YOUTH CANCER EUROPE

European Network of YOUTH CANCER SURVIVORS

Co-funded by the European Union

Equity, Diversity and Inclusion Principles in Cancer Care

Train-the-Trainer Toolkit

Contents

Introduction

Throughout the research conducted by Youth Cancer Europe, inequalities in research and healthcare became apparent. The need for further knowledge and understanding around equality, diversity and inclusion in healthcare staff, was a common theme across study respondents, with many respondents highlighting the need for more knowledge around personalising care based on needs relating to age, ethnicity, sexual orientation, gender identity, religion, nationality, language, and socio-economic status. Enhancing discussions around how mental health and fertility care, link closely with youth cancer care was also an important topic. It was also highlighted, that approaches to research need to be more inclusive to address the knowledge base on the impacts of cancer treatment on minoritised groups, especially in relation to gender and ethnicity.

This workbook is designed to support the learning you will receive in your training sessions and provide you with further information and support. This will allow you to embed different tools and techniques into your approach to healthcare, research and patient advocacy, to ultimately improve the quality of care for young people with cancer.

Cultural Awareness and Competence

Culture is a central concept in sociology and anthropology.

Foundational understanding began to develop in the 19th century through the work of key theorists of modern social science, such as German philosophers Karl Marx and Max Weber, and French sociologist Émile Durkheim. Durkheim in

particular, introduced the idea of 'collective consciousness', which he defined as: *"The totality of beliefs and sentiments common to average members of the same society"*. (1)

More recently, based on his experience as manager of personnel research at IBM, Dutch social psychologist Geert Hofstede defined culture as:

"The collective programming of the mind distinguishing the members of one group or category of people from others". (2)

As the analysis of culture evolved throughout the 20th century, fields of study like cultural studies and cultural sociology established themselves, increasing the knowledge and understanding of how cultures evolve in relation to systems of power, social phenomena and contemporary processes like globalisation.

Culture is a nuanced concept. It is about history, food, music, dance and other performing arts, architecture, nationality, language and communication styles, clothing and dress codes, faith and beliefs, rituals, festivals and celebrations, values, morals, attitudes, rules and behaviours, traditions, family and relationships, customs and practices, discipline, expectations, and so on.

Cultures are complex, and go beyond religion, nationality, and folklore observed by outsiders.

In 1976, US anthropologist and cross-cultural researcher Edward Twitchell Hall Jr (3) developed the Iceberg Model of Culture. He suggested that if we picture culture like an iceberg, only 10% of it is made of explicit, tangible, and visible elements 'above water'. In order to fully comprehend a culture, it's therefore necessary to go deeper. The 'below water' elements refer to implicit cultural phenomena such as communication styles and rules, or notions of fairness and unfairness. Understanding the less obvious and outward aspects of a culture takes time and effort.

The concept of culture ties in with identity, as cultural identity provides a very important element of our sense of self and belonging. Yet, identity is dynamic and intersectional, whereby multiple and overlapping elements of self-identification define us as individuals, impact our experiences and may fluctuate in significance over the course of our lives. These intersecting experiences may bring us closer or further away from positions of power and privilege over the course of our lives.

It is also important to recognise that no one is ever only part of one culture. Culture is multi-dimensional and may offer individuals alternative or additional forms of identification and affiliation. Think about different generations (e.g., Millennials, Generation Z, etc.), fans of a particular type of music (e.g., metal, rap, goth, etc.) and concepts like pop culture, queer culture, black culture, and indeed organisational culture. People may be embracing different aspects of different cultures at the same time, depending on context, upbringing, influences, personal preferences, and so on.

"Culture hides more than it reveals, and strangely enough what it hides, it hides most effectively from its own participants". (4)

The key message of this quote by Edward T Hall, is the idea that awareness starts with knowing ourselves, rather than learning about others. To understand different cultures, we need to first achieve a greater understanding of our own culture, and the stances which inform the way we filter the world around us.

"Someone's cultural awareness is their understanding of the differences between themselves and people from other countries or other backgrounds, especially differences in attitudes and values".

This definition by The Collins' Dictionary brings together the concepts of culture and self-awareness. Self-awareness is a fundamental starting point, as without

understanding our own value systems and perspectives, we can't fully appreciate other people's points of view. Self-awareness also relates to the reflection on our own biases, and the pre-conceptions, assumptions and expectations which may inform some of the stereotyped and distorted ideas we have of other groups and cultures.

Cultural bias is defined as the interpretation of information and situations based on the parameters and standards of one's own culture. In a world which is more interconnected than ever before, cultural bias is pervasive across everyday life including businesses and workplaces, healthcare, education, interpersonal relations, etc. Cultural bias can lead to more favourable or less favourable judgements than we can evidence or justify. Typically, it occurs when we judge and make assumptions about other cultural norms, on conduct dos and don'ts, hand gestures, body language and so on, as well as attitudes and behaviours around family, age, love, duties and responsibilities, work, illness, death, etc.

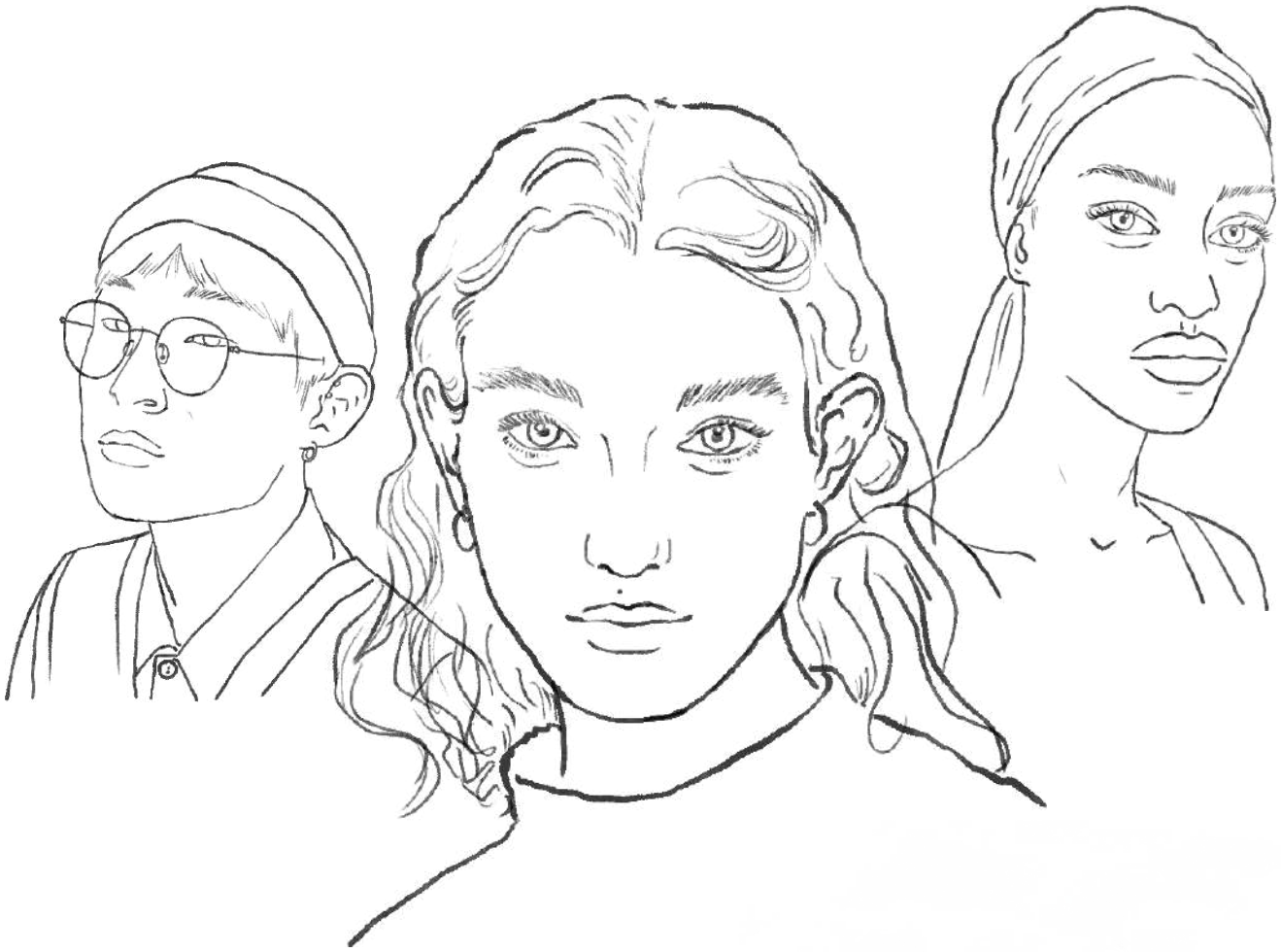
It's important to appreciate that the combination of self-analysis and knowledge about others is a powerful exercise which can teach us a lot about ourselves, and the rest of the world.

Acknowledging our own Privilege

Privilege is a societal advantage or entitlement that has developed over time because of historical inequalities. Privilege links to power, which benefits individuals from favoured groups and gives them greater recognition and leverage across settings, including work and healthcare.

White privilege (5) is one example of privilege, experienced by white people through the majority of the Western hemisphere to the detriment of groups who do not identify as white. Typically, the more privilege you have, the more power you have. Because of systemic inequalities throughout long periods of time across the world, you can't control the amount of privilege you have. However, you can make the most of it to support disadvantaged people.

It is important to appreciate that cultural awareness, links to the consideration of various types of bias at play in your brain, and the recognition of different forms of privilege in your life. When developing your cultural humility, you may want to ask yourself questions which challenge how you acknowledge and define who you are, and how this influences your wider understanding of others.



Activity 1 – Considering the impacts of privilege and bias

Take some time and consider the answers to the questions below.

Would your answers change if you were a different gender, ethnicity, nationality, socio-economic status, etc.

- Do the people with power and influence in your life look and sound like you (e.g. your boss, your landlord, your political leaders)?
- Is any part of your identity considered 'the norm', hence giving you an unearned privilege and advantage over others?
- Are there aspects of your identity or culture which are stigmatised, stereotyped, or overly simplified and polarised? Why, how, and by whom?
- Are people perplexed or surprised about your job role in the organisation because of given assumptions?
- Are there aspects of your physical fitness or appearance that are considered more or less likeable and desirable than others?
- Do you need to think about your personal safety before showing your partner or family affection in public?
- Can you easily access the support and health services you need without worrying about the financial impact?
- Can you wear the clothing you choose, without fear of others' reactions or behaviour?

History, economy, and geopolitics add depth and complexity to cultural awareness, as these feed into internalised categorisations of the world. Colonial history, past and recent wars, migration, globalisation, international affairs, and the rise of mass media and social networks, have all contributed to shape the world we live in and influence how we perceive people from other cultures and relate to them. This includes bias, misrepresentations, misconceptions, and expectations which impact the way groups from certain geographical regions and cultures may be regarded.

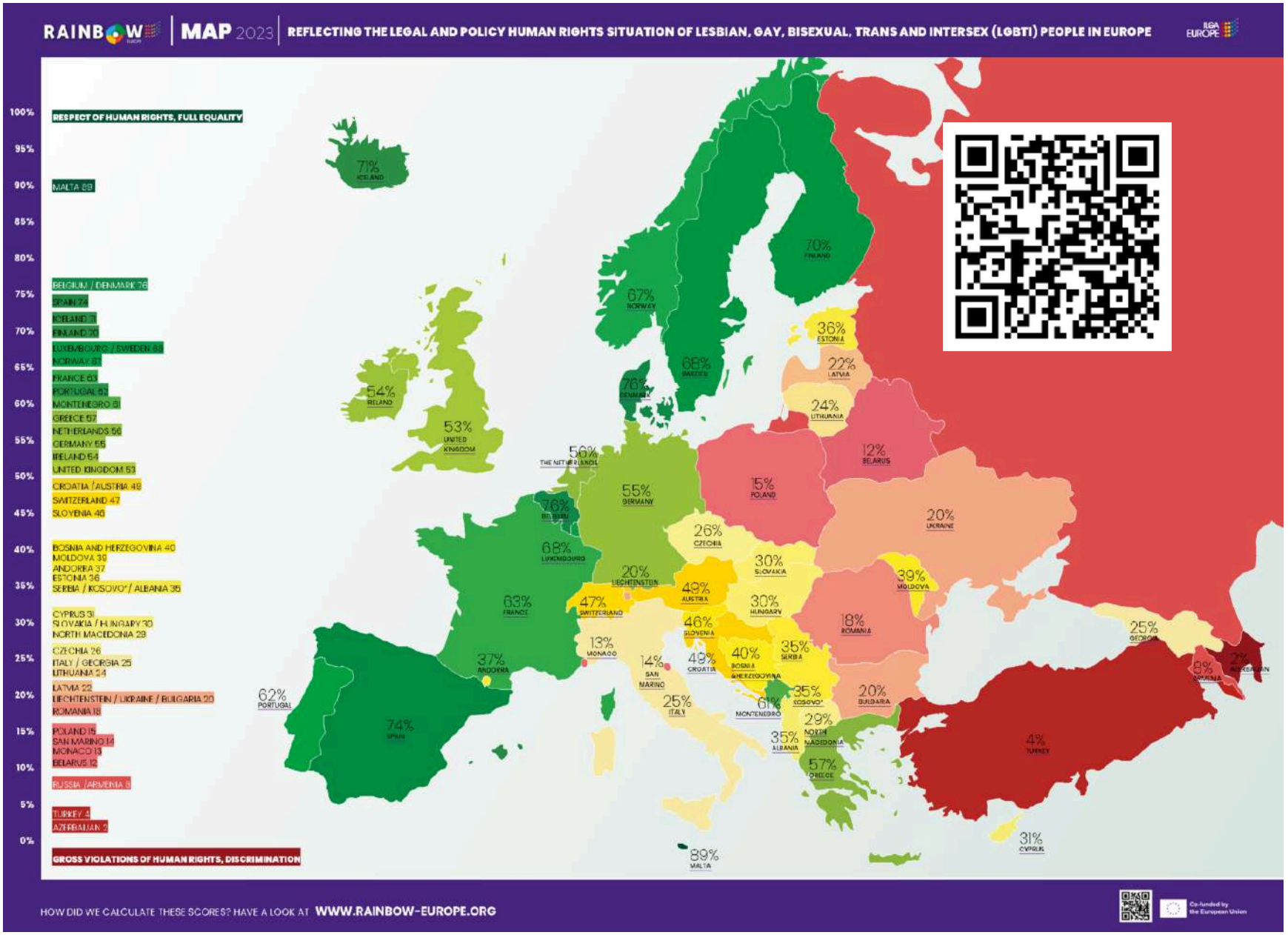
Societal and Health Inequalities

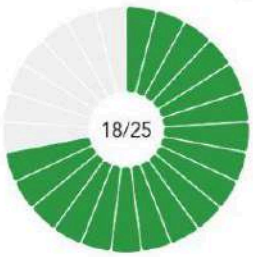
Inequalities in healthcare and wider society are a large contributing factor to the quality of care a patient receives during their healthcare journey. This section will introduce some information about inequalities across Europe. This is not an exhaustive list, but just a summary to help you identify areas you would be interested in learning more about.

Legal Inequalities

The legal protection for different groups differs massively across Europe. The map below illustrates the Rainbow Map and Index ranks for 49 European countries on their respective legal and policy practices for LGBTI people, from 0-100%. In order to create our country ranking, ILGA-Europe examined the laws and policies in 49 countries using 74 criteria, divided between seven thematic categories: equality and non-discrimination; family; hate crime and hate speech; legal gender recognition; intersex bodily integrity; civil society space; and asylum. Those countries with the higher scores (green) have lower levels of inequalities for LGBTQ+ people and those with lower scores (red) are countries that have more barriers or inequalities.

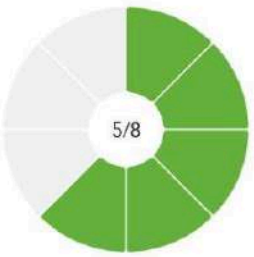
For the eighth year in a row, Malta continues to occupy the number one spot on the Rainbow Europe Map, with a score of 89%. With 76 points, Belgium now occupies the second place with a rise of four points due to the inclusion of gender identity and sex characteristics as aggravating factors in the country's penal code. Denmark comes third palace with a score of 76 with the rise of two points due to its new equality action plan, which includes specific measures on sexual orientation and gender identity but falls short of inclusion of projects on sex characteristics.


RAINBOW
MAP 2023
REFLECTING THE LEGAL AND POLICY HUMAN RIGHTS SITUATION OF LESBIAN, GAY, BISEXUAL, TRANS AND INTERSEX (LGBTI) PEOPLE IN EUROPE
ILGA EUROPE
100%
95%
90%
85%
80%
75%
70%
65%
60%
55%
50%
45%
40%
35%
30%
25%
20%
15%
10%
5%
0%
RESPECT OF HUMAN RIGHTS, FULL EQUALITY
MALTA 89
BELGIUM / DENMARK 76
SPAIN 74
ICELAND 71
FINLAND 70
LUXEMBOURG / SWEDEN 68
NORWAY 67
FRANCE 63
PORTUGAL 62
MONTENEGRO 61
GREECE 57
NETHERLANDS 56
GERMANY 55
IRELAND 54
UNITED KINGDOM 53
CROATIA / AUSTRIA 49
SWITZERLAND 47
SLOVENIA 46
BOSNIA AND HERZEGOVINA 40
MOLDOVA 39
ANDORRA 37
ESTONIA 36
SERBIA / KOSOVO* / ALBANIA 35
CYPRUS 31
SLOVAKIA / HUNGARY 30
NORTH MACEDONIA 29
CZECHIA 26
ITALY / GEORGIA 25
LITHUANIA 24
LATVIA 22
LIECHTENSTEIN / UKRAINE / BULGARIA 20
ROMANIA 18
POLAND 15
SAN MARINO 14
MONACO 13
BELARUS 12
RUSSIA / ARMENIA 8
TURKEY 4
AZERBAIJAN 2
GROSS VIOLATIONS OF HUMAN RIGHTS, DISCRIMINATION
71% ICELAND
70% FINLAND
67% NORWAY
68% SWEDEN
76% DENMARK
54% IRELAND
53% UNITED KINGDOM
56% THE NETHERLANDS
55% GERMANY
76% BELGIUM
68% LUXEMBOURG
63% FRANCE
62% PORTUGAL
74% SPAIN
37% ANDORRA
20% LIECHTENSTEIN
47% SWITZERLAND
48% AUSTRIA
46% SLOVENIA
13% MONACO
14% SAN MARINO
25% ITALY
49% CROATIA
40% BOSNIA AND HERZEGOVINA
35% SERBIA
35% KOSOVO*
61% MONTENEGRO
29% NORTH MACEDONIA
35% ALBANIA
57% GREECE
89% MALTA
36% ESTONIA
22% LATVIA
24% LITHUANIA
12% BELARUS
15% POLAND
26% CZECHIA
30% SLOVAKIA
30% HUNGARY
20% UKRAINE
39% MOLDOVA
18% ROMANIA
20% BULGARIA
25% GEORGIA
8% ARMENIA
2% AZERBAIJAN
4% TURKEY
31% CYPRUS
HOW DID WE CALCULATE THESE SCORES? HAVE A LOOK AT WWW.RAINBOW-EUROPE.ORG
Co-funded by the European Union

