



**Northumbria  
University**  
NEWCASTLE

# Involving people with learning disabilities and people with severe mental illness in cancer prevention research: Methods, approaches and what next?

Dr Kate Sykes

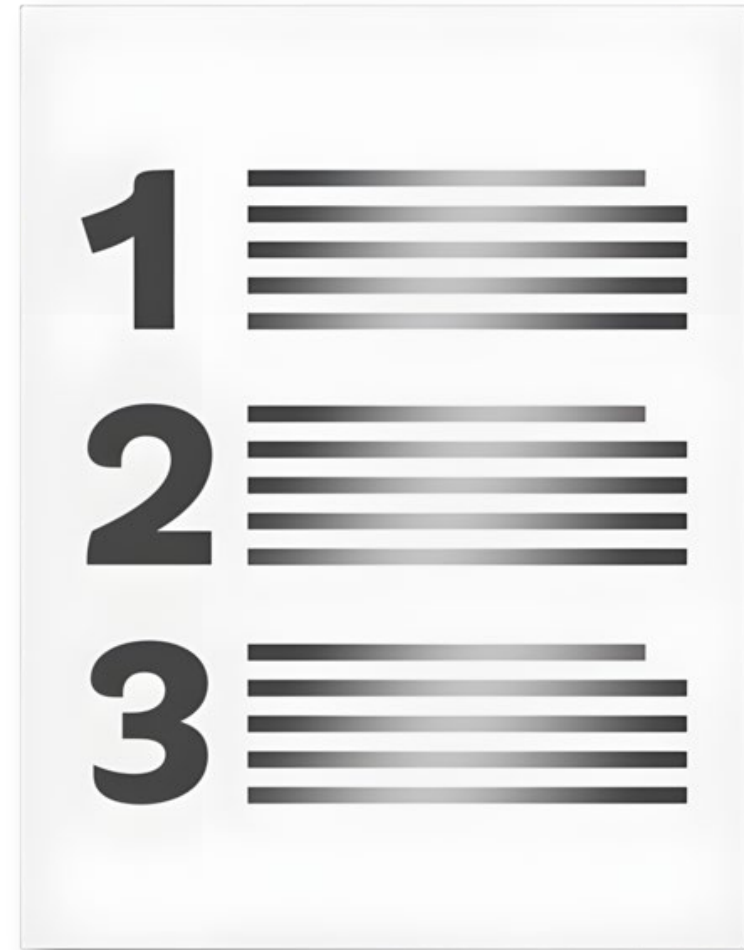
Assistant Professor in Community Wellbeing

Northumbria University

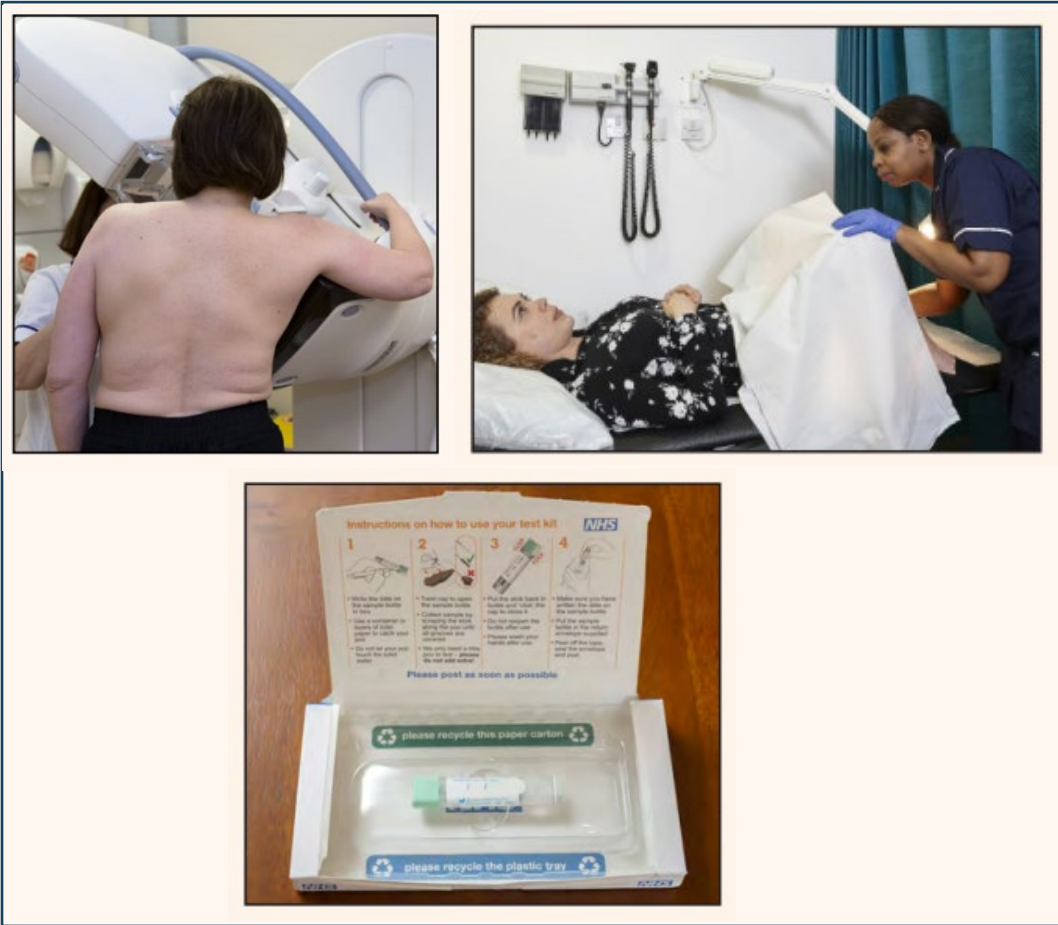
[Kate.sykes@northumbria.ac.uk](mailto:Kate.sykes@northumbria.ac.uk)

