The Health and Social Care Alliance Scotland (the ALLIANCE)

Health and human rights:

Rights-based decision-making in healthcare settings

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ALLIANCE
HEALTH AND SOCIAL CARE ALLIANCE SCOTLAND
people at the centre

University of Strathclyde Glasgow

Public Health Scotland

Contents

Executive summary

Scotland is on a journey towards building a positive culture of human rights where rights are embedded into law and enjoyed every day. The Scottish Human Rights Bill, which the Scottish Government has committed to, would ensure that several international human rights treaties are enforceable. In addition, Scotland's second National Human Rights Action Plan (SNAP 2)[1] includes actions designed to support the realisation of human rights and lead to better outcomes for everyone.

This preliminary mapping exercise was undertaken by the Health and Social Care Alliance Scotland (the ALLIANCE) as a member of the Health and Human Rights Partnership – an exemplar partnership between us, Public Health Scotland and the Centre for Health Policy at the University of Strathclyde. The Health and Human Rights Partnership seek to promote participation and co-production in health and human rights, including peer research.

This mapping exercise aimed to identify real world examples of rights-based decision making in healthcare settings. It takes forward an action of SNAP 2 and provides a foundation for further research and engagement.

The PANEL Principles[2] were used as a framework to understand and identify examples of a human rights-based approach in practice. Within the scope of this research, the Health and Human Rights Partnership (HHRP) agreed that all PANEL Principles would need to be present for an example to be considered fully compliant with a human rights-based approach.

The mapping identified that the language and terminology in healthcare policy and practice often places more emphasis on person centred and shared decision-making approaches than an explicit human rights-based approach. The lack of explicit reference to human rights, the PANEL Principles and human rights-based approach in decision-making make it difficult to identify real world good practice examples which meet the required standards. However, a small number of examples were identified and analysed that highlight promising practice, albeit with limitations.

The examples we have uncovered reveal that greater attention is placed on some elements of the five PANEL Principles than others, particularly the participation and empowerment principles. It has been challenging to identify real world examples which align with all aspects of the PANEL Principles.

Meanwhile, existing rights-based decision-making tools place a greater emphasis on the lawful, legitimate, and proportionate restriction of individuals' human rights rather than the positive promotion and fulfilment of rights.

In the absence of robust real world examples or tools, the Health and Human Rights Partnership have developed the Rights Based Decision Making Flowchart, which demonstrates how a human rights-based approach to decision-making can be implemented in practice (Appendix 1). The flowchart is designed to consider how policies or decisions can positively promote rights, not just limit them. It can be used in conjunction with Equality and Human Rights Impact Assessments (EQHRIA) as part of a wider approach to equality mainstreaming. The research identified further opportunities to support the implementation and embedding of rights-based decision-making across healthcare settings.

The report makes a series of recommendations for how to implement and embed rights-based decision making across Scotland's healthcare settings. The recommendations cover themes relating to research and engagement, information provision, training and capability building. We have identified the need to engage with healthcare staff to explore their understanding and awareness of rights-based decision making and assess current approaches. Further primary research is required to identify and frame real world examples which fully align with the PANEL Principles. We also recommend testing the Rights Based Decision Making Flowchart with health and care professionals and developing a bank of composite case studies to support future implementation. Further training and capability building would support staff to understand how they can practically apply the Rights Based Decision Making Flowchart and align it with existing equality mainstreaming approaches. Language needs to be aligned in health and care guidance and training to ensure that professionals understand the relationship and interconnection between policy and practice in person centred care, shared decision-making and a human rights-based approach. Building knowledge and capacity of rights-based decision making will help ensure we are positively progressing human rights for everyone.

Introduction and background

Scotland is on a journey towards building a positive culture of human rights where rights are embedded into law and enjoyed every day.

The Health and Human Rights Partnership aims to provide leadership and capacity building to support the implementation of rights-based decision making across Scotland.[3] Since 2015, the Health and Social Care Alliance Scotland (the ALLIANCE), Public Health Scotland, and the Centre for Health Policy at the University of Strathclyde have developed an exemplar partnership to promote participation and co-production in health and human rights, including peer research.

In 2023, the Scottish Government consulted on the incorporation of human rights treaties into Scots law by way of a Human Rights Bill for Scotland.[4] Treaties proposed to be incorporated via a framework model include: the International Covenant on Economic, Social and Cultural Rights (ICESCR), the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW), the Convention on the Rights of Persons with Disabilities (CRPD), and the Convention on the Elimination of All Forms of Racial Discrimination (CERD), as well as recognition of the right to a healthy environment.

There is already a well-established legal and policy landscape in Scotland; any new legal human rights framework would not be introduced in a vacuum.[5] Existing practice, in some instances, can move beyond the demands of human rights and related equality law. However, integrating human rights and related equality law would ensure that current gaps are identified and addressed, helping Scotland to achieve the minimum standard as set out in international human rights law.

> "The task of integrating human rights and related equality law does nevertheless lead to a challenging task of trying to integrate these legal protections into existing landscapes. Further, this process must be addressed, not only in relation to existing legal and policy landscapes, but also organisational cultures and professional practice."[6]

Although there has been a delay to the introduction of the Human Rights Bill, the Scottish Government has 'committed to legislation to incorporate international treaties into Scots law'.[7] In the meantime, the Scottish Government has committed to developing public sector human rights capability and a national human rights tracker tool.

In 2023 Scotland's second National Human Rights Action Plan (SNAP 2)[8] was published. It contains 54 recommended practical actions designed to help advance the realisation of human rights and lead to better outcomes for everyone.

Rights-based decision-making in healthcare settings

As part of the work of the Health and Human Rights Partnership, and with funding from Public Health Scotland, the ALLIANCE undertook research to identify good practice examples of rights-based decision-making (Rights Based Decision Making) in healthcare settings. This activity helps to achieve one of the SNAP 2 actions:

> "To help reduce inequalities and tackle discrimination, carry out a mapping exercise to identify good practice examples of rights-based decision-making in healthcare settings with people whose rights are most at risk. Use the findings and good practice examples to inform, improve and support the implementation of rights-based policy and practice across healthcare in Scotland."[9]

This activity complements other activity in 2024-2025 by the Health and Human Rights Partnership, including the publication of practice guidance for duty bearers on how to commission peer research and use existing peer research within their planning and decision-making, and a briefing paper for duty bearers on how public health duties align with human rights legislation.

This mapping exercise of rights-based decision making in healthcare settings aligns with activity of all Health and Human Rights Partnership programmes, including building upon two 2023 ALLIANCE research projects on human rights and their recommendations. The first of these explores 'Investigating knowledge and understanding of the right to health.'[10] One of its recommendations is for the ALLIANCE to "support and inform policy makers in designing health policy that is inclusive and intersectional". The second project is 'The opportunity is now - human rights in health and social care' report.[11] This recommends that "organisations which claim to use a human rights-based approach should clearly evidence how rights holders are involved at each stage of their process".

Human rights and the right to health

Human rights are the basic rights and freedoms to which all humans are entitled, without discrimination. International human rights law lays down the obligation and duties for states under international law to respect, protect and fulfil human rights.[12]

- Respect: states must refrain from interfering or curtailing the enjoyment of rights.
- Protect: states must protect individuals and groups from human rights abuses.
- Fulfil: states must take positive action to facilitate the enjoyment of basic human rights.

In the UK, the Human Rights Act (1998) incorporates the European Convention on Human Rights (ECHR) into domestic law and makes rights enforceable in national courts, promoting accountability and access to justice.[13] The ECHR largely aligns with the International Covenant on Civil and Political Rights (ICCPR). In 2024, the United Nations Convention on the Rights of the Child (Incorporation) Scotland Act[14] came into force in Scotland. This incorporates the United Nations Convention on the Rights of the Child (UNCRC) into domestic law.

The Scottish Human Rights Bill would make rights included within other treaties enforceable in Scotland. The Bill would include the incorporation of ICESCR which together with ICCPR and the Universal Declaration of Human Rights (UDHR) forms the International Bill of Human Rights.

Article 12 of ICESCR relates to the right to health:

> "The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health."[15]

The right to health underpins our ability to enjoy other rights. As the UN notes: "Health is a fundamental human right indispensable for the exercise of other human rights."[16]

Articles relating to the right to health can be found across other treaties including CEDAW, CERD, CRPD and the UNCRC.

The AAAQ framework (Availability, Accessibility, Adaptability and Quality) sets out the essential elements of the right to health.[17] The AAAQ is a useful framework for unpacking states' obligations.