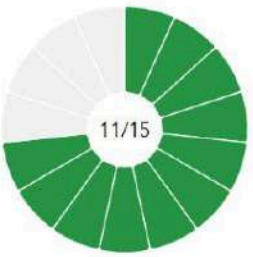


EQUALITY & NON-DISCRIMINATION

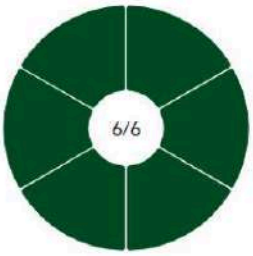
FAMILY



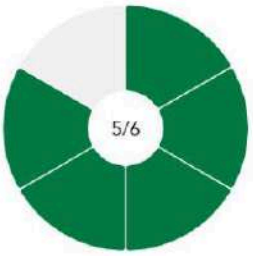
HATE CRIME & HATE SPEECH



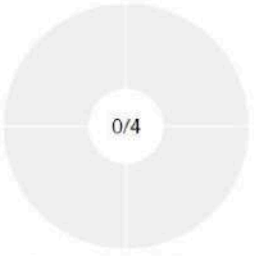
LEGAL GENDER RECOGNITION



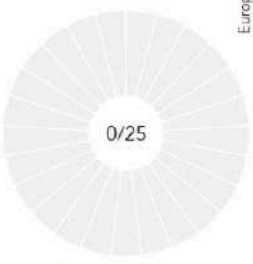
CIVIL SOCIETY SPACE



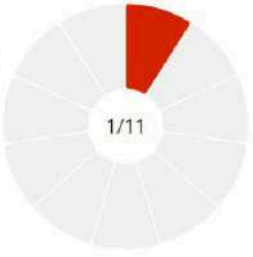
ASYLUM



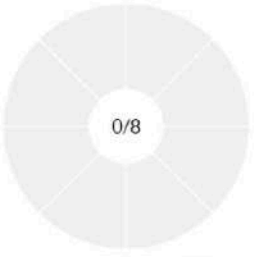
INTERSEX BODILY INTEGRITY



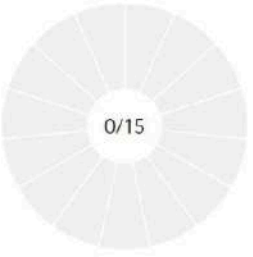
EQUALITY & NON-DISCRIMINATION



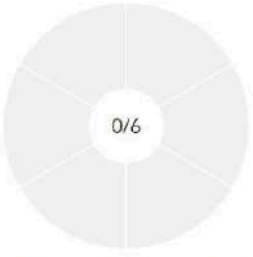
FAMILY



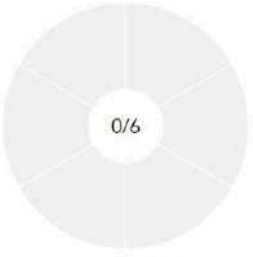
HATE CRIME & HATE SPEECH



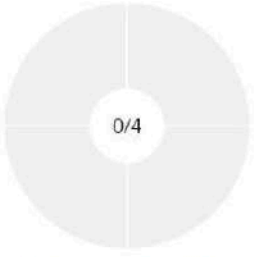
LEGAL GENDER RECOGNITION



CIVIL SOCIETY SPACE



ASYLUM



INTERSEX BODILY INTEGRITY

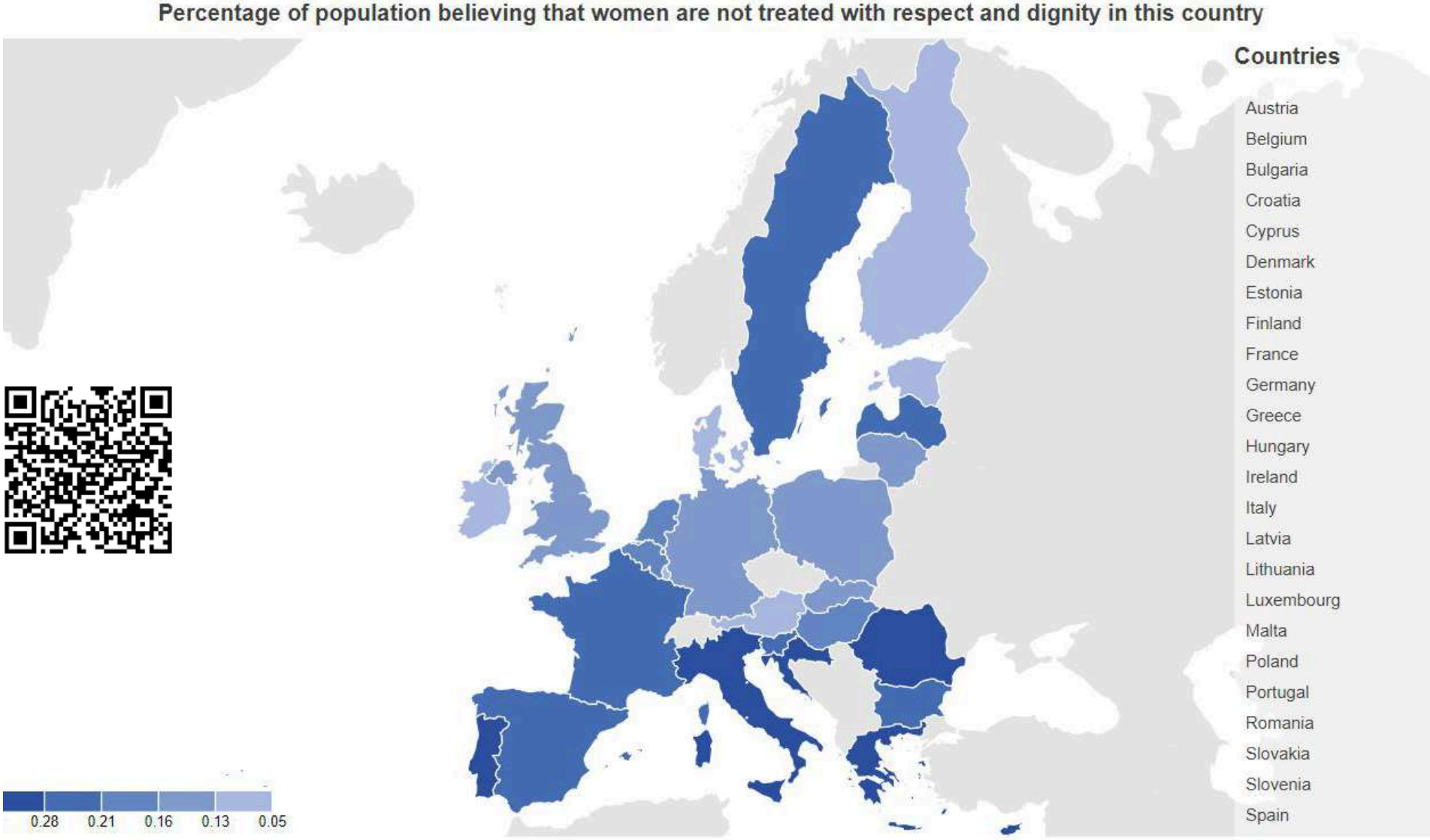
The three countries at the other end of the Rainbow Europe scale are Azerbaijan (2%), Turkey (4%), and Armenia (9%), exactly the same as the last three years. Among them, only Armenia increased an index point after revoking its ban on blood donations from men who have sex with men. Spain, Iceland, Finland, Moldova, Switzerland, and Croatia are the countries with the biggest jump in scores. Spain introduced a comprehensive law that regulates legal gender recognition (LGR) based on self-determination, banned genital mutilations on intersex minors, prohibited so-called "conversion" practices and outlawed discrimination based on sexual orientation, gender identity, and sex characteristics. Iceland adopted an equality action plan, included gender identity and sex characteristics in their equality law, and added sex characteristics protection in the penal code. Moldova also amended its equality law and penal code to include sexual orientation and gender identity. Finland adopted its Trans Law which regulates LGR based on self-determination. Switzerland's legislation on marriage equality came into effect, which also gave the right to joint adoption and medically assisted insemination for same-sex couples. In Croatia, same-sex couples can now apply for joint adoption and second-parent adoption after a court decision.

For further information about the ILGA-Europe and to explore their individual country breakdowns go here:

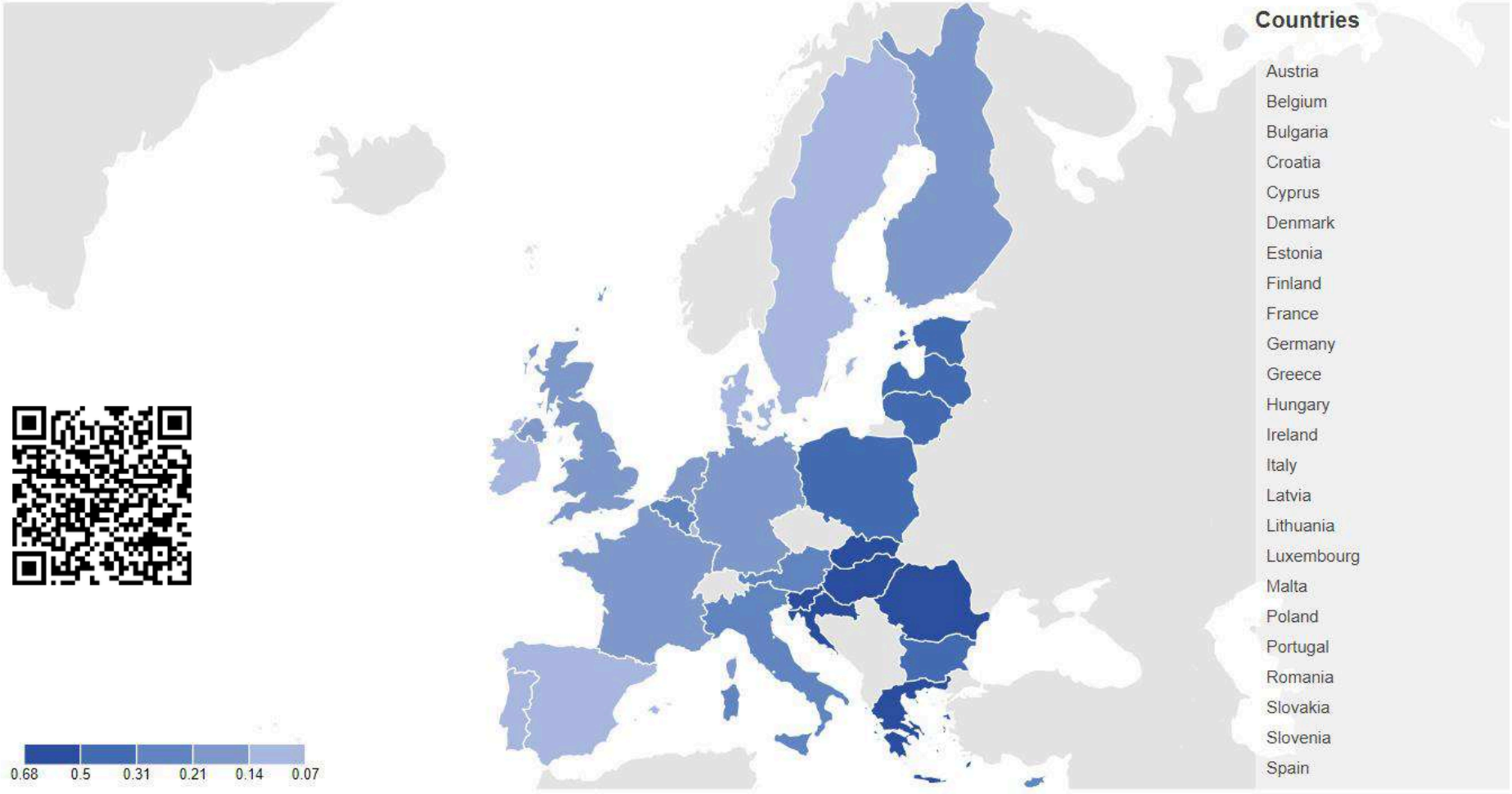
www.rainbowmap.ilga-europe.org

Social Inequalities

The EU Multidimensional Inequality Monitoring Framework is an interactive tool to monitor, map, track and compare inequalities across the EU. The tool was produced as part of an exploratory research project to develop a structured indicator framework for monitoring and analysing inequalities in the EU. The framework spans 10 key life domains, from knowledge, health and material wellbeing to culture and environmental conditions. Each of these can be explored in further detail and mapped across the EU to compare trends and outcomes across countries. The Map below illustrates the percentage of the population who believe that their country is not a place where women are treated with respect and dignity. The countries in darker blue are countries where a larger percentage of the population feel women are not treated with dignity and respect, in 2023 Romania and Portugal were the countries where the highest percentage of the population believed women were not treated with respect and dignity.


Percentage of population believing that women are not treated with respect and dignity in this country
Countries
Austria
Belgium
Bulgaria
Croatia
Cyprus
Denmark
Estonia
Finland
France
Germany
Greece
Hungary
Ireland
Italy
Latvia
Lithuania
Luxembourg
Malta
Poland
Portugal
Romania
Slovakia
Slovenia
Spain
0.28
0.21
0.16
0.13
0.05

Percentage of population believing that the area where they live is not a good place to live for immigrants



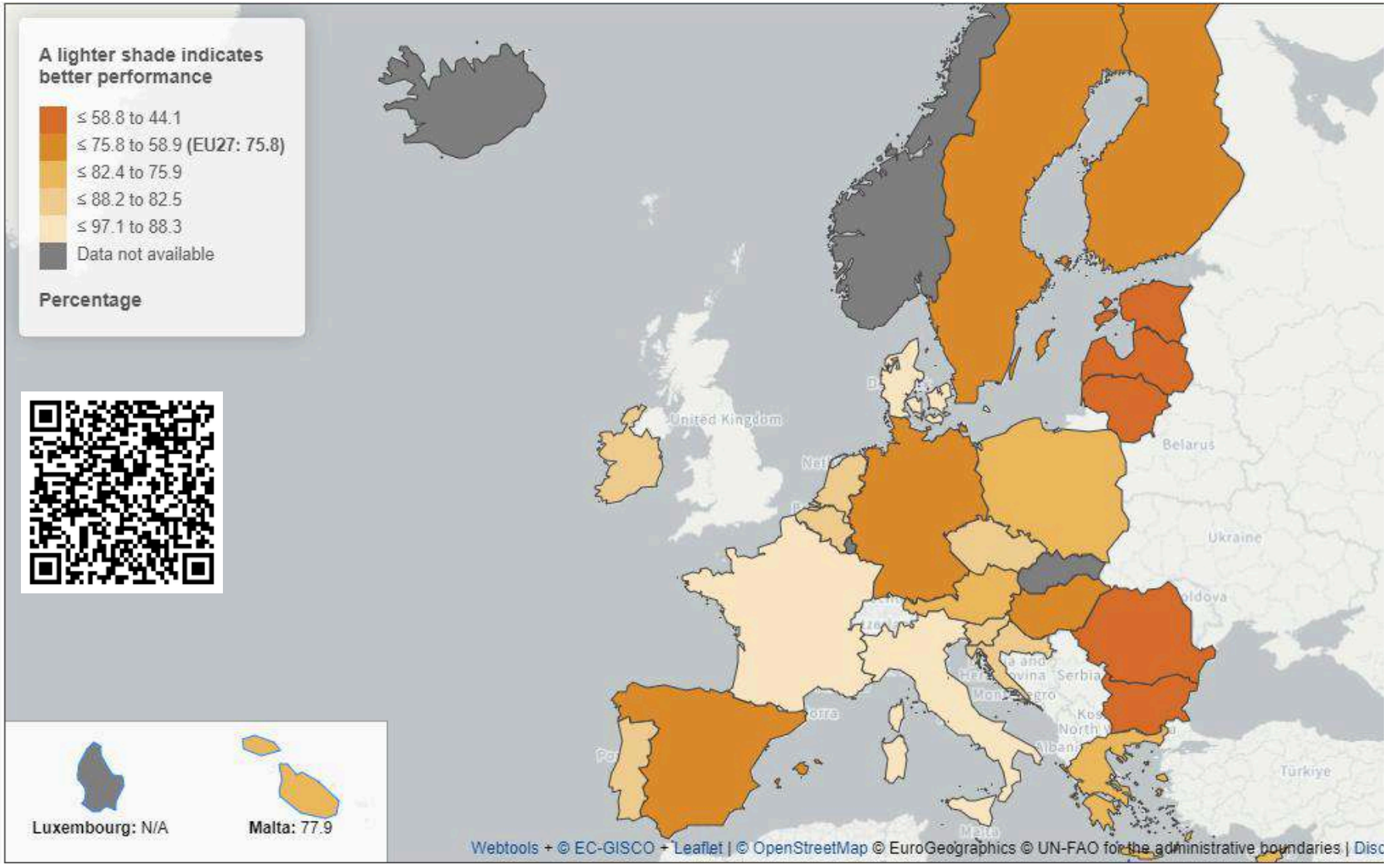
This second map highlights the population perceptions around the safety and quality of life for immigrant populations. In 2023, Croatia and Hungary were the countries where the largest percentage of the population identified that their country was not a good place for immigrant populations to live.

To further explore the EU Multidimensional Inequality Monitoring Framework inequality maps and country profiles go here: Home | EU Multidimensional Inequality Monitoring Framework (europa.eu) (see page 42)

Health Inequalities

The European Cancer Inequalities Registry is a flagship initiative of Europe's Beating Cancer Plan. It provides sound and reliable data on cancer prevention and care to identify trends, disparities and inequalities between Member States and regions. The map below presents the percentage of medicines used in paediatric cancer patients aged 0 to 18 years available in each country, out of the 68 medicines identified as essential in the study from Vassal et al., 2021 (6). The shade of colour relates to the ranking of the data, according to the data range for each indicator in five categories. The countries coloured with the lightest shade were among the 20% of highest-performing countries for the percentage of medicines used in paediatric cancer patients in terms of cancer inequality. The grey colour indicates the data is unavailable for that particular country.

The European Cancer Inequalities Registry also allows for exploration by country to gain a deeper understanding of the cancer related health inequalities in your region. To explore further go here: European Cancer Inequalities Registry (ECIR) | ECIR – European Cancer Inequalities Registry (europa.eu) (see page 45)


A lighter shade indicates better performance
≤ 58.8 to 44.1
≤ 75.8 to 58.9 (EU27: 75.8)
≤ 82.4 to 75.9
≤ 88.2 to 82.5
≤ 97.1 to 88.3
Data not available
Percentage
Luxembourg: N/A
Malta: 77.9
United Kingdom
Belarus
Ukraine
Serbia
Türkiye
Webtools + © EC-GISCO + Leaflet | © OpenStreetMap © EuroGeographics © UN-FAO for the administrative boundaries | Disc

Inclusive and Accessible Communication

Inclusive communications means sharing information in ways that everyone can easily understand and access, and is important to help ensure more people can access, digest, and understand relevant information around their care. Inclusive communication covers all forms of communications, including: verbal communication, non-verbal communication, written communication and signage/information. Accessible information is a mechanism to ensure inclusive communications. For example, when communicating with young patients, particular thought should be given to the language and detail used to ensure all information is given in a way they can understand. Alternatively, accessible communication could be subtitles on video content for those who may not have access to speakers/headphones on a computer and/or for individuals with a hearing impairment. Whilst we often think about disability when considering accessibility, inclusive and accessible communication benefits everyone and reduces the risks of misunderstandings that can be very harmful in a healthcare setting.

The way people across cultures communicate is a vast and complex topic, and spoken language is one of the most fascinating and palpable aspects of cross-cultural communication. Research and experience in this space have helped to develop a spectrum which positions direct and indirect communication styles on each end. Different people can be anywhere on the continuum depending on culture (and personal traits as well).

Direct	Indirect
Wording is unambiguous. Task is clear. Honesty is valued.	No need to say everything in words. Group harmony is maintained. Diplomacy is valued.

Indirect communication cultures are likely to rely on unspoken elements of communication such as body language to avoid open confrontation and public challenge. In several Asian countries, especially those influenced by Confucianism and Buddhism like China and Japan, protecting group harmony is very important. Here, indirect communication is predominant: it helps preserve stability, and give people a sense of meaning, purpose, and connection. Indirect communication tends to correlate with formalities, which in turn reinforce hierarchy, structure, and a sense of place and preservation for everyone, feeding back to the idea of group harmony. In indirect communication cultures, there tends to be a much stricter sense of what you can and cannot say, and how and to whom.

Conversely, in countries like Finland and the Netherlands, direct communication is preferred to navigate relationships through clarity. People tend to be less stability-focused, and more prone to challenges and changes. These cultures usually place less importance on formalities, which are seen as related to status or hierarchy. They tend to be egalitarian cultures and societies, and value individuals' freedoms and rights to express themselves.