# Content of talk

1. Cancer screening and cancer prevention
2. Research studies and PPIE activities completed
3. Easy to read information and principles
4. Q&A



# Cancer screening and cancer prevention



# Research history

## PhD

- Teesside University
- Barriers to women with learning disabilities accessing cervical and breast cancer screening.
- 2017-2021

## Funded study

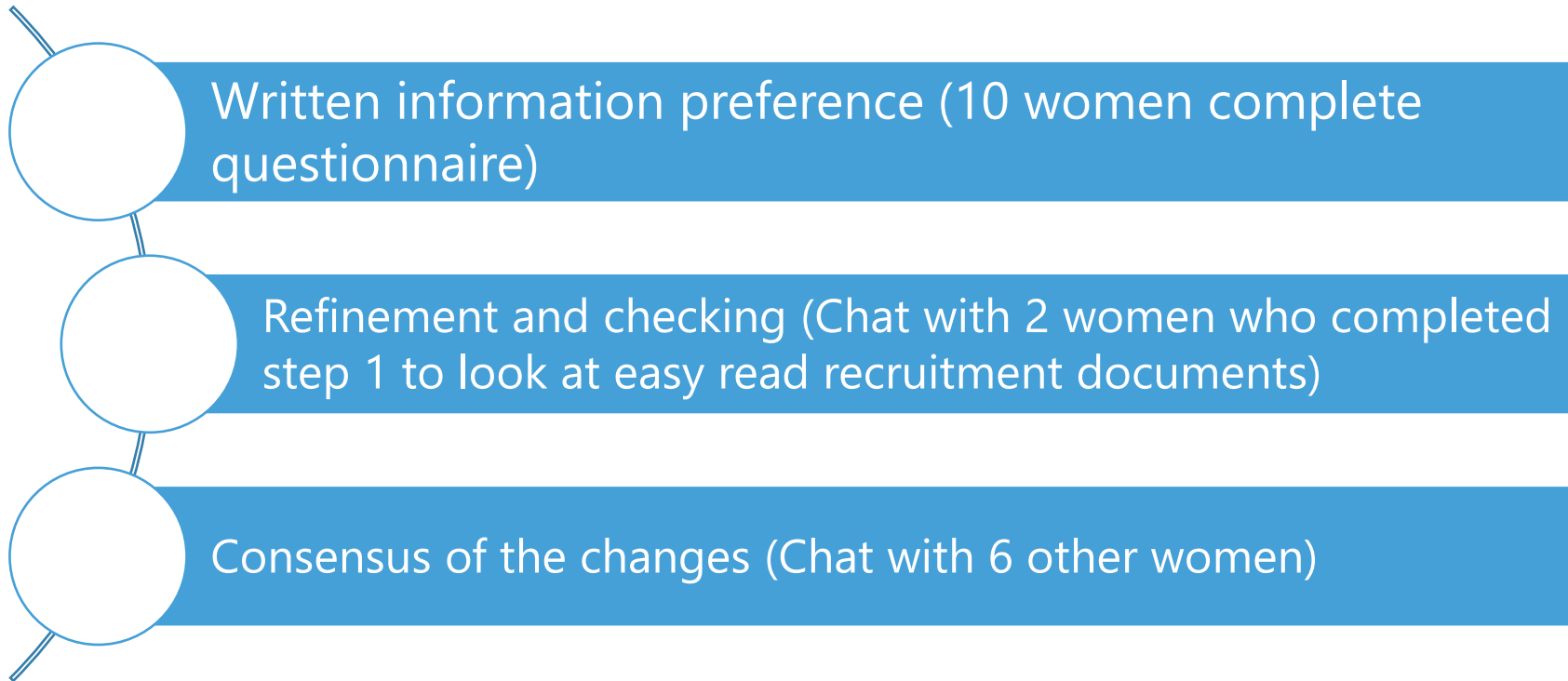
- NIHR North East and North Cumbria Applied Research Collaboration Funding
- Identifying the barriers and facilitators for people with severe mental illness and/or learning disabilities for person centred cancer screening <https://hosting.northumbria.ac.uk/peccs/>
- 2022-2023

## Awaiting response

- Breast Cancer Now
- Identifying, synthesising and embedding reasonable adjustments for seldom heard populations in the breast screening pathway to support informed decision making and access: A mixed method study.
- Awaiting decision – Due August 2025