Identifying healthcare settings

This mapping exercise focuses on examples of rights-based decision making in the context of healthcare settings, rather than the broader landscape of health and care.

Nevertheless, “healthcare setting” itself represents a broad and diverse range of services and places where healthcare occurs. It is helpful to draw on understandings as set out by Article 12 of ICESCR,[18] and relevant ICESCR Committee General Comments on health rights.[19]

Healthcare can include facilities, goods and services. As part of this mapping exercise, the Health and Human Rights Partnership agreed that good practice examples from public healthcare services can include those provided by GP practices, local pharmacies, hospitals or clinics and emergency services as well as specialist and community services.

The right to health goes beyond the provision of healthcare goods, services and facilities to include the social determinants of health, which include housing, employment, environment, equality, and community. It was beyond the scope of our mapping to explore examples relating to health from this wider perspective. However, we did identify that it can be challenging to disentangle individual settings when a more integrated approach is adopted. This is significant when looking at specific population groups and given the growing shift towards a more holistic approach that emphasises “health creation” and the role of joined up working and community support.

Defining rights-based decision-making

A human rights-based approach ensures that dignity is at the centre of decision-making. International human rights frameworks and principles are at the heart of a human rights-based approach.[20]

In healthcare, a human rights-based approach involves empowering people to understand and claim their rights. It increases the accountability of individuals and organisations who are responsible for upholding rights and encourages people to seek remedy when they believe their rights have been infringed.[21]

To help identify real world good practice examples of rights-based decision making in healthcare settings, it is important to understand what a human rights-based approach to decision-making means in this context. One of the key frameworks used to understand a human rights-based approach are the well-known PANEL Principles. PANEL stands for:

- Participation
- Accountability
- Non-discrimination and equality
- Empowerment
- Legality

The FAIR Approach, developed by the Scottish Human Rights Commission, is a flowchart which can help with the application of human rights standards and principles into practice.[22] FAIR stands for:

- Facts,
- Analyse rights,
- Identify responsibilities, and
- Review actions.

For more information on the PANEL Principles and FAIR Approach, please see Appendix 2.

There are other frameworks that set out rights-based approaches, like the FREDA Principles (Fairness, Respect, Equality, Dignity and Autonomy) and the PANTHER Principles (Participation, Accountability, Non-discrimination, Transparency, Human dignity, Empowerment and Rule of law).[23] [24] However, the Health and Human Rights Partnership agreed to focus on the PANEL Principles and FAIR Approach as these are widely recognised in Scotland.

Literature on the PANEL Principles and FAIR Approach frameworks highlights the importance of engaging with all aspects – not just some of their elements – for an approach to be considered as fully aligned with a human rights-based approach.[25] In Scotland, we are now at the stage of moving beyond introductory approaches towards increasingly effective and impactful translation of human rights into everyday practice. Human rights-based approaches have been promoted in Scotland for several years, including in healthcare. The Health and Human Rights Partnership believe it is now time to progress our human rights approaches.

Therefore, when developing our approach to identifying real world good practice examples of rights-based decision making in healthcare settings, substantial thought was given as to whether all the principles and elements of the PANEL Principles and FAIR Approach would need to be present. It was recognised that this would be challenging, and indeed our findings demonstrate that existing examples and case studies tend to be stronger on one or more, rather than all, of the elements. However, the Health and Human Rights Partnership's view is that the presence of all five PANEL Principles is required for decision-making to be considered as fully compliant with a human rights-based approach.

Populations whose rights are most at risk

The research focused on gathering good practice examples of rights-based decision making in healthcare settings with people whose rights are most at risk, which could also be considered an "inclusion health" approach. Adopting an intersectional approach, recognises that people's intersecting identities make them at higher risk of multiple forms of stigma and discrimination, which are barriers for the realisation of their rights.

Previous ALLIANCE research that examined accessible information on the right to health identified groups who are more likely to experience marginalisation due to structural and systemic inequalities. Identified groups include, but are not limited to, asylum seekers and refugees, paid and unpaid carers, Gypsy/Travellers and Roma groups, older people, women, people with lived experience of substance use, people who have experienced homelessness, people who do not speak English as their first language, have experienced mental ill health, and people who live in areas of social and economic deprivation.[26] Appendix 3 provides some examples of the population groups whose rights could be at most at risk in healthcare settings.

Populations within the scope of this research

Recognising that it was beyond the scope of our mapping exercise to include every population group whose rights could be at risk in healthcare settings, the Health and Human Rights Partnership agreed to focus this exercise on women, disabled people, people experiencing homelessness, and black and ethnic minority groups. This decision was informed by the current policy landscape and in recognition of the wide basis of work and legislation in relation to other population groups.

The Scottish Human Rights Bill will incorporate treaties which include specific rights relating to these population groups (CEDAW, CRPD, ICESCR, and CERD). We recognise that there are existing supportive policy drivers for these population groups. For example, the Women's Health Plan (2021 to 2024)[27] which acknowledges the unique health inequalities that women can face and sets out how the Scottish Government intends to reduce health inequality outcomes. The development of NHS Board Anti-Racism Plans are aimed at addressing racialised health inequalities. The proposed Housing (Scotland) Bill[28] includes specific prevention duties on Public Bodies by 'asking and acting on a risk of homelessness'. Concerted action highlights the commitment to tackling the inequality in outcomes for these specific population groups. The 2025 Disability Equality Plan is intended to improve the lives of disabled people and put their experiences and concerns at the heart of policymaking.[29]

Methodology

Desk based research was undertaken by the ALLIANCE from November 2024 to March 2025. This included a combination of scoping the Public Health Scotland Knowledge Exchange database and grey literature. The review of grey literature included, but was not limited to, government documents and reports, conference papers, government consultation responses, organisational reports, blogs, research reports, newsletters, website pages, survey results and tweets. Grey literature offered the advantage of providing access to current and up to date information sources, which was important when trying to identify real world best practice examples. Academic resources reviewed as part of initial scoping highlighted a lack of practical examples within recent timeframes.

The desk based research involved scoping and drawing on evidence from over 40 sources including, but not limited to, the ALLIANCE, Public Health Scotland, Audit Scotland, Healthcare Improvement Scotland, Together (Scottish Alliance for Children's Rights), Engender, British Institute of Human Rights (BIHR), Homeless Network Scotland, Coalition for Racial Equality and Rights (CRER), Scottish Care, What Matters to You, Scottish Government, and Care Opinion.

Public Health Scotland Knowledge Services

A preliminary search of the Knowledge Exchange database was undertaken by the Public Health Scotland Knowledge Services team. Key search words were used including the following: human rights, hospitals, clinics, care homes (includes residential care homes and nursing homes), dental services, homecare, GP services, mental health, community-based health and care services, primary care, optometry, dentistry, podiatry.

The results from the search revealed several reports, articles and blogs with information about rights-based approaches in both health and social care settings. The results highlighted population groups including children and young people, groups with experience of substance use, people with mental health conditions and people experiencing dementia. The majority of these were from academic journal articles and lacked practical examples. Many of these articles promoted the use of rights-based approaches and suggested there was a need for greater awareness and understanding for implementing these approaches in practice. This suggests that there is still a gap in implementing a human rights-based approach.

> "It was identified there was a need to develop guidance to support health and social care staff in understanding a human rights-based approach to care and support and to assist them in the implementation and application of human rights principles in their everyday work."[30]

Additionally, whilst there was information on rights-based approaches, there were limited references to human rights-based approach in relation to decision-making within the articles identified via the Knowledge Exchange database.

Care Opinion

A search was conducted on Care Opinion to identify potential examples of good practice in relation to rights-based decision-making in healthcare settings.[31] Care Opinion is a non-profit organisation funded through subscriptions from health and care organisations. It allows those receiving health and care services, and carers, to share stories and experiences both positive and negative.

It should be noted that this is unprompted data which hasn't undergone analysis or been selected to support a thematic narrative within a report. However, it offers insights into human rights-based approach to decision-making from an individual perspective. Key search words used included the following: human rights, choice, decisions, person centred, listened to, and involved.

Research and reports

Snapshots of good practice were primarily identified in reports and other sources produced by organisations Including Health Improvement Scotland, Engender, the ALLIANCE and Self Directed Support Scotland (SDSS), and The National Collaborative. Good practice was evidenced through case studies, quotes and narrative reports. Evidence tended to be framed from a particular thematic perspective; this meant it was challenging to identify how much they aligned with rights-based approaches as there were gaps in the information provided. This highlighted a need for greater emphasis and framing of examples using a human rights-based approach.