Depending on how different communication styles position themselves along the spectrum, people from certain cultures may perceive colleagues as too direct or inconsiderate, or too ambiguous and guarded. It's important to appreciate that most cultures will sit somewhere in the middle of the continuum. For example, British people can be direct, but they can often frame and word their messages in ways which may feel less confrontational, and more polite and diplomatic. In British culture, there tends to be elements of direct and indirect communication.

The way a culture communicates provides great insight into the way its people think, and in turn, work and conduct business. Most of the time, communication transcends spoken words and messages are conveyed through voice, body language and other clues.

Top tips for increasing the accessibility and inclusivity of your communication:

Be authentic.

The art of being an inclusive communicator is about being authentic, genuine, and honest. It's usually evident when a person is being 'fake' or not telling the truth. Unconscious bias can also play a factor in how people communicate with others, and how this may lead to inclusion or exclusion. Body language can contribute to our sense of feeling included or excluded. Have a think about your own body language during particular times of the day (especially when you are busy), how this may impact others, and how you could be more actively inclusive.

Admit to your mistakes.

Being able to show vulnerability in a healthcare setting is often very difficult for many people, but to be more inclusive in your communication when an honest mistake is made or something is done wrong/poorly, do not try to hide it. Nobody is an expert at everything and not everybody has all the answers. People are

more likely to respond in a supportive and positive way when we admit to our errors, rather than trying to hide them or cover them up, and then being found out. The same can be applied when there is a lack of understanding about a situation or scenario. Asking for clarity or a further explanation is not a weakness, or a lack of assertiveness, it's a strength. By asking "Sorry, I don't understand that – can you tell me what that means?" shows a willingness to learn and gain clarity of a situation. This is especially important in relation to inclusion and diversity. There are so many characteristics and different lived experiences, chances are, mistakes will happen, and we will not know everything. The world, language, and terminology are ever-changing, so always try to remain open-minded, be willing to be corrected, and ask questions to gain clarity and learn from mistakes.

Be self-reflective.

There can often be moments such as "that didn't come out quite right" or "that didn't come across in the way it was intended to". The intention of actions does not excuse the impact if somebody feels excluded. The best response is to realise the mistake, apologise for the impact caused, and do the utmost to correct the situation and not make the person feel excluded again in the future.

Be flexible.

Some people best respond to stories, others with facts and evidence. Consider you can be flexible with your communication styles to best suit the needs of the audience, rather than suit your own preferences. For example, someone in your team may work best when given very clear and direct instructions as they are very methodical and may not work well with vague concepts, however others may prefer the freedom to be creative and provide solutions. Consider how to cater for different individuals within the team. This is also relevant when working with young people, some young people may want all the information at once so

they can make an informed choice, others may prefer to have information written down so they can have time to think about it. Having open conversations with young people about how they want you to give them information throughout their care can help to ensure effective communication.

Think about their needs.

Often, we can get stuck in the same pattern of communication. Sharing the details of a diagnosis can sometimes feel like a familiar script, which means we forget that it may be the fifth time we have said those words that day, but it could be the first time your patient is hearing them. Take the time to value the positive impact of empathy here. Take the time to also think about how you can make the conversation easier. Do they need information in a different language?

Would they benefit from pictures or a diagram to understand an operation? Imagery can often help explain difficult concepts to young people and can serve as a support to conversations for people with social communication support needs.

It's also important to remember that you don't need to have all the answers. If you're not sure what would help the person you're interacting with, consider asking them, and see how you might be able to accommodate their needs. Fostering patience and creating a supportive atmosphere is really valuable here.

Press pause.

If miscommunication occurs, pause, and reevaluate the situation. Most people operate in their fast-thinking brains most of the time, especially when busy, stressed or under time-pressure. Building in time to think and reflect can help to ensure you are learning from your interactions with colleagues, patients and family to ensure a continual improvement in your inclusion skills.

Activity 2: Inclusion passport

It is important when having conversations that we can accurately assess and understand someone's needs. The following prompts can help you to shape your conversation when talking to patients, colleagues or anyone else who may need your support. Writing these responses down and ensuring the information is passed on (with permission) saves the individual from having to repeat themselves every time they move around the organisation.

- Tell me about things that affect your experience on a day-to-day basis? What has the most impact on you?
- What adjustments can I make to help you engage the most in your experience/role?
- You know what works best for you, so please share some ideas about how I can amend my approach to meet your needs?
- We understand that when things happen to, or with, people we care about this can impact upon our experiences. Please share any details you are comfortable with that would allow us to better understand the people around you.
- Would you like any more information on health and wellbeing support?
- What is your preferred communication style? E.g. face-to-face, phone calls, emails, text
- Is there a particular way you prefer to receive new information? E.g. in person, written report, bullet points
- How often would you like to be updated when things change? And how?
- Is there anything else that would be helpful for me to know to ensure you are able to have the best experience possible?

Actively Challenging Discrimination

The term bystander is often used as a neutral term to describe a person who is a witness to an often unpleasant situation, which can include bullying, harassment, and discrimination. This section will help you understand the difference between a passive and active ally, the importance of moving from a passive ally to an active ally, as well as top tips on how to become an active ally and create a truly inclusive environment.

An active bystander is a person who intervenes to challenge behaviour that is discriminatory. A passive bystander can be a person who believes in doing the right thing but does not call out those in the wrong. Being an active bystander often takes a lot of courage, but the most important part is that action is always taken.

Being a bystander is when an individual is less likely to offer help to someone in need when there are others present. People may feel uncomfortable or unwilling to help for different reasons which may include:

- **Social influence / identity** – thinking that if no one else is doing anything, the victim may not need help, want help, or does not deserve the help / does not belong.
- **Audience inhibition** – fear of embarrassment and standing out by being the first to react. A person may not want to cause a scene or stand out.
- **Fear of negative consequences** – feeling at risk of repercussions or feeling

unsafe to act.

- **Diffusion of responsibility** – the belief that someone else will deal with the situation.
- **Incorrect assumptions** – sometimes people mistakenly believe that others predominantly hold an opinion different from their own

When individuals do not speak up when they see problematic behaviour, they are assuming that there is a consensus that this behaviour is commonplace and/or acceptable. So, there is a responsibility on those in the majority, to call out negative actions and behaviours with healthy, positive behaviour, to stop the problematic behaviour becoming viewed as acceptable.

Active bystanders are able to:

- **Notice the event** – they witness a situation and the negative behaviours demonstrated.
- **Interpret it as a problem** – they do not assume the problem has been resolved or underestimate its significance.
- **Feel responsible for dealing with it** – they empathise with the victim and understand that not intervening means being indirectly complicit.
- **Possess the necessary skills to act** – they have the courage and confidence in their ability to intervene.

Moving from a passive bystander to an active bystander can take time, courage, knowledge, as well as specific training on topics such as courageous conversations and psychological safety. Below are some top tips to help you move from a passive bystander to an active bystander.

Stop/Pause – Take some time to assess the situation and think about the most appropriate course of action. Being an active bystander does not mean putting yourself in harm's way. It means assessing the situation and deciding on a sensible course of action to protect everyone involved.

Recognise potential situations – Be aware of the surroundings and recognise when a situation may potentially escalate into harm. This could include situations where someone is being harassed, bullied, or threatened. If it is not possible to act in the moment, check-in with the affected individual afterwards and offer ongoing support and a next course of action.

Affecting change – If physically/psychologically safe to do so, firmly challenge the behaviour with body language, facial expressions and/or words all the while considering everybody's safety within the situation. It could be an idea to 'call in' the perpetrator and start a conversation about why the behaviour was inappropriate, rather than 'call out' the actions which may cause conflict.

Distract – This can be a less direct approach. Draw attention to something else, interrupt the perpetrator and/or change the conversation. It can support the victim in getting out of harm's way. This is particularly effective in instances of microaggressions.

Take notes – When witnessing non-inclusive behaviour, take notes about the situation or in more serious cases, record the situation using a voice recorder and/or video on a mobile phone to offer supporting evidence. Always ask the affected individual what they would like to do with the documentation before acting further.

Validate the experience – If a person shares their experience of harm, practise active listening by showing empathy, acknowledging their experience, and offering support and resources.

Seek help – Harassment and/or discrimination sometimes requires more serious intervention. If this is apparent, seek help from somebody else, report unacceptable behaviour, and escalate problems using formal procedures and speaking to HR.

Offer support – This could include checking in with the individual affected, offering to walk with them to a safe location, or simply letting them know that you are there for them and willing to continue to support them after the situation.

Further education and support – seek out training programmes and learning resources to learn more about how to become an effective active bystander. Also seek out mechanisms of support for yourself after intervening. Explore books such as The Bystander Effect by Catherine Sanderson or The Upstander: How to Change the World by Standing Up When Others Don't by Rose Brock. If you prefer to learn through watching and listening, you may want to explore documentaries such as The Hunting Ground (2015) – a documentary film explores the epidemic of sexual assault on college campuses in the United States and highlights the importance of active bystanders in preventing and responding to these incidents, or The Kindness Diaries (2017) – a documentary series follows the journey of a man who travels around the world on a motorcycle, relying only on the kindness of strangers. The series highlights the power of individual acts of kindness and the importance of being an active bystander in everyday life.

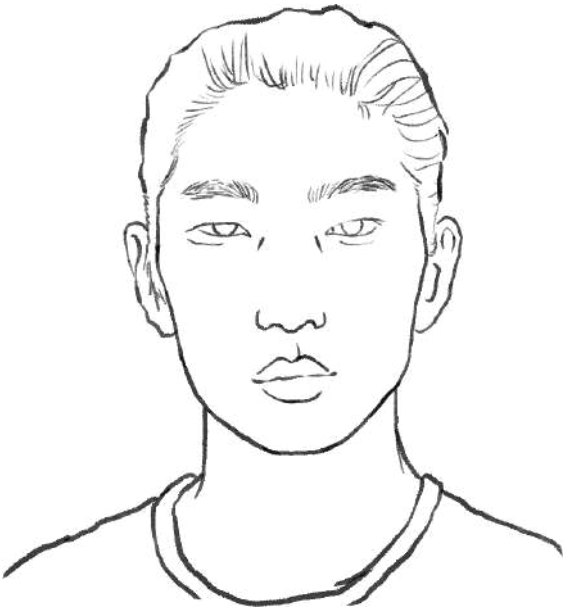
Techniques for challenging discriminatory language and behaviour

There are several techniques for challenging offensive language, you will need to select the approach that works best for you and the situation at hand. Think about what outcome you want to achieve: is it to set an assertive boundary

around what is acceptable, or is it to get someone into a learning space where you can educate them?

There are a small percentage of people who are openly racist / sexist / homophobic / transphobic, etc., and will not have their minds changed. The aim for this group is to give them consequences for what they've said. For example, saying something clear and assertive like "what you have just said is racist and offensive. Please do not say that around me again". If they continue to use discriminatory and offensive language and refuse to recognise their behaviour, then say, "You are continuing to be racist after I asked you not to. I am leaving now", and walk away. What you have just done is given them clear consequences for their actions. If everyone in society did this consistently with people who are openly hateful then they would learn that 1) their opinions are not to be shared in public and hopefully 2) why that is the case.

The far larger group are people who say or do discriminatory things, use offensive words or terms but wouldn't consider themselves discriminatory. In fact, being seen as racist would probably make them feel ashamed, which then means they get defensive and resistant to change. The aim with this group is to get them into a space where they feel able to accept they're wrong and commit to changing that. Often, they don't understand why what they have said is discriminatory.



Technique 1

1. When they say something offensive you could say "hey, that word/phrase isn't OK to use anymore because it's really hurtful to (XXX) people". The key is saying this in a kind way and being ready for them to have a reaction.
2. They might say "oh, OK I didn't realise that..." or they might get defensive or exasperated. If they do, stay calm and empathic and relate it back to them e.g. "if someone called you a name you didn't like, wouldn't you want to be able to ask them to stop doing that?"
3. Try to engage their empathy. Usually, the best way to do this is to relate it to their experience. So, using the "what if you were in this situation..." approach is helpful, or if you know them and can relate it directly to their personal experience or family that can be even more powerful e.g. "how would you feel if you had to explain to us as kids what to do so we didn't get shot by police?" Unfortunately, a lot of people don't easily feel compassion for people they don't know, so you need to lead them to it via what is important to them.

Technique 2

1. When they say something racist (e.g. 'I don't think race is an excuse for poverty, all the XX community need to do is pull themselves up like we did') you could ask "oh really, why do you think that?"
2. Keep asking calm, open questions to dig a bit deeper.
3. This should help them work through their own thought processes too and see that they're repeating offensive stereotypes that aren't founded on anything, or at least get them into a less sure state of mind where they're open to other ideas.
4. You could then say "OK well according to this (a reputable source you've

got on your phone, or a statistic you've memorised) XX community earn 20% less than their YY counterparts in the same job - that doesn't seem fair does it?" Or "it was unfair on us too, and I know that was painful for us. So don't you want other people to not have to go through the same struggle just to survive?"

If you'd like to find out more, research 'assertive communication techniques' and 'non-violent communication' (also known as NVC) on the internet. There are lots of different techniques, and videos of examples of this in action too.

How should I respond if someone challenges me?

It can be upsetting to be told that what you have said is offensive, especially if you feel your intentions were not malicious. However, you need to reframe it as a chance to learn and change. We live in a society where racist, homophobic, transphobic, ableist, sexist and other discriminatory language, ideas and stereotypes can be perceived to be the norm, and it can be easy to use them without thinking. The key is to be open to questioning your assumptions, your belief in those stereotypes and being able to change your behaviour. If you are challenged on using a particular phrase or stereotype, the best way to react is:

- Pause. Listen to what the other person is saying.
- Apologise for what you said. If you aren't sure what was upsetting about what you said, calmly ask the other person if they would be able to explain. If they can't, or don't want to, make a note to research it later.
- Reflect on the situation and then change your behaviour.
- Research more widely around the topic to expand your understanding.

The Importance of Advocating for Young People and their Families

It is so important that patients are at the centre of their care, especially when it is busy we can sometimes forget that healthcare can be a scary and confusing place for patients and it's our job not just to support them to get better if they can, but also to ensure they come through the process with as much support and reassurance as possible.

Patient-centred care is an approach that involves patients in their own healthcare decisions and places the utmost importance on their dignity, autonomy and respect. Whereas doctor-centred care priorities the opinions and decisions of the healthcare professional over the wishes and decisions of the patient. Skills and approaches associated with taking a patient-centred approach where empathy, autonomy and patient empowerment are centre has been linked with higher quality of care and better outcomes (7).

One way to ensure you are cantering your young patients in their own healthcare is to empower them to feel confident to ask questions and let you know when they don't understand or need more information. You can do this by:

1. **Just listen** – too often we focus on getting the patient to listen to us, but it is also important to take the time to listen to them. When we take the time to truly hear another person's perspective it can be very empowering.
2. **Buddies** – sometimes healthcare can be a scary place for young people, especially when they are interacting almost exclusively with adults. Having the opportunity to talk to others closer to their age about different aspects of their experience can really help them to understand more about what is going on and the options .
3. **Raise up young staff** – again in a lot of societies we are driven by the

expectation that the older person in the room must be the expert, but empowering younger staff and giving them the space to take the lead and develop you are showing young patients that this is a place where they can be heard.

4. **Be humble** – it can be very difficult to admit when we are wrong and can often be something professionals are very reluctant to do. Especially when it comes to inclusion there is so much we can learn from young people and patients, but to do that we need to be honest with ourselves and others when we don't know something.
5. **Give young people a seat at the table** – engaging young people in patient advocacy and patient forums can ensure that service provision and research is really meeting the needs of young patients. They have so much value to bring if we give them a seat at the table.

The role of a parent has changed significantly over the years. Previously the responsibility of caring stood firmly with women, today the title of a parent is not strictly reserved for those with biological ties. Individuals become parents in different ways including and not exclusive to adoption, marriage, or fostering. The role of a parent is the shared support across all members of a family unit. When creating a family-friendly organisation, there is a lot more to consider than just competitive maternity or paternity policies. Today, the evidence for supporting parents' emotional and physical well-being is well documented and undisputed. Organisations understand that unless they can offer good support during this period, they could put themselves in the position of negatively impacting the care of the young person and the family. Take your time to understand the needs of the parents separately from the needs of the young person to ensure you are able to provide for both. But remember, even if your patient is young, it is their

care you are primarily responsible for so they should have an input into this with the support of their parents.

Inclusive Language Glossary

Inclusive language is a topic of great discussion, but unfortunately inclusive language is not universally agreed. Language that works for some groups may not work for others, and even within groups language one person prefers may not work for another person in the same group. This is especially complex when considering communicating in a second language or considering translations into multiple languages. Below is some guidance around particular words and phrases in a number of different languages, but the most important approach when considering your language is to always refer to the individual you are speaking to and use the words they are most comfortable with. It could sometimes also be beneficial to consider using everyday language, rather than academic terminology when speaking with someone whose native language is not English.

Disability

Language around the topic of disability differs a considerable amount across Europe. There are two models that explain how we tend to think about disability. The medical model sees disability as an illness or something that needs fixed or helped. For many it can feel that this model assumes that the issue is with the disabled person. The social model of disability reframes this and sees society as the barrier, in this model the issue is the outside world – there is nothing wrong with the disabled person. If we built systems, buildings, workplace etc with inclusion in mind then a person's disability would not impact (or would lesser impact) on their engagement in various settings. However, in healthcare it is not that simple, there are many disabling conditions that can be treated to a point

that they do not have to have long term effects on the individual, cancer is a great example of this. In English the medical model of disability would predominantly use a person first language approach e.g. person with a disability, whereas the social model of disability (often preferred by disability advocates) would predominantly use an identity first language approach e.g. disabled person. Whereas in some European languages such as French, identity first language is seen as the most inclusive approach e.g. une personne en situation de handicap.

For some people, a first language can be helpful as it helps to see that the disability is not the whole sum of the person, just a part of who they are, whereas for others identity first language can be most helpful as it recognises their disability as an important aspect of their identity. It is not as simple as one is right and one is wrong, it is dependent on the situation, the condition, and the individual. For example, you would not say someone is a 'cancer person', you would say they are a 'person living with cancer', however you may find people using the term 'autistic person' as a preferred alternative to 'person with autism'.

When considering translating language around disability this presents another complex issue as often direct translations can result in accidental non-inclusive language. For example, the commonly used word for disability in Russian is 'инвалидность' . This directly translated to English would mean 'handicapped', which in English would be seen as an offensive way to refer to disability. This is due to the way the word 'handicapped' has evolved. It is suggested that the word evolved from a piece of legislation passed in 1504 to legalise begging for disabled veterans as it was felt they would be unable to work a job, this was referred to as 'cap in hand' which is where the term 'handicap' came from. So, in English this word has a negative connotation and is a belittling way to refer to disability, yet in Russian it does not have this history attached to it and is just a

word that has been introduced from another language to refer to disability and is completely acceptable as a term.