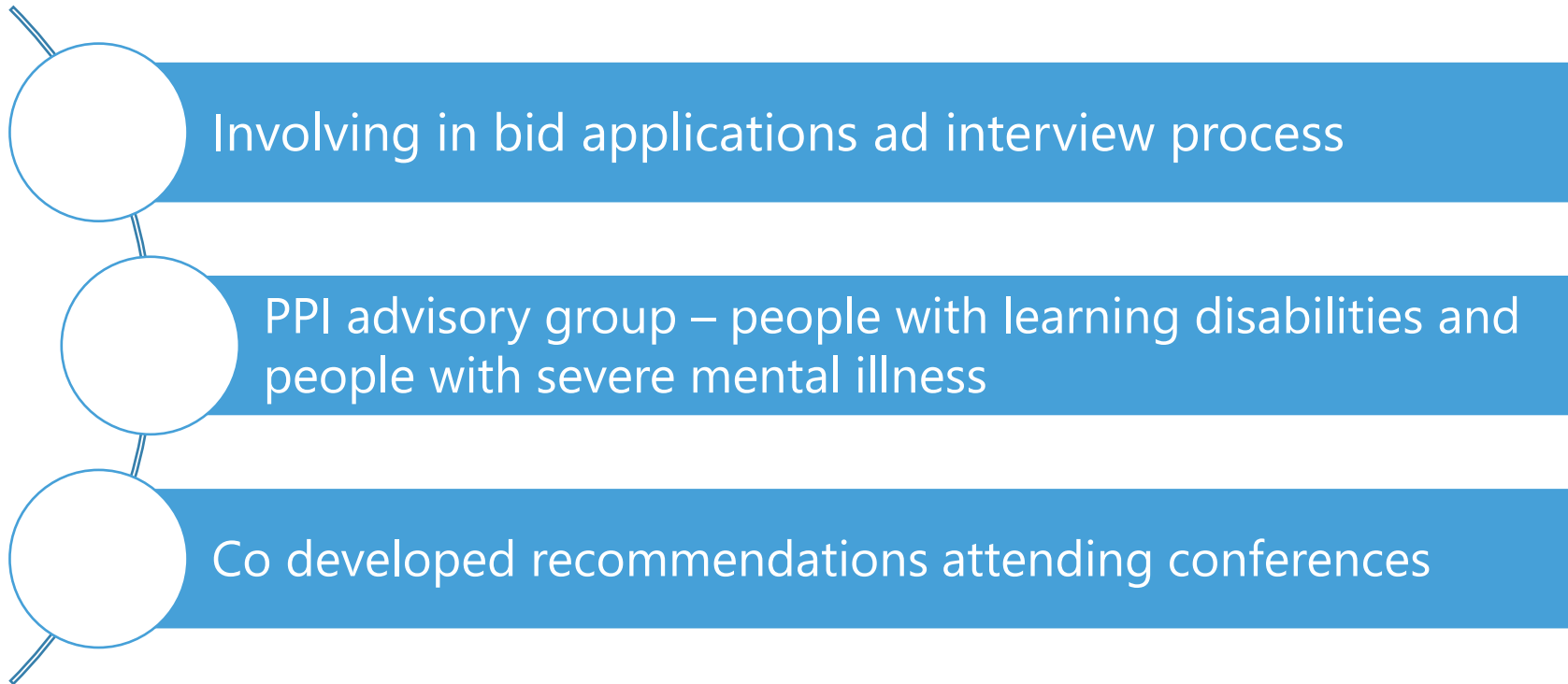
# PPIE activities completed across studies

PhD – Women with learning disabilities accessing cervical and breast screening



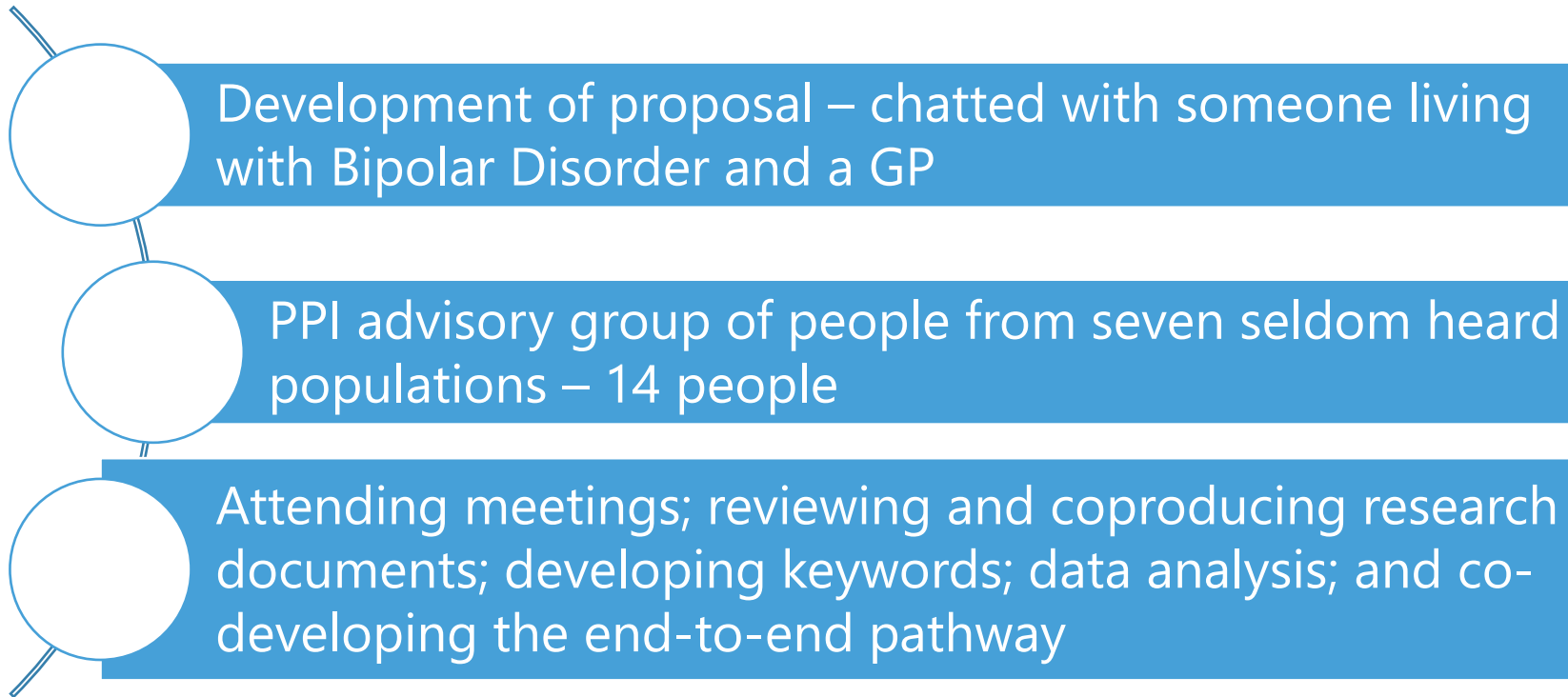
# PPIE activities completed across studies

