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Report:

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# Investigating knowledge and understanding of the right to health

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Commissioned by the Health and Social Care Alliance Scotland  
(the ALLIANCE)

[www.alliance-scotland.org.uk](http://www.alliance-scotland.org.uk)



While there will be a cost to realising human rights, we have known for a long time that if we prevent violations in the first place, that is a lot more effective than pushing (rights holders) into crisis and then trying to mop up.<sup>1</sup>

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Equity is just so much cheaper.<sup>2</sup>

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# Executive Summary

This research was commissioned by the Health and Social Care Alliance Scotland (the ALLIANCE) as part of the [Health and Social Care Academy](#) to investigate the accessibility of information on the right to health in Scotland, across different groups. The research was undertaken by an independent researcher.

The definition of the right to health used in the research is based on that found in the United Nations' International Covenant on Economic, Social and Cultural Rights, the UK Human Rights Act 1998, the Scotland Act 1998, and Scotland's second National Action Plan for Human Rights.

The research considers input from organisations representing several population groups and considers how limitations in access to information about the right to health, alongside challenges in claiming and complaining about the right to health, could present a barrier to the rights of those groups to achieve equal access to the highest attainable standard of health.

## **The aims and objective of this research were:**

- To briefly quantify the level of understanding of the concept of the right to health across different groups in Scotland.
- To seek an understanding of the barriers of access to information on the right to health in Scotland.
- To form a picture of the work being undertaken and being planned by representatives of different groups to inform and support individuals who access services to claim their right to health.
- To investigate opportunities for the ALLIANCE to develop information and education resources on the right to health for representatives of different groups and people they support.

One-to-one, semi-structured, online interviews were undertaken with thirteen respondents. Interviews were conducted with participants representing bodies who engage with different groups in relation to rights, and the right to health. Recurring themes, key words, and recommendations were identified from transcriptions of the interviews; findings reflect the views of the interview respondents. Time and financial limitations meant that the research could only include a limited number of interviews with representatives from different groups in Scottish society. The research sought to safeguard the welfare of respondents by actively incorporating ethical considerations into its methodology and approach. See appendix 1 for further information on the chosen research methods.

# Main Findings Summary

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## Findings summary section 1: Barriers to accessing information on the right to health

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Findings from the research suggest that there is a prevalent lack of understanding within the public of both the right to health and of how to access information on the right to health. Respondents detailed how information provision on claiming rights in general for the public is very poor. Respondents observed that people do not know how to access information on their rights, and subsequently how to claim their rights.

Respondents underlined how the lack of understanding in accessing information on the right to health is likely to be particularly significant for underrepresented groups. Observing that the broader principles of structural inequalities apply to the provision of information on the right to health, respondents called for effective evaluation to ensure that health information reaches all groups.

Respondents noted that the design and content of health information can affect accessibility. They called for improved information dissemination across all groups, a deeper understanding of diverse cultural experiences, and more empathetic language and content in information provision. Further to this, they observed that the complex language of health, alongside the complicated nature of human rights can be a barrier to understanding and accessing information on the right to health.

The right to health was described by respondents as being “too complex”, and not yet “alive” as a policy issue. They argued that framing health information from a human rights perspective can make it less accessible for individuals. There was a general agreement by the respondents that until the right to health is better understood and defined in practical terms both at policy level and at street level, any information provision would be at risk of being inaccessible and redundant.

Some respondents argued that there is a shortfall in understanding by NHS staff and services of people’s entitlement to the right to health. Respondents described how people they support feel power imbalances between rights holders and duty bearers which can allow duty bearers to be unaccountable for failures to fulfil rights. Furthermore, respondents observed that there is no accessible recourse for people whose human rights are not being met, despite the Scottish Government’s promise to incorporate human rights into legislation in Scotland.

Respondents questioned the integrity of governmental assertions of the fulfilment of the right to health in Scotland, given the challenges faced by healthcare services after a decade of austerity and service cuts, and called for policy action to address those social and economic determinants of health that have a negative effect.

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## **Findings summary section 2: What happens when the right to health is not fulfilled?**

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Respondents agreed that people often do not understand how to make a complaint about their right to health not being fulfilled and observed that only a small proportion of people may have the resources, education, space, and experience to be able to make complaints. They pointed out that complaints processes are long, complex, and difficult to navigate, and observed the re-traumatising effects of making a complaint. Furthermore, respondents described people's experiences of early gatekeeping and 'blame culture' in the complaints process, where their concerns were dismissed by duty bearers, and agreed that underrepresented and minority groups would be reluctant to make a complaint for fear of repercussion and victimisation.