When considering language around disability in Europe consider the following:

Don't say	Do say
WHEELCHAIR BOUND CONFINÉ(E) AU FAUTEUIL ROULANT AN DEN ROLLSTUHL GEBUNDEN ÎN SCAUN CU ROTILE ПРИКОВАН КЪМ ИНВАЛИДНА КОЛИЧКА	WHEELCHAIR USER UNE PERSONNE EN FAUTEUIL ROULANT ROLLSTUHLFAHRER:IN UTILIZATOR DE SCAUN CU ROTILE ПОЛЗВАТЕЛ НА ИНВАЛИДНА КОЛИЧКА
CANCER VICTIM VICTIME D'UN CANCER KREBSOPFER VICTIMĂ A CANCERULUI ЖЕРТВА НА РАК	CANCER SURVIVOR / PERSON LIVING WITH OR BEYOND CANCER SURVIVANT DU CANCER / PERSONNE VIVANT AVEC OU APRÈS UN CANCER KREBSÜBERLEBENDE:R / PERSON, DIE MIT ODER NACH KREBS LEBT SUPRAVIEȚUITOR DE CANCER / PERSOANĂ CARE TRĂIEȘTE CU SAU DINCOLO DE CANCER ОЦЕЛЯЛ ОТ РАК / ЧЕЛОВЕК, ЖИВУЩИЙ С РАКОМ ИЛИ ПОСЛЕ НЕГО
MENTALLY ILL UNE PERSONNE MALADE MENTALE BOLNAV MINTAL ПСИХИЧНО БОЛЕН	PERSON EXPERIENCING MENTAL ILLNESS UNE PERSONNE AVEC DES TROUBLES DE SANTÉ MENTALE PERSOANĂ CARE SE CONFRUNTĂ CU O BOALĂ PSIHICĂ ЛИЦЕ, СТРАДАЩО ОТ ПСИХИЧНО ЗАБОЛЯВАНЕ
THE DISABLED ADAPTÉ AUX HANDICAPÉS CEI CU HANDICAP ИНВАЛИДНИ ХОРА	DISABLED PEOPLE SANS BARRIÈRE, SANS OBSTACLE PERSOANE CU DIZABILITĂȚI ХОРА С УВРЕЖДАНИЯ

Ethnicity/Race

Like many other topics, language around ethnicity and race is very different across Europe. Initially, we can start with understanding the difference between the terms ethnicity and race, as they are often used interchangeably in English but do have slightly different meanings. The term race is understood today to be a grouping term for people with shared physical characteristics and commonalities in ancestry, culture and history, such as skin colour and hair type. While the term ethnicity is understood to refer to the groups who share social, cultural, linguistic origins and traditions. However, both are social constructs used to categorise people in population groups. There is a level of genetic variation across the human genome, historically some of these variations were attributed to different parts of the world, but due to the vast amount of human movement over a long period of time it is now impossible to detect race on a genetic basis. Despite this the concept of race still shapes human experience for the better and the worse. Racial bias is the basis for discrimination, exclusion, and violence, and this can dramatically change the experiences of different groups when engaging in healthcare.

In understanding ethnicity and race, it's crucial to acknowledge that both are social constructs, not grounded in genetics. Humans share 99% of their DNA, with the minor variations not aligning with racial categories. Studies in genomics reveal that genetic diversity within so-called racial groups often exceeds that between them, challenging the notion of distinct biological races. This emphasises that race and ethnicity are shaped more by historical and social influences, notably colonialism, which has perpetuated discrimination and link inequality. These constructs significantly impact healthcare experiences,

underlining the need to view human diversity through a lens informed by social context rather than outdated biological assumptions.

Language around race and ethnicity differs dramatically based on lots of different factors such as cultural, religious, historical, and colonial contexts. Even when we consider the word 'race', whilst this is a perfectly acceptable term in English it has disappeared from vocabulary in many European countries following World War 2. A study by Laura Führer in 2021 (8) found that in Norway the term ethnic minority is virtually exclusively used to refer to non-white groups, while the word ethnicity is linked to national background. Despite this, the findings of her study demonstrated that ethnicity was primarily used to denote skin colour, participants suggested that when they thought of the word immigrant, they thought of people who are dark-skinned or not from Europe. Even though the word simply refers to someone who was born outside of the country and had moved to that country. Those participants who did have black or brown skin described microaggressions around their race and ethnicity being commonplace, for example being complimented on their language ability because the assumption is that someone with darker skin could not be born in Norway or fluent in Norwegian. This lack of comfort around language relating to race and ethnicity is not isolated to Norway and a common experience across Europe.

In many languages the guidance is to avoid using the word race in favour of the word ethnicity, this is often because the direct translation for the word 'race' is often the word 'breed' which has obvious negative connotations. Additionally try to use adjectives rather than nouns when describing ethnicity. When considering the terminology relating to particular racial identities and ethnic groups the words in one language may be perceived as offensive when read or heard by someone who does not speak that language. For example, the term 'negro' is a

widely understood to be an offensive term for the black community which has been historically and recently used as a term of abuse, and that referring to someone as 'black' is more inclusive and appropriate. Yet the masculine Spanish word for black is 'negro', which can cause some confusion for those who are not Spanish speakers. Also the exact same word can have very different connotations between countries for example the word 'Tigan' is used in Romania as an offensive term and translates to 'Gypsy' in English, yet the same word in Russian 'Цыган' is an acceptable descriptive term for people from travelling or nomadic heritage.

Even though the topic can be difficult, conversations around race and ethnicity must be had to develop a deeper understanding of correct terminology, without confidence to begin the conversations understanding around language will never develop.

When considering language around race and ethnicity in Europe consider the following:

Don't	**Do**
USE ETHNICITY AS A NOUN E.G. A BLACK UNE COLORÉ·E	USE ETHNICITY AS AN ADJECTIVE E.G. A BLACK PERSON UNE PERSONNE NOIRE
ETHNIC MINORITY GROUPE RACIAL, MINORITÉ VISIBLE MINORIA ETHNICA	MINORITISED ETHNIC GROUP GROUPE RACISÉ GRUPO ÉTNICO MINORIZADO

Sexual Orientation and Gender Identity

When discussing language around sexual orientation and gender identity the main source of discussion is gender neutral language. This is where you look to avoid reference to any particular sex/gender, remove gender assumptions from your language and offer a gender free alternative that is inclusive of all genders.

Historically, the use of masculine language as a default is very common across Europe, for example, if you are in a room full of women but there is one man, you will address the group using the masculine form. Yet, in the late twentieth century we began to see movement away from a masculine default and the rise of feminine language alternatives in line with increases in gender activism and suffrage. Recently the move toward gender neutrality outside of the masculine/feminine binary has begun to increase, with many communities both within and outside of the LGBTQ+ community seeking to find gender neutral language to better describe their experience. This has however been made into a contentious topic in many countries, with many in the younger generation pushing for a neutral form, as opposed to masculine or feminine. However, in many European languages the gender neutral alternatives are seen as more informal and there is more resistance to those with more traditional approaches to language. The nature of language is that it develops over time, these changes coincide with changes in culture, migration and many other factors. Recently there has been a lot of change in language around sexual orientation and gender identity in a short space of time, leaving many confused and nervous about what to say, but like any aspect of inclusive language, the only way to get more confident on what to say is to get involved in the conversation and learn more.

When exploring gender neutrality in language, European languages fall into 3 main categories. Genderless languages, Natural gender languages, and grammatically gendered languages.

In genderless languages gender neutral words are usually very easily available. In Natural gender languages the words exist but normally refer to a group, for example the 'they' pronoun. In grammatically gendered languages all nouns are either masculine or feminine and often it is traditional to use the masculine form of nouns and pronouns when referring to males and females collectively. When trying to embed gender neutrality there are a number of different methods, but it often involves introducing a new word or new spelling. For example, replacing the ending of –o or –a with the letter x or e to create a new word. Others have introduced the use of a slash to have both the feminine and masculine spelling to create a neutral word. There is no universal approach to gender neutrality in grammatically gendered languages, but the more people have conversations about the topic the easier it will be to find a solution that works.

Genderless Languages	Natural gender languages	Grammatically gendered languages
Languages were where there is no grammatical gender and no pronominal gender, meaning most words are already neutral. There may still be some gendered nouns, but they are often influences from other languages. e.g. Georgian neutral pronoun "ის"(is)	Where personal nouns are mostly gender-neutral and there are personal pronouns specific for each gender, meaning often gender-neutral language means repurposing existing words in a new context e.g. English pronoun 'they' or Danish pronoun 'de'	Where every noun has a grammatical gender, and the gender of personal pronouns usually matches the reference noun. This means new words are needed to allow for gender neutrality, so it is a much slower process. e.g. el/la candidato/a or candidate (to replace candidato)
Estonian Finnish Hungarian Georgian Erzya	Danish English Swedish	German French Bulgarian Polish Czech Ukrainian

Language around sexual orientation has also developed a lot over the past 20 – 30 years, this is in line with the decriminalisation of homosexuality in the late twentieth century. With 80% of decriminalisation legislation changes happening between 1972 and 2005. Whilst the level of cultural and societal acceptance differs dramatically across Europe, conversations around LGBTQ+ inclusion are becoming increasingly more common and important. It is important not to avoid labelling individuals, rather allow them to provide you with the language and vocabulary that is most relevant and important to them. Moreover, if that language is unfamiliar to you, try not to see this as something to be sceptical or dismissive of, but as an opportunity to learn new vocabulary.

When considering how you can make you language more inclusive for the LGBTQ+ community consider the following:

Don't	Do
Don't use gender terms when neutral terms are available or make assumptions. MOTHER / FATHER / HUSBAND / WIFE / SON / DAUGHTER MÈRE / PÈRE / MARI / ÉPOUSE / FILS / FILLE MĀTE / TĒVS / VĪRS / SIEVA / DĒLS / MEITA	Use neutral terms where possible and ask what language people prefer. PARENT / PARTNER / CHILD PARENT/E / PARTENAIRE / ENFANT VECĀKS / PARTNERIS / BĒRNS
Avoid using masculine as the default. POLICEMAN POLICIER POLICISTS	Use grouping terms where neutral terms are not available. POLICE OFFICER OFFICIER DE POLICE LIKUMA DARBINIEKS
Don't focus just on biology: BORN AS MALE AND HAS A TESTICULAR INJURY NÉ EN TANT QUE MÂLE ET A UNE BLESSURE AUX TESTICULES DZIMIS VĪRIETIS AR SĒKLINIEKU TRAUMU	Use the identity language people offer you: IDENTIFIES A NON-BINARY PRESENTING WITH TESTICULAR INJURY IDENTIFIE UNE PRÉSENTATION NON BINAIRE AVEC UNE LÉSION TESTICULAIRE IDENTIFICĒ NEBINĀRU PREZENTĀCIJU AR SĒKLINIEKU BOJĀJUMU

Further Learning Resources

From Prejudice to Progress: Equity, Diversity & Inclusion event in Romania
https://www.youtube.com/watch?v=FXO2Scuo44s&list=PLitnOttC-M8wyewTcOQK6UehyvcW23ZG4&index=3

The European Network of Youth Cancer Survivors launches its first Policy Paper

https://www.youtube.com/watch?v=gzWmPgDBMQY&list=PLitnOttC-M8wyewTcOQK6UehyvcW23ZG4&index=9

Recommendations for Equitable, Diverse, and Inclusive Cancer Care

https://www.youthcancereurope.org/the-european-network-of-youth-cancer-survivors-launches-its-recommendations-for-equitable-diverse-and-inclusive-cancer-care-in-europe/

EU Multidimensional Inequality Monitoring Framework inequality maps and

country profiles:

https://composite-indicators.jrc.ec.europa.eu/multidimensional-inequality

The European Cancer Inequalities Registry

https://cancer-inequalities.jrc.ec.europa.eu/

Tackling inequalities in cancer care in the European Union

https://ihe.se/app/uploads/2024/01/IHE-REPORT-2024_1_.pdf

The “how to” of inclusive policy design | The World Bank

https://blogs.worldbank.org/en/education/how-inclusive-policy-design

Gender

Menopause and the workplace

https://www.inclusiveemployers.co.uk/blog/menopause-and-the-workplace/

Talking inclusion with Podcast … Menopause at work

https://open.spotify.com/episode/09OtsDolLnj8Y8Duh7XbXG

How employers can create safer workplaces for women

https://www.inclusiveemployers.co.uk/blog/help-women-feel-safe-in-the-wake-of-sarah-everards-murder/

Disability

Understanding Disability Using Spoon Theory

https://www.inclusiveemployers.co.uk/blog/understanding-disability-using-spoon-theory/

The stigma behind disclosing disabilities at work

https://www.inclusiveemployers.co.uk/blog/the-stigma-behind-disclosing-disabilities-at-work/

"You don't look disabled" and other 'fun' things you hear as a disabled person

https://www.inclusiveemployers.co.uk/blog/you-dont-look-disabled-and-other-fun-things-you-hear-as-a-disabled-person/

Neurodiversity Glossary

https://www.inclusiveemployers.co.uk/blog/neurodiversity-glossary/

Talking inclusion with Podcast … Disability in the workplace

https://open.spotify.com/episode/46QO9U8vn1vT6MU9XvpFFh

Talking inclusion with Podcast … Neurodiversity in the workplace

https://open.spotify.com/episode/737IkNHqOPpwVv1nu5P79p

Inequality in Cancer Care for People with a Disability | The Lancet Oncology

https://www.youtube.com/watch?v=bIKTcNv17RI

Ethnicity/Race

How to show solidarity to Black Women in the workplace
https://www.inclusiveemployers.co.uk/blog/how-to-show-solidarity-to-black-women-in-the-workplace/

Talking inclusion with Podcast … Race and social mobility
https://open.spotify.com/episode/7siS4CNg6pUlJcO9D88sf0

Race Equality Foundation - Cancer and black and minority ethnic communities
https://raceequalityfoundation.org.uk/wp-content/uploads/2022/10/REF-Better-Health-471-1.pdf

There isn't much representation of people from black & Asian communities telling their cancer story - Leanne Pero (Video)

https://www.youtube.com/watch?v=hTgDrHoKLgg&list=PLitnOttC-M8za6gN6p3TRU25zNOH2UQKI&index=6

"The racial abuse I've received has been horrendous" - Black Women Rising's Leanne Pero (Video)

https://www.youtube.com/watch?v=8r_k689hmYk&list=PLitnOttC-M8za6gN6p3TRU25zNOH2UQKI&index=9&t=5s

"Cultural myths in certain communities is making the cancer journey 10 times worse" - Leanne Pero (Video)

https://www.youtube.com/watch?v=G9IxhZ1djrc&list=PLitnOttC-M8za6gN6p3TRU25zNOH2UQKI&index=10

LGBTQ+

Becoming an LGBTQ+ parent – the other mother, or just "Mum" is fine -

https://www.inclusiveemployers.co.uk/blog/becoming-an-lgbtq-parent-the-other-mother-or-just-mum-is-fine/

Five ways to becoming a better transgender ally

https://www.inclusiveemployers.co.uk/blog/five-ways-to-becoming-a-better-transgender-ally/

Talking inclusion with Podcast … Supporting LGBTQ+ colleagues

https://open.spotify.com/episode/6JGmoANsXy6LgGxhcfHV3I

"1 in 7 members of the LGBT+ community in the UK are avoiding healthcare for fear of discrimination" - Brad Gudger (Video)

https://www.youtube.com/watch?v=BaukVzoGfP0&list=PLitnOttC-M8za6gN6p3TRU25zNOH2UQKI&index=11

Religion and Faith

How to understand and celebrate faith in the workplace

https://www.inclusiveemployers.co.uk/blog/why-employers-need-to-think-about-faith-right-now/

Understanding hijab inclusion in the workplace

https://www.inclusiveemployers.co.uk/blog/hijab-inclusion-in-the-workplace/

Talking inclusion with Podcast … Religion, Faith, and Belief at Work

https://open.spotify.com/episode/77qoJ63MZj6441zQt3cf1C

Youth cancer and fertility in Europe - Patient On Patient interview with Emi & Andrea (Video)

https://www.youtube.com/watch?v=sqNNW5q84jk&list=PLitnOttC-M8zP6lV_hXrIxzA72oZlCpRI

Immigrant and Migrant Communities

What is International Migrants Day? Everything You Need to Know
https://www.inclusiveemployers.co.uk/blog/what-is-international-migrants-day-everything-you-need-to-know/

Natalia's story Getting patients out of Ukraine (Video)

https://www.youtube.com/watch?v=6UGYNGjlNks

Anna & Inessa story Treatment in Ukraine (Video)

https://www.youtube.com/watch?v=zOi4OVu4E0s

Financial and Socio-Economic Status

Two steps to socio-economic inclusion
https://www.inclusiveemployers.co.uk/blog/why-social-mobility-is-often-overlooked/

Mental Health and Wellbeing

Top tips for improving your mental health

https://www.inclusiveemployers.co.uk/blog/top-tips-for-improving-your-mental-health/

Talking inclusion with Podcast … Let's talk about mental health

https://open.spotify.com/episode/6P92XV5Yf5vq1cZGYGn5V3

YCE's patient advocate Nicola Unterecker speaks at the 2023 World Mental Health Day Conference (Video)

https://www.youtube.com/watch?v=IqqB9EO3EJQ

YCE in a Policy Dialogue on mental health with EU Health Commissioner (Video)

https://www.youtube.com/watch?v=oZNMnoy6_wY

Parents and Carers

Supporting Working Parents: balancing changing needs with organisational priorities

https://www.inclusiveemployers.co.uk/blog/supporting-working-parents-balancing-changing-needs-with-organisational-priorities/

Talking inclusion with Podcast … Parents and Carers at work

https://open.spotify.com/episode/4LiGGz1guBzTRn0l8TjE3r

Panel discussion: Fertility preservation in young people with cancer WCC 2022, Geneva (Video)

https://www.youtube.com/watch?v=PZ1JYf3Uz-U

Training slides

Understanding Inequality and Cultural Awareness in Cancer Care

Co-funded by the European Union

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European Network of Youth Cancer Survivors

Inclusive Employers

Youth Cancer Europe

Housekeeping

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- Questions and participation are welcomed – please raise your hand.

Session Aims

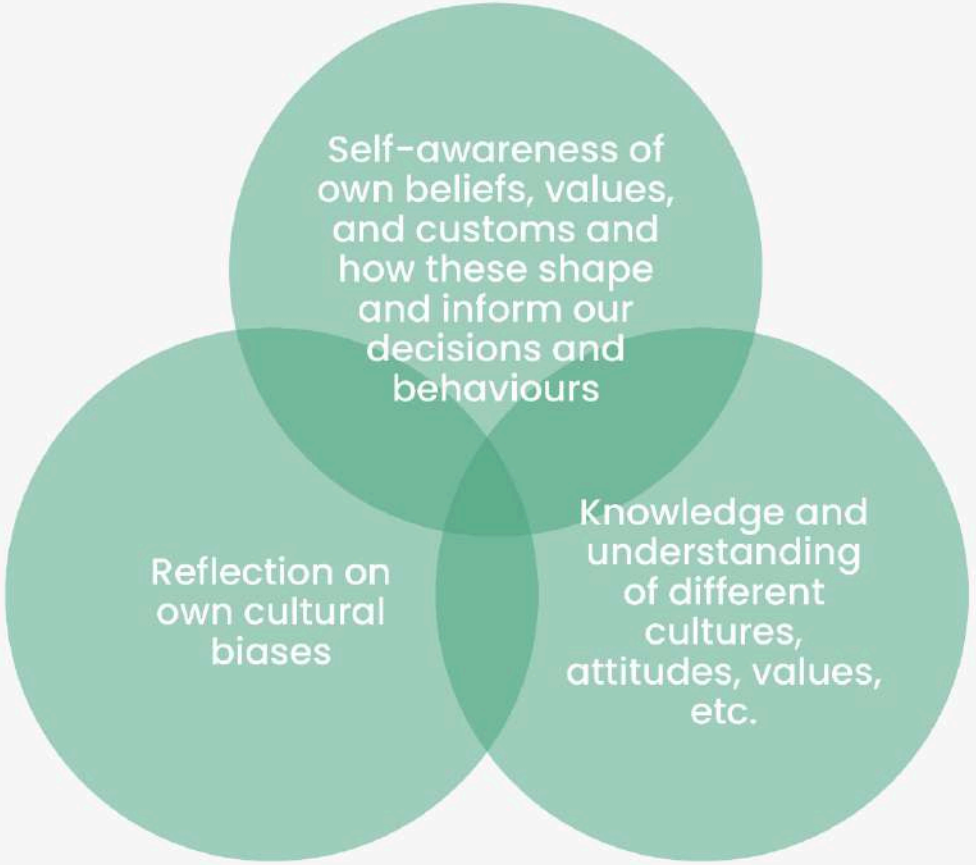
- Understanding the importance and foundations of cultural awareness
- Understanding the legal context of inequality in Europe
- Understanding the and cultural context of inequality in Europe
- Exploring cancer care inequalities in Europe
- Frameworks to help collaborate across cultures


How would you
define culture?