Barriers and facilitators for people with severe mental illness and/or learning disabilities going to cancer screening



# PPIE activities completed across studies

Breast Cancer Now bid – developing person centred pathways

- 
- Development of proposal – chatted with someone living with Bipolar Disorder and a GP
  - PPI advisory group of people from seven seldom heard populations – 14 people
  - Attending meetings; reviewing and coproducing research documents; developing keywords; data analysis; and co-developing the end-to-end pathway

# Research Needs Experts by Experience: Here is our Story

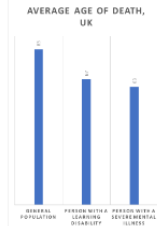
**Experts by Lived Experience:**  
Karen Manton  
Stephen O'Driscoll  
Sarah Robson

**PErson Centred Cancer Screening services (PECCS)**

**Project Co-Leads:**  
Kate Skyes & Jill Barker  
**Research Associate:**  
Emma Tuschick

## 1. About the study

Cancer screening uptake for people with severe mental illness and/or learning disabilities is low (NHS Digital, 2021; Public Health England, 2021). We aim to help change this by identifying how the cancer screening services can be adapted to support the uptake of this group. We will do this by:



Phase 1a A mixed methods systematic review of barriers and facilitators for people with severe mental illness accessing cancer screening services.	Phase 1b Semi structured interviews of people with severe mental illness whose voice has not been represented in the systematic review.
Phase 2a Triangulation of phase 1a and 1b, with research already completed involving people with learning disabilities.	Phase 2b Future research planning, recommendations to practice, and protocol development.

## 2. Our Public Involvement and Community Engagement (PICE)

We presented the research idea, and planned methods to the North-East North Cumbria Research Design Service's patient and public involvement consumer panel. We now have an advisory group involving people with lived experience.

Co-production of the systematic review search strategy and interview schedule



Advising on the ethics application

Recruiting the research associate

Advising on the use of language and terminology throughout the project

Co-producing the conference poster

- Future tasks include engagement in the design, management, analysis, evaluation, and dissemination of research outputs.
- We are using the GRIPP2 tool to report our PICE activity throughout the project (Staniszewska et al., 2017).
- By reflecting on our communications, we aim to improve the quality, transparency, and consistency of our PICE.



## 3. Valuing our experience, hearing our voice

- Starting from day one, we feel like a **big** part of the project.
- Everyday can be different for us and we feel **supported**.
- Public involvement is so **important** and needs to continue in the future.
- Being in an advisory group is a great way to have your voice **heard** and get the message out there.
- We feel **respected**, this makes a difference and makes us feel **valued**.
- We may have the same diagnosis, but we are treated **individually**.
- Overall, we are very **happy** with being part of the project and feel **listened** to.

## 4. Key messages

- "We want to be included and to share our own voice"
- "We need to think of people as people and listen to their needs and preferences"
- "No one is hard to reach if we listen and engage with people. People are not listening appropriately to those who are speaking"
- "It is great to be able to ask questions and to communicate with people at different levels"
- "Research' can be a scary word, but it can make a change for the future"



Inclusion

Accessibility

Perspective

## 5. Why we got involved in research

- Awareness**
  - To promote the need for reasonable change to adapt to individual needs.
  - Services need to wake up and get to know who we are and what we need.
- Stigma**
  - To reduce the feelings of stigma.
  - To stop feeling judged.
- Making Change**
  - To change the ways of working and practices.
  - To be able to help others.

## 6. Recommendations for other researchers

- Researchers need to base the research on **real life and those that experience it**.
- Make our journey easy by giving us **options**, such as; reasonable and negotiated deadlines, prompts and flexibility.
- Ensuring instructions are **clear** and easily understood. **Listening and acting** on our feedback.
- Regular **check-ins** to see how we are feeling.
- Not putting everyone in the same box and try to get a range of people with **different** experiences.

