

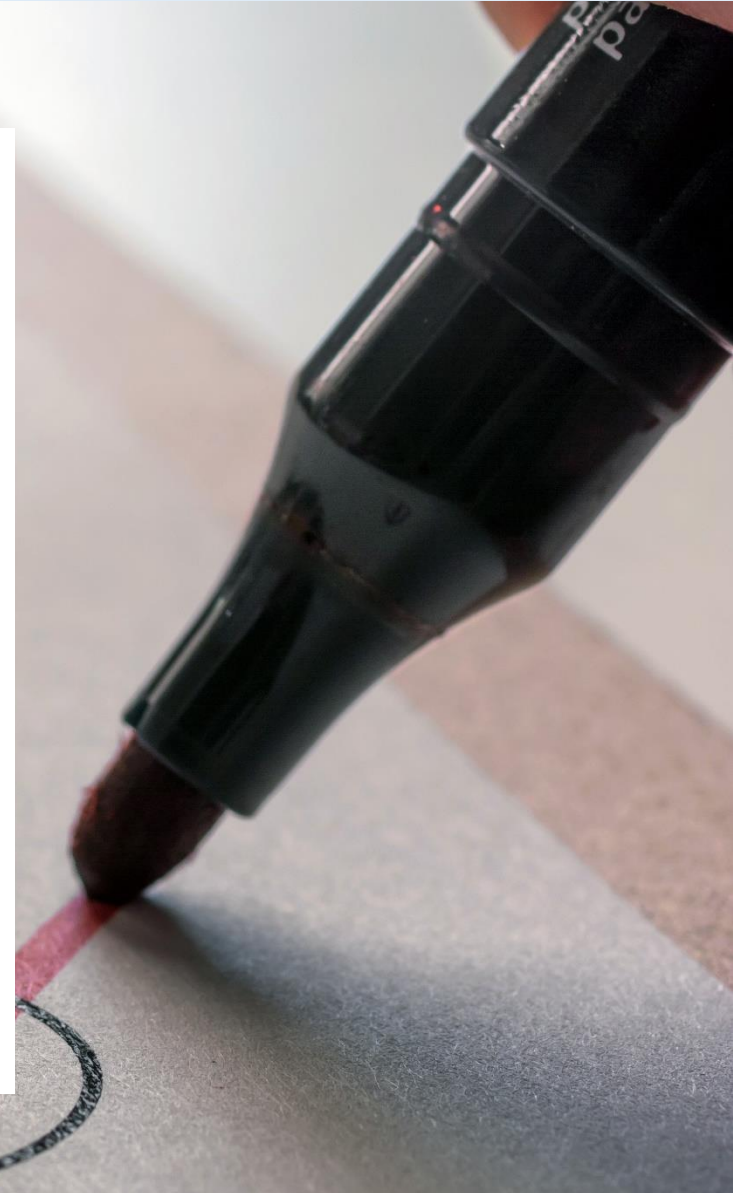
# From Awareness to Action: Tools to Close the Cancer Health Equity Gap

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# Objectives

1. Understand sources of **local cancer inequalities** and how to identify them
2. Explore how **research and behavioural science** can be used to develop actionable insights
3. Gain **practical tools** to work with your communities to co-design interventions to tackle local cancer inequalities



# The roadmap for today

**Getting to  
know each  
other**

**What are  
cancer  
inequalities?**

**Research to  
identify and  
address  
cancer  
inequalities**

**Co-designing  
an  
intervention  
to reduce  
inequalities**



# Getting to know each other

**What is your role and where have you joined from?**

**What is your main goal for attending the session?**

# The roadmap for today

**Getting to  
know each  
other**

**What is the  
cancer equity  
gap?**

**Research to  
identify and  
address the  
cancer equity  
gap**

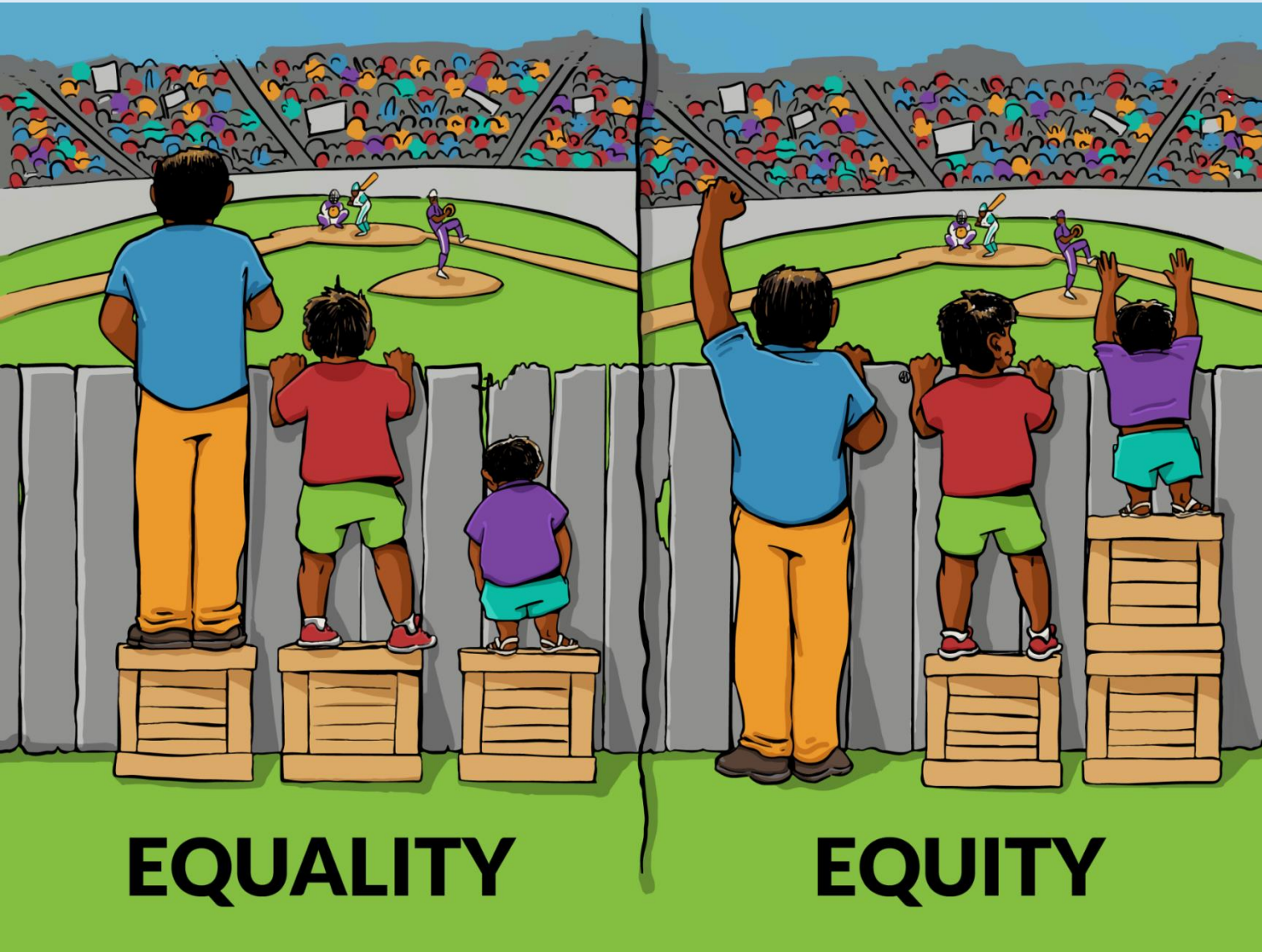
**Co-designing  
an  
intervention  
to reduce the  
gap**



# What is the cancer health equity gap?



# What is the cancer health equity gap?

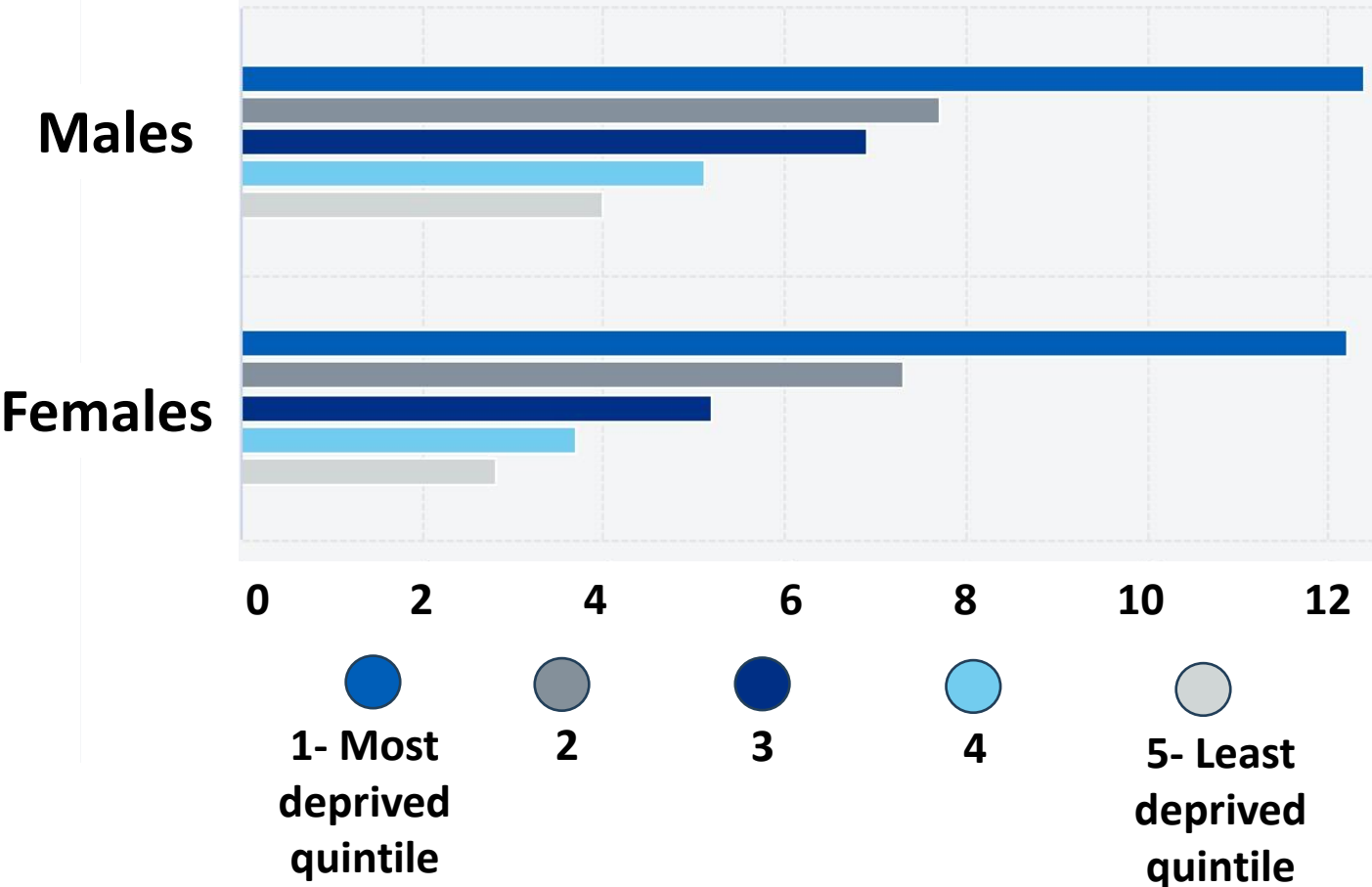


Cancer inequalities are **unfair and avoidable differences in cancer-related outcomes** across the population, and between different groups within society<sup>1</sup>.