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## **Findings summary section 3: What are organisations doing in relation to information on the right to health**

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In the main, respondents stated that although they underpin their work with a human rights-based approach, they do not offer explicit support or outreach or produce resources on how to access information on the right to health. Resources and activities undertaken by those respondents' organisations that do produce information on the right to health include accessible representations of case studies of good practice in fulfilling the right to health, programmes for people accessing services based on health rights and self management skills, and a series of school visits to increase awareness of healthcare provision and expectations. Other respondent organisations undertook activities and generated resources on human rights in general including public health messaging, policy analysis and advocacy, research, training and development, helpline services for individuals, outreach sessions, information resource production and collaborative work with other organisations.

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## **Findings summary section 4: Other factors**

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Respondents flagged that the level of trust that some groups have in public institutions and service providers has an impact on the efficacy of information provision on the right to health. Furthermore, they argued that people's ability and willingness to engage with their right to health can be tied to their self-identity, their self-perception of worth, and their social status.

Respondents discussed who should be held accountable for the fulfilment of people's rights, noting that responsibility is placed on rights holders, requiring them to have the capability and capacity to negotiate what can be a complex and inaccessible system. They questioned power imbalances between rights holders and duty bearers. They highlighted that the onus is on individuals to claim their rights rather than the responsibility of duty bearers to deliver rights.

The importance of effective data collection for ensuring that everyone can access the right to health was emphasised. There was a call for effective use of data, intelligence, and evidence to identify those people who are least likely to claim their rights and most likely to be impacted by a failure by society and systems to recognise their rights.

Respondents considered where the right to health sat in the bigger picture. They argued there is a failure to consider the structural changes required for rights to be realised in the first place. They noted the importance of recognition that poor health is impacted by failure to meet all rights, resulting in the social determinants of health, and argued that people should be enabled and empowered to claim all their rights, not just the right to health. Observing the need for a societal shift to a culture where human rights and practices are embedded, respondents noted the considerable demands of the training, capacity building, and resourcing that this shift would require.

## Recommendations summary

Analysis of the interview data identified recurring themes and findings which informed several recommendations. The following summary of those recommendations serves as a brief overview; for a comprehensive understanding of the research findings, it is advisable to read the full recommendations. The recommendations reflect the views of the interview respondents and have been organised into three categories: Scottish Government and Healthcare Public Bodies, Third Sector, and recommendations for the ALLIANCE.

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### Scottish Government and Healthcare Public Bodies

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Respondents called on both groups to promote rights fulfilment at leadership levels and underlined the importance of engagement with community and group leaders in the design and dissemination of healthcare information. They cited a need for the development of accessible information resources on human rights and advised that government and healthcare institutions collaborate internally and externally to prevent duplication and improve policy coherence. Respondents emphatically called for healthcare complaints processes to be streamlined and made more accessible, and that human rights training should be systematically incorporated into healthcare education. They pointed to the social determinants of health as a major barrier to people's ability to claim both their human rights, including the right to health. Finally, respondents underlined the importance of adaptability in healthcare policy and service design.