## 7. References

NHS Digital (2021). Health and care of people with learning disabilities. [online]. Available at: <https://digital.nhs.uk/data-and-information/data-tools-and-services/data-services/general-practice-data-hub/health-and-care-of-people-with-learning-disabilities#top>.  
Public Health England (2021). Severe mental illness (SMI): inequalities in cancer screening uptake report. [online]. Available at: <https://www.gov.uk/government/publications/severe-mental-illness-inequalities-in-cancer-screening-uptake>.  
Staniszewska S, Brett J, Simera I, Seers K, Mockford C, Goodlad S, Altman D G, Moher D, Barber R, Denegri S, Entwistle A, Littlejohns P, Morris C, Suleman R, Thomas V, & Tysall C. (2017). GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. BMJ, j3453. <https://doi.org/10.1136/bmj.j3453>



Feeling Scared

- Very clear about timelines
  - Text if there will be a delay
  - Talk about it - give clear information
- Short
- Best longer appointment system so they are aware of culture - clawing back - specific to

100 Short request

- Short
- Request longer appointment
  - Note on system so they are aware
  - Change culture - clawing back time
  - Clinic days - specific to screening
- Others attitudes
- Always ask person
  - Clocks in 10am

Others attitudes

- Always ask person!
- Training / awareness
- Mindful
- People with experience
- Unbiased.
- From feedback / mistakes

\* Culture of environment? Code of conduct  
↓  
always ask!

- Promotion
- Make it normal
- Loss of 'naïve attitude'
- Accessible 1990

Noisy Room

- Generate thinking room (quiet)
- Guest hours (in slots) (4-6 pm)
- Privacy
- Disposable ear plugs
- Prepare them that it might be noisy + can bring earphones etc.
- Design of the room (color) → Green to help / calm walls.

Not Homely

- Small better
- Pictures (eg labrador)
- Music
- Ask people what they like (spelling)
- Colours (green, white)
- Rug on room
- Comfort at chairs
- Therapy room

Give  
Phions  
at 1000  
CERVICAL

- Handwritten notes on a piece of paper, possibly a map or diagram, with the word "CIVIL" visible at the top. The notes include:
- Rocky landscape
  - Forest
  - River
  - Lake
  - Mountains
  - Sea of music
  - (CIVIL)
  - (CIVIL)



