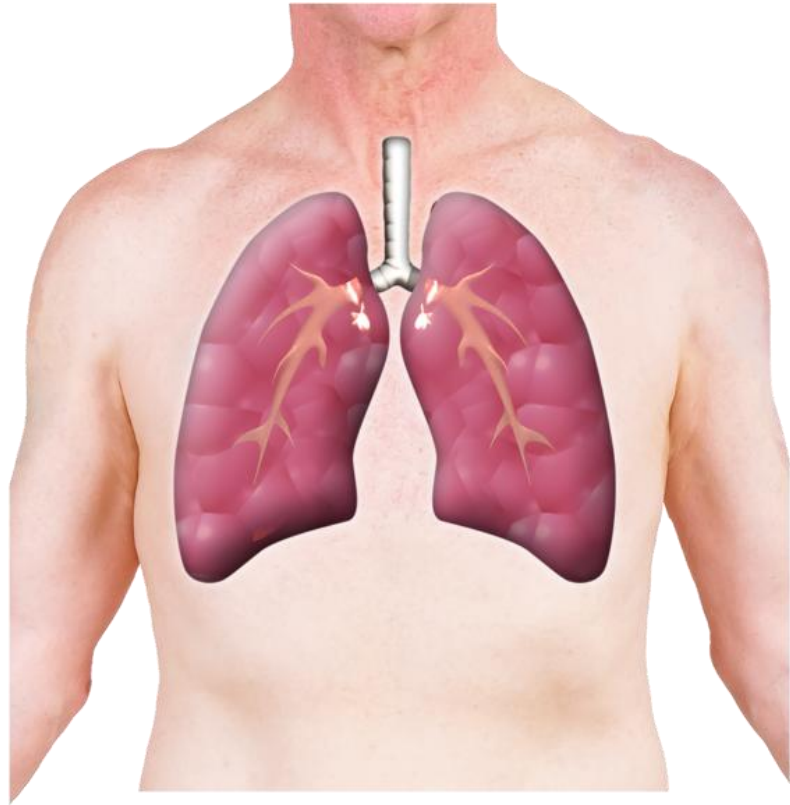


- Males and females are invited.
- Equipment sent to the persons house.
- Tests a sample of faeces (poo) for blood that you might not be able to see.
- The sample is checked to see how much blood is in the poo.

# Targeted cancer screening programmes (UK)



# Targeted lung cancer screening (UK)



- Males and females.
- Aged between 55 and 74
- Current or former smoker
- The check looks at how well your lungs are working and can help diagnose lung cancer as early as possible.

# Targeted prostate screening



- Males only.
- Aged between 45 and 69.
- Only people with a mutation in genes called BRCA1 or BRCA2.
- This can lead to aggressive forms of prostate cancer.

# Good and bad points about screening



1. False negative results = This means sometimes the test may give a 'negative' or 'normal' result, but it has missed something.
2. False positive results = Screening test suggests you might have cancer or possible sign of cancer, when you don't.