Defining culture

- Shared set of customs, beliefs, rituals, values, behaviours and ways of life of people
- Complex and multifaced framework to make sense of the world and interact with society
- Tangible and intangible elements
- Dynamic and ever evolving

Cultural Awareness



Developing Cultural Awareness

Cultural Competence

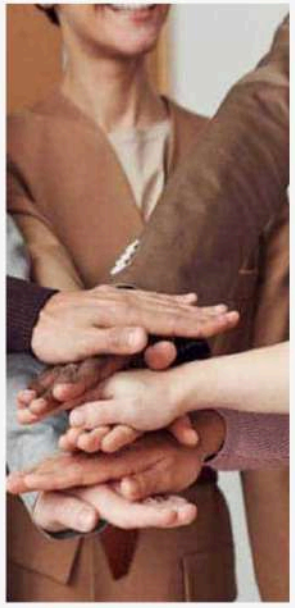
- Ability to engage knowledgeably and effectively across cultures.
- Ability to make sense of culturally diverse settings
- Having knowledge, awareness and appreciation for differences.

Cultural Humility

- A mindset with no end point
- Ongoing process of learning, understanding and self-critique
- An approach of openness which values diversity, and recognises and challenges imbalances

Source: Psych Hub

Understanding cultural dimensions



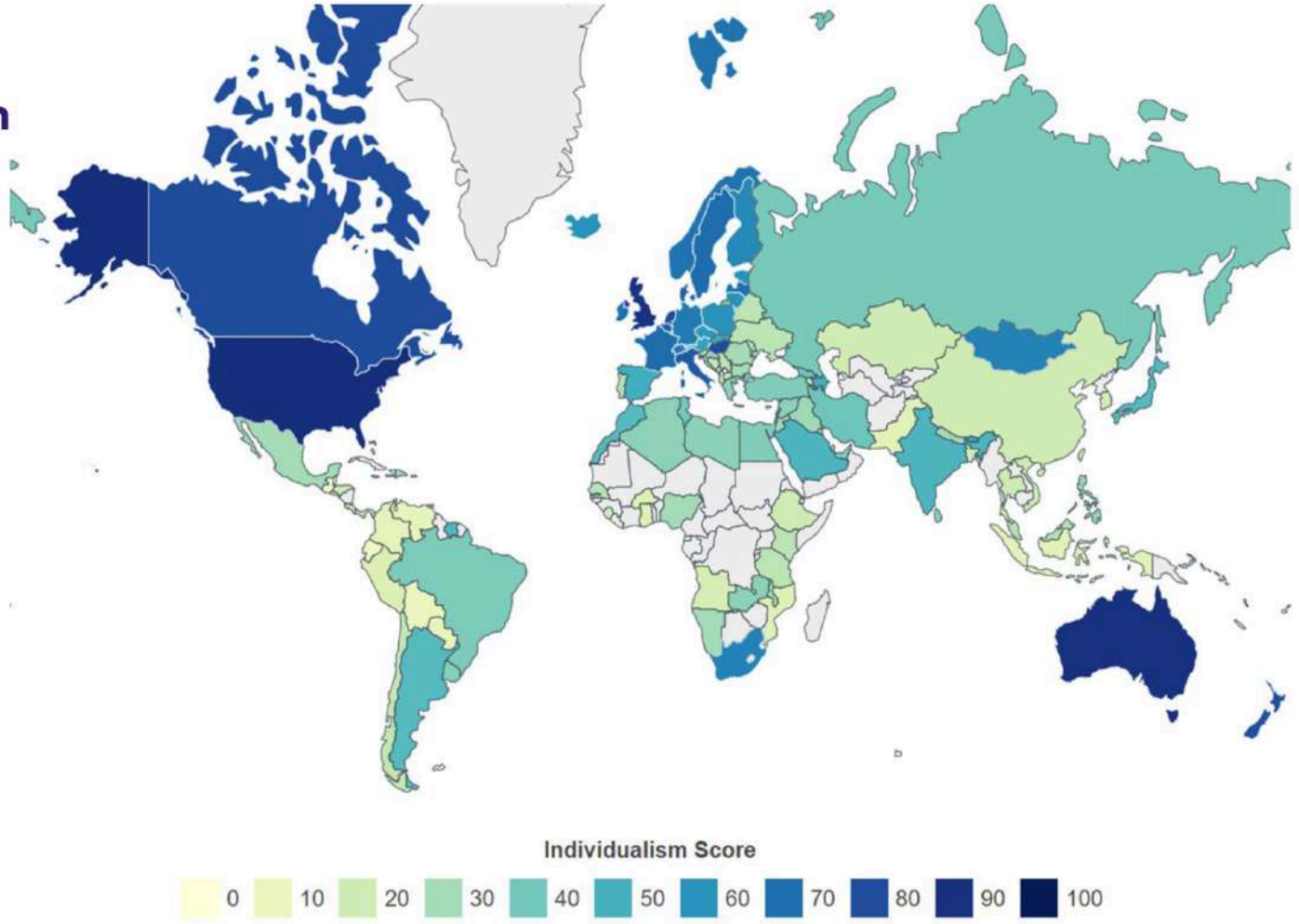
Collectivism

- Society above individuals
- Group harmony
- Values collaboration and team-work

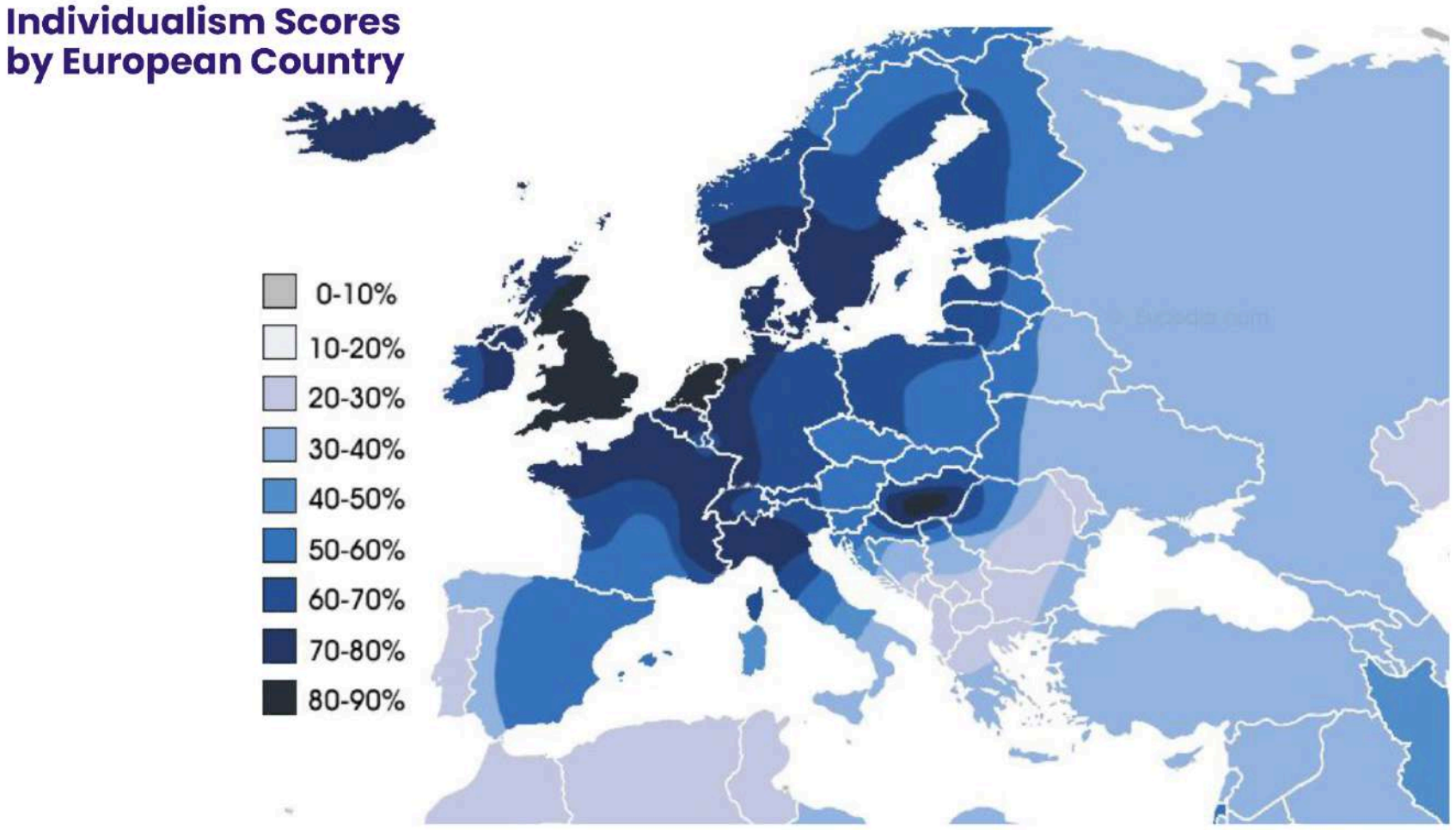
Individualism

- Personal time and space
- Independence and privacy
- Values self-driven and competitive mindset

Individualism Map



Higher score = more individualistic culture
Lower score = more collectivist culture
Grey = no data


Individualism Scores
by European Country
0-10%
10-20%
20-30%
30-40%
40-50%
50-60%
60-70%
70-80%
80-90%


How might cultural differences affect how we deliver cancer care?

Cultural impacts on Healthcare and Cancer Care

- Wellbeing is linked more closely to positive health outcomes in individualist cultures (Okely, Weiss & Gale, 2018)
- Higher levels of collectivism are linked to more positive attitudes towards breast cancer screening (Nguyen & Clark, 2014)
- Cultural differences amplifies the barriers around decision making in cancer care faced by patients across all cultural backgrounds (Hurst et al. 2022)
- Cancer patients in more democratic nations have a higher willingness spend more on their health (Chaikumbung, 2021)


Characteristics Protected by law
Belgium
Czech Republic
Denmark
Finland
France
Germany
Hungary
Italy
Netherlands
Poland
Slovakia
Spain
Sweden
UK
Age
Disability
Gender Identity
Religion/Faith
Sexual Orientation
Race/Ethnicity
Marital/Civil Status
Caring Responsibilities
Socio-economic status
Political beliefs
Place of residence
Language
Pregnancy/Child birth

Culture is not just the law

Law has changed without considering culture

Culture has developed beyond the law


How might different characteristics impact how people engage with cancer care?

How might these identify factors impact on quality of cancer care?

Age	Socio-Economic Status	Country of Residence
• In some European countries there is very limited access to clinical trials for under 18s	• In 2020, across Europe people in low income groups are on average 11.5% less likely to get a regular smear test	• There is a 127% difference in the rate of premature cancer mortality across Europe

Source: European Cancer Inequalities Registry

Source: World Health Organisation


Questions?

Next Steps

- Chat with others about what you have learnt
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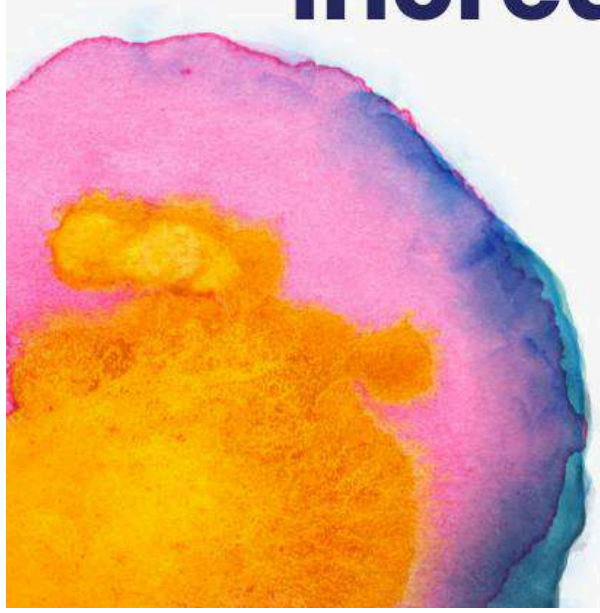
Using Language and Communication to Increase Quality of Care



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Session Aims

- Understanding inclusive and non-inclusive language across cultures
- Exploring communication styles to increase psychological safety
- Understanding the role of communication in supporting the whole family and building patient autonomy
- Activities to explore inclusive and accessible communication

What do we mean by Inclusive Communication?

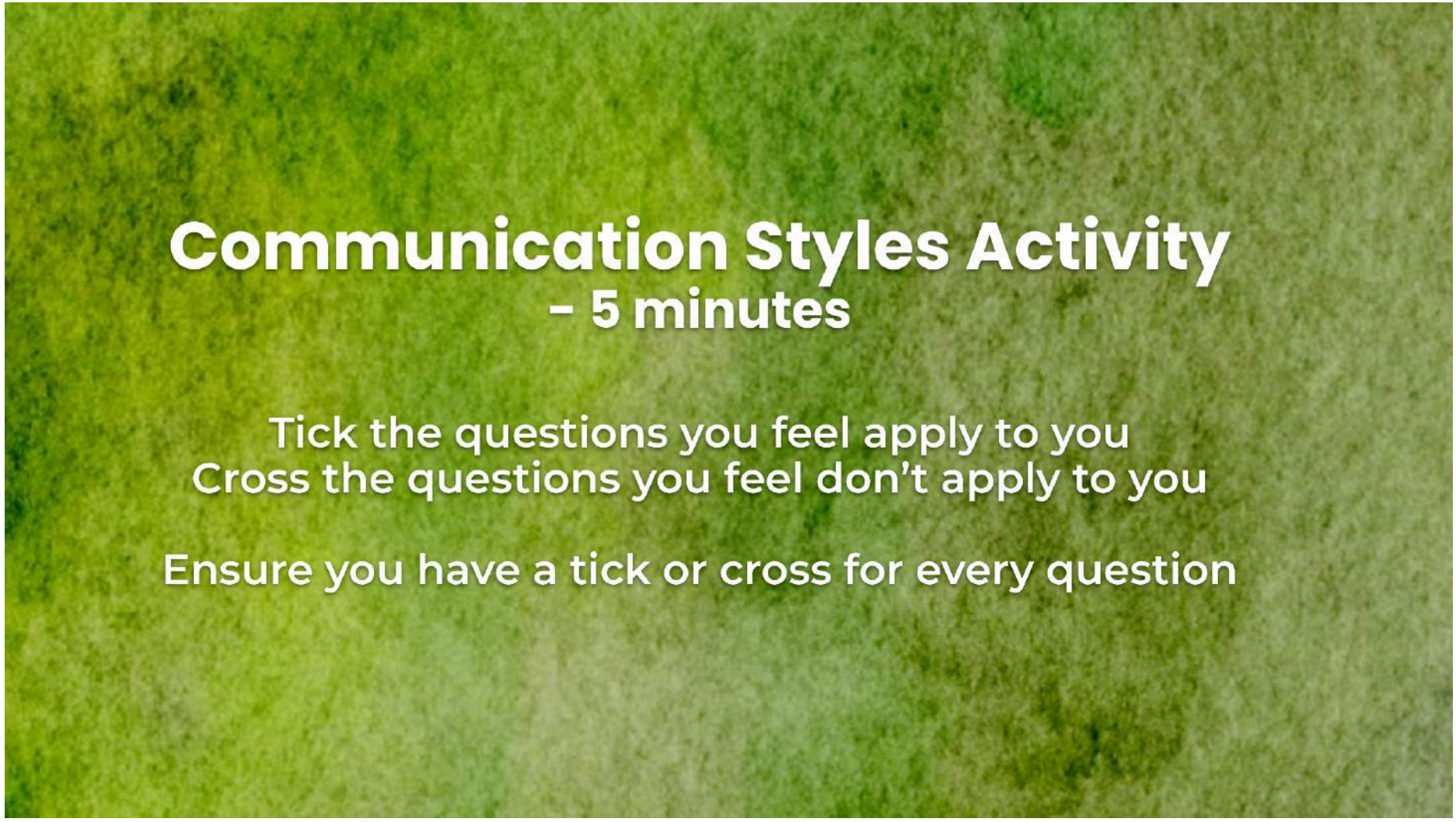
- Sharing information in a way that everybody can understand
- Delivering communication in a way that is inclusive to different identities and experiences.

That includes...

- Verbal communications
- Non-verbal communications
- Written communications
- Signage and information
- Social media and website

What are some of the potential causes and consequences of poor communication?

Causes	Consequences
• Incomplete responses • Wrong style • Spreading gossip • Failing to edit • Making assumptions • Too much information	• Wastes time/ resources • Increases staff turnover • Strains relationships • Reduces revenue • Leads to more work • Causes misunderstandings • Impacts team dynamics • Reduces productivity


Communication Styles Activity
- 5 minutes
Tick the questions you feel apply to you
Cross the questions you feel don't apply to you
Ensure you have a tick or cross for every question

Communication Styles Activity – Marking

	Activist	Pragmatist	Theorist	Reflector
Question numbers	2 10 12 ✓ 16 20 ✓	3 ✓ 6 ✓ 8 ✓ 13 17	1 ✓ 5 7 15 19	4 ✓ 9 ✓ 11 14 18 ✓
Number of Ticks	**2**	**3**	**1**	**3**

0-2 = low
3 = moderate
4-5 = high

Communication Styles Activity – Marking

* **Activists** like to roll their sleeves up, get 'stuck in' and learn as they go. Prefer to learn by doing, to work things out on the fly and they enjoy trying new things and welcoming new experiences.

  Check in regularly to reassess a decision

* **Pragmatists** want to know how to apply what they are learning in the real world and are interested in what works and how it gives results.

  Detailed explanations of impacts, side effects and different treatment options

* **Theorists** learn well from concepts and models. They prefer to have a conceptual framework to make sense of new information and thinking about what they are learning in abstract terms.

  Explain the thinking behind a decision and your thought process for why you think it is the best option

* **Reflectors** prefer to observe others doing something before trying it themselves. They like to have time to absorb information and think about it.

  Encourage to help patient to talk to others who have gone through the situation


What challenges might we face when communicating in a European healthcare setting ?

Communication challenges

- Language barriers
- Religion/belief
- Cultural contexts
- Family dynamics
- People migration
- Patient understanding level
- Patient age

Current best practice:
Disability

People-first language

- People with disabilities
- Child with autism
- Person with dyslexia, diabetes, etc.

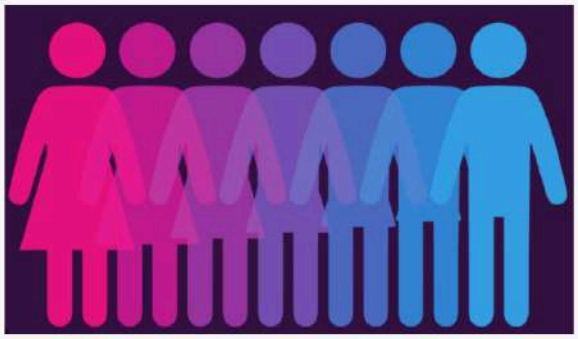
Identity first language

- Disabled people *(social model of disability)*
- Autistic child
- Dyslexic person, diabetic person, etc.

Avoid	Use
He suffers from...	He has x condition/disability
Slow	A person with a learning disability
Wheelchair bound	Wheelchair user

Handicap Albanian, Bosnian, Check, Danish, Dutch,
Handikap French, Italian, Romanian, Slovak, Slovenian,
Handikep Spanish

Current best practice:
Sex and Gender



Sex: physical and physiological characteristics of a person, usually assigned at birth as female or male

Gender: social and cultural constructs, norms, behaviours and roles associated with being a masculine or feminine as well as relationships with each other.

Gender identity: inner sense of self, may or may not align with sex

Gender expression: the way in which a person expresses a gender identity, typically through their appearance, dress, and behaviour.