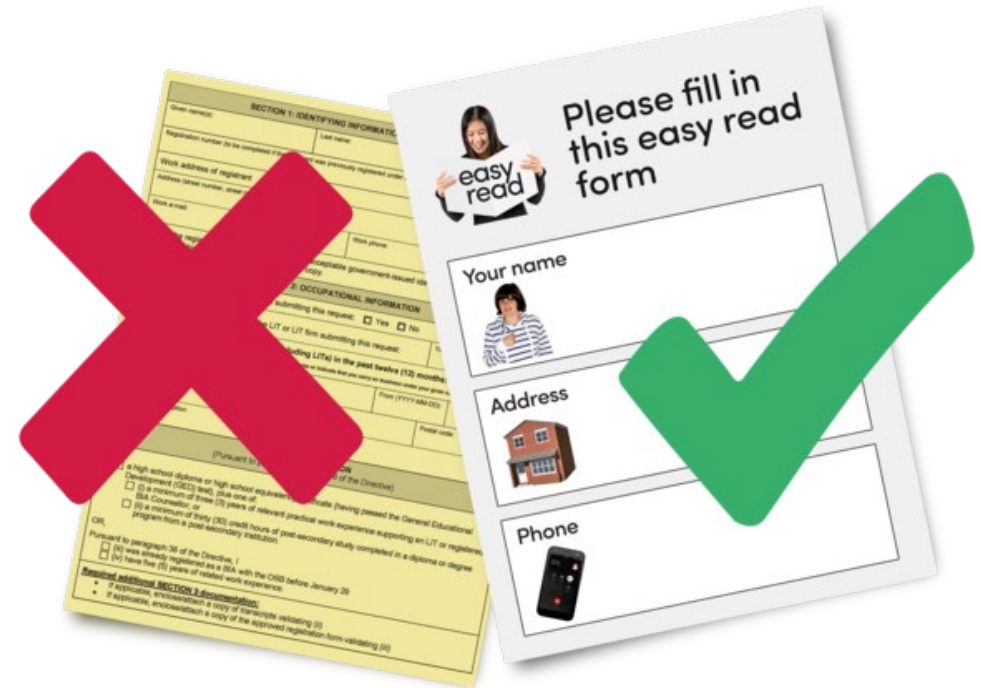




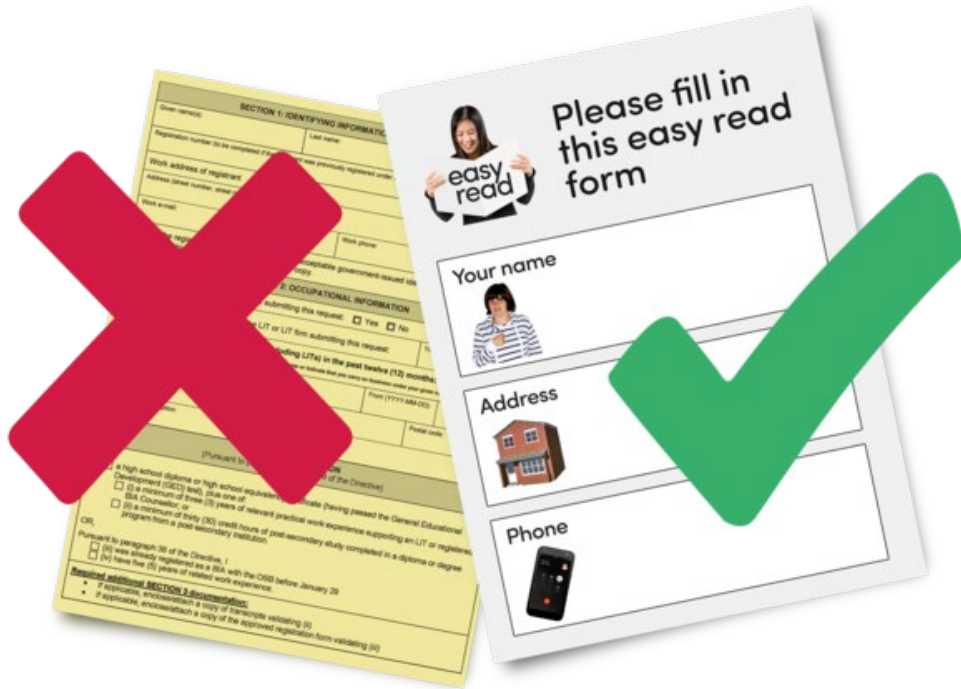




Easy to read  
information and  
principles

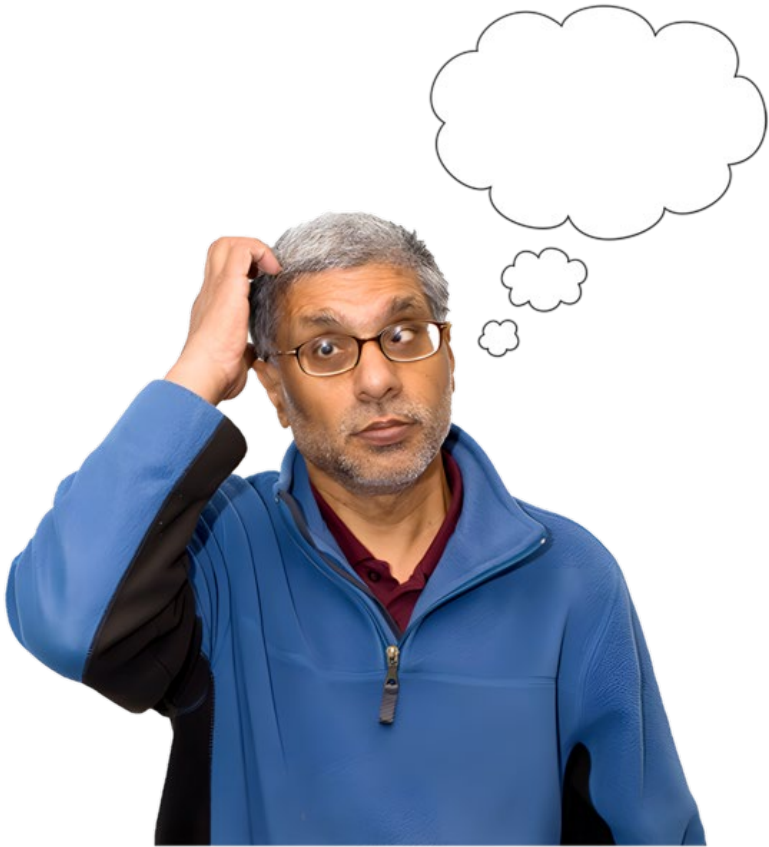


# What are “easy reads”?



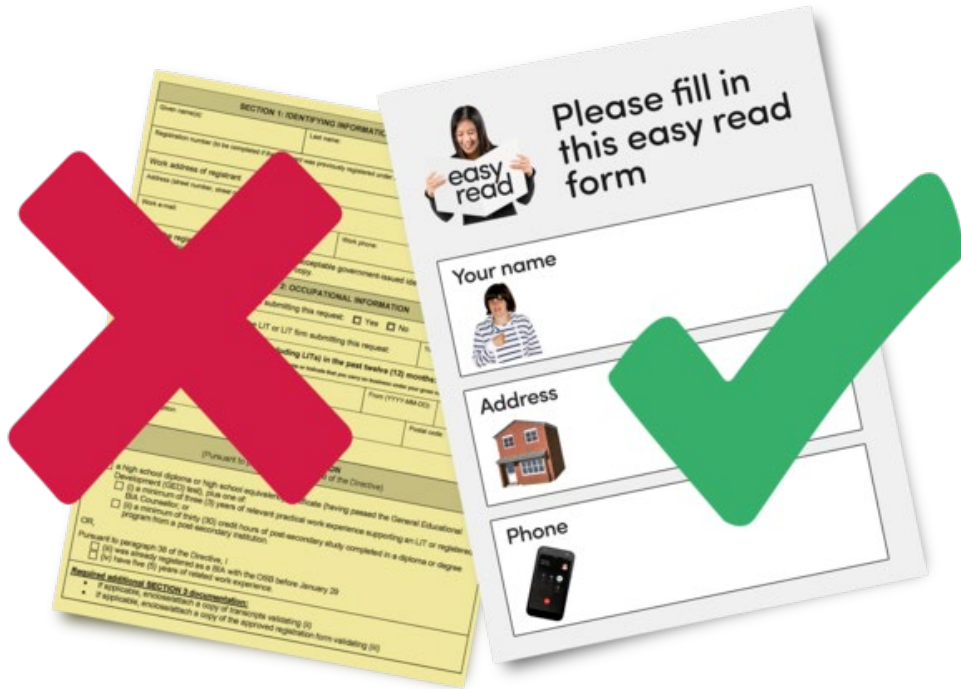
- Simple sentence.
- Jargon free.
- Easy to follow information
- Have pictures that support the writing.
- It helps people understand information.