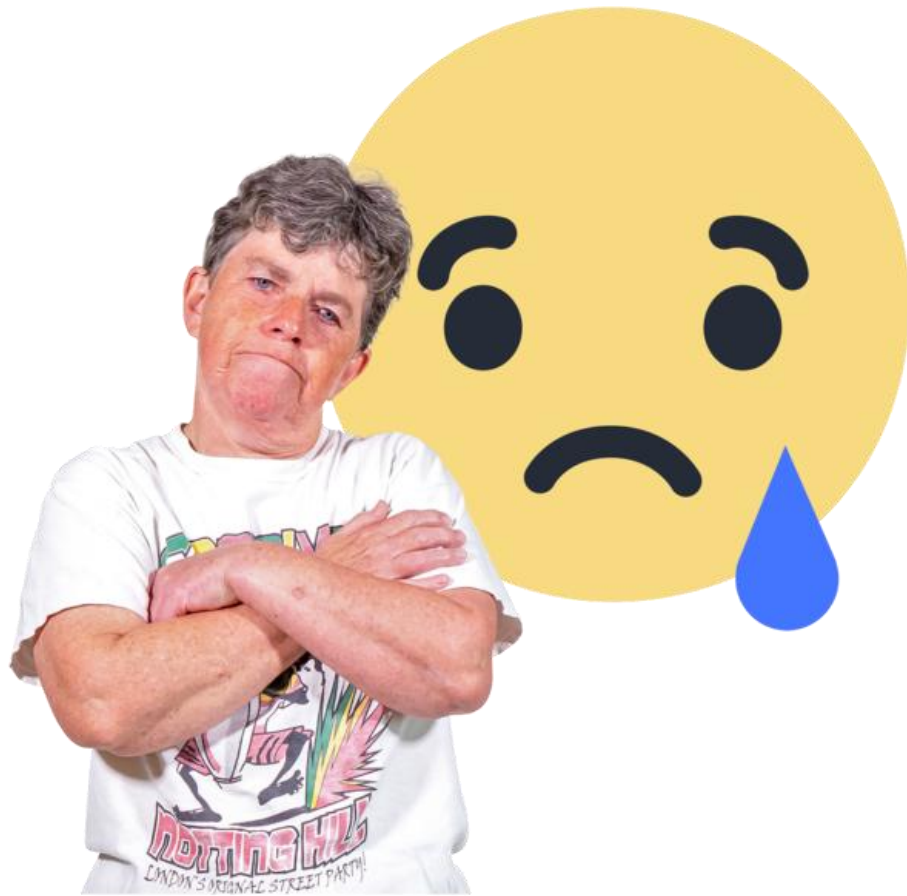
# Good and bad points about screening



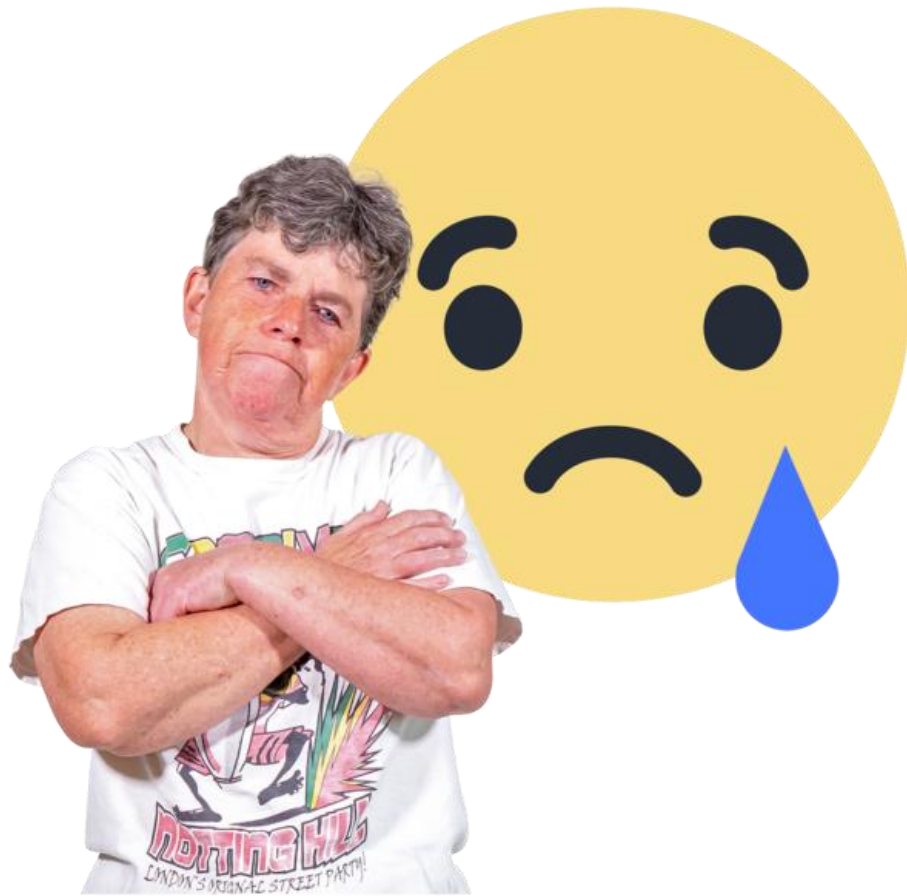
3. Overdiagnosis = Screening test finds a cancer that would never have caused any problems.
4. Side effects = Screening tests are safe, but some tests can have side effects, for example, uncomfy (cervical/breast), light bleeding (cervical), uncomfortable being in contact with poo (bowel screening).