Limitations

There are limitations with this mapping exercise, which focused on secondary published data. Firstly, research was carried out within a short timescale from November 2024 to March 2025. During this short period, it was challenging to find publicly available information about real world good practice examples that demonstrate each of the five PANEL Principles. While information available in the public domain offers snapshots of promising practice, detail is lacking to determine if this practice is consistent and fully aligned with a human rights-based approach as defined by the Health and Huma Rights Partnership for this mapping exercise. Examples we identified tend to be focused around one or more specific aspects of the PANEL Principles (e.g. participation) but provide little or no information relating to the others. In particular, there appears to be a real lack of publicly available information about how the 'accountability' PANEL principle is applied in practice. Furthermore, although we identified some existing rights-based decision-making tools, these appear to place a greater emphasis on determining whether there is a lawful, legitimate, and proportionate restriction of individuals' human rights alone, without considering the positive promotion and fulfilment of rights.

Anecdotally, it has been suggested to the Health and Human Rights Partnership that there are real world examples of a human rights-based approach to decision-making in healthcare (or other) settings, however they have either not been published at all, or in a way that our mapping could uncover, or are not currently framed as a human rights-based approach example. To understand the full picture of existing practice, we recommend further research to collect, analyse and publish primary data, using surveys, focus groups, interviews, and the development of case studies.

The parameters of this mapping exercise means that the focus is restricted to healthcare settings, which impacted the examples that could be identified. The right to health goes beyond the delivery of healthcare goods and services to include wider provisions. Given the increasing integration between health and social care, it can be challenging to separate and identify the specific role that rights-based decision making plays within the context of a healthcare setting alone.

In addition, it should be recognised that even when frameworks such as Equality and Human Rights Impact Assessments are available, there can be significant barriers to adoption in practice. These include resource implications, competing priorities within health and care settings, and organisational cultures that may deny or minimise the extent to which current practices contribute to rights-related challenges. Such factors can limit the consistent and meaningful application of rights-based decision-making at both practitioner and system level.

Clarifying language and terminology

During the mapping exercise we noted the importance of using clear and unambiguous rights-based language and terminology. For example, within the context of Scottish healthcare policy and practice there is generally a stronger emphasis on concepts like “person centred care” and less explicit reference to human rights or a human rights-based approach.

Defining “person centred care” can be challenging, and it has been recognised that there are a “diversity in definitions”.[32] However, there is a generally agreed set of principles which underpin the approach. Person centred care is defined by NHS Education for Scotland (NES) as:

> “Care that is about ensuring the people who use services are at the centre of everything. It is delivered when health and social care professionals work together with people to tailor services to support what matters to them. It ensures that care is personalised, co-ordinated and enabling so that people can make choices, manage their own health and live independent lives, where possible.”[33]

Literature on person centred care emphasises some of the needs and rights of the person in their personal and social circumstances as well as within a healthcare setting.[34] The practical approach to person centred care, ‘Must Do With Me’, encourages conversations which start by asking the person: “What matters to you?”.[35]

Another concept that is more prevalent than an explicit human rights-based approach in healthcare policy and practice is “shared decision-making”, Shared decision-making is a person centred approach which recognises that there are two experts in the decision-making process, the healthcare professional and the person with lived experience.

Both person centred approaches and shared decision-making are key elements of Realistic Medicine, which is promoted by the Chief Medical Officer for Scotland. Realistic Medicine advocates for an approach to healthcare which supports people and their families to feel empowered to discuss their treatment and makes them the centre of decisions about their care.[36]

Some elements of person centred approaches and shared decision-making align to an extent with a human rights-based approach to decision-making. For example, both can contribute to the participation and empowerment PANEL Principles. However, it is unclear the extent to which person centred care and shared decision-making engage all elements of the PANEL Principles and not just a selective few.

Conversely, it could be argued that implementing a human rights-based approach would provide for person centred care,[37] and what is known as “supported decision-making”, which maximises a person’s ability to make decisions for themselves, with support if required.[38]

Snapshots of good practice

A lack of explicit reference to human rights-based approach in decision-making examples has made it difficult to identify real world good practice which meet the requirements of this mapping exercise, including for the specific populations groups that have been identified. For example, whilst there is evidence of action, investment and initiatives to tackle racialised health inequalities, it has been challenging to identify examples that demonstrate meaningful impact.

We have identified a small number of examples that highlight promising practice with limitations, including a lack of publicly available information and evidence. The examples explored below focus on population groups who experience barriers to the enjoyment of their rights and have some elements that align with a human rights-based approach. The population groups involved include women, those with experience of substance use, and disabled people. However, it should be recognised that intersectionality plays an important role when understanding the interconnectedness of human rights. The examples highlight the overlapping nature of people's identities and the need to understand the impact on rights from a holistic point of view.

Informed decision-making and dignified care

A search of the Care Opinion website identified several stories which highlight good practice relating to some of the PANEL Principles, particularly participation and empowerment. Several examples relate specifically to women's health, which could imply that Care Opinion is more actively promoted by this part of the healthcare system and/or that women experience, in some instances, greater positive interactions with women's specialised healthcare services.

In the examples we analysed, individuals said they were provided with enough information to help them make decisions about their care and treatment and treated with dignity and respect throughout the process.

> "I was provided with information to enable to make an informed decision that work for my own particular situation and preferences." (Royal Infirmary in Edinburgh, Endoscopy)[39]

> "At every stage of this experience in Inverness, I was treated with dignity and was included in all decisions." (Raigmore Hospital, Gynaecology)[40]

> "I voiced my concerns to Dr and discussed my options. We agreed not to make a decision at this appointment and she arranged an appointment with a

> menopause specialist a few weeks down the line for me to discuss all options." (Fife Community Services, Sexual Health)[41]
> "You are each autonomous and responsible and accountable for safe, compassionate, person centred, evidence-based nursing that respects and maintains every persons dignity and human rights.
>
> You have treated me as a person, taking genuine interest in me and my needs showing empathy and compassion and really hearing my story. You each have shown professionalism and integrity and work within recognised professional, ethical and legal frameworks. I have felt safe and secure in the care you have provided me and have fully trusted your professionalism and competency. I have also witnessed how well you work in partnership with other health and social care professionals and departments and most importantly patients, putting relationship based practice at the heart of all that you do." (Perth Royal Infirmary, Clinical Investigations Unit)[42]

Telemedical abortion care

During the COVID-19 pandemic, temporary measures were introduced which allowed for early medical abortions to be taken at home without the need for in person appointments.[43] Telemedical abortions were included within the Equality Impact Assessment which was undertaken in September 2020 to ensure that women and pregnant people were not negatively impacted by delayed or restricted access to abortion care.[44]

A joint research report by Engender and the ALLIANCE published in 2023 highlighted the positive implications this decision had for women by providing them with flexibility over treatment options.

> "I thought it was great that I could have it at home. I had to pick up the medication from our local hospital. The instructions were very clear and the doctor went through all the information on the phone very clearly. It was awful to experience but being able to do it in my home made it better." [45]

In an evaluation of telemedicine early medical abortion at home it was highlighted that it allowed for "improved access and more patient-centred care, giving patients more autonomy over the process".[46]

The example of telemedical abortion aligns with aspects of a human rights-based approach to decision-making, including the participation and empowerment PANEL Principles. It allows women to have the choice, control and autonomy over the abortion process helping them to realise their "reproductive autonomy".[47] Telemedical abortion care also aligns with the non-discrimination and equality

PANEL Principle because it provides easier access for groups who are often disproportionately impacted when trying to access abortion services. For example, it:

- Removes geographical barriers which are experienced by women living in remote and rural areas.
- Helps remove hidden costs which can impact people from lower socio-economic circumstances including travel and childcare costs.[48]
- Negates physical access challenges for disabled women and supports a more inclusive and equitable approach.
- Helps to protect and keep women safe who are at risk of abuse of coercion by a partner by allowing them to access the service discreetly.

As part of an independent evaluation, a survey was conducted to gather the views of people who had undergone an early medical abortion which highlighted positive support for retaining options.[49] Survey respondents highlighted the positive benefits associated with a telephone appointment including "privacy, convenience, comfort and flexibility". In response to feedback from rights holders the decision was taken to continue with the policy. In December 2024, an approval was granted which allowed for early medical abortions to be undertaken at home in certain circumstances.[50]

Abortion supports the right to life, health, freedom from torture or cruel, inhuman and degrading treatment and privacy. The interpretation of existing human rights covers sexual and reproductive health to include abortion.[51] The UN Committees that oversee the implementation of CEDAW and ICESCR have set standards which states should follow. For a Scottish approach to fully align with all the PANEL Principles, the legality principle should be addressed. For example, there could be more explicit reference to human rights and specific rights impacted, which is currently lacking within policy documentation.