# Where to find easy reads?



- MENCAP = [https://www.mencap.org.uk/search?f%5B0%5D=all\\_content\\_type\\_so\\_l%3Aeasy\\_read\\_page](https://www.mencap.org.uk/search?f%5B0%5D=all_content_type_so_l%3Aeasy_read_page)
- British Heart Foundation = <https://www.bhf.org.uk/informationsupport/support/accessible-health-content/easy-read-booklets>
- MacMillan = <https://www.macmillan.org.uk/cancer-information-and-support/get-help/translations-and-other-formats/easy-read-cancer-information>

# Why use easy reads?



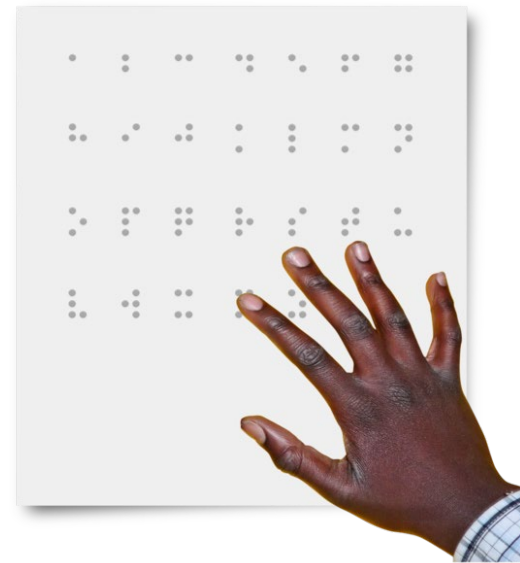
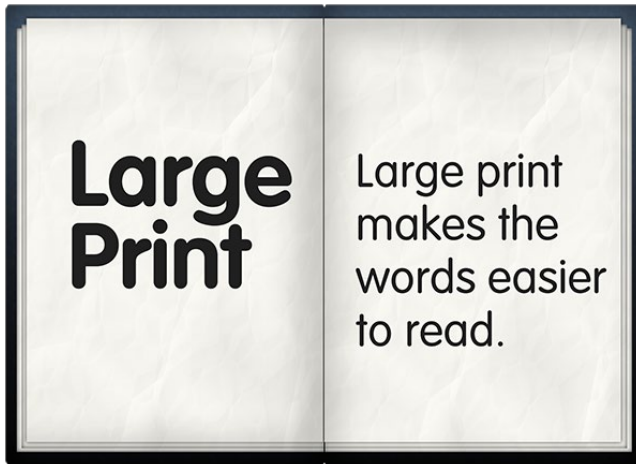
- The majority of people in England have a reading age of between 11-14 year old.
- However, across the UK 7.1 million adults read and write at or below the level of a 9 year old.
- 43% of adults do not understand written health information.

'Easy read for all'!





# Easy reads are one way to ensure information is accessible.



# Easy reads vs plain English



Easy reads

Plain English

Standard  
text



# How do I make an easy read? Co-production is key!

They know what works for them and what does not.

Find out what information people want.



Can gain a strong insight into the audience experience.

# For Example - Word Checking



- I asked women with learning disabilities to check the easy read documents.

- “screening” to “cancer screening” where possible;
- “self-examination” was changed to “check”;
- “prior preparation” was changed to “talking to”;
- “procedure” was changed to “steps” ;
- “equal rights” was changed to “given the same treatment”;
- “positive experiences” was changed to “good stories”;
- “help put them at ease” was changed to “relax”; and
- “cervical” and “breast” were changed to “lady bits” and “boobs”;

# For Example - Word Checking



"I am writing to invite you to talk to me about cervical ("lady bits") and breast ("boobs") cancer screening"

"Cancer is a very serious illness which could get worse if not treated."

# Layout



- Presented on A4 pages.
- Text aligned on the right hand side.
- Images aligned on the left hand side.

# Size and style of font

- Text should be in a large font size, minimum 14pt.
- Ideal font size is 16
- Fonts should not have a serif
- Recommended font styles are:

Arial  
Verdana  
Helvetica  
Candara  
Segoe

Tahoma  
Myriad  
Calibri  
Corbel  
Gill Sans

cat

font without serifs



cat

font with serifs



# Other writing tips



- **Bold** key words/phrases.
- Use numbers, instead of words
- Use 'do not', 'can not'
- Use bullet points and sub-headings
- Keep each sentence as short as possible
- Avoid using commas



# Language



- Language should be simple.
- Any **necessary** complicated words/terms should be explained.

# Example from bowel screening invitation letter



Bowel screening by Faecal Immunochemical Test (FIT) aims to detect colorectal cancers at the earliest possible time so that treatment may be offered promptly.

The programme invites all men and women between the ages of 60 to 74 years, in England, who is registered with a General Practice. All eligible individuals will be routinely recalled every two years.

Dear Mrs Anne Belinda (example subject)



We are inviting you to do a test at home soon to check if your bowel is healthy.



In about 2 weeks we will send you a screening test kit in the post.

The kit has instructions on what to do.



There is an easy guide leaflet with this letter that tells you about bowel cancer screening.

The leaflet can help you decide if you want to do the test.