**Why is this important for  
people with intellectual  
disability?**



- Shorter life expectancy.
- Many deaths are avoidable.
- Cancer is one of the leading causes of death.
- Some are more likely to get certain types of cancers.
- They are often diagnosed later, when cancer is harder to treat.



- Some people with intellectual disabilities won't check themselves.
- Won't think about needing to check themselves.
- Less likely to get screened.
- Face more barriers to accessing health services.
- Might not know how to be healthy.
- Might find it harder to take up new things to prevent cancer.
- More likely to have symptoms overlooked.

# Why Simon thinks its important...

We go to the doctors regularly. Sometimes people with disabilities are not supported to get screening.

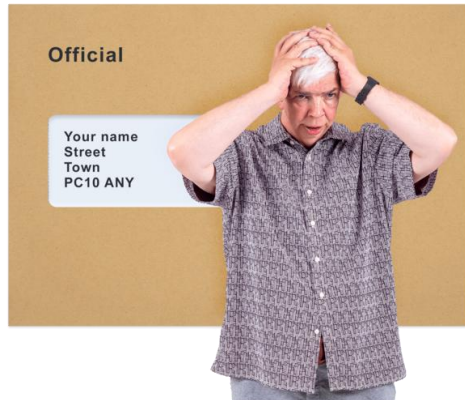


It's better to get it done, than not, it can help them have a longer life. Especially if they get cancer and they didn't get screening when they were meant to.

# What gets in the way?



- Confusing letters and appointment systems.
- Fear or anxiety.
- Not getting the right support.
- Not using accessible communication.
- Being told screening is not for them.
- And lots more reasons!



# Here's what Simon said gets in the way...

Not being able to get to where screening is based on support hours. But my support here is brilliant.

Exercise is important. Keeps you healthy. Some people find it difficult to do exercise. Someone in a wheelchair might find it difficult.

Some people might not understand about what is healthy and what is unhealthy.

Letters are not always easy to read.



# Everyone needs the right support



- People with intellectual disabilities may need extra support to make healthy choices.
- May need support to understand what screening is, and if they want to do it.
- This is not about blame — it's about removing barriers.
- Accessible and inclusive.
- We all must work together.

# Take away messages



1. Access to screening and prevention is a **right**, not a privilege.
2. People with intellectual disabilities should be supported to have healthy lives, and have screening (if they want to)
3. Through the CUPID COST EU project, we are identifying ways to improve prevention and screening.
4. When people with an intellectual disability get the support they need, everyone benefits!

# Final words from Simon...





Thank you for listening.

Are there any questions?

# Useful links/ resources

1. <https://www.macmillan.org.uk/cancer-information-and-support/stories-and-media/booklets/what-is-cancer-easy-read>
2. <https://www.cancerresearchuk.org/about-cancer/causes-of-cancer/can-cancer-be-prevented>
3. <https://www.who.int/activities/preventing-cancer>
4. <https://www.england.nhs.uk/cancer/prevention/>
5. <https://www.cancerresearchuk.org/about-cancer/spot-cancer-early/cancer-symptoms>
6. <https://nds.healthwatch.co.uk/reports-library/improving-access-bowel-cancer-screening-individuals-learning-disabilities-and>
7. <https://onlinelibrary.wiley.com/doi/10.1111/bld.12587>
8. [https://www.northerncanceralliance.nhs.uk/wp-content/uploads/2019/08/LDN\\_cancer\\_pack\\_2.pdf](https://www.northerncanceralliance.nhs.uk/wp-content/uploads/2019/08/LDN_cancer_pack_2.pdf)
9. <https://news.cancerresearchuk.org/2022/09/23/health-inequalities-breaking-down-barriers-to-cancer-screening/>
10. [https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667\(25\)00037-4/fulltext](https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667(25)00037-4/fulltext)

# CANCER-SCREENING AND PREVENTION FOR PEOPLE WITH INTELLECTUAL DISABILITY (CUPID): LUNCH & LEARN - WEBINAR SERIES



*Dr. Martin McMahon*

**29 April 2026**

13:00 to 13:45 (GMT)  
14:00 to 14:45 (CET)



*Dr. Kálya Yasmine Lima*

**THE NUMBERS BEHIND THE NEEDS: CANCER STATISTICS,  
SCREENING UPTAKES AND CANCER INEQUALITIES**



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## **COST Description**

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## **Weblink**

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