Non-binary: gender identities that are not solely either male or female

Gender fluid: non-set gender identities and expressions that may shift and change

Genderless Languages	Natural gender languages	Grammatically gendered languages
Languages were where there is no grammatical gender and no pronominal gender, meaning most words are already neutral. e.g. Georgian neutral pronoun "ის"(is)	Where nouns are mostly gender-neutral and there are personal pronouns specific for each gender. e.g. English pronoun 'they' or Danish pronoun 'de'	Where every noun has a grammatical gender, and the gender of personal pronouns usually matches the reference noun. e.g. el/la candidato/a or candidate (to replace candidato)
Estonian Finnish Hungarian Georgian Erzya	Danish English Swedish	German French Bulgarian Polish Czech Ukrainian Spanish

Gender Neutral Language

	Example of gendered language	Example of neutral alternative
1. Avoid gendered / binary language where possible / be as inclusive as possible	Guys / ladies and gentlemen	folks/team/everyone/ all
	Husband/wife	spouse, partner
2. Avoid the "universal male"	Mankind, Chairman, spokesman, manpower, policeman, fireman	Humankind, Chair, spokesperson, workforce, police officer, fire fighter
3. Encourage and acknowledge personal pronouns	She/her he/his	they/theirs

Current best practice: Race and Ethnicity

Race - a grouping term for people with shared physical characteristics and commonalities in ancestry, culture and history, such as skin colour and hair type.

Ethnicity - groups who share social, cultural, linguistic origins and traditions.

However, both are social constructs used to categorise people in population groups.

Ethnic minority	**Global majority**
People of Colour	**BAME**
Multiracial	**Dual Heritage**

Get comfortable with inclusive language

The importance of communication in cancer care

Source: Youth Cancer Europe


Questions?

Next Steps

- Chat with others about what you have learnt
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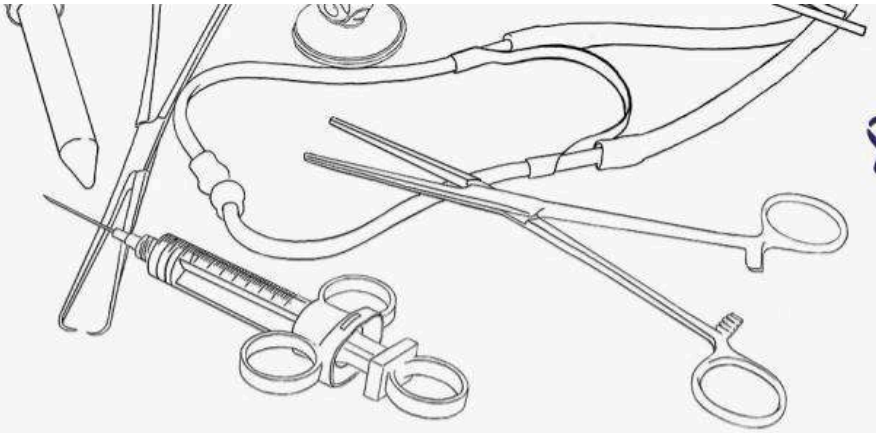

European Network of Youth Cancer Survivors

Inclusive Employers

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The Role of the Healthcare Provider in Inclusive Cancer Care

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Housekeeping

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Session Aims

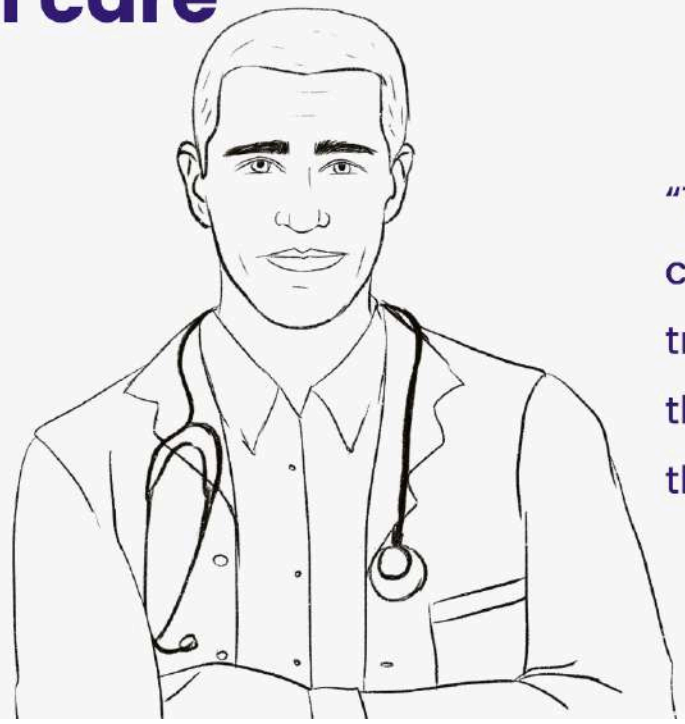
- Understanding the impact of the healthcare provider on quality of care
- Identifying overt and covert discrimination in healthcare practices
- Understanding and assessing the needs of the whole patient experience
- Exploring personal and organizational learning and development needs


How does
someone's identity
impact on their
cancer care?

Impacts of identity on care

"The medical community has been nothing but abusive and exploitative regarding my intersex body. I've been subjected to medical photography, forced sedation, forced invasive examinations, forced surgical procedures, and lied to about needing surgical procedures under the claim that I had cancerous growths."

Impacts of identity on care

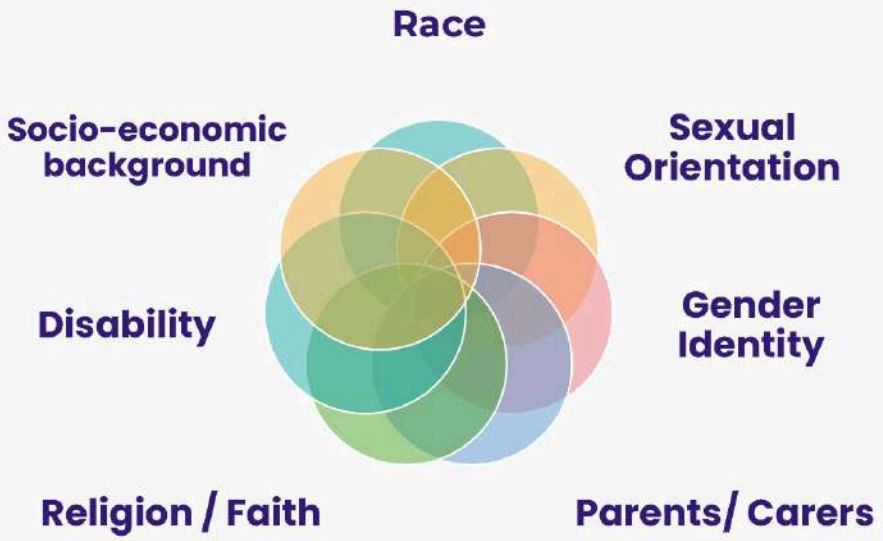


"There are too many doctors in the country right now to worry about training a handicapped physician. If that means some people get left by the wayside, so be it"

Impacts of identity on care

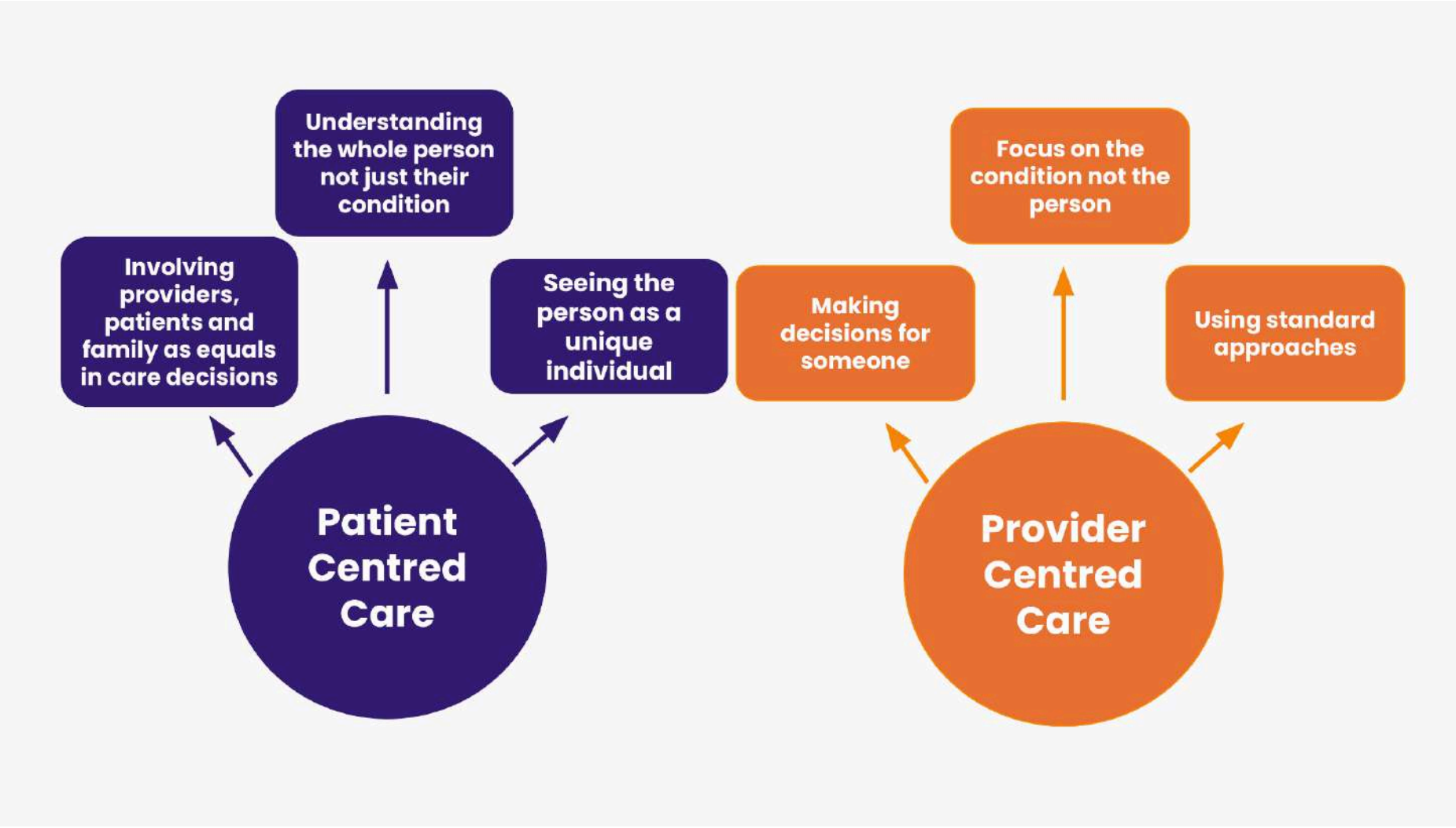
"It took me a year to be diagnosed, and I got that diagnosis at 15, when I was in my GCSE year. I went from getting top grades to having to miss my mock exams and my grades just dropped. I felt such pressure, especially because I am from an Arab background and my family was quite strict on that academic focus. "

Intersectionality



Intersectionality is the idea that we don't experience the world based on one characteristic, and the ways these different characteristics intersect impact the way we experience different challenges


What does inclusive
and accessible
healthcare look like?


Understanding the whole person not just their condition
Involving providers, patients and family as equals in care decisions
Seeing the person as a unique individual
Patient Centred Care
Focus on the condition not the person
Making decisions for someone
Using standard approaches
Provider Centred Care

Discrimination in healthcare statistics

* Women with mobility disabilities were 70% less likely to be asked about contraception

* Patients who are members of Black (18.6%) and Asian (15.4%) groups were less likely to trust and have confidence in doctors or nurses than white ethnic groups.

* 40.7% of doctors said they were confident about their ability to provide the same quality of care to disabled patients.

* Only 8% of clinicians agreed that they were confident in their knowledge of specific LGBTQ+ patient healthcare needs, and very few routine asked about sexual orientation (5%), gender identity (3%) and preferred pronouns (2%).

An evaluation of self-perceived knowledge, attitudes and behaviours of UK oncologists about LGBTQ+ patients with cancer - ESMO Open
Physicians' Perceptions Of People With Disability And Their Health Care - PubMed (nih.gov)
Microsoft Word - REF - Better Health 47 - Cancer (raceequalityfoundation.org.uk)

Overt Discrimination

Blatant, obvious, and intentional act of treating someone unfairly

e.g. refusing care to someone due to their gender identity or charging someone from Roma heritage more for services

Covert Discrimination

Subtle, often unintentional, and may be rooted in unconscious biases

e.g. assuming someone will not understand because they are young or assuming a same sex companion is a sibling rather than a partner

Impact vs Intention

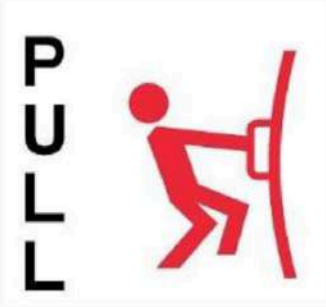
What you said
(Intention)

vs.

What they heard
(Impact)

We all say and do things with good intention but sometimes that don't have the impact we were expecting often because our audience has a different worldview to us.

Challenging Behaviour



* Open questions
* Pulling out views
* Active Listening

* Suggesting
* Giving Information
* Asserting

The Importance of Empowering Young Patients

Source: Youth Cancer Europe


How can we
increase inclusivity
of healthcare?

Twelve ways to increase inclusivity of healthcare

Beware of assumptions and stereotypes	Replace labels with appropriate terminology	Use inclusive language	Ensure inclusivity of physical space
Ensuring effective communicatio n methods	Adopting a strengths-base d approach	Ensuring inclusive healthcare research	Expanding the scope of healthcare delivery
Advocating for an inclusive system	Use inclusive and appropriate signs and symbols	Self-education	Individual and organisational commitments

Can you think of an example for each of these that you might want to change in your organisation?

Source: Florian Steger et al., 2023

Ensure inclusivity of physical space

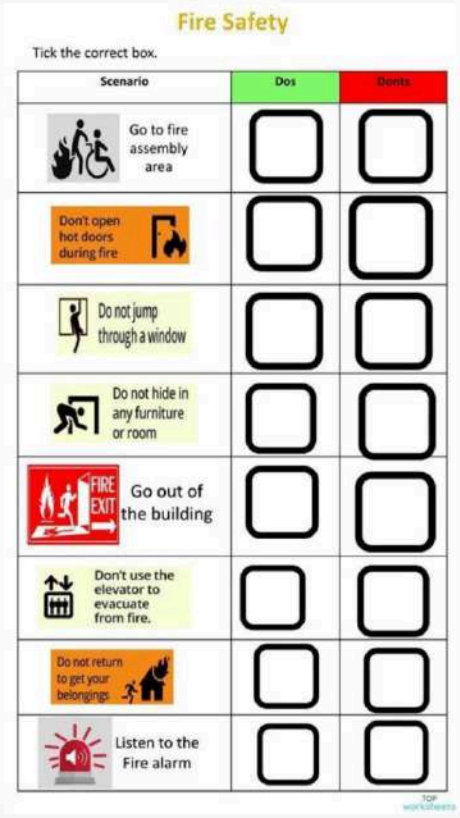
We usually think about:

- Width of doorways
- Placement of furniture
- Access to wheelchairs

But are we thinking about:

- Suitable sized gowns or blood pressure cuffs
- Impact of lighting, heating or sound
- Colour and contrast of information and signs
- Space for prayer or quite time

Use inclusive and appropriate signs and symbols



Boundaries of the role

Healthcare Provider must be:

- Visible supporters of inclusion
- Actively listening to understand
- Constantly seeking to educate themselves and others
- Champions of patient and under-represented groups by bringing them into circles of power
- Kind on themselves, this is a journey of learning not blaming
- **Upstanders who challenge exclusion**

Healthcare Providers don't have to be:

* Inclusion specialists
* Thought police
* Politicians

Where are your skills?

The Speaker – vocally supports

The Champion – encourages people to the front

The Amplifier – amplifies voices

The Advocate – brings under-represented groups into circles of power

The Scholar – listen and learn, read and research

The Upstander – pushes back on offensive comments or jokes

The Confidant – provides a space for support


Questions?

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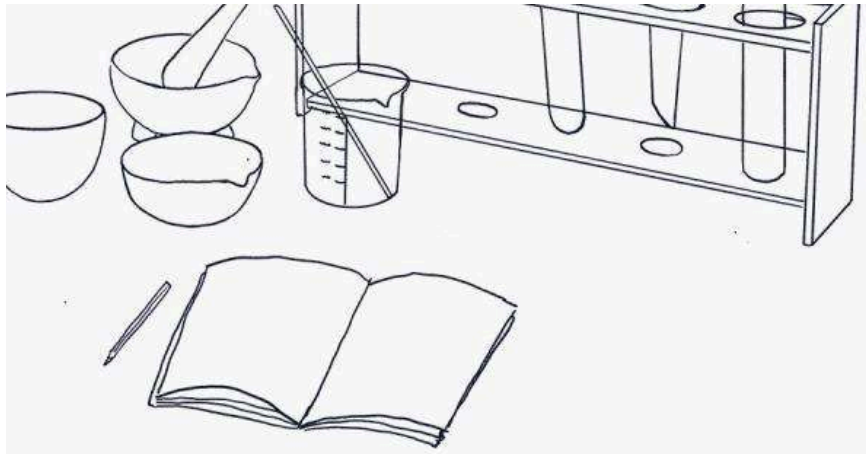

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The Role of the Researcher in Inclusive Cancer Care

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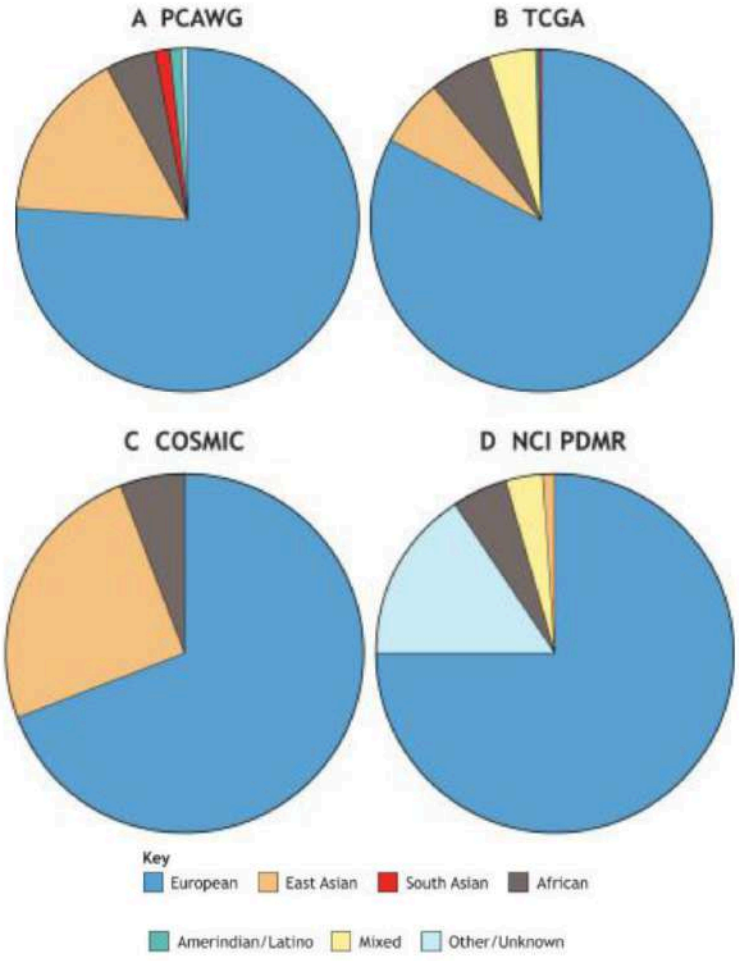
Session Aims

* Understanding the role of research in challenging inequality in cancer research
* Exploring common pitfalls for research that contribute to inequality of care
* Exploring inclusive research practices through the research lifecycle
* Exploring personal and organisational learning and development needs


What are the challenges to conducting inclusive cancer research?