The equity gap refers to the size, shape and position of those unfair and avoidable differences

# Who experiences the gap? **The higher the deprivation level, the higher the risk of getting cancer**<sup>2</sup>

Age-standardised small cell lung cancer incidence rates per 100,000 people by IMD quintile, England, 2021



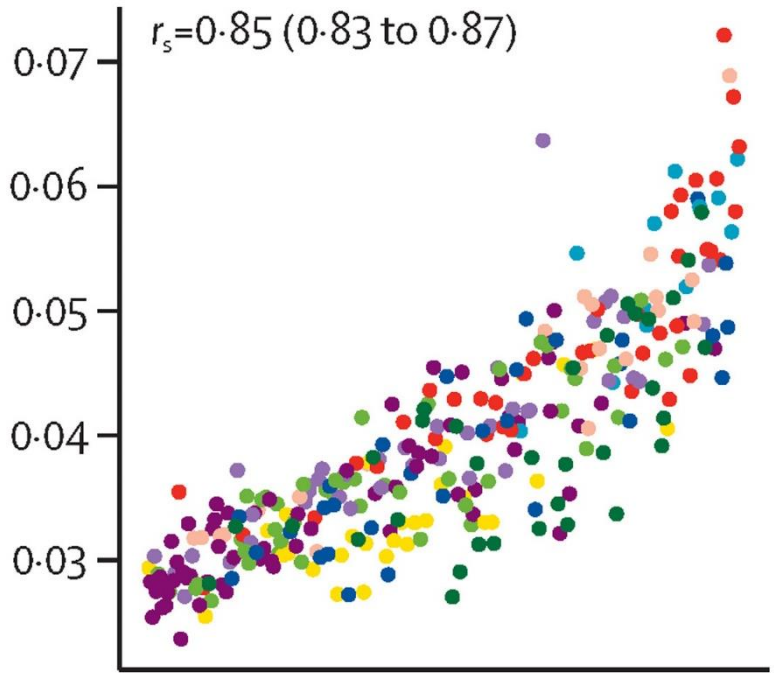
For most types of cancer, incidence is higher in the most deprived quintiles for both males and females. Although for some cancers (eg, skin, breast), the opposite is true.



- Small cell lung cancer has some of the biggest proportionate changes between quintiles for both males and females:
- 4x higher for females living in the most deprived areas compared with the least deprived
  - 3 x higher for males living in the most deprived areas compared with the least deprived areas

# Who experiences the gap? **The higher the deprivation, the higher the risk of dying from cancer**<sup>3</sup>

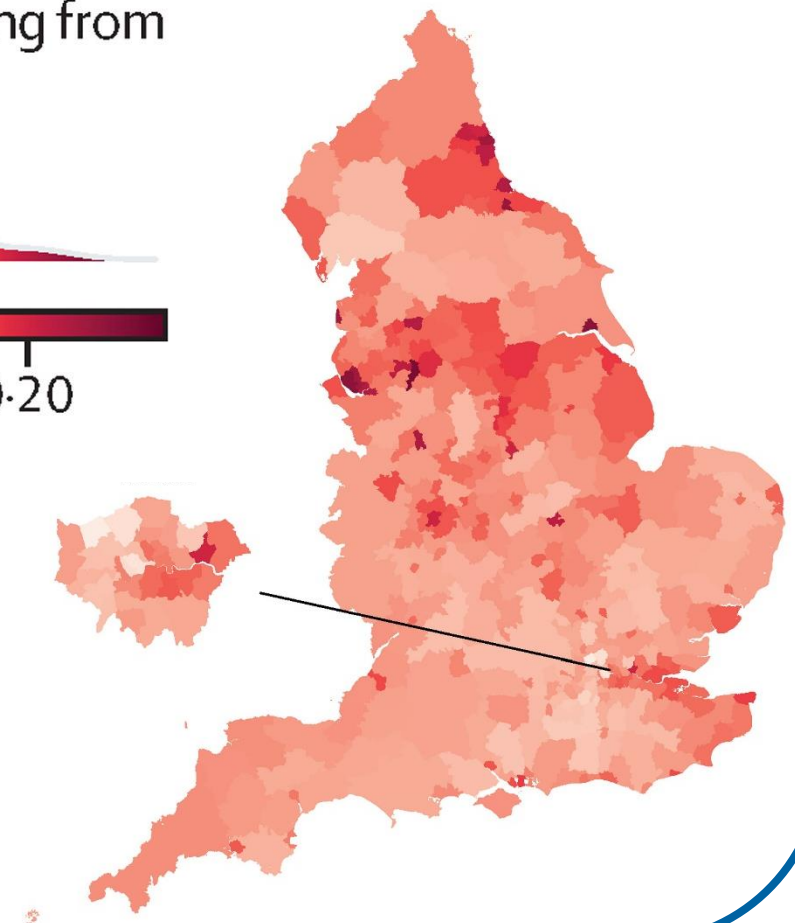
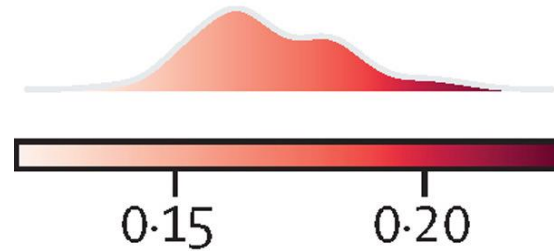
Probability of dying of lung cancer in 2019 (men)



Income deprivation rank

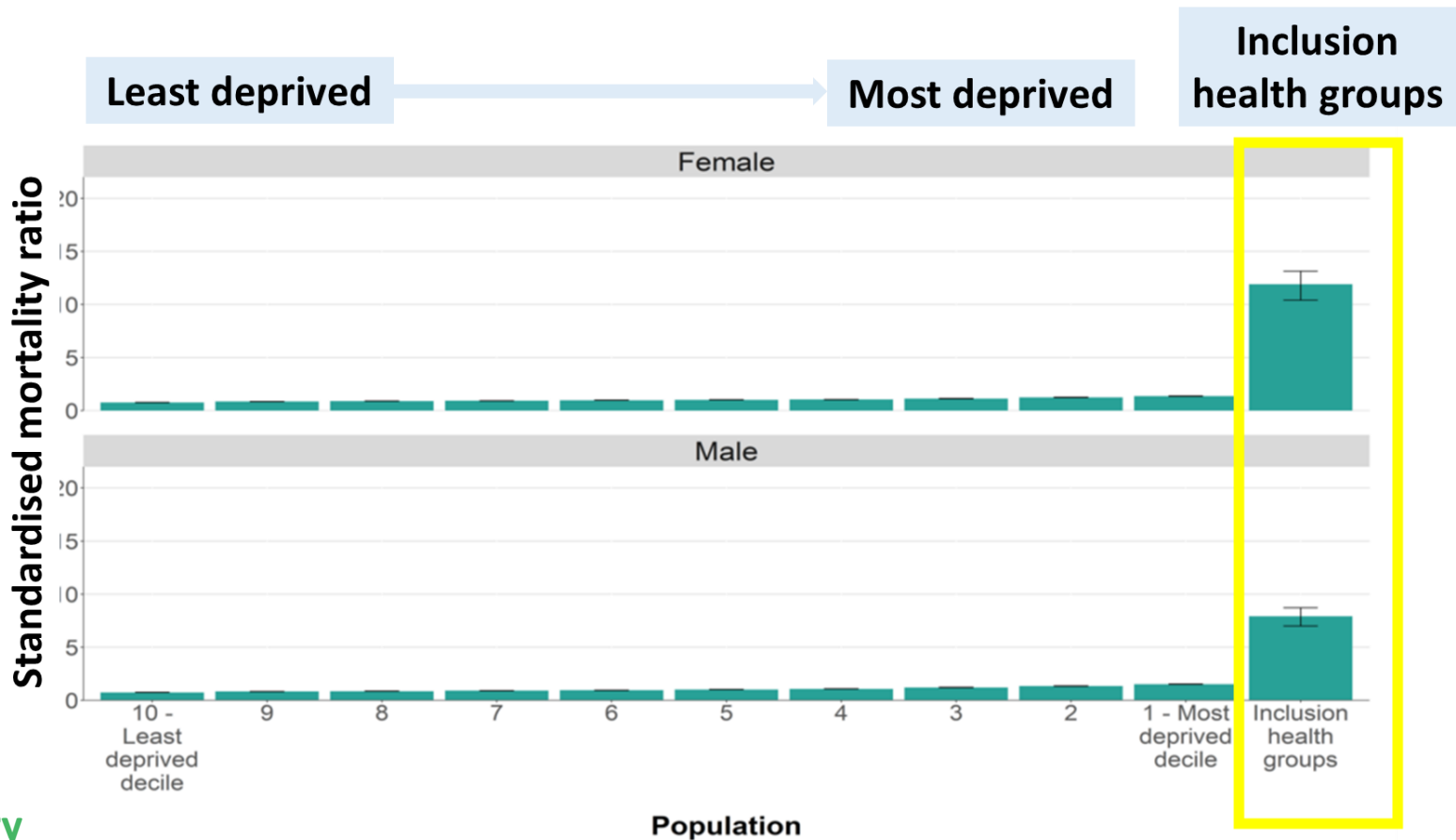
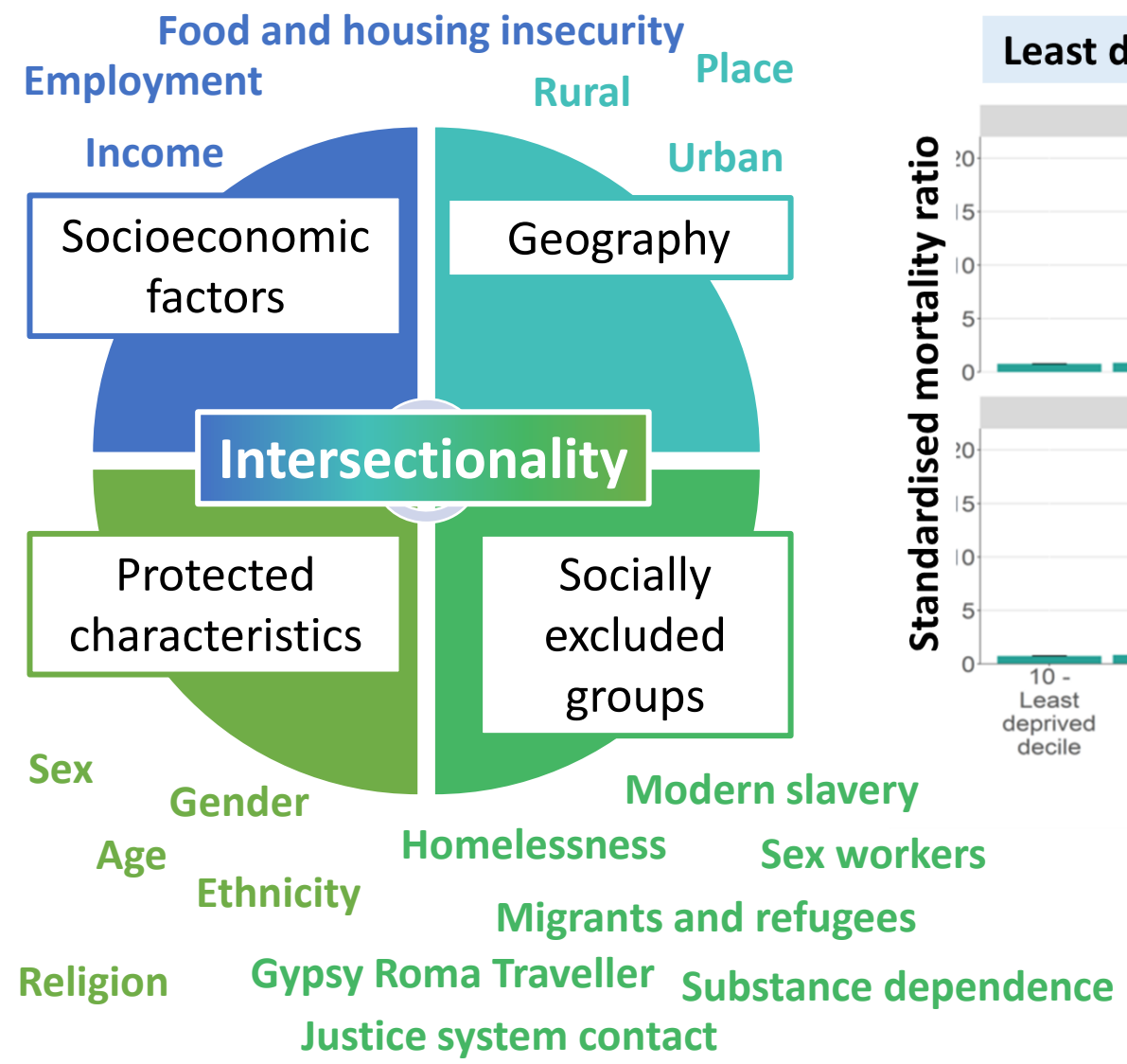
Men