Self-directed Support (SDS)

The ALLIANCE and SDSS 2021 report 'My Support, My Choice: People's Experiences of Self-directed Support and Social Care in Moray' [52] (MSMC: Moray) highlights an example where a person had a sense of control over their care and treatment in hospital. Although this example sits within the wider context of Self-directed Support (SDS) and social care, it highlights the interconnected relationship with health and takes place in a healthcare setting. This examples, aligns with both the participation and empowerment PANEL Principles. In this case, the individual was able to request that their Personal Assistants (PAs) support their personal care rather than hospital staff because of their established relationship and approach to communication.

> "One person recounted that hospital staff understood SDS and allowed the SDS user's PAs to carry out their daily personal care (e.g. feeding) and

> helped with communication between the interviewee and medical professionals. This was very helpful, as the PAs knew the interviewee's communication methods and preferences better than any hospital staff, and were able to use that expertise, following the interviewee's wishes."

As with other examples, there is unfortunately not enough available information to assess whether this example fully aligns with a human rights-based approach to decision-making.

Near-fatal overdose response

One example was identified within an Audit Scotland report on alcohol and drug services published in 2024[53] and relates to effective data and information sharing. Whilst it is not explicitly described within the context of a human rights-based approach to decision-making, it does align with some elements of the PANEL Principles.

In this example, the Scottish Ambulance Service identified that Angela (not her real name) was at high risk of drug-related harm and implemented the non-fatal overdose response. This response involved taking a holistic approach and working with Angela to develop a package of support. Although rights are not explicitly referenced, this approach considers the rights to life, to the highest attainable standard of mental and physical health, to an adequate standard of living, and to freedom from torture and other cruel, inhuman, or degrading treatment or punishment. By doing so, and taking a holistic approach, the example somewhat aligns with the legality PANEL Principle. It aligns with the 'non-discrimination and equality' PANEL Principle due to the provisions put in place to protect Angela from experiencing abuse in the future (she was referred to Women's Aid and supported through a women's only recovery group).

> "Good information sharing between stakeholders can lead to a better experience of services and improved outcomes 'Angela' has suffered domestic and sexual violence for most of her life and has been using drugs for around 15 years. She was financially dependent on her abusive partner who also used drugs. Abandoned by her partner, Angela was left to die in a derelict property until someone found her and called for an ambulance. This triggered the near-fatal overdose response in which an outreach team sought to contact Angela to check on her welfare. The assertive outreach team located Angela and, by gaining her trust and providing support, coordinated a bespoke package of support to help her, including the following:
>
> - referral to Women's Aid for further support
> - placement in a women-only hostel

- offer of support and same-day prescribing (however Angela was not ready to engage with this)
- provision of harm reduction advice and regular contact.

Within a year, Angela was rehoused in another area to escape her ex-partner. Links to the GP and benefits system were all maintained to allow a smooth relocation. She now attends a local women-only recovery group and has begun opioid substitution treatment. Angela is on a pathway to recovery, and her general health and wellbeing are considerably improved."

There is not enough evidence provided to assess the extent to which Angela participated in, and was empowered by, the decision-making process. It is inferred that Angela made the decision not to engage with support for same-day prescribing, however we do not know if or how she was involved in positive decisions about her care and treatment.

National Collaborative

The National Collaborative's vision is to integrate human rights into drug and alcohol policy leading to better outcomes for people affected by substance use. It is a dynamic process involving people with experience of problem substance use as well as people responsible for delivering support services.[54]

A call for evidence was undertaken as part of the National Collaborative's initial scoping stages. This revealed that people impacted by substance use experience barriers to meaningful involvement in decision-making around care planning.[55] The findings also emphasised that people with lived and living experience of substance use are being tokenistically involved in local decision-making and policy development.

In December 2024, the 'National Charter of Rights for People Affected by Substance Use' was launched.[56] The Charter aims to help people to be aware of their rights and the support they can expect to receive. It provides a guide for how to adopt a human rights-based approach to decision-making. The Charter provides information on how rights holders can hold services to account if they feel their rights have not been met. It was developed using extensive engagement with people affected by substance use and those responsible for the design, delivery and monitoring of support services.[57] The Charter is accompanied by a range of practical resources to support its implementation for both rights holders and duty bearers. These include 'Guidance on balancing rights' using the FAIR approach, 'FAIR approach for Alcohol and Drug Partnerships (ADPs) and Lived and Living Experience (LLE)', and 'The FAIR Approach for frontline services.'[58]

The Charter Toolkit provides a space for emerging practice of how the Charter is being implemented in practice including plans to produce case studies to highlight good practice examples of human rights-based approach to decision-making. The National Collaborative and Charter example highlights potentially promising practice in relation to the design of a human rights-based approach to decision-making which is underpinned by all five PANEL Principles.

Rights Based Decision Making Flowchart and guidance

In the absence of robust real world examples that fully align with a human rights-based approach to decision-making in healthcare settings, the Health and Human Rights Partnership developed a Rights-Based Decision-Making Flowchart and guidance to support healthcare practitioners and policymakers (Appendix 1).

The Rights-Based Decision-Making Flowchart is a tool to support rights-based decision-making in healthcare settings. The flowchart can be used in conjunction with Equality and Human Rights Impact Assessments (EQHRIA) and integrated as part of equality mainstreaming approaches. It draws upon both the PANEL Principles and FAIR Approach frameworks.

Several flowcharts already exist that are designed to support individuals and organisations to approach decision-making through a human rights lens. These are primarily underpinned by the Human Rights Act (1998) – which incorporates the rights in the European Convention on Human Rights into domestic law – and focus on whether restricting a qualified right is justified. The difference with the Health and Human Rights Partnership Rights Based Decision Making Flowchart is that it also focuses on international treaty rights that create positive as well as negative obligations. The inclusion of these rights means that decision makers must also consider how the policies and decisions they undertake proactively promote and fulfil rights, not just legitimately limit them.

Conclusion

To achieve a Scotland that actively promotes a positive culture of human rights, policy makers and practitioners need to have a robust awareness and understanding of human rights-based approach and have confidence applying it in decision-making.

Although this mapping exercise is limited, our findings suggest that there is a lack of explicit reference to rights in current decision-making processes. None of the published real- world examples demonstrate good practice against every one of the five PANEL Principles. Within existing decision-making flowcharts there is an emphasis on situations where rights can be legitimately limited rather than proactively fulfilled.

Emerging good practice examples identified place a greater emphasis on some elements of the PANEL Principles than others, particularly the participation and empowerment principles. Non-discrimination and equality were recognised, to an extent. For example, there was recognition that certain groups may experience overlapping inequalities particularly in the context of telemedical abortions and non-fatal overdose.

The legality principle featured to an extent within the examples we uncovered, however there needs to be more explicit reference to specific rights and the treaties they relate to as well as relevant national policy and legislation.

Within the snapshot of examples analysed here, there is far less emphasis on the accountability principle. Accountability tends to be given a stronger focus when rights have been breached, rather than fulfilled. As our Rights Based Decision Making Flowchart demonstrates, good practice can highlight proactive accountability measures as part of a decision-making process. Accountability should not just be a consideration after rights have been breached.

Within the context of healthcare, the language and terminology emphasises concepts like “person centred” care and “shared decision- making”. A human rights-based approach to decision-making can underpin and strengthen all these approaches. Greater clarity and coherence are required to ensure that policy makers and practitioners understand how these approaches interact with one another and can be applied in practice.

Further primary research is required to identify real world examples of a human rights-based approach to decision-making that explicitly and fully align with all elements of the PANEL Principles. In the absence of robust examples, tools like our Rights Based Decision Making Flowchart can be used to guide this approach in practice.

We are at a pivotal point in Scotland and can work together to build knowledge and capabilities, to ensure we progress everyone's human rights.