Diversity is missing in cancer research

- There is a lack of representation of samples from non-European ancestry in large public repositories
  (Molina-Aguilar & Robles-Espinoza, 2023, Conti et al., 2021, Fernandez-Rozadilla et al., 2022)
- Women have a greater risk of developing an adverse reaction to a drug because most drugs are tested on men
  (Lee & Wen, 2020)
- Eligibility criteria often disproportionately impact disabled people. Out of 98 studies only 17 studies allowed mechanisms to support disabled people to consent
  (DeCormier Plosky, 2022)



All of Us Research Program

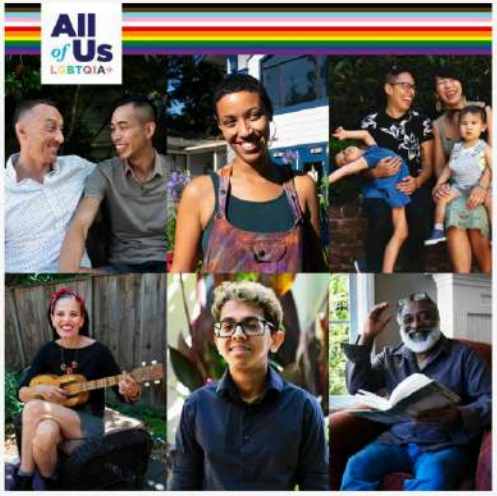
Indigenous communities

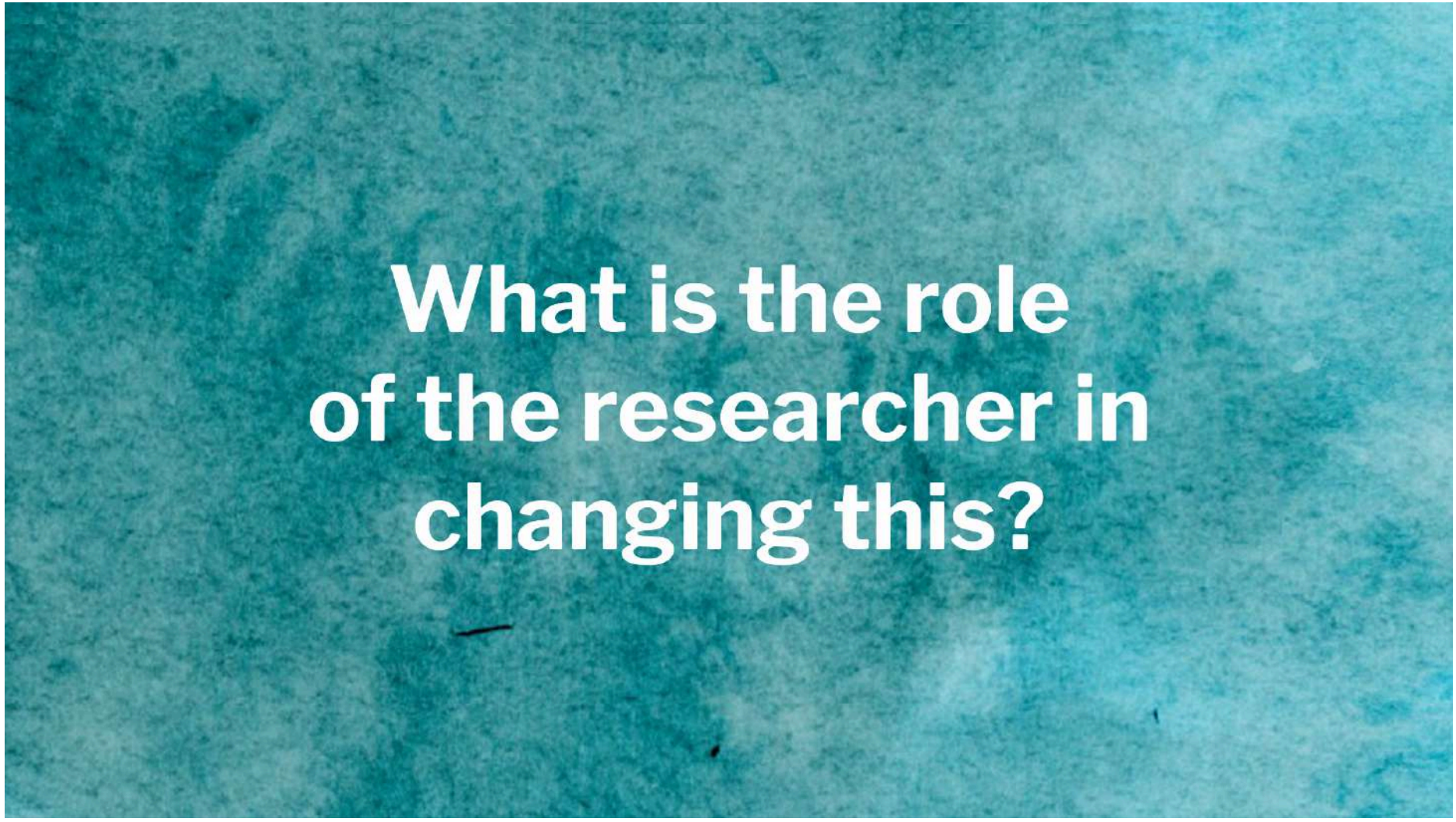
* Connecting with first nation and indigenous communities to understand how best to engage them in research
* Making clear commitments and processes to recognise and uphold the sovereignty, customs, culture, and laws during all research

LGBTQ+ Community

* Expanding the demographic data collection to cover sexual orientation, sex assigned at birth, and gender identity as standard

Source: All of Us Research Program | National Institutes of Health (NIH)




What is the role
of the researcher in
changing this?

Boundaries of the role

Researchers must be:

- Visible supporters of inclusion
- Actively listening to understand
- Constantly seeking to educate themselves and others
- Champions of patient and under-represented groups by bringing them into circles of power
- Kind on themselves, this is a journey of learning not blaming
- **Upstanders who challenge exclusion**

Researchers don't have to be:

* Healthcare Providers
* Therapists
* Inclusion specialists
* Thought police
* Politicians
* Scientists
* PhD graduates

Where are your skills?

The Speaker – vocally supports

The Champion – encourages people to the front

The Amplifier – amplifies voices

The Advocate – brings under-represented groups into circles of power

The Scholar – listen and learn, read and research

The Upstander – pushes back on offensive comments or jokes

The Confidant – provides a space for support

How have you approached inclusion in your research so far?

Activity

Work in groups to highlight the different steps in your usual research lifecycle and how you have considered inclusivity at each of these steps

Are there any areas where you don't currently consider inclusion?

How might you change this?

Patient and Public Engagement

Source: Queens University Belfast

Considering inclusion during study design

Example 1: Using talking mats to enable participation for people with learning disabilities (Mitchell and Sloper, 2011)

Challenge
Semi-structured interview approach would have been difficult for young people with learning or communication disabilities to engage with

Solution
Talking Mats, whereby participants were asked simply worded questions and invited to choose the symbols that matched their ideas and feelings.

Impact
Enabled young people with learning and/or communication impairments to participate in the project and provide real insights into the choices/decisions that they make and want to make, how they make them and how they fell about decision making processes


How might you consider inclusion in participant recruitment and data collection?

Considering inclusion during participant recruitment

Example 2: Using videos as an alternative for long participant information sheets (Johnson et al., 2022)

Challenge
Young people fed back that they struggled to engage with lengthy participant information sheets, and it made them less likely to engage with research.

Solution
Using videos and infographics to present research study information in an easy and engaging way.

Impact
Many young people highlighted they found it much easier to engage with the information this way, which made it easier for them to make an informed decision about engaging with the research or not.

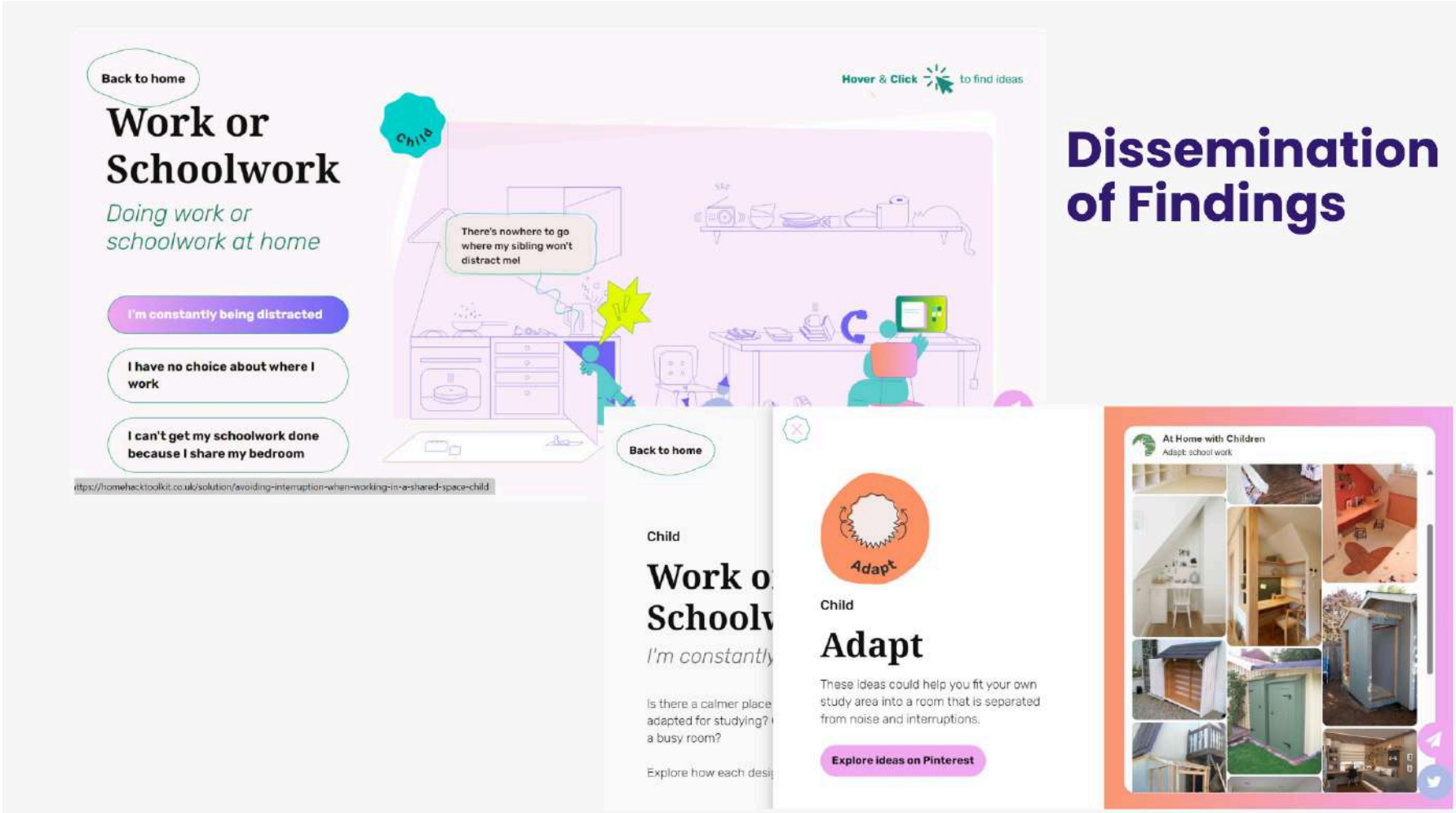
Considering inclusion during data collection

Example 3: Using WhatsApp to create safe spaces for LGBTQ+ young people (McDermott et al., 2024)

Challenge
Difficulty recruiting and retaining LGBTQ+ young people to talk about mental health, school and healthcare experiences

Solution
Using a WhatsApp messenger to conduct interviews as a preferred method of communication for many young people

Impact
Using a method of communication familiar to young people allowed them to express themselves in a way that felt safe and engaging to them. The lack of a face-to-face interviewer (whether in person or virtual) increased the likelihood of sustained engagment with the study.


Back to home
Work or Schoolwork
Doing work or schoolwork at home
I'm constantly being distracted
I have no choice about where I work
I can't get my schoolwork done because I share my bedroom
Hover & Click to find ideas
Child
There's nowhere to go where my sibling won't distract me!
https://homehacktoolkit.co.uk/solution/avoiding-interruption-when-working-in-a-shared-space-child
Dissemination of Findings
Back to home
Child
Adapt
These ideas could help you fit your own study area into a room that is separated from noise and interruptions.
Explore ideas on Pinterest
At Home with Children
Adapt: school work


Questions?

Next Steps

- Chat with others about what you have learnt
- Complete the activities in your workbook
- Check when your next session will be
- Reach out for further support if needed

European Network of Youth Cancer Survivors

Inclusive Employers

Youth Cancer Europe

The Role of the Patient Advocate in Inclusive Cancer Care

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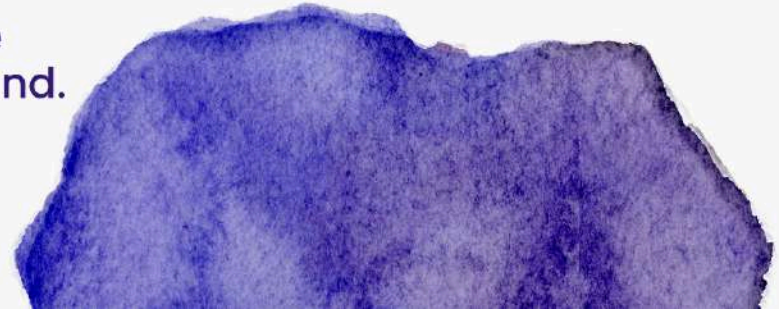
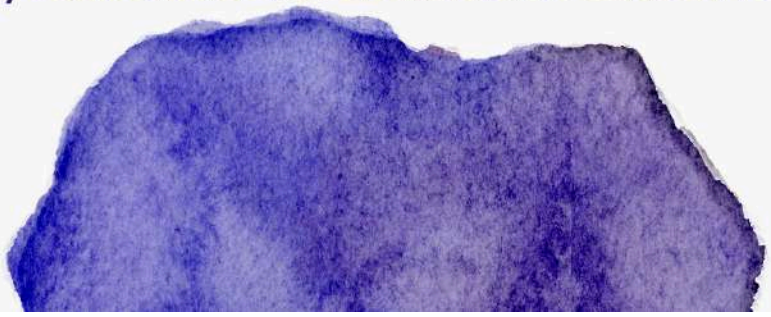
Housekeeping

* Let's pledge to create an environment where people feel safe to participate.
* Give people the space to share their opinion, ensuring we do so in a non-judgemental way
* Be considerate that there may be people in the room with lived experience of this topic.
* Questions and participation are welcomed – please raise your hand.



Session Aims

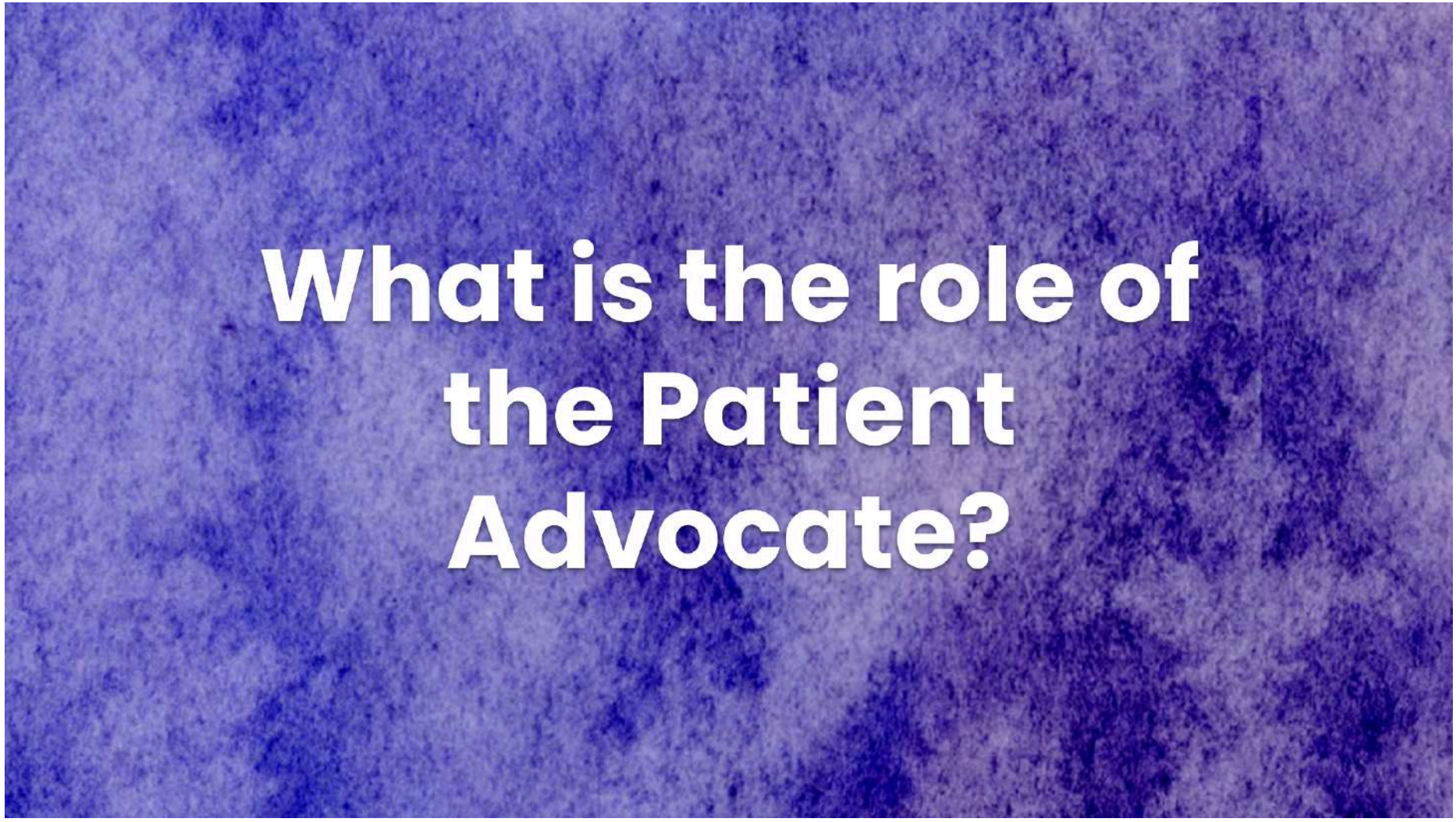
* Understanding the role of patient advocates in challenging inequality in cancer care
* Identifying overt and covert discrimination in healthcare practices
* Exploring inclusive allyship and effective advocacy
* Understanding how to engage key stakeholders for inclusive outcomes




What are the challenges young patients have during their cancer care?

Statistics around discrimination in healthcare

* Women with mobility disabilities were **70%** less likely to be asked about contraception
* Patients who are members of Black (**18.6%**) and Asian (**15.4%**) groups were less likely to trust and have confidence in doctors or nurses than white ethnic groups.
* **40.7%** of doctors said they were confident about their ability to provide the same quality of care to disabled patients.
* Only **8%** of clinicians agreed that they were confident in their knowledge of specific LGBTQ+ patient healthcare needs, and very few routine asked about sexual orientation (**5%**), gender identity (**3%**) and preferred pronouns (**2%**).


What is the role of the Patient Advocate?

Boundaries of the role

Patient Advocates must be:

- Visible supporters of inclusion
- Actively listening to understand
- Constantly seeking to educate themselves and others
- Champions of patient and under-represented groups by bringing them into circles of power
- Kind on themselves, this is a journey of learning not blaming
- **Upstanders who challenge exclusion**

Patient Advocates don't have to be:

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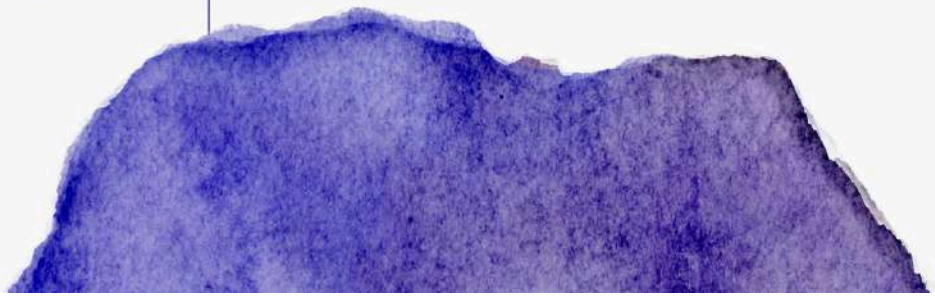
- Thought police
- Politicians



Where are your skills?