Probability of dying from a cancer in 2019



# Who experiences the health equity gap?<sup>4</sup>

## Education




# Health equity and inclusion groups<sup>4</sup>

**Inclusion health is an umbrella term used to describe people who are socially excluded, who typically experience multiple interacting risk factors for poor health, such as stigma, discrimination, poverty, violence, and complex trauma.**

## **Likely to experience:**

- Discrimination and stigma
- Violence and the experience of trauma
- Poverty
- Invisibility in health datasets



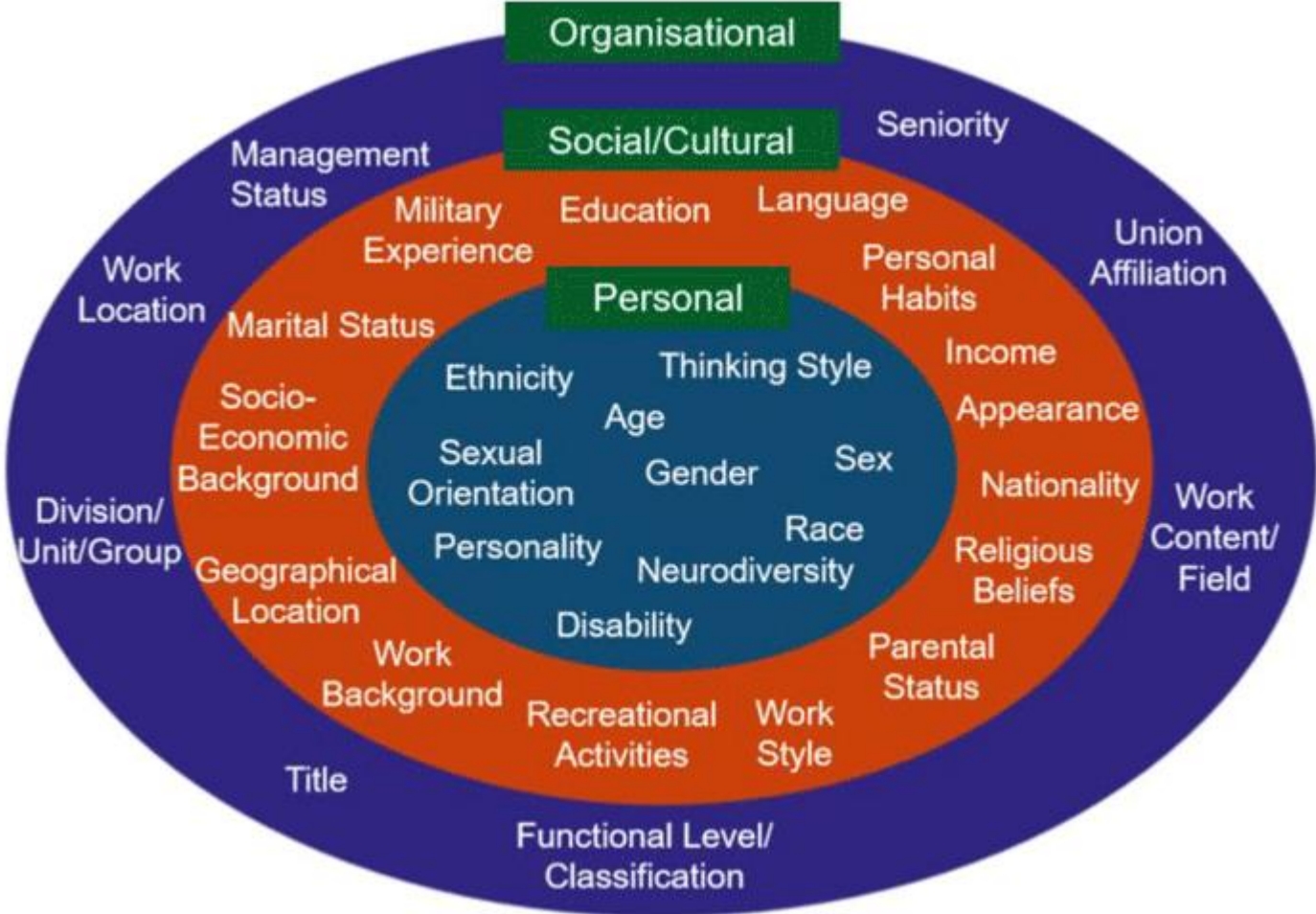
People who experience homelessness  
People with drug and alcohol dependence  
Vulnerable migrants and refugees  
Gypsy, Roma, and Traveller communities  
People in contact with the justice system  
Victims of modern slavery  
Sex workers  
Other marginalised groups

## **Resulting in:**

- Insecure and inadequate housing
- Very poor access to healthcare services due to service design
- Poor experience of public services
- Poorer health than people in other socially disadvantaged groups

# Health equity, intersectionality and the diversity wheel<sup>5</sup>

"Intersectionality is a metaphor for understanding the ways that **multiple forms of inequality or disadvantage sometimes compound themselves and create obstacles** that often are not understood among conventional ways of thinking."



# How can we close the gap? CORE20Plus5 approach<sup>8</sup>



## REDUCING HEALTHCARE INEQUALITIES

**CORE20**  
The most deprived **20%** of the national population as identified by the Index of Multiple Deprivation



The Core20PLUS5 approach is designed to support Integrated Care Systems to drive targeted action in healthcare inequalities improvement

**PLUS**  
ICS-chosen population groups experiencing poorer-than-average health access, experience and/or outcomes, who may not be captured within the Core20 alone and would benefit from a tailored healthcare approach e.g. inclusion health groups

Target population

# CORE20 PLUS5



Key clinical areas of health inequalities

1



### MATERNITY

ensuring continuity of care for women from Black, Asian and minority ethnic communities and from the most deprived groups

2



### SEVERE MENTAL ILLNESS (SMI)

ensure annual Physical Health Checks for people with SMI to at least, nationally set targets

3



### CHRONIC RESPIRATORY DISEASE

a clear focus on Chronic Obstructive Pulmonary Disease (COPD), driving up uptake of Covid, Flu and Pneumonia vaccines to reduce infective exacerbations and emergency hospital admissions due to those exacerbations

4



### EARLY CANCER DIAGNOSIS

75% of cases diagnosed at stage 1 or 2 by 2028

5



### HYPERTENSION CASE-FINDING and optimal management and lipid optimal management

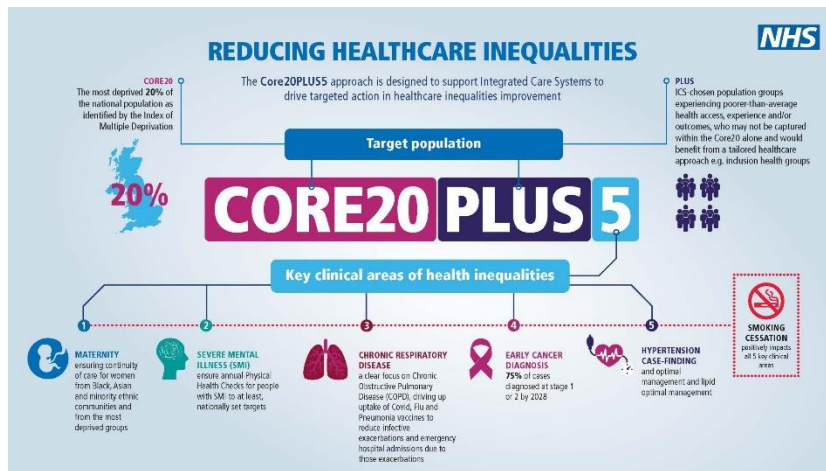


### SMOKING CESSATION

positively impacts all 5 key clinical areas

# How can we close the gap? CORE20Plus5 approach<sup>8</sup>

The CORE20Plus 5 framework provides an approach to identifying groups and clinical areas to focus on to reduce key inequalities