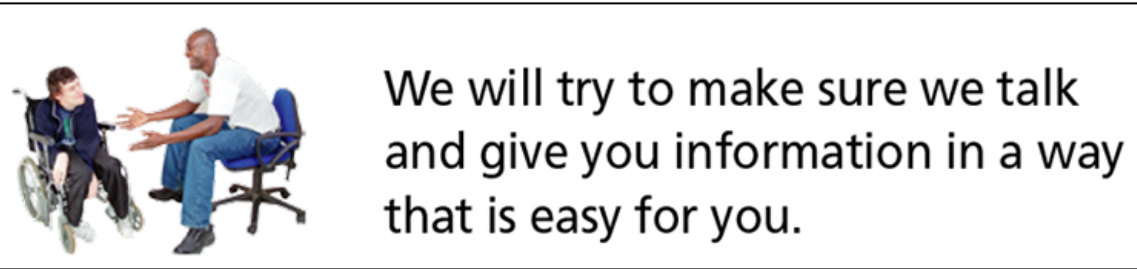


For help or more information, speak to:

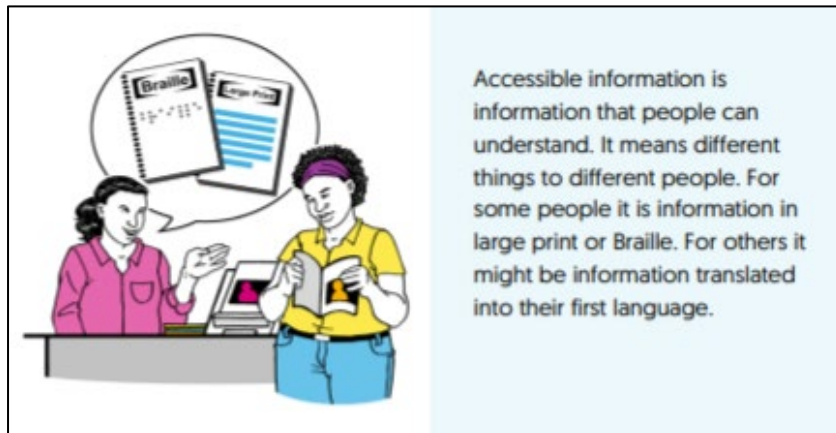
- our helpline on 0800 707 6060
- your learning disability team or doctor
- your local screening centre on [Click here to enter text.](#)

Or you can ask someone you trust to help you with this.

# Pictures

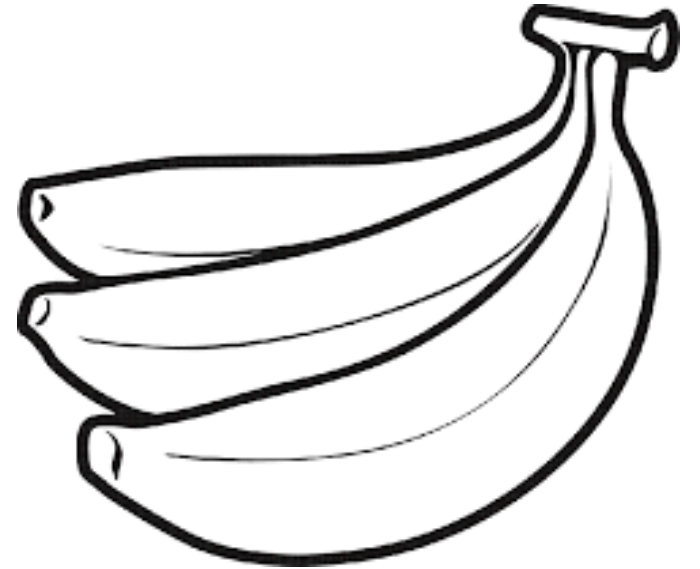
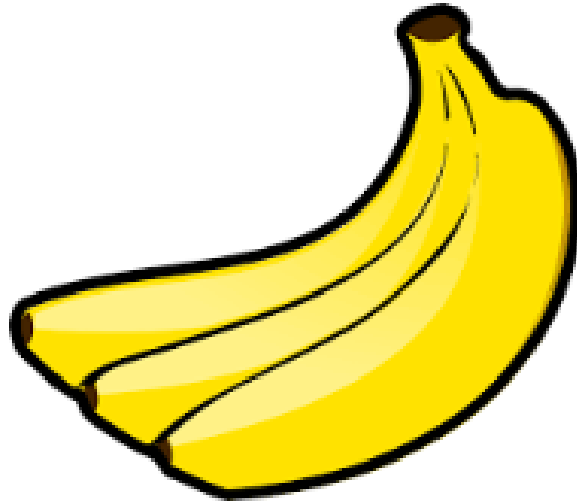


OR



- Just by putting a picture alongside information does not make it 'Easy Read'
- Images should be selected to represent each sentence of text where possible.

# Symbolic understanding





If there is anything you need for this appointment, for example a translator, information in braille or sign language, or anything else, please let us know.



The details of your 2020 annual health check are:

Date:

Time:

Where:

Who will do your annual health check:

Face to face

Telephone

Video call

Think about this scenario:

You are waiting for a appointment letter from your doctors. The letter arrives in the post, and it is an easy read format like this.

How would you feel?

Have you received information like this before?



Thank you for listening!



Does anyone have any questions?

[Kate.sykes@northumbria.ac.uk](mailto:Kate.sykes@northumbria.ac.uk)