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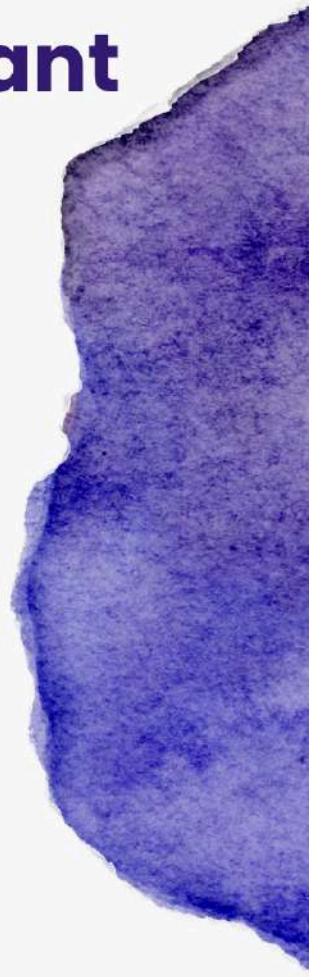
The Confidant – provides a space for support

Why is patient advocacy important in cancer care?

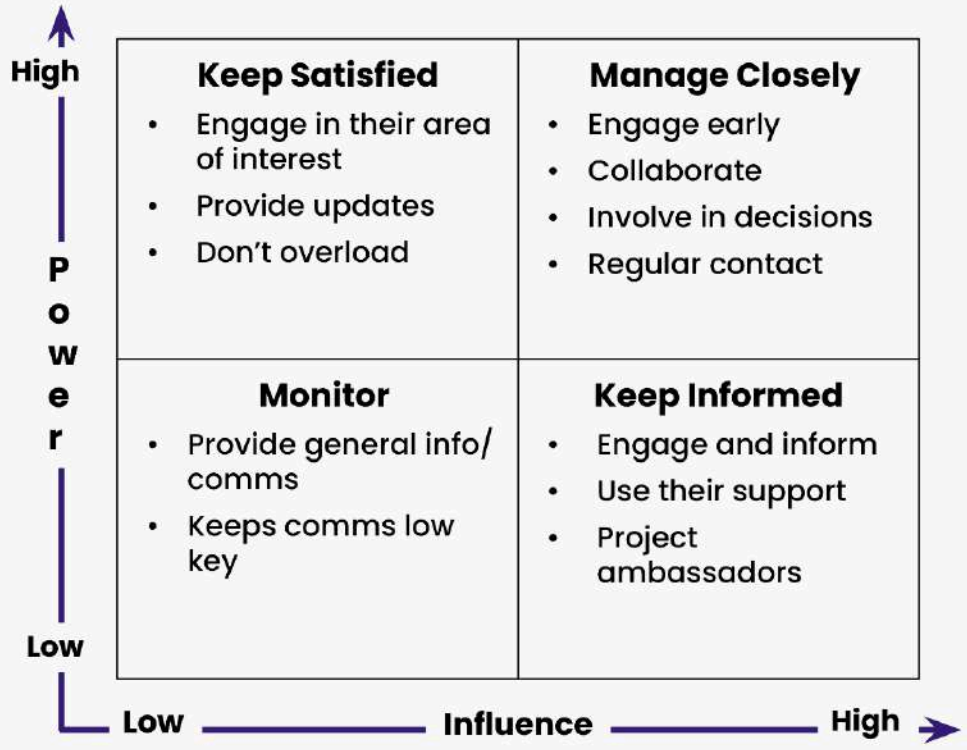
- Allows healthcare providers and policymakers to better understand the patient's needs and experiences
- Linked to increased quality of life and treatment outcomes
  Improves health literacy in patients
- Provides a voice for people who are not being heard
- Holds the healthcare system accountable



Who are the stakeholders in inclusive cancer care?

Whose voice is missing from your usual cancer care conversations...?

Understand their influence and interest



Source: adapted from Burford (2013, p.56)

Who are the key stakeholders? Where do they fit on the power influence model? What methods would you use to engage them?

Case Study 1

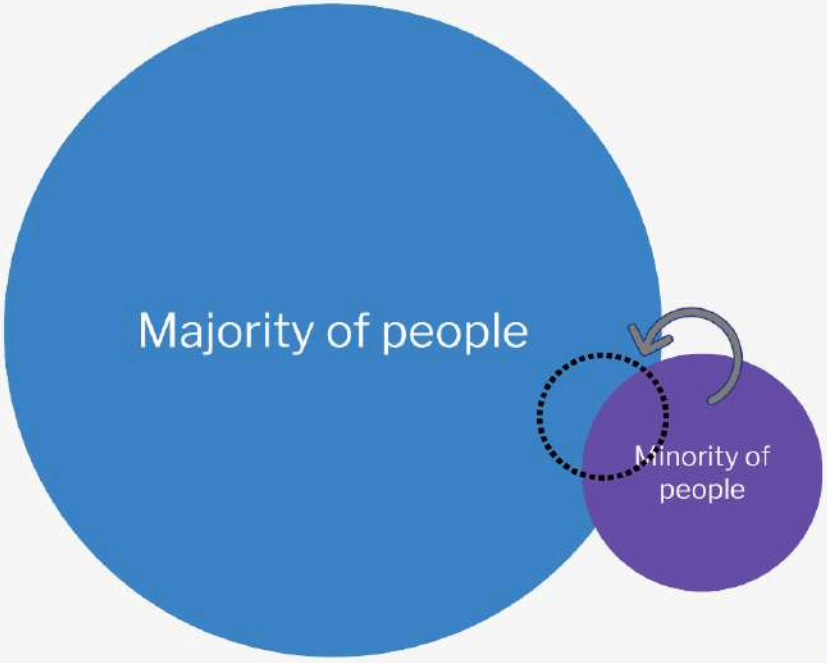
Julia (15 years old) is undergoing treatment for cancer in Poland. Her oncologist would like to enrol her in a new clinical trial she meets all the eligibility criteria. She and her parents do not speak Polish which is making them nervous about the study as they do not understand the information they have been given.

Case Study 2

Raffy (22 years old) has come to you because they are unhappy with the treatment, they have received during their most recent hospital stay. Their boyfriend was not allowed to visit them during their recovery as he was not deemed family. Raffy would like your support to address this policy, so it does not happen again and impact other LGBTQ+ couples.

Courageous Conversations: getting the best outcome

Courageous Conversations: getting the best outcome



Remember **intent vs impact**

The behaviour **feels the same** if you are on the receiving end of it

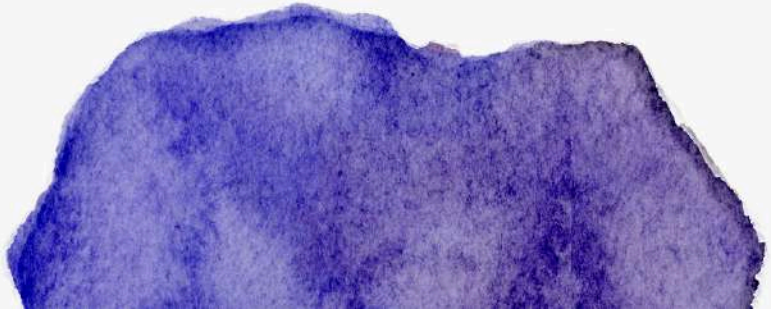
Impact vs Intention

What you said
(Intention)

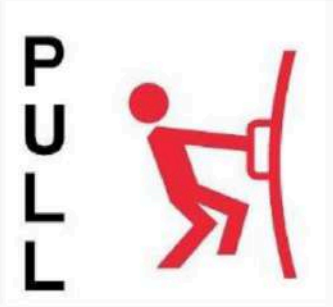
vs.

What they heard
(Impact)

We all say and do things with good intention but sometimes that don't have the impact we were expecting often because our audience has a different worldview to us.



Challenging Behaviour



* Open questions
* Pulling out views
* Active Listening

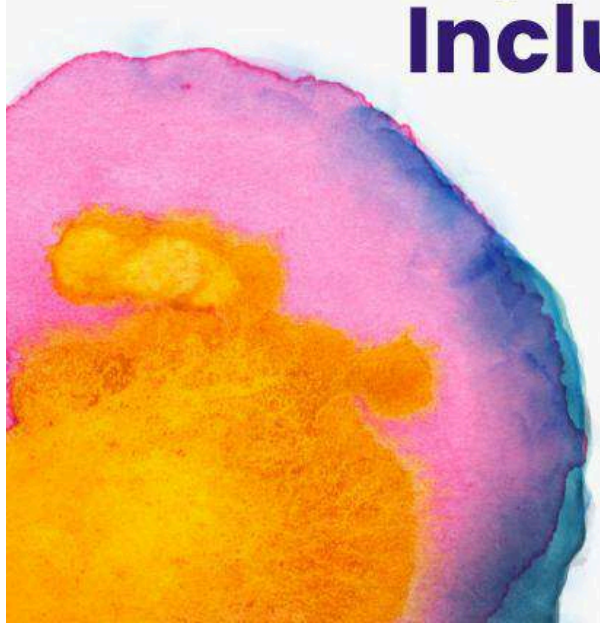
* Suggesting
* Giving Information
* Asserting


Questions?

Next Steps

- Chat with others about what you have learnt
- Complete the activities in your workbook
- Check when your next session will be
- Reach out for further support if needed

Inspiring Others through Inclusion Training and Discussion



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Housekeeping

- Let's pledge to create an environment where people feel safe to participate.
- Give people the space to share their opinion, ensuring we do so in a non-judgemental way
- Be considerate that there may be people in the room with lived experience of this topic.
- Questions and participation are welcomed – please raise your hand.

Session Aims

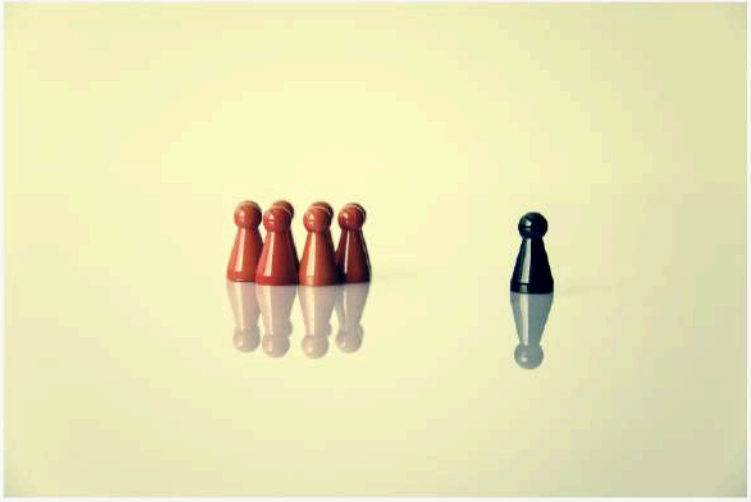
- Reflect on what we have covered so far and the challenges of bringing this learning back into your organisation
- Making the case for inclusion
- Managing difficult conversations
- Empowering others to start their journey


How have you approached making the business case for inclusion to your colleagues and leaders?

What is the impact of exclusion in the workplace and quality of care?

Think about a time at work when you or someone you know felt excluded:

- What was the impact on you/them personally?
- How did it impact on performance?



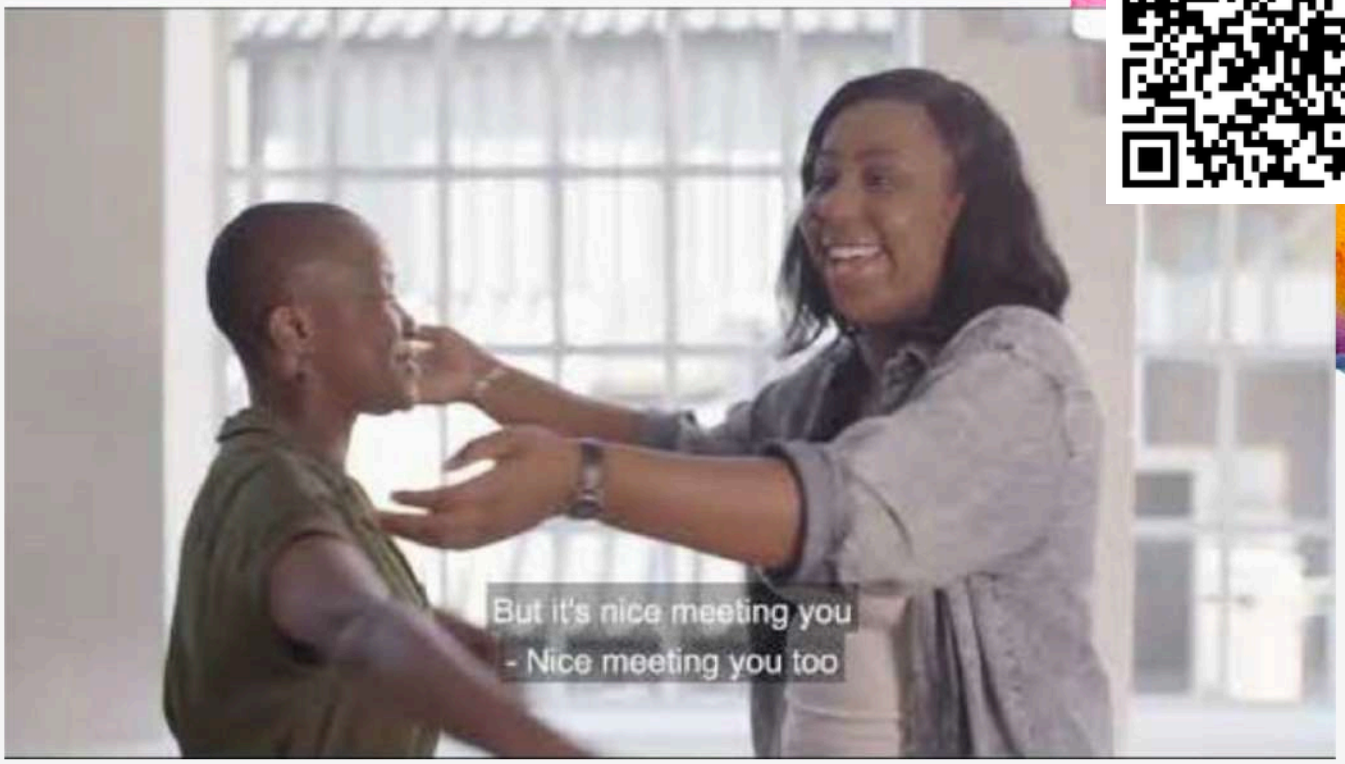
What is the impact of exclusion in the workplace and quality of care?

People

- Lower levels of engagement
- Higher absence
- Retention issues
- Mental ill health
- Job dissatisfaction
- Poor morale
- Poor relationships

Performance

- Less productivity
- Damage to reputation
- Loss of revenue
- Quality suffers
- Targets not met
- Customer satisfaction reduced
- Poor decision making



Source: Vodafone LGBT+ and Friends

Why is being inclusive important?

It creates "Psychological Safety"

- **Psychological safety:**
  - safe to take risks without fear of reprisal
  - safe to admit mistakes, ask questions, suggest ideas
- **Benefits:**
  - retention
  - diversity of thought/innovation
  - increased revenue
  - perceived as more effective


Why might people dismiss diversity and inclusion?

Reasons for Dismissal Narratives

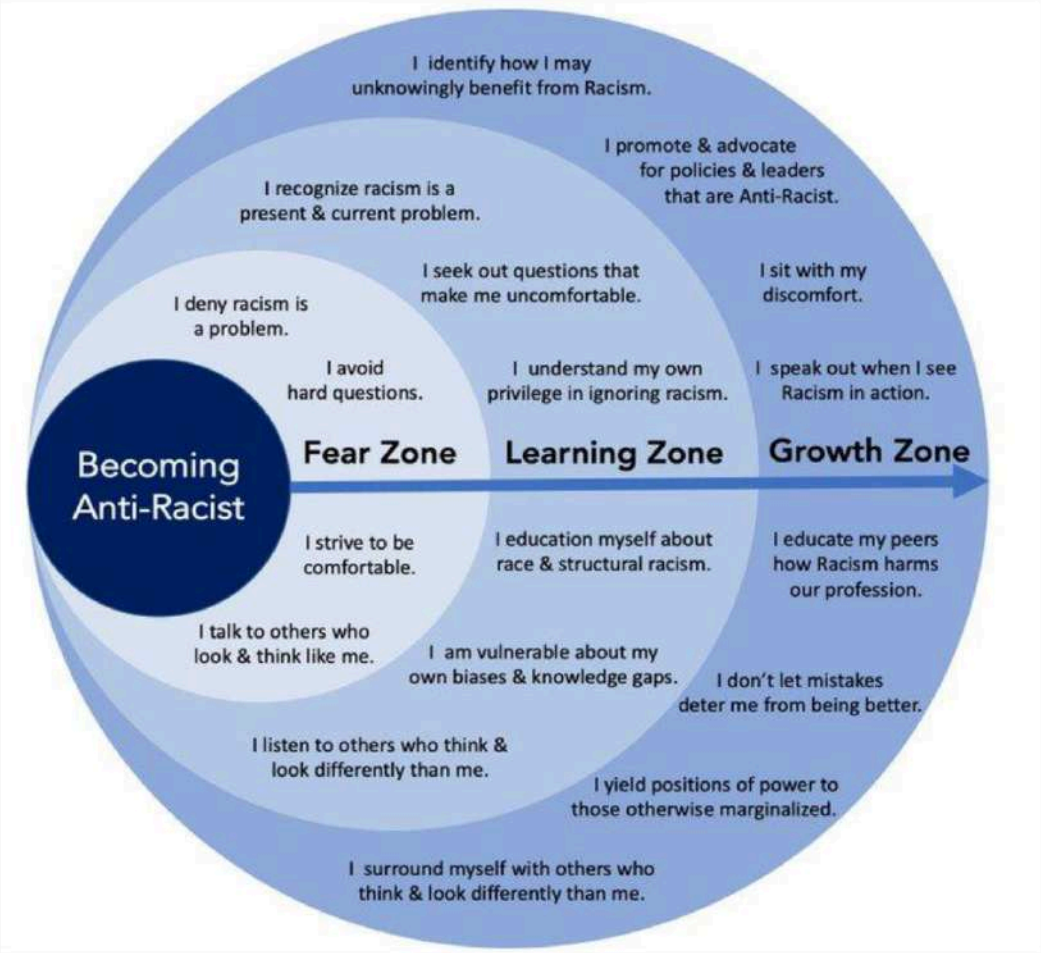
Fear

Moral panic

Influence of misinformation

Challenges their idea of the world


How can we support/influence someone who disagrees with us without making them feel silenced?



The best outcome: growth

- Aiming to move someone from their comfort zone/place of bias and habit
- Into the learning zone, minimizing fear and shame
- Ultimate aim is the growth zone

Chart was adapted by Andrew M. Ibrahim MD, MSc from "Who Do I Want to Be During COVID-19" chart (original author unknown) with ideas drawn from Ibram X. Kendi's work

Action:

"When you did this..."

(specific example of behaviour)

When you spoke over the young person rather than to them

Impact:

"It meant that..."

(impact of behaviour)

It made them feel like they were not included in the decision and actually made them more scared of the treatment

Do:

"In future, can you..."

(suggest different way to behave)

Even if you aren't sure if they understand talk to them rather than their carer, and ask if they need any further support to understand

Charrette:

a meeting in which all stakeholders in a project attempt to resolve conflicts and map solutions

Dialogue Method

Step 1: Ask people what they think the other group/person thinks about them to highlight the damaging impact of stereotypes and assumptions

Step 2: Facilitate moderated discussion, where people can share their views in a respectful and open forum to feel listened to and valued

Step 3: Encourage individuals to find highlight areas where they can learn from each other and expand their knowledge through curiosity and empathy

https://www.ted.com/talks/eve_pearlman_how_to_lead_a_conversation_between_people_who_disagree

Group Discussion

* Where is your confidence to discuss the topics we have covered with your colleagues?
* What challenges did you identify when bringing this learning back into your organisation?
* What additional support do you feel you would need?


Questions?

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European Network of YOUTH CANCER SURVIVORS

For more information please see the event programme and other details on www.beatcancer.eu

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