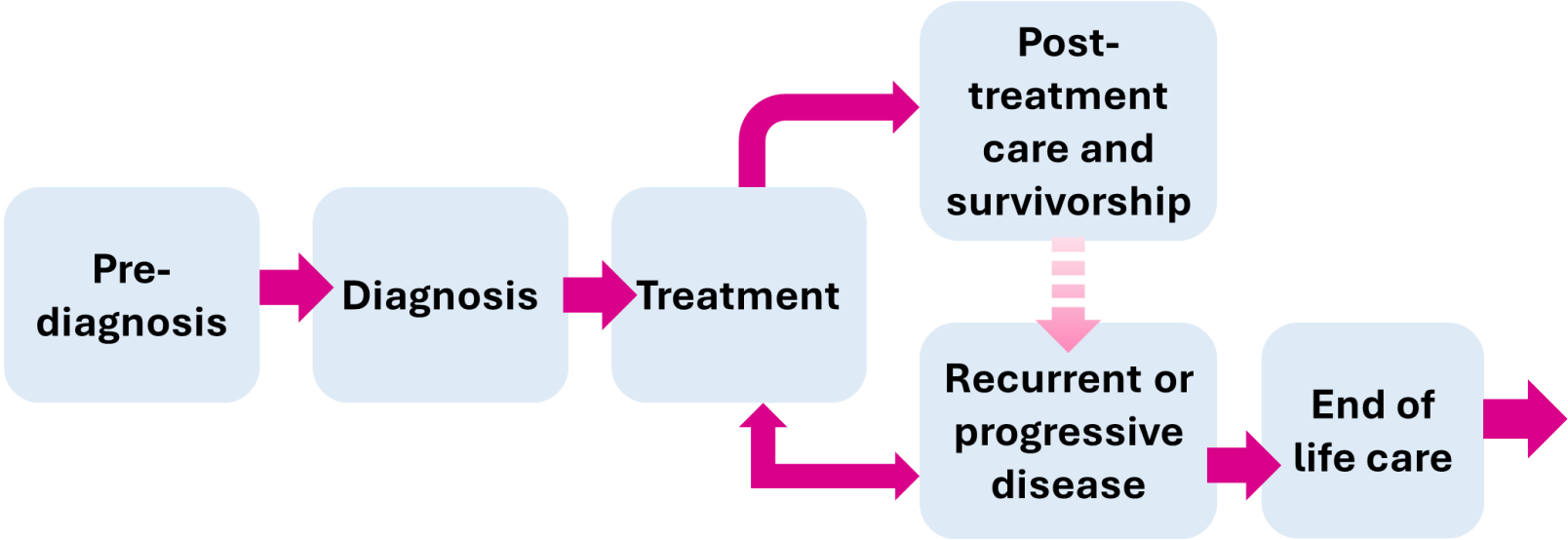
**KEY CLINICAL AREA: EARLY CANCER DIAGNOSIS**  
75% CASES DIAGNOSED AT STAGE 1/2 BY 2028

**KEY POPULATION: CORE20**  
Most deprived 20% of the national population identified by Index of Multiple Deprivation

**KEY POPULATION: PLUS**  
Locally-identified groups experiencing poorer than average health access, experience and/or outcomes, who may not be captured within the CORE20

# Where are there equity gaps on the cancer pathway? <sup>6</sup>

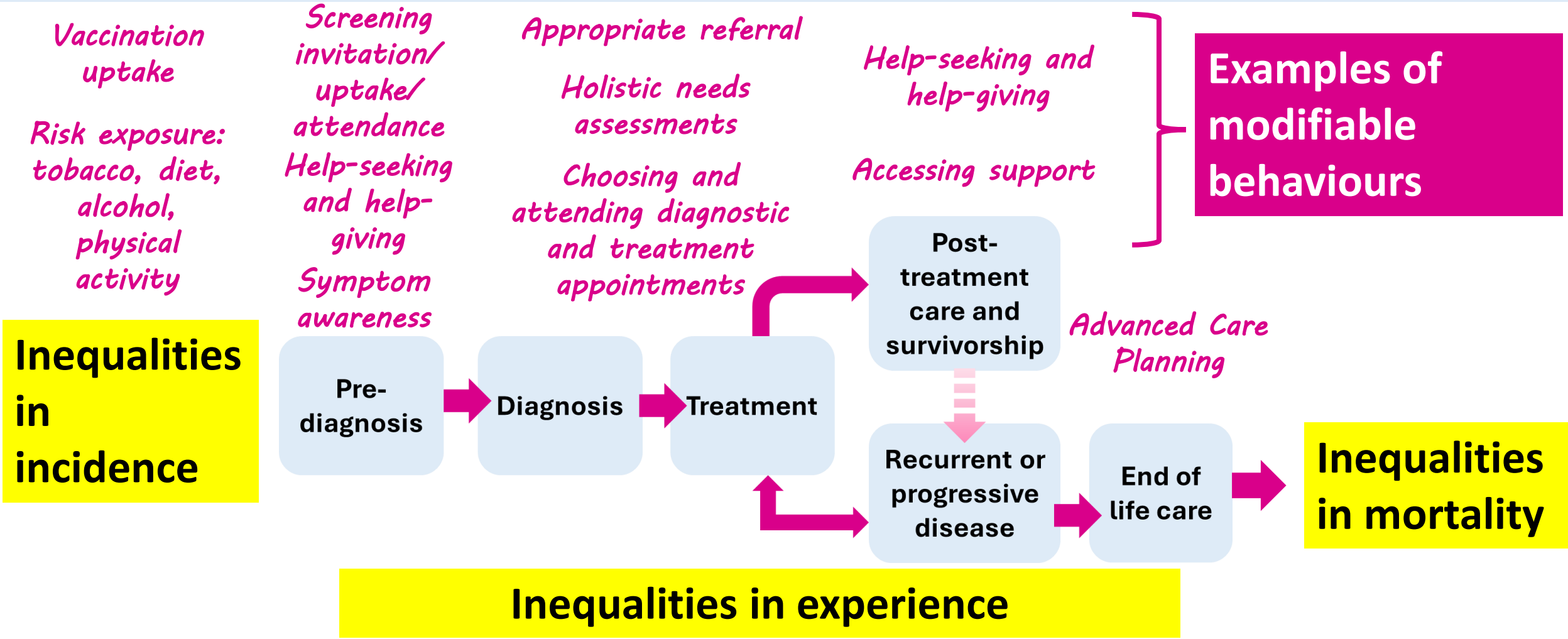
**Inequalities in incidence**



**Inequalities in experience**

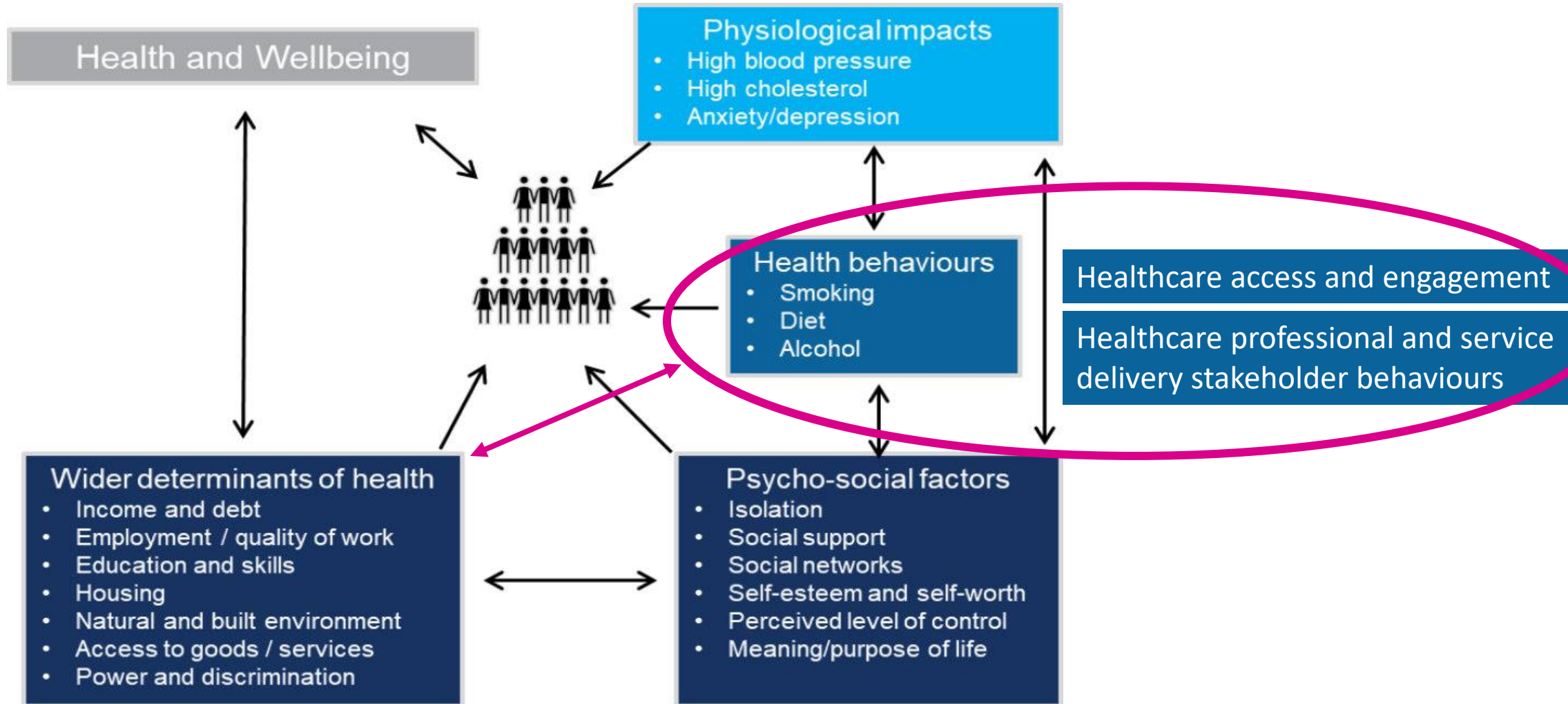
In Surrey we are undertaking a journey mapping exercise for people experiencing deprivation to understand their full journey across the lung, colorectal and lung cancer pathways: what factors lead to inequalities? Which of these are modifiable and how?