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### Third Sector

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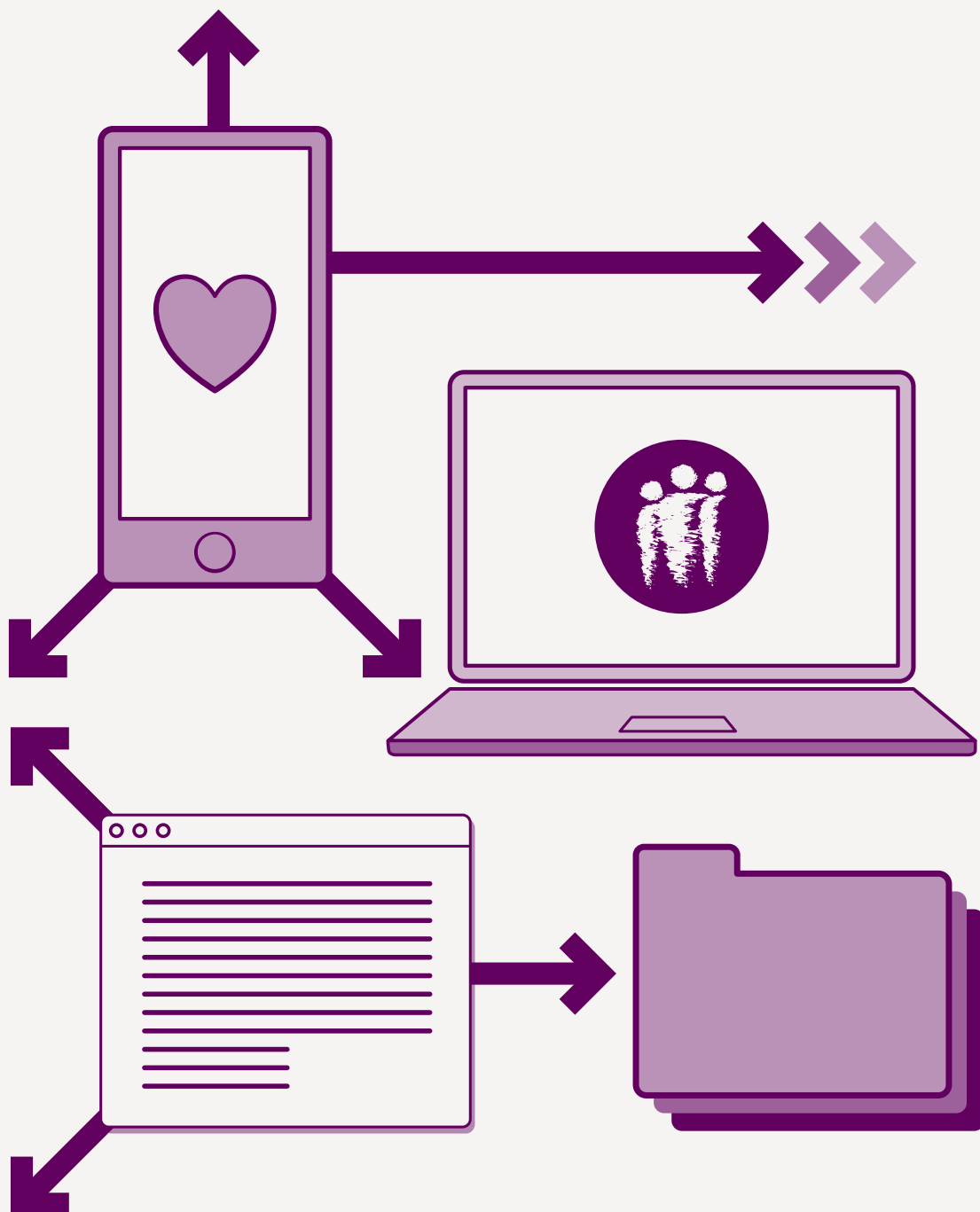
Recommendations for the third sector emphasised the importance of holding duty bearers accountable, participating in policy influence, and conducting research and community engagement to address trust gaps. Respondents also advocated for a review of health data collection and called for the creation of a 'community leader network'.

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## The ALLIANCE

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Respondents emphasised the ALLIANCE's advantageous position to be able to support policy makers, whilst maintaining pressure on the Scottish Government and duty bearers to address failings in the realisation of people's right to health, particularly in relation to marginalised groups. They called on the ALLIANCE to support the provision of information on the right to health by fostering engagement among various stakeholders, conducting further research, supporting individuals from disadvantaged backgrounds, and facilitating the development of community leader networks. They suggested collaborative opportunities which encompass co-creation and dissemination of information, co-design of training and outreach events, and co-production of media resources.