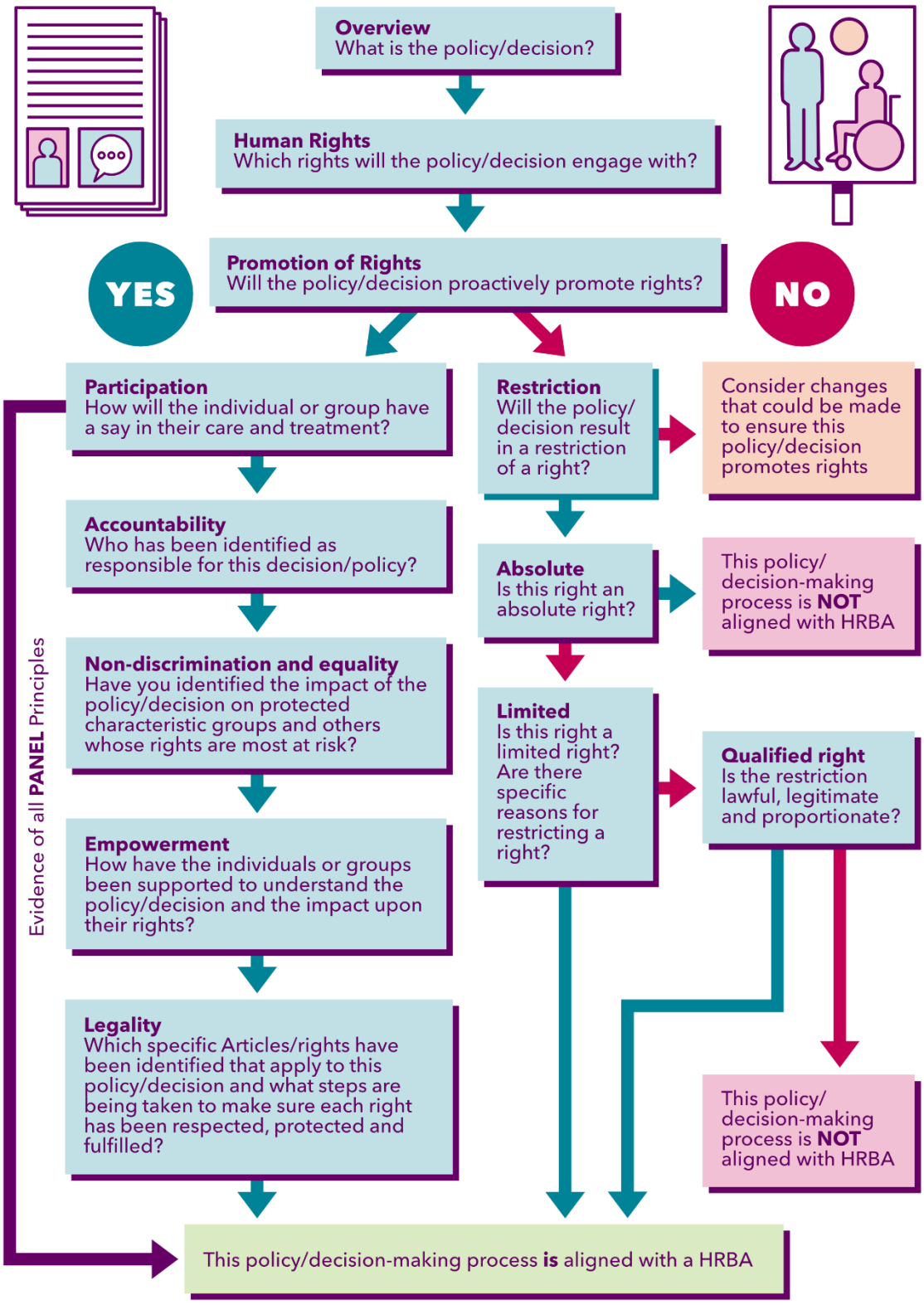
Many thanks to the Health and Social Care Alliance Scotland, Public Health Scotland, University of Strathclyde for exploring human-rights based-decision making in healthcare settings as part of the Health and Human Rights Partnership.

Recommendations

Through undertaking this mapping exercise, we have developed a series of key recommendations for the next stage in implementing and embedding rights-based decision-making in Scotland's healthcare settings. Our recommendations cover themes related to further research and engagement, the provision of practical and accessible information, training and capability building.

- Engage with healthcare staff to gather their insights, understanding and awareness of rights-based decision making in healthcare settings. This engagement should seek to understand public bodies' current approaches to decision-making and alignment with a human rights-based approach.
- Carry out further research and engagement to collect primary data and examples, with a focus on specific population groups, of rights-based decision making that fully aligns with all five of the PANEL Principles.
- Undertake robust engagement on and testing of the Health and Human Rights Partnership Rights Based Decision Making Flowchart with health and care practitioners.
- Coproduce a bank of composite case studies with healthcare professionals to highlight how the Rights Based Decision Making Flowchart can be applied in practice. Case studies will highlight examples of decisions in relation to system change, commissioning, service design and individual care.
- Identify and design training and capability building to support health and social care staff to understand the human rights-based approach to decision-making, how to implement in practice using the Health and Human Rights Partnership Flowchart and guidance and how it aligns with an Equality and Human Rights Impact Assessments (EQHRIA) and equality mainstreaming approaches.
- Align language in health and social care guidance and training to ensure that professionals understand the relationship and interconnection between policy and practice in person centred care, shared decision-making and a human rights-based approach.

Appendix 1: Rights Based Decision Making Flowchart and guidance



Understanding the flowchart

The Rights Based Decision Making Flowchart is a tool to support rights-based decision-making in healthcare settings. It draws upon both the PANEL Principles and FAIR Approach. For this process, it is important to consider each policy or decision individually. You may wish to revisit the flowchart if changes are made after you originally undertook the decision or developed the policy in question.

Several flowcharts already exist which are designed to support individuals and organisations to approach decision-making through a human rights lens. These are primarily underpinned by the Human Rights Act (1998),
which makes the rights in the European Convention on Human Rights enforceable in domestic law in the UK, and focus on whether restricting a qualified right is justified [59] Qualified rights are those that come with a list of legitimate reasons for restricting a person's enjoyment of that right.

A difference with the Rights Based Decision Making Flowchart is that it includes additional international treaty rights that cover a wider range of public authority obligations. The inclusion of such rights means that duty bearers must also consider how their policies and decisions proactively promote rights, not just how they might legitimately limit rights.

When using this Rights Based Decision Making Flowchart, consider the different types of decision-making that take place within settings. For example, the decision-making process in a clinical setting may be strictly time-bound, which will differ from the development of a longer term policy.

Navigating the flowchart

Overview

What is the policy or decision?

This question asks you to provide an overview of the policy or decision that you are planning/need to make. Completing this ensures that information is in one central place.

Who will be affected by the policy/decision?

Identify the individuals or groups who are going to be impacted by this policy or decision. Consider that more than one individual or group may be impacted. This is important when thinking about how this policy or decision relates to human rights. Decisions or policies may have different consequences for groups involved and

impact their rights differently - both positively and negatively. A non-exhaustive list of population groups whose rights could be impacted are set out in Appendix 3.

What is the intended outcome/s of the policy/decision?

You will need to set out what this policy or decision aims to achieve. To inform this decision you should have worked with individuals or groups impacted to develop rights-based person-centred outcomes.

Who is making the decision? Do they have a duty to uphold human rights?

You will need to specify who is making this decision, there should be robust accountability processes in place. Duty bearers have the responsibility or obligation to respect, protect and fulfil human rights. Duty bearers include organisations like the Scottish Government and those that deliver public services, like local government, Health Boards, Health and Social Care Partnerships, and the police.

All duty bearers must take account of a range of legal frameworks. For example, in healthcare delivery settings, other legal frameworks that are relevant, include laws that imposes a duty of care on practitioners, whether they are Healthcare Assistants, Assistant Practitioners, students, registered nurses, doctors or others (further information on a human rights-based approach to healthcare delivery decision-making can be found in the free online course DIGNISPACE, produced by the University of Strathclyde and the University of Edinburgh Public bodies who count as human rights duty bearers should include human rights law as a fundamental consideration in their decision-making.[60]

Shared decision-making is an approach which recognises that there are two experts in the process, those with lived experience and the healthcare professionals, and supports people to make informed choices. As a result, people should be viewed as equal partners in their own care and treatment and be involved in as much of the decision-making process as they would like to be. Aspects of shared decision-making align with the participation and empowerment principles of rights-based decision making and may be helpful to consider. To find out more about shared decision-making NHS Education for Scotland (NES) have produced a module to provide information on how to structure a shared decision-making conversation.[61]

Human rights

Which rights does the policy/decision engage?

At this stage in this process, you will identify the rights that could be relevant to the individuals or groups involved in the decision/policy.