# Where are there equity gaps on the cancer pathway? <sup>6</sup>



In Surrey we are undertaking a journey mapping exercise for people experiencing deprivation to understand their full journey across the lung, colorectal and bowel cancer pathways: what factors lead to inequalities? Which of these are modifiable and how?

# Identifying the sources of inequalities: the Labonte model<sup>7</sup>



**What cancer inequalities are you aware of in your local area? And how do you know about them?**



# The roadmap for today

**Getting to know each other**

**What is the cancer equity gap?**

**Research to identify and address the cancer equity gap**

**Co-designing an intervention to reduce the gap**



# What is behavioural science research?



**Research is the creation of new knowledge**

“It can be 'blue-sky' research – driven by curiosity about what may be possible – or focused on addressing particular issues...such as healthcare.”<sup>9</sup>

**Behavioural science is the systematic study of**

**human behaviour:** *“an evidence-based understanding of how people actually behave, make decisions and respond to programmes, policies, and incentives”*<sup>10</sup>; it generates insights into why patients and healthcare practitioners behave the way that they do, and practical tools to change unhelpful behaviours



# Step 1: Get curious – what (potential) inequality should you focus on, and why?

**A specific group or community? A particular outcome or point of the pathway?**



- **Notice potential inequalities** (guided by frameworks we talked about earlier)
- **What are the challenges of your local communities?** Local authority Joint Strategic Needs Assessments can help, but don't be restricted by them!
- What have you **heard from your communities?** Have you noticed any potential inequalities in your **day-to-day work?**
- Have you **read or heard about any inequalities**, and wonder if and how they affect your local population?
- Look at **national and local data**



[NHS Futures](#)

[OHID Fingertips](#)

[National Cancer Patient Experience Survey](#)

[NHS England Cancer Data Hub](#)

# Step 2: Focus in – what do you already know about that equity gap?

## Collect and examine existing knowledge about that (potential) inequality



[Inclusion Health](#)

[NHS England Inequalities in Cancer](#)

[The Lancet: “Cancer Inequalities: a major public health concern”](#)

- **Explore the data in more detail:**
  - What can you tell from it?
  - What can you not tell from it?
- **Look at the literature:**
  - Peer reviewed publications (systematic reviews)
  - Reports (national, charities, think tanks)
  - What have they found? What are they recommending needs more research?
- **Talk to your networks and communities:**
  - Is anyone already working on this?
  - What do they know? What don't they know? What do they wish they did?

# Step 3: Define your aims and research question

**Get specific: What do we need to know in order to take steps to closing that equity gap? What specific behaviour(s) does this relate to?**



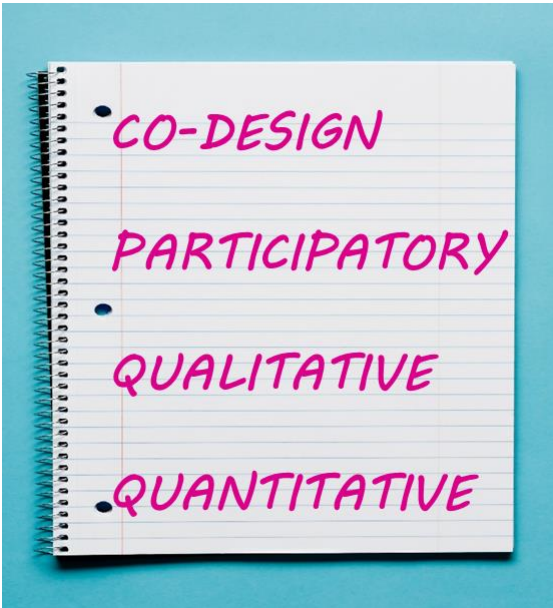
- Do you need to know **if** a suspected inequality exists in your local population?
- Do you need to understand more about **who** is at the highest risk of experiencing inequalities within the at-risk group?
- Do you already know an inequality exists but need to know **what** factors are driving it?
- Do you know what factors are driving the inequalities but need to know **solutions** to overcoming them?
- **Do you know the recommended solutions but need to test if they are effective at reducing the inequality?**
- Do you know the effective solutions but need to check if and how they can be **implemented?**



[NHS England: Turn your idea into a research question](#)

# Step 4: Work out the best way(s) to answer that question

What do you need to know in order to reduce an equity gap? How can you collect that information?



<b>Who</b>	Do you need to look at <b>routinely recorded data</b> ?
<b>What</b>	Do you need to understand the experiences and perspectives of people <b>receiving a service</b> ?
<b>When</b>	Do you need to understand the experiences and perspectives of people <b>delivering a service</b> ?
<b>Where</b>	Do you need to understand the experiences and perspectives of people <b>delivering a service</b> ?
<b>How</b>	Do you need to <b>collect health outcomes</b> data to measure the effect of an intervention?

- Interviews*
- Epidemiological studies*
- Focus groups*
- Co-design workshops*
- Ethnographic studies*
- Surveys*
- Delphi studies*
- Pilot studies*
- Implementation studies*
- Randomised Controlled Trials*



[NCRM: How to choose a research method](#)

# The golden thread: patient and public involvement (PPI)<sup>13,14</sup>

## The jargon free research process

**Step 1: What inequality should you focus on?**

**Step 2: What do you already know about that inequality?**

**Step 3: Define the aims and research question**

**Step 4: What is best way(s) to answer that question?**

**Step 5: Collect your data, analyse it, write it up and share it!**

**Embedding PPI at every stage of the research process enables higher quality research**



**Doing research with, not 'for' or 'on'**

**Insights into the reality of facing, or living with cancer**

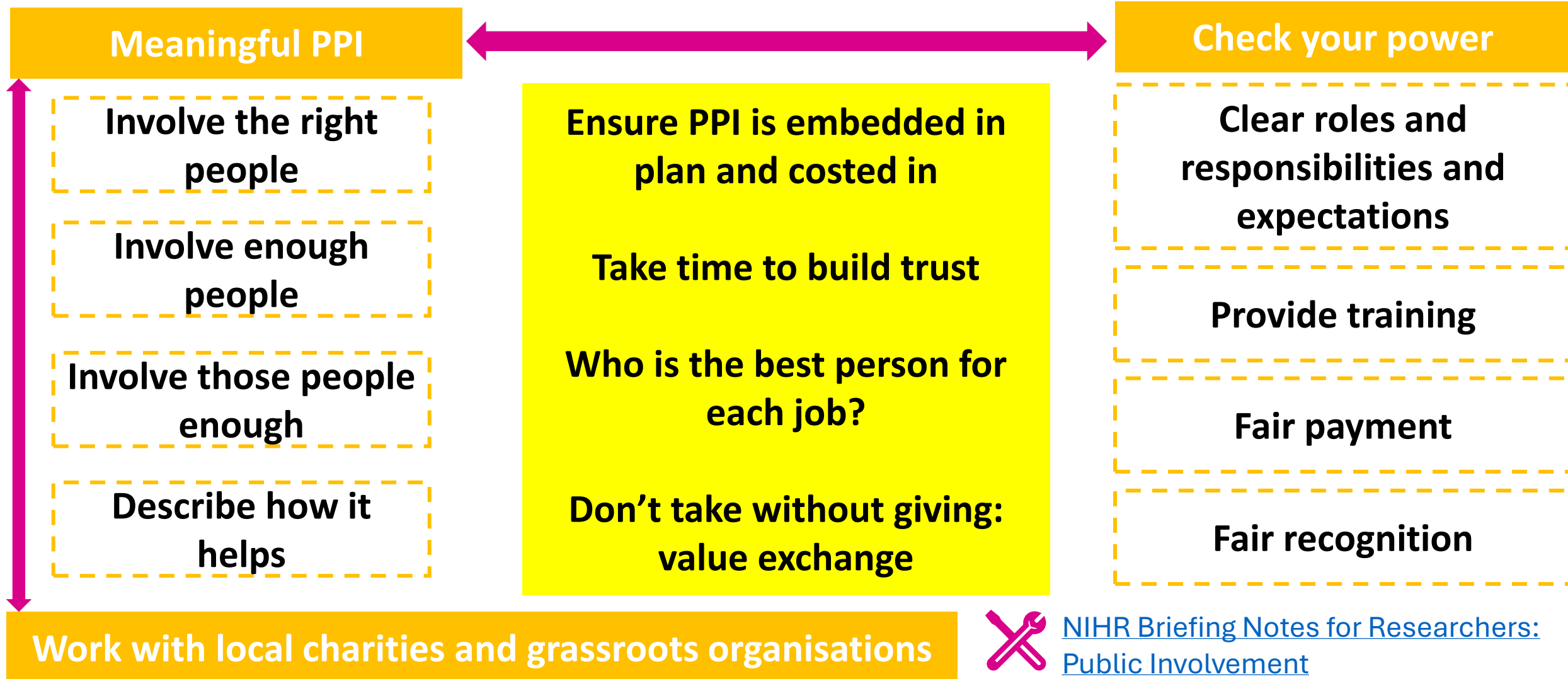
**Help better characterise the challenges, needs and priorities**

**Ensure research question is relevant**

**Ensure research methods are ethical, acceptable and understandable -> improved experience and recruitment**

**Enable better interpretation and communication of results**

# Core principles of patient and public involvement (PPI): doing 'with' or 'by', not 'for' or 'on' <sup>13,14</sup>



# Core principles of patient and public involvement (PPI): doing 'with' or 'by', not 'for' or 'on' <sup>15</sup>



NIHR Oxford BRC patient and public involvement and engagement

# The roadmap for today

**Getting to  
know each  
other**

**What is the  
cancer equity  
gap?**

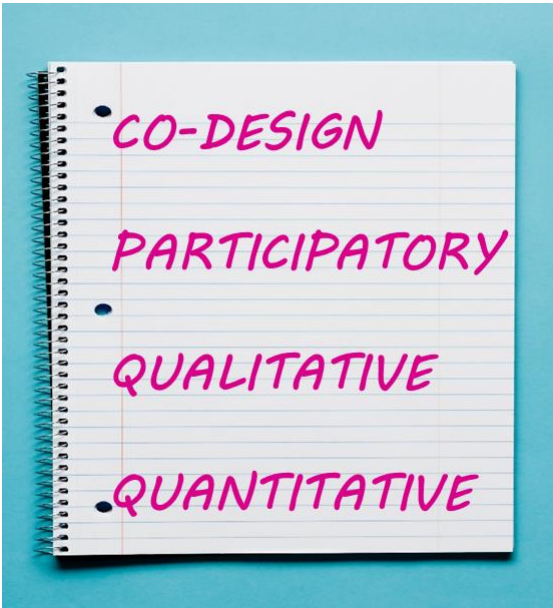
**Research to  
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**Co-designing  
an  
intervention  
to reduce the  
gap**



# Step 4: Work out the best way(s) to answer that question?

What do you need to know in order to reduce an equity gap? How can you collect that information?