Rights-based decision-making in healthcare settings

Human rights are basic rights and freedoms to which all humans are entitled. These rights are found in international agreements which states like the UK, including Scotland, are bound to uphold. International human rights law sets out duties under international law to respect, protect and fulfil human rights.[62]

- Respect: states must refrain from interfering or curtailing the enjoyment of rights.
- Protect: states must protect individuals and groups from human rights abuses.
- Fulfil: states must take positive action to facilitate the enjoyment of human rights.

Rights are contained in the following treaties which have been ratified (approved) by the UK, and in relevant domestic (national) law. Please note that there will be some rights which are present across multiple treaties, for example, the right to the highest attainable standard of health. The legal sources included in the Rights Based Decision Making Flowchart are:

- International Covenant on Civil and Political Rights (ICCPR).
- International Covenant on Economic, Social and Cultural Rights (ICESCR).
- European Convention on Human Rights (ECHR).
- Convention on the Elimination of all forms of Discrimination Against Women (CEDAW).
- Convention on the Elimination of All Forms of Racial Discrimination (CERD).
- Convention on the Rights of Persons with Disabilities (CRPD).
- United Nations Convention on the Rights of the Child (UNCRC).
- Human Rights Act 1998 (HRA).
- United Nations Convention on the Rights of the Child (Incorporation) (Scotland) Act 2024.

Additionally, the right to a healthy environment has been recognised by the UN General Assembly and has been included in proposals for a Scottish Human Rights Bill.[63] [64]

For more information, please see Appendix 4 which lists a selection of human rights and relevant legal sources.

There are two pathways in the flowchart one which looks at how the policy or decision supports the “promotion” (fulfilment) of rights and one that looks at the “restriction” of rights.

Promotion of rights

Once you have decided which rights the policy/decision engages, you will need to assess whether you think the policy/decision will positively promote (protect and fulfil) the individual or groups' human rights.

Yes

If you decide that the policy/decision will help positively promote rights, then you will outline how it aligns with each of the elements of a rights-based approach as set out by the PANEL Principles.[65] All elements of the framework will need to be evidenced for the decision or action to be defined as taking a rights-based approach.

Participation

Everyone has the right to participate in decisions which affect their human rights. Participation must be active, free, meaningful and give attention to issues of accessibility, including access to information in a form and a language which can be understood.

How will the decision or policy support the individual or group have a say in their care and treatment? Have you ensured inclusive communication and accessibility requirements?

As highlighted it is essential that people participate in decisions around their care and treatment to help lead to better outcomes. This question asks you to outline how the views of those impacted have been taken into consideration with regards to the decision or development of the policy. This should take place at all levels of decision-making from the individual level to service design and commissioning processes. To make informed decisions rights holders need to have access to appropriate information, inclusive communication and advice and support.

Accountability

Accountability requires effective monitoring of human rights standards as well as effective remedies for human rights breaches. For accountability to be effective there must be appropriate policies, institutions, administrative procedures and mechanisms of redress to secure human rights.

Who has been identified as responsible for this policy/decision? What accountability processes are in place in case rights have not been protected or fulfilled?

This question is asking you to identify who has the responsibility for the policy or decision. Who is ultimately responsible will be set out in legislation. If individuals and groups have been engaged with as part of this process, they should be informed as to who is accountable.

You will need to set out what processes people can follow if they feel that their rights have not been protected or fulfilled. This could be outlining the feedback and complaints mechanisms that are available, including where people can go and who they can speak to if they have concerns about the policy or decision.

How will the outcomes of this decision/policy be monitored and evaluated?

Clear processes for monitoring and evaluation should be in place to outline how success is being measured against the identified outcomes. These processes reinforce accountability and highlight the responsibility of decision makers for respecting, protecting and fulfilling human rights.

Non-discrimination and equality

A human rights-based approach means that all forms of discrimination (such as age, gender, sexual orientation or ethnicity) in the realisation of rights must be prohibited, prevented and eliminated. It also requires the prioritisation of those in the most marginalised or vulnerable situations who face the biggest barriers to realising their rights.

Have you identified the impact of the policy/decision on protected characteristic groups and others whose rights are most at risk?

This question encourages you to consider how this policy or decision will impact specific groups whose rights are most at risk. It is important to take an intersectional approach and consider that some individuals may face multiple forms of discrimination.

How would this decision or policy positively promote equality and non-discrimination of the identified individual or groups?

This question asks you to reflect on the identified groups and highlight how this policy or decision will positively promote human rights. You may wish to think about how it will contribute to addressing barriers some groups experience in the context of healthcare settings.

Empowerment

Individuals and communities should understand their rights and be fully supported to participate in the development of policy and practices which affect their lives. Individuals and communities should be able to claim their rights where necessary.

How have individuals and groups been supported to understand the decision/policy and the impact upon their rights?
How can individuals or groups claim their rights?

Ensure that individuals/groups have received accessible information on planned decisions or policies. Make sure that measures are in place for people to provide feedback on these plans. Even when a decision is made in an urgent context, accessible information in some form should be provided where possible, and individuals should have an opportunity to provide feedback if human rights are at stake.

Individuals and groups should be aware of the process for challenging a policy or decision if they feel it will not be, or has not been, rights respecting. Complaints processes must be accessible and user friendly.

Legality

A human rights-based approach requires the recognition of rights as legal entitlements and is linked to national and international human rights law. It should be noted that currently not all human rights are legally enforceable in the UK or Scotland. This may change over time.

Which specific rights ('articles' in international treaties) have been identified that apply to this decision/policy and what steps are being taken to make sure each right has been protected, respected and fulfilled?

Reflecting on the rights identified earlier in the flowchart, highlight how this decision or policy will ensure that identified rights are being protected/fulfilled.

If there is evidence of all PANEL Principles, then you can be confident that you have adopted a rights-based approach to decision-making.

Restriction of rights

Rights that cannot be restricted

No

If you decide that the decision or policy won't lead to the progression of rights, you will need to decide whether it will restrict any of the rights involved. Your assessment of whether a policy/decision could be incompatible with rights may consider failures to act as well as acting.

Yes

Absolute rights are fundamental and cannot be interfered with under any circumstance, for example the right to freedom from inhuman or degrading treatment.

If you decide that this decision or policy is impacting or likely to impact an absolute right, then this decision or policy process is NOT likely to be aligned with a human rights-based approach. This person or group's rights must be protected and cannot be restricted under any circumstance.

No

If you decide that this policy or decision doesn't restrict rights, then consider if there are changes that could be made to make this policy or decision compatible with the promotion of rights and start the flowchart process again.

Rights that can be restricted in specific circumstances

Some rights can be limited, for example there are certain defined limited circumstances when you can legitimately be deprived of your right to liberty.[66]
If you decide that a limited right is at stake, you should check the permissible circumstances in which the right can be restricted. These permissible justifications will be set out under the individual Article. Each Article protects an individual right or freedom and is set out in relevant national legislation or regional or international treaties.

Yes

If you decide the right in question is a limited right, then you can be confident that your process is aligned with a human-rights based-approach.

You should outline how you plan to monitor and evaluate the impact of your policy or decision. Consider when you will review this policy or decision and how you will ensure the person/s are involved in the process. Identify who will have responsibility for reviewing this decision.

No

If you decide this right is not a limited right, then you will need to continue to the qualified rights section of the flowchart.

Qualified Right

A qualified right can be restricted in some circumstances and within limits.[67] They can be restricted to protect, for example, the rights of others or wider public interest. The first part of the Article sets out the right to be protected and the second part sets out the permissible reasons for interfering with the right. These permissible justifications are often broadly construed - you should record the reasons for restricting a right in as much detail as possible.

Is the restriction lawful, legitimate and proportionate?

You will need to ensure that the restriction of a qualified right is compatible with the following principles:

Lawful

There must be a legal basis which is clearly understood.

Legitimate

There needs to be a specific reason for restricting this right. For example, the protection of other people's rights, national security or public health.

Proportionate

The decision or policy is necessary in a democracy and in response to a 'pressing social need'.[68] It must be the minimum necessary restriction of the right.

Yes

If you feel the restriction of the qualified right is lawful, legitimate and proportionate then you can be confident that your process to decision-making is aligned with a rights-based approach to decision-making.

No

If the decision or policy fails to meet the following principles of being lawful, legitimate and proportionate **then your process is not** aligned with a rights-based approach to decision-making. You will need to change your policy or decision.

Ongoing development

As part of the ongoing development of the Rights-Based Decision-Making Flowchart feedback on how it has been applied and implemented in practice would be welcomed. The flowchart is open to future development and refinement as we understand how it works in individual settings to support different forms of decision-making. If you would be interested in working with the Health and Human Rights Partnership to test the use of the flowchart, please get in touch with us.

Appendix 2: PANEL Principles and FAIR Approach

PANEL Principles

The PANEL Principles are one of the frameworks which form the basis of a human rights-based approach. The Principles are the following:

Participation
Everyone has the right to participate in decisions which affect their human rights. Participation must be active, free, meaningful and give attention to issues of accessibility, including access to information in a form and a language which can be understood.

Accountability
Accountability requires effective monitoring of human rights standards as well as effective remedies for human rights breaches. For accountability to be effective there must be appropriate laws, policies, institutions, administrative procedures and mechanisms of redress to secure human rights.

Non-discrimination and equality
A human rights-based approach means that all forms of discrimination (such as age, gender, sexual orientation or ethnicity) in the realisation of rights must be prohibited, prevented and eliminated. It also requires the prioritisation of those in the most marginalised or vulnerable situations who face the biggest barriers to realising their rights.

Empowerment
Individuals and communities should understand their rights and be fully supported to participate in the development of policy and practices which affect their lives. Individuals and communities should be able to claim their rights where necessary.

Legality
A human rights-based approach requires the recognition of rights as legally enforceable entitlements and is linked into national and international human rights law.

FAIR Approach

The FAIR approach was designed by the Scottish Human Rights Commission to help guide people when undertaking a human rights-based approach.

Facts

Establish the situation and the important facts. What is the experience of the individual, have they been supported to have their views heard?

Analysis
What are the human rights at stake? Are rights at risk of being restricted, is the justification lawful, legitimate and proportionate?

Identify
What changes are necessary and who is responsible for making the necessary changes?

Record and Review
Have the actions been taken recorded and reviewed? Has the individual impacted been involved in this process?

Appendix 3: Rights holder examples

In Scotland, some people may experience bigger challenges in realising their rights due to inequality and discrimination related to their characteristics or how their characteristics intersect. People whose rights are most at risk can vary from issue to issue. The following table provides a non-exhaustive list of people whose rights could be most at risk in healthcare settings.

Rights holder group (and source)	Definition/example
Age (PC)	The Equality Act (2010) defines age as: "A person belonging to a particular age or range of ages". For example, 18-20 year olds. This can include children, teenagers, adults, older people. Age discrimination can occur in various forms and involves the negative treatment or unjustifiable exclusion from activities because of your age.
Disability (PC)	Under the Equality Act, disability includes people who are disabled, people who have learning disabilities and people living with long term conditions. Click here for more information on the definition of disability as a protected characteristic.
Gender reassignment (PC)	The Equality Act (2010) defines gender reassignment as: a person has the protected characteristic of gender reassignment if the person is proposing to undergo, is undergoing, or has undergone a process (or part of a process) for the purpose of reassigning their sex by changing physiological or other attributes of sex. For a full legal definition of gender reassignment, click this link to visit the Equality Act 2010
Marriage and civil partnership (PC)	The Equality Act (2010) defines as: A person has the protected characteristic of marriage and civil partnership if the person is married or is a civil partner.

Pregnancy and Maternity (PC)	The Equality Act (2010) defines pregnancy as: the experience of being pregnant or expecting a baby. The Equality Act (2010) defines maternity as: the time period after birth. Protection against maternity discrimination is for 26 weeks after giving birth and this includes treating a breast feeding individual unfavourably because they are breastfeeding.
Race/ethnicity (PC)	The Equality Act (2010) defines race/ethnicity as a "group of people defined by their colour, nationality (including their citizenship), ethnicity or national origins. A racial group can be made up of more than one distinct racial group, such as Black British".
Religion or belief (PC)	Within the Equality Act (2010) this is reference to any religion including a lack of religion. Belief means any religious or philosophical belief or a reference to a lack of belief.
Sex (PC)	Within the context of the Equality Act (2010) sex refers to a male or female of any age. The protected characteristic of sex also refers to groups of people such as a group of men, boys, women and/or girls.
Sexual orientation (PC)	The LGBTQI+ community. Within the Equality Act (2010) sexual orientation refers to: A person's sexual orientation towards (a) persons of the same sex, (b) persons of the opposite sex, (c) persons of either sex"
Socio-economic disadvantage (FSD)	The Scottish Government defines socio-economic disadvantage as: a person or group of people that have low/no wealth; low income; reside in an area of deprivation or that have material deprivation.

	Material deprivation is a direct measure of poverty that results from the lack of items and activities deemed to be necessary for an acceptable standard of living.
Unpaid carers (HI)	The Scottish Government defines unpaid carers as individuals who provide care and support to family members, friends and/or neighbours. The people they care for may have lived experience of a broad range of conditions.
Sensory Loss/Impairment (PC/HI)	Lived experience of Deafness, Deafblindness or Visual impairment. For more information of sensory loss/impairment visit the Scottish Sensory Hub on the ALLIANCE website.
Homelessness (HI)	Shelter Scotland and the Scottish Government outline the legal definition of homelessness in Scotland. Someone is considered homeless if they: have nowhere to stay, are staying somewhere their family cannot live with them, staying in temporary accommodation like a hotel or a friend's house, they have accommodation but it is unsafe and/or unreasonable for them to keep staying there due to domestic violence for example.
Involvement in the criminal justice system (HI)	The Criminal Justice Alliance defines lived experience of the criminal justice system as people who have been: "stopped and searched, spent time in prison or been the victim of a crime".
Addictions and substance use (HI)	A person or group of people with lived/living experience of substance use. This includes alcohol and drugs both legal and illegal. This also includes being impacted by substance use through caring for a family member or friend who has experienced substance use and/or addiction.
Low health literacy (HI)	The NHS define health literacy as the" knowledge, understanding, skills and confidence to use health information".

Living in remote, rural and island locations (HI)	The Scottish Government officially classes specific areas of Scotland as rural. Accordingly, rural Scotland is defined as settlements with a population of less than 3,000. These commonly include: - Aberdeenshire - Angus - Argyll and Bute - Dumfries and Galloway - East Ayrshire - Highland - Moray - Na h-Eileanan Siar - Orkney Islands - Perth and Kinross - Scottish Borders - Shetland Islands - South Ayrshire - Stirling
Digitally excluded (HI)	Digital exclusion is defined by the Scottish Government's Digital Exclusion Index as: "people who are not capable of using the internet, either because they lack digital skills or confidence in using a computer and online services and/or they do not have access to the internet". You can view the latest statistics for digital exclusion by clicking this link to the Digital Exclusion Index.
Socially isolated (HI)	The Scottish Government defines social isolation as "an objective lack of social relationships in terms of quality and/or quantity at the individual, group, community and/or societal level.

Appendix 4: Human rights examples

The table below lists a selection of human rights and relevant legal sources. The Human Rights Act (HRA) is UK law and makes rights in the European Convention on Human Rights (ECHR) as a regional treaty, enforceable. The ECHR is largely aligned with the International Covenant on Civil and Political Rights (ICCPR). The ICCPR and its sister treaty, the International Covenant on Economic, Social and Cultural Rights (ICESCR) are international laws that the UK has signed up to. The Scottish Human Rights Bill, which the Scottish Government has committed to developing, would aim to make rights in ICESCR (and other group-focused treaties) enforceable in Scotland. General Comments are another useful source of information around human rights. General Comments, or recommendations, act as guides which provide more information on specific obligations and can be referred to by states. The table also provides some examples of which rights holders could be impacted by an infringement of each right – there will be many other examples and things that need to be considered. These examples may be useful when developing Equality Impact Assessments.

Human right (and treaties)	Potential rights holder groups impacted by an infringement of the right	Things to consider
Non-discrimination (race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status) (ICCPR) Prohibition of discrimination. (ECHR, HRA)	Minority ethnic communities LGBTQIA+ Religious communities (See protected characteristics) Disability Refugees and asylum seekers Socio-economic disadvantage	Will this policy or decision inadvertently discriminate against a particular group?