**Who**  
**What**  
**When**  
**Where**  
**How**

Do you need to look at **routinely recorded data**?

Do you need to understand the experiences and perspectives of people **receiving a service**?

Do you need to understand the experiences and perspectives of people **delivering a service**?

Do you need to **collect health outcomes** data to measure the effect of an intervention?

*Interviews*

*Epidemiological studies*

*Focus groups*

*Co-design workshops*

*Ethnographic studies*

*Surveys*

*Delphi studies*

*Pilot studies*

*Implementation studies*

*Randomised Controlled Trials*



[NCRM: How to choose a research method](#)

# Research to co-design an intervention informed by behavioural science<sup>12</sup>

## The jargon free research process

Step 1: What inequality should you focus on?

Step 2: What do you already know about that inequality?

Step 3: Define the aims and research question

Step 4: What is best way(s) to answer that question?

Step 5: Collect, analyse, write up and share

## Co-design with patients and public



Patient and  
public  
involvement

## Using behavioural science

**CAPABILITY**

Physical and Psychological

**OPPORTUNITY**

Physical and Social

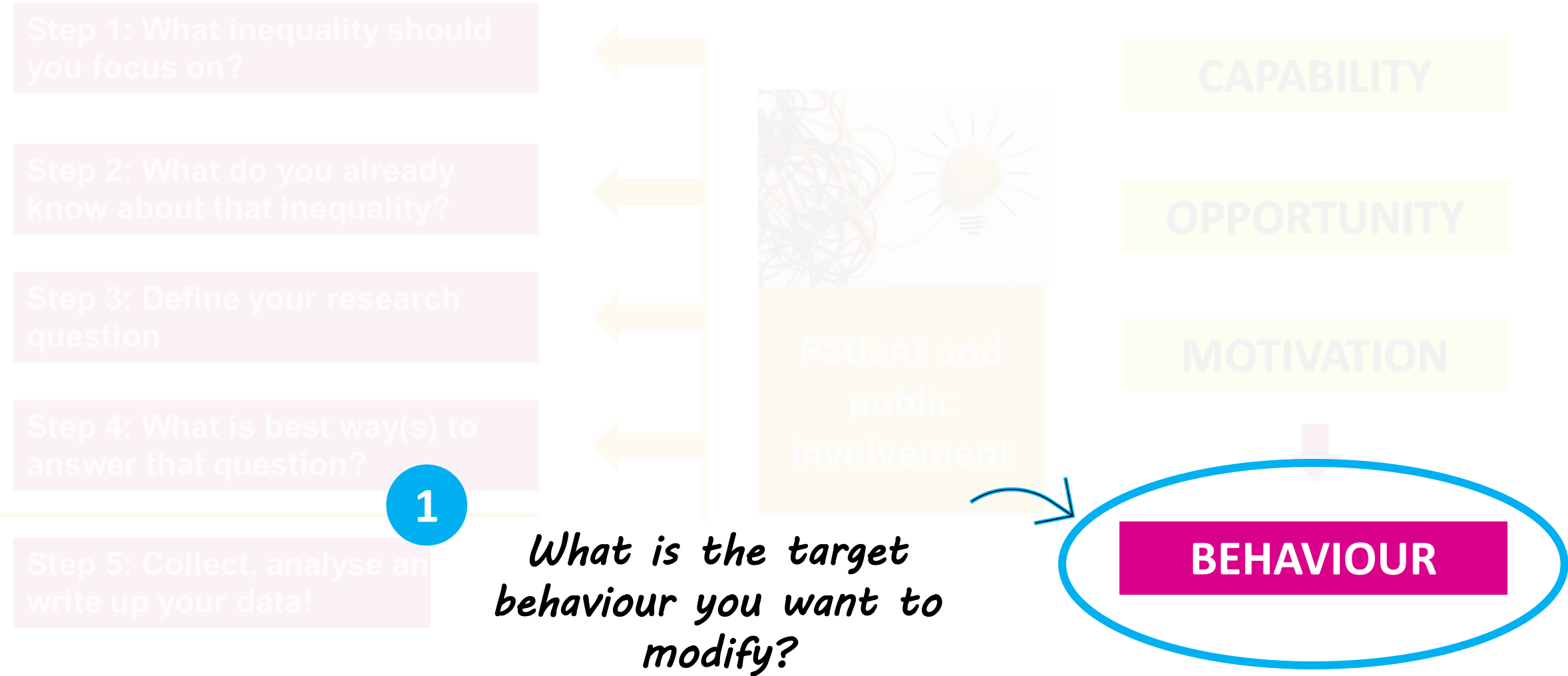
**MOTIVATION**

Automatic and Reflexive



**BEHAVIOUR**

# Co-designing an intervention informed by behavioural science: **defining the target behaviour**<sup>12</sup>



# Co-designing an intervention informed by behavioural science: **sources of behaviour**<sup>12</sup>

Step 1: What inequalities exist and what do you want to focus on?

2

*What factors make it easier for an individual to perform those behaviours?*

*What factors make it harder for an individual to perform those behaviours?*

Step 2: What do you already know about that inequality?

Step 3: Define your research question

Step 4: What is the best way(s) to answer that question?

Step 5: Collect, analyse and write up your data!

1

*What is the target behaviour you want to modify?*



# Co-designing an intervention informed by behavioural science: **modifying behaviours**<sup>12</sup>

**3** *What could maximise exposure to these factors?*

*What could minimise exposure to these factors?*

**2** *What factors make it easier for an individual to perform those behaviours?*

*What factors make it harder for an individual to perform those behaviours?*

**1** *What is the target behaviour you want to modify?*

**CAPABILITY**

Physical and Psychological

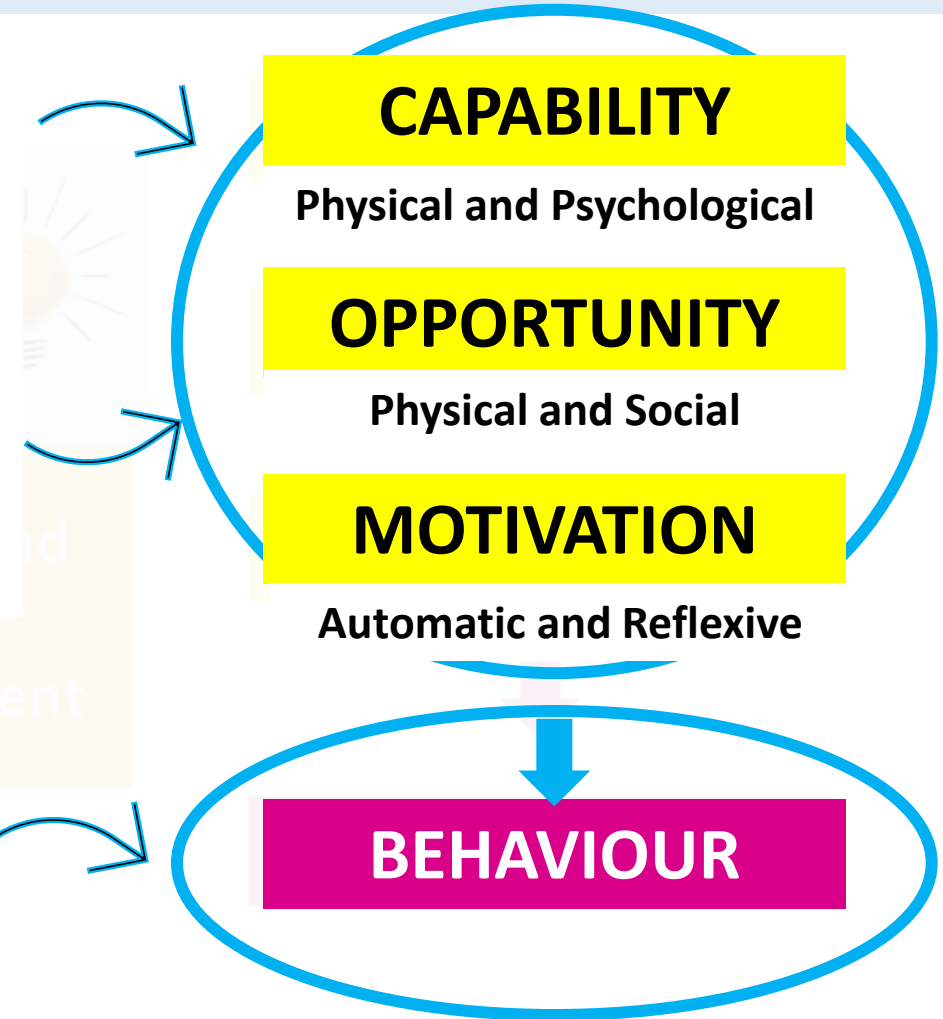
**OPPORTUNITY**

Physical and Social

**MOTIVATION**

Automatic and Reflexive

**BEHAVIOUR**



# Co-designing an intervention informed by behavioural science: **modifying behaviours**<sup>12</sup>

**3** *What could maximise exposure to these factors?*

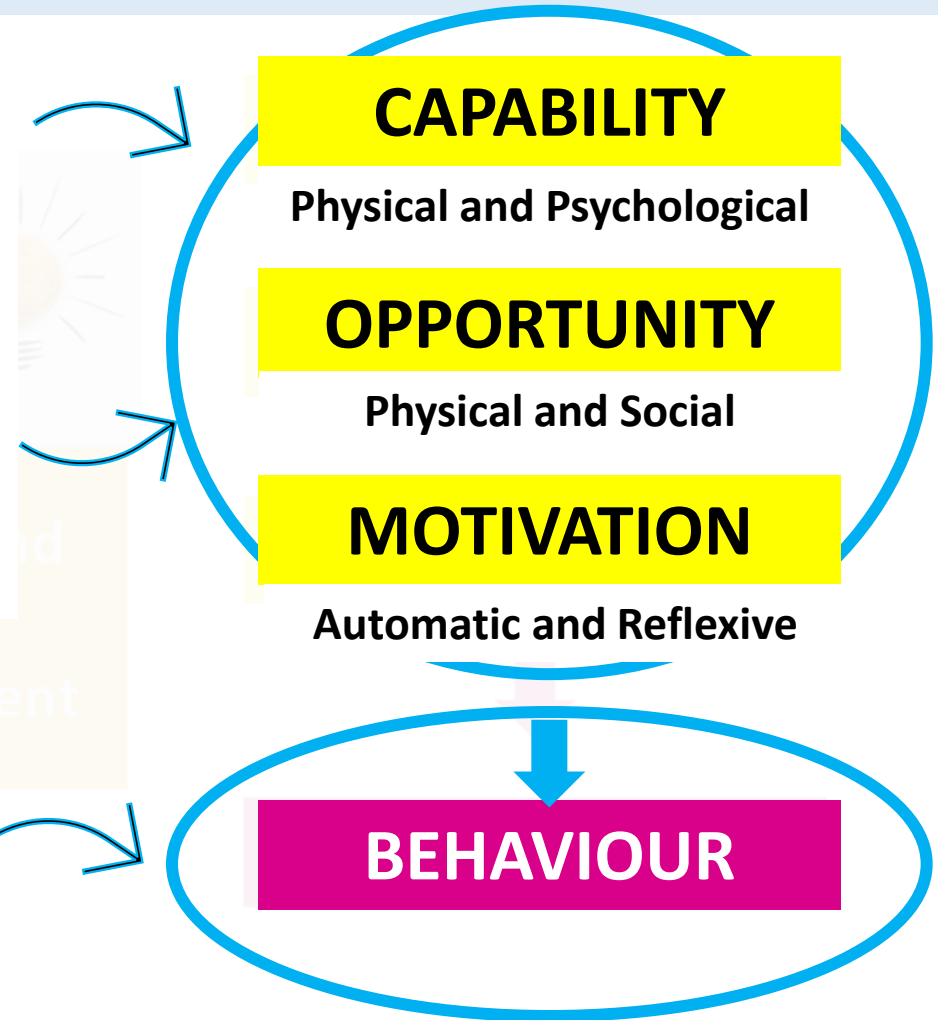
*What could minimise exposure to these factors?*

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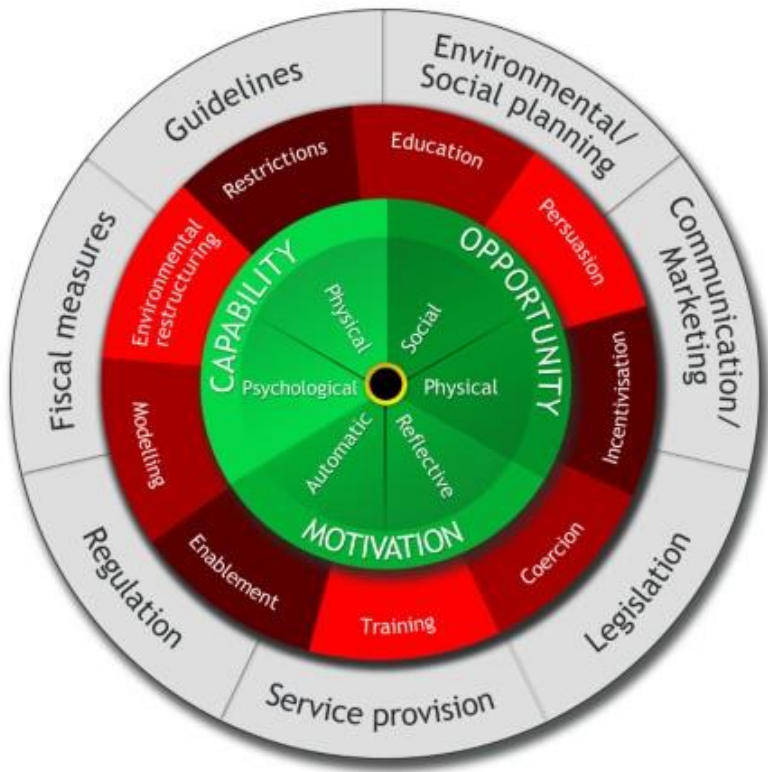
[Behaviour Change Technique Taxonomy](#)



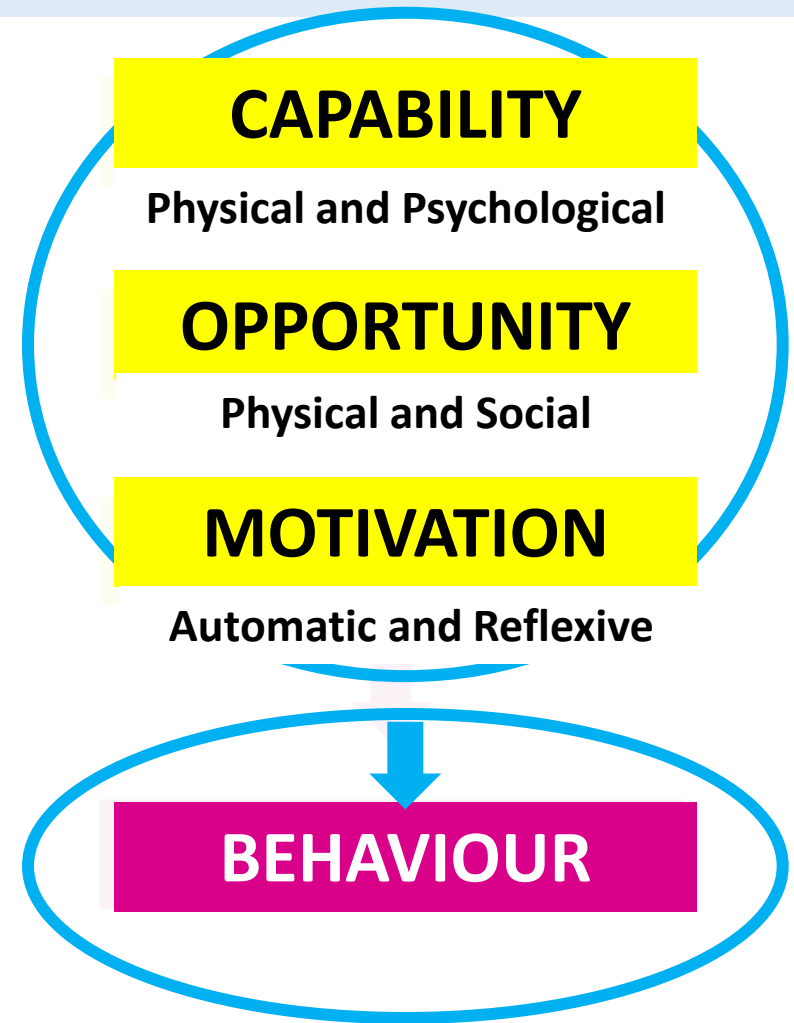
# Co-designing an intervention informed by behavioural science: **behaviour change techniques**<sup>12</sup>

- Education
- Persuasion
- Incentivisation
- Coercion
- Training
- Enablement
- Modelling
- Environmental restructuring
- Restrictions

■ Sources of behaviour  
■ Intervention functions  
■ Policy categories



**Behaviour Change  
Technique Taxonomy**



# Co-designing an intervention informed by behavioural science: **co-design techniques**<sup>16-18</sup>

**Co-design the co-design** through meaningful **patient and public involvement** from the start of the process

## **Establish your co-design group:**

Who should be involved? How and when would they like to and best be able to contribute?

**Co-create a 'Trigger film':** highlighting the findings/issues/experiences the co-design process is aiming to address as a springboard for the co-design groups

**Host your co-design workshops:** How many do you need? What is the purpose of each workshop? What **accessible, inclusive and creative methods** can you use?

Easy-read

Ice-breaker  
games

Reflection  
rounds

Time-outs

Feedback  
between  
groups

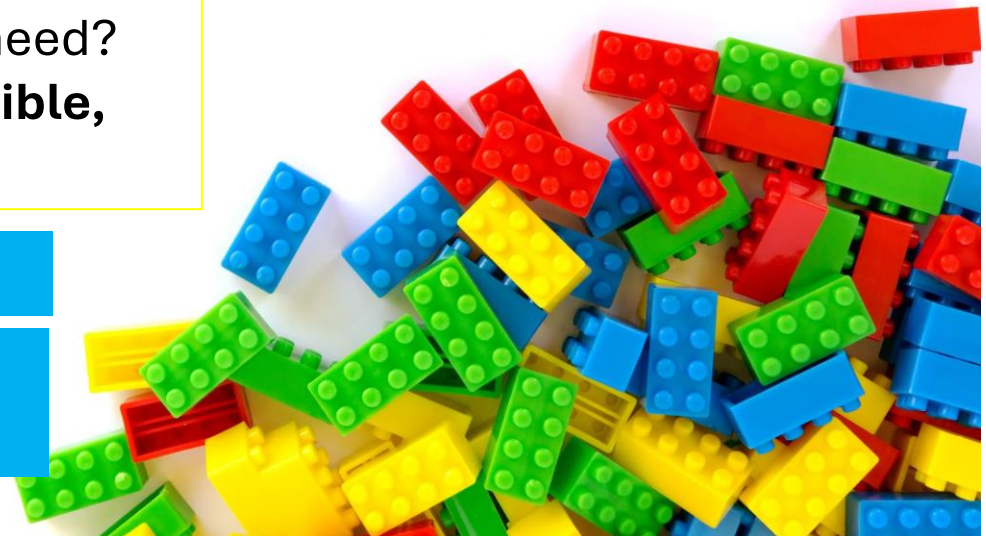
Videos

Illustrations

Physical  
prototypes

Solo sessions

Feedback loops



# Co-designing an intervention informed by behavioural science: an example from Surrey

## Step 1: What inequality should you focus on?

There is low cervical cancer screening uptake for people with Learning Disabilities and Autism (PwLDA), and for people with Severe Mental Illness (PwSMI) nationally and in Surrey<sup>19,20</sup>

## Step 2: What do you already know about that inequality?

Interviews with PwLDA and PwSMI, and with service providers, have identified distinct and shared enablers and barriers to taking part in cervical cancer screening<sup>21,22</sup>

Healthcare professionals + stakeholders

PwSMI

PwLDA

Stigma and misunderstanding – cancer screening staff attitudes and worries

Awareness and understanding of cancer screening: what it is, what to expect

Prioritisation of other needs over cancer screening

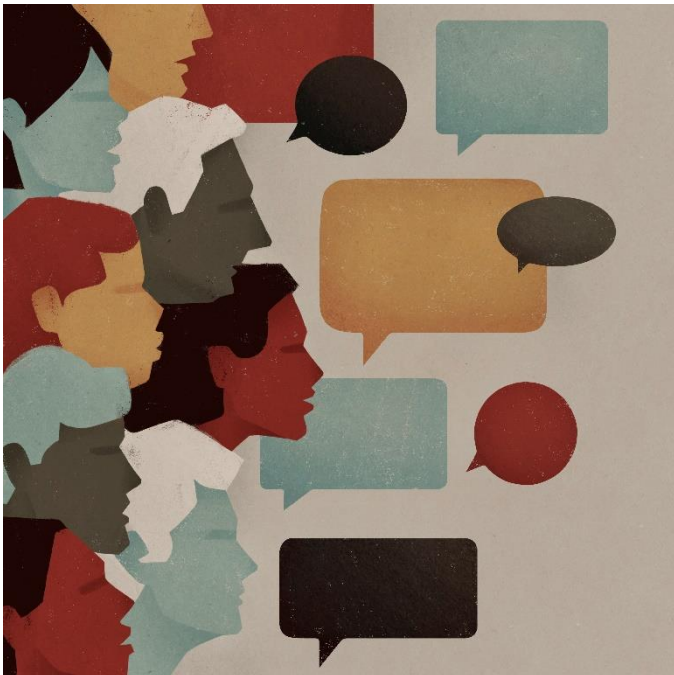
Aspects of experience - delusions, paranoia, trauma, stigma, motivation, fear