Effective remedy (if the violation has been committed by persons acting in an official capacity) (ICCPR, ECHR, HRA)	All groups	Is there a mechanism to signpost individuals to remedy procedures if they feel their rights have been breached?
All persons deprived of their liberty shall be treated with humanity and with respect for the inherent dignity of the human person. (ICCPR)	Individuals who have or who are experiencing the criminal justice system	If involving this group, are your programme materials and activities respectful?
No one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence, nor to unlawful attacks on his honour and reputation. (the right to privacy). (ICCPR, ECHR, HRA)	All groups	Have you considered how to protect the privacy of the individuals your programme involves?
Everyone shall have the right to hold opinions without interference. (ICCPR, ECHR, HRA)	All groups	Are you actively engaging with individuals impacted by this policy or decision and supporting them to share their opinions and experiences?
Everyone shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless	All groups	Are you actively engaging with individuals impacted by this policy or decision and supporting them to share their opinions and experiences?

of frontiers, either orally, in writing or in print, in the form of art, or through any other media of his choice, (ICCPR, ECHR, HRA)		
Everyone shall have the right to freedom of association with others, including the right to form and join trade unions for the protection of his interests. (ICCPR, ECHR, HRA)	All groups	Are you ensuring that health and care staff have opportunities to engage with Trade Unions?
In those States in which ethnic, religious or linguistic minorities exist, persons belonging to such minorities shall not be denied the right, in community with the other members of their group, to enjoy their own culture, to profess and practise their own religion, or to use their own language. (ICCPR, ECHR, HRA)	Minority ethnic communities Religious communities Cultural communities (including Deaf culture)	Are you providing translation services/for engagement to be carried out in the first language of the individuals or groups impacted?
To work. (ICESCR)	Individuals recruited as volunteers	Are you providing health and care staff with favourable working conditions?
To renumeration. (ICESCR)	All groups	Has consideration been given for how to renumerate individuals' participation

		including for their time, energy and expertise?
To safe and healthy working conditions. (ICESCR)	Staff	Staff working according to organisational health and safety policy and according to staff accessibility requirements.
To rest and leisure and reasonable limitation of working hours. (ICESCR)	Staff To a lesser extent: Volunteers	Be mindful of the 'ask' towards those that you are engaging with if you are not able to renumerate them for their involvement.
To form trade unions. (ICESCR) To strike. (ICESCR) To maternity leave. (ICESCR)	Staff	Are staff able to participate and freely join a trade union? Does the decision impact access to paid maternity leave?
To be free from hunger. (ICESCR)	All groups. In particular: Individuals from areas of deprivation/poverty Socio-economic disadvantage	Does your policy or decision involve increasing knowledge on nutrition and healthy eating?
To the highest attainable standard of physical and mental health including: - Reduction of still-birth rate and of infant mortality and for the healthy development of the child	All groups	Are you gathering lived experience of accessing health services to inform the development of your policy or decision?

the improvement of all aspects of environmental and industrial hygiene; - The prevention, treatment and control of epidemic, endemic, occupational and other diseases; - The creation of conditions which would assure to all medical service and medical attention in the event of sickness. (ICESCR)		Are you engaging with those who have a lived experience of specific health conditions?
To take part in cultural life. (ICESCR)	Minority ethnic communities Cultural communities (including Deaf culture)	Is this policy or decision culturally informed? Are you providing translation services/for engagement to be carried out in the first language of the individuals or groups impacted?
Freedom of thought, conscience and religion. (ECHR, HRA, ICCPR)	All groups. In particular: Religious communities	Are you actively engaging with individuals impacted by this policy or decision and supporting them to share their opinions and experiences?
Not to be subjected to torture or to cruel, inhuman or degrading treatment or punishment (ICCPR, ECHR, HRA)	All groups	Are you assessing the impact that this policy or decision is having on an individual's quality of life and wellbeing?

To liberty and security. No one shall be deprived of liberty except on such grounds and in accordance with such procedure as are established by law. (ICCPR, ECHR, HRA)	All groups	Are you considering how this decision might impact an individual's ability to liberty? (e.g. are they able to come and go without restriction)
To education. - Primary education shall be compulsory and available free to all. - Secondary education in its different forms shall be made generally available and accessible and in particular by the progressive introduction of free education. - Higher education shall be made equally accessible to all. (ICESCR) (ECHR, ICCPR, HRA First Protocol Article 2)	Children and young people	Are you considering the impact this action would have on an individuals' ability to access their education?

Endnotes

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About The ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector membership organisation for the health and social care sector. We bring together over 3,700 people and organisations dedicated to achieving our vision of a Scotland where everyone has a strong voice and enjoys the right to live well, with dignity and respect. Our members are essential in creating a society in which we all can thrive, and we believe that by working together, our voice is stronger.

We work to improve the wellbeing of people and communities across Scotland by supporting change in health, social care and other public services so they better meet the needs of everyone in Scotland. We do this by bringing together the expertise of people with lived experience, the third sector, and organisations across health and social care to shape better services and support positive change.

The ALLIANCE has three core aims.

We seek to:

- **Empower people with lived experience:** we ensure disabled people, people with long term conditions, and unpaid carers are heard and that their needs remain at the heart of the services and communities.
- **Support positive change**: we work within communities to promote co-production, self management, human rights, and independent living.
- **Champion the third sector:** we work with, support and encourage co-operation between the third sector and health and social care organisations.

The ALLIANCE is committed to upholding human rights. We embed lived experience in our work and aim to ensure people are meaningfully involved at every level of decision-making.

Working together creates positive, long-lasting impact. We work in partnership with the Scottish Government, NHS Boards, universities, and other key organisations within health, social care, housing, and digital technology to manage funding and develop successful projects. Together, our voice is stronger, and we can create meaningful change.

Contact

The Health and Social Care Alliance Scotland
E: info@alliance-scotland.org.uk
T: 0141 404 0231
W: http://www.alliance-scotland.org.uk/

ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre

Public Health Scotland

Public Health Scotland (PHS) is Scotland's national public health agency, established on 1 April 2020. It brings together the former functions of NHS Health Scotland, Health Protection Scotland, and the Information Services Division (ISD). Operating as a Special Health Board jointly sponsored by the Scottish Government and COSLA, PHS plays a central role in improving and protecting the health and wellbeing of people in Scotland.

Led by Chief Executive Paul Johnston, PHS's vision is for a Scotland where everybody thrives. The agency works collaboratively acrossor, and private partners to address the wider determinants of health, reduce health inequalities, and increase healthy life expectancy through prevention and early intervention.

PHS focuses on three key areas:

1. **Prevent disease** – through leadership on immunisation, infectious disease control, and pandemic preparedness.
2. **Prolong healthy life** – by reducing premature mortality (e.g. from drugs, alcohol, tobacco) and using data to support improvements in health and care services.
3. **Promote health and wellbeing** – by tackling root causes of inequality such as poor housing, child poverty, and lack of access to greenspace, and by influencing policy and supporting local communities.

All of this is underpinned by data, evidence, and intelligence, with a strong emphasis on place-based approaches, public service reform, and human rights. The organisation is guided by the values of respect, collaboration, innovation, excellence, and integrity.

Contact

Public Health Scotland
T: 0345 646 0238
W: Contact us - Public Health Scotland

Public Health Scotland

University of Strathclyde

Contributions to the Health and Human Rights Partnership have evolved from the Centre for Health Policy to also include Strathclyde's Centre for Doctoral Training in Human Rights-Based Decision Making.

The Centre for Health Policy s led by Co-Directors, Professor Kat Smith and Lee Knifton, and Associate Directors, Dr Lisa Garnham and Dr Jackie Stewart. It was established in 2014 by Lee Knifton and Professor Neil Quinn, with support from Professor Sir Harry Burns. CHP is an academic hub for fresh perspectives on healthcare and public health policy. We are firmly rooted in Scotland, but with strong international engagement generating valuable comparative insights and learning. We value relationships with policy and practice, work directly with affected communities, and protect space for critical and conceptual academic analysis. We spearhead innovative qualitative and mixed methods research into health policy, including participatory research with communities. The Centre's current cross-disciplinary activities cover the following five broad thematic areas:

- Reducing inequalities
- Public mental health
- Participation and Engagement in Health
- Innovation in health systems, policy and practice
- Long-term perspectives in health and wellbeing

The Strathclyde Centre for Doctoral Training in Human Rights-based Decision Making, launched in 2023, is a cross-disciplinary hub for PhD researchers focused on enhancing understanding of the complex challenges and opportunities related to human rights-based decision making by a range of actors/institutions in the public, private, and third sector. Its aim is to bring together a cohort of postgraduate researchers to build interdisciplinary skills and knowledge needed to help tackle the major challenges of translating international legal protections into more just institutions, processes, and equitable outcomes for people in their everyday lives. Doctoral researchers affiliated with the Centre for Doctoral Training are trained by, and collaborate with, a broad supervisory team to grow a critical knowledge base around understanding how human rights standards can become integrated in strategic and operational decision making.

Contact

Dr Elaine Webster
University of Strathclyde
E: elaine.webster@strath.ac.uk
T: 0141 548 4428
W: www.strath.ac.uk/staff/websterelainedr/

University of Strathclyde Glasgow