**Not being told enough information about screening in appropriate form**

**Not booking a screening appointment**

**Not attending a screening appointment**

**Not undergoing screening at the appointment**



# Co-designing an intervention informed by behavioural science: **an example from Surrey**

**Step 1: What inequality should you focus on?**

There is low cervical cancer screening uptake for people with Learning Disabilities and Autism (PwLDA), and for people with Severe Mental Illness (PwSMI) nationally and in Surrey<sup>19,20</sup>

**Step 2: What do you already know about that inequality?**

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Healthcare professionals + stakeholders

PwSMI

PwLDA

**Step 3: Define the aims and research question**

What interventions can be implemented at a local level to improve PwLDA and PwSMI's capability, opportunity and motivation to take part in cervical cancer screening in Surrey?

**Step 4: What is best way(s) to answer that question?**

Co-design workshops PwLDA, PwSMI's and service delivery stakeholders, with interviews: approaches to be informed by Patient and Public Involvement

**Step 5: Collect, analyse, write up and share**

**Watch this space!**

# Your 10 minute mission: get curious!

**What inequality do you want to focus on and why? Cancer type? Point on pathway? Specific group? Specific place?**

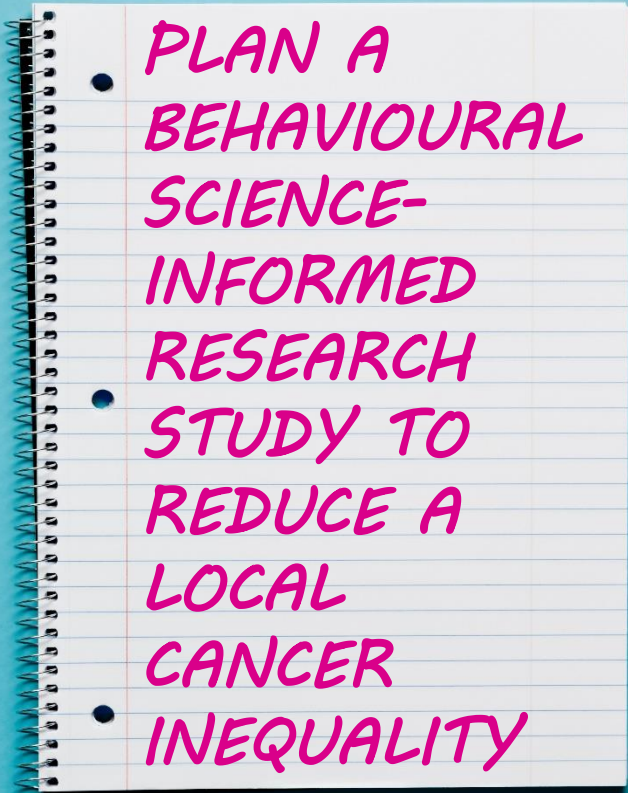
**What do you already know? What don't you know?**

**Define the aims and research question**

**How will you answer your research question? Who, what, when, where, how?**

**How could you incorporate behavioural science?**  
How will you identify the target behaviour? How will you work out how to modify the target behaviour?

**How and when will you engage with patients and the public?**



• **PLAN A  
BEHAVIOURAL  
SCIENCE-  
INFORMED  
RESEARCH  
STUDY TO  
REDUCE A  
LOCAL  
CANCER  
INEQUALITY**

# Your 10 minute mission: group feedback!

**What inequality do you want to focus on and why? Cancer type? Point on pathway? Specific group? Specific place?**

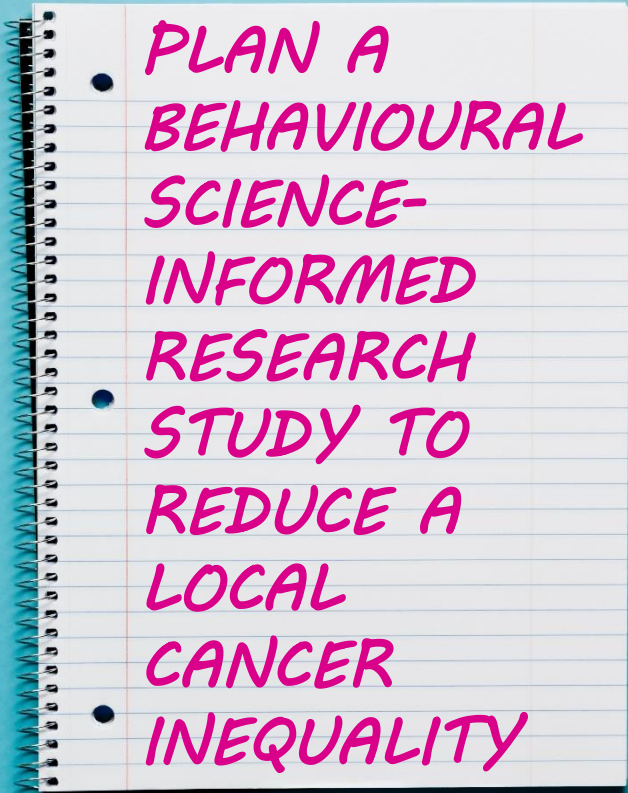
**What do you already know? What don't you know?**

**Define the aims and research question**

**How will you answer your research question? Who, what, when, where, how?**

**How could you incorporate behavioural science?**  
How will you identify the target behaviour? How will you work out how to modify the target behaviour?

**How and when will you engage with patients and the public?**



• **PLAN A  
BEHAVIOURAL  
SCIENCE-  
INFORMED  
RESEARCH  
STUDY TO  
REDUCE A  
LOCAL  
CANCER  
INEQUALITY**

# What we have covered today

**Getting to know each other**

**Stay in touch!**

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@surreycc.gov.uk**

**sarafrazshekary.negin  
@surreycc.gov.uk**

**What is the cancer equity gap?**

**Unfair and avoidable differences in cancer-related outcomes**

**CORE20Plus5**

**Health inclusion**

**Labonte model**

**Research to identify and address the cancer equity gap**

**Research process: where should you focus? What do you know? What don't you know? How can you find out?**

**Meaningful Patient and Public Involvement**

**Co-designing an intervention to reduce the gap**

**Behavioural science: COM-B model and Behaviour Change Technique Taxonomy**

**Introduction to co-design**

**Designing your own research study**

**What next?  
Evaluating the intervention**



# The take-home cancer inequalities toolbox



## Understanding cancer inequalities

[NHS England: CORE20Plus5 framework](#)

[NHS England: A national framework for NHS – action on inclusion health.](#)

[Place-based approaches for reducing health inequalities](#)

[ICON: Inequalities in Cancer Outcomes Network \(LSHTM\)](#)

[Transformation Partners in Health and Care: Cancer Inequalities Toolkit](#)

[NHS England: Cancer Registration Statistics, 2022](#)

**Data sources:** [NHS Futures](#) [OHID Fingertips](#) [Cancer Patient Experience Survey](#) [Cancer Data Hub](#)

## Applied health research methods and behavioural science

[National Centre for Research Methods](#) [Handbook of Theory and Methods in Applied Health Research](#)

[NCRM: How to choose a research method](#) [NIHR Funding Your Research](#)

[Behaviour Change Technique Taxonomy](#) [HRA Research Planning Guidance](#)

## Co-design and patient and public involvement

[Health Research Authority: Public Involvement in Research](#)

[NIHR Briefing Notes for Researchers: Public Involvement in Health Research](#)

[NIHR Payment Guidance for Researchers and Professionals](#)

[Funding sources for Public Engagement](#)

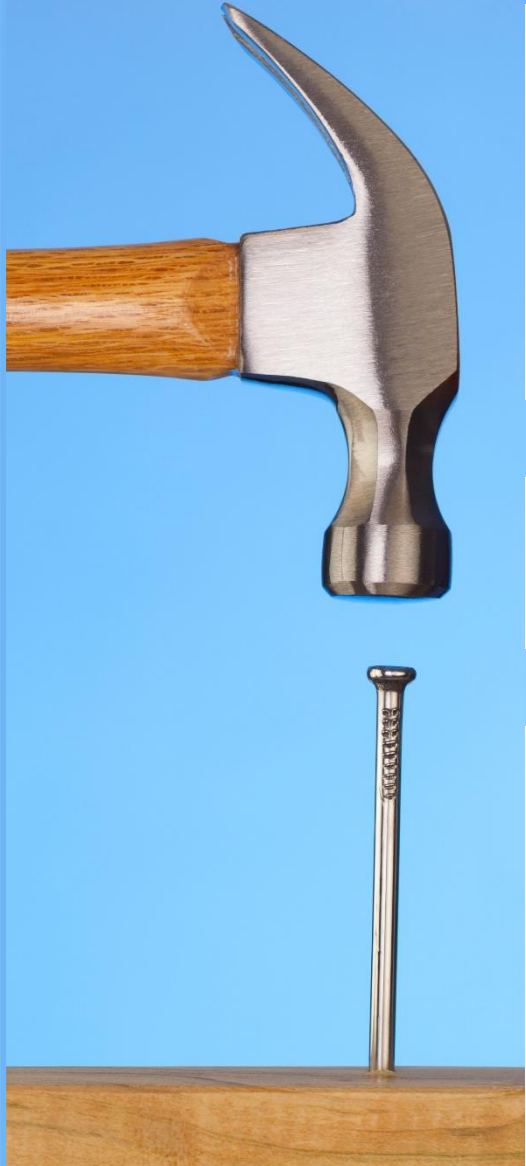
[NIHR Guidance on Co-Producing a Research Project](#)

[UKRI Co-Production Resources](#)

[Nature Reviews Methods Primer: Participatory Action Research](#)

[Point of Care Foundation: Experience Based Co-Design](#) [NPC Co-Design Toolkit](#)

[MRC framework for developing and evaluating complex health interventions](#)



# References

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