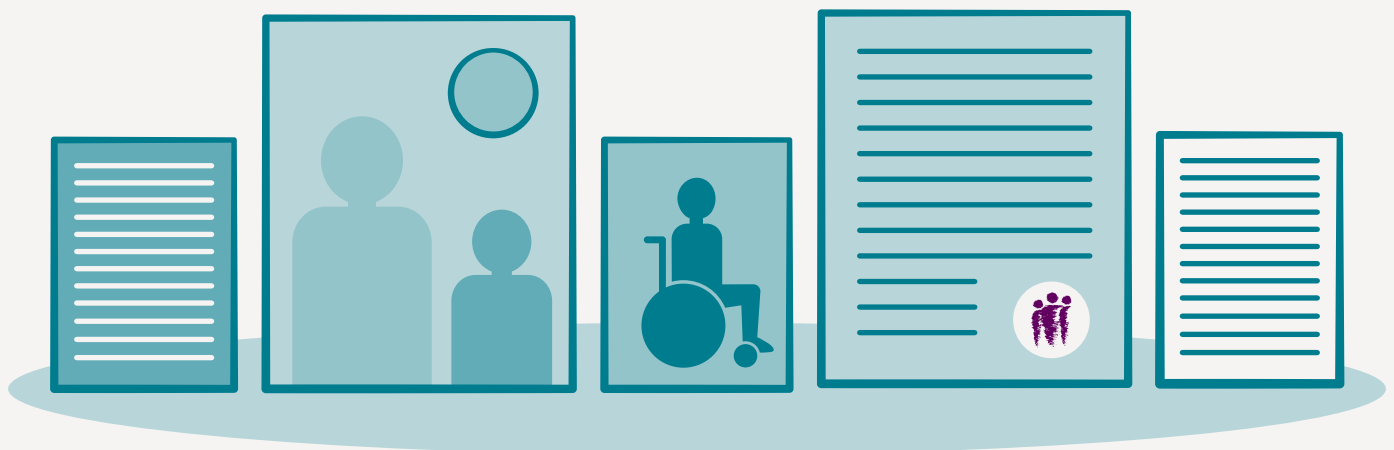
# Introduction and background

## What is the purpose of this research?

The purpose of this research is to examine to what extent understanding of, and access to information about the right to health is prevalent, in particular across those groups who might experience health inequalities. The rationale of the research is to gain an understanding of the availability and accessibility of information on the right to health, to what extent information provision is consistent for different groups, and how the ALLIANCE may contribute to improving information provision and dissemination.

The research aims to support the ALLIANCE's response to Scotland's second National Action Plan for Human Rights' 2023-2030 (SNAP 2) action plan call to "develop and deliver a strategic programme across Scotland to significantly increase understanding of human rights, human rights law and a human rights-based approach amongst rights holders – particularly those whose rights are most at risk – and those who work in public services".<sup>3</sup>

Additionally, the research is timely as the recently published Scottish Government Programme for Government 2023<sup>4</sup> includes a pledge to introduce a Human Rights Bill,<sup>5</sup> and to re-introduce the United Nations Convention on the Rights of the Child (Incorporation)(Scotland) Bill (UNCRC) for reconsideration in the 2023-24 session.<sup>6</sup> The Human Rights Bill seeks to incorporate four of the United Nations human rights treaties into Scots law. These include: The International Covenant on Economic, Social and Cultural Rights (ICESCR), The International Convention on the Elimination of All Forms of Racial Discrimination (ICERD), The Convention on the Elimination of Discrimination Against Women (CEDAW) and The Convention on the Rights of Persons with Disabilities (CRPD). The UNCRC Incorporation Bill seeks to incorporate the UN Convention on the Rights of the Child (UNCRC) into domestic law.



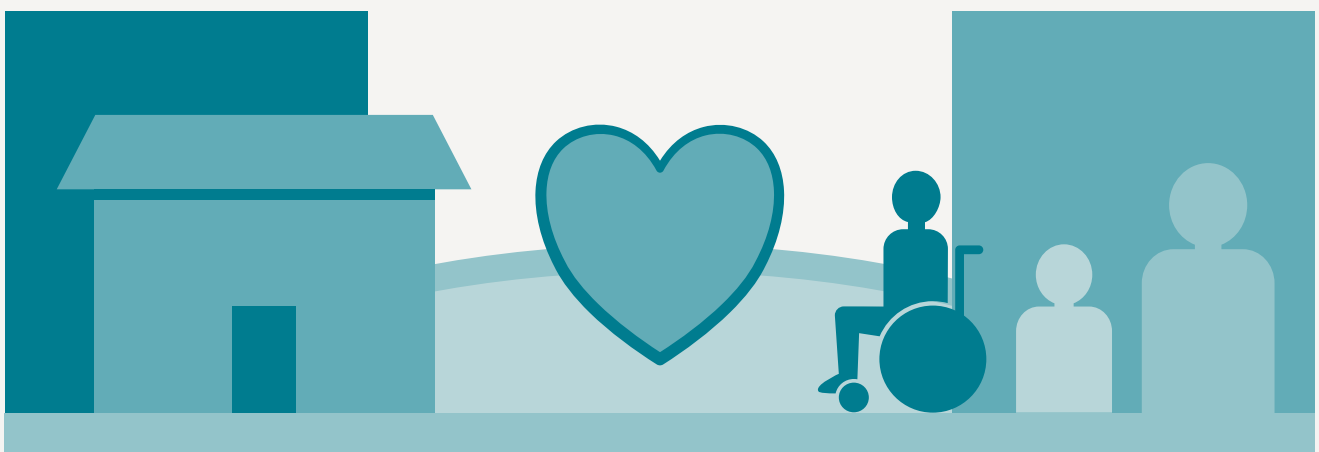
## What is the right to health?

The right to health as “the highest attainable standard of physical and mental health”, is defined by the World Health Organization as a “fundamental right(s) of every human being without distinction of race, religion, political belief, economic or social condition”.<sup>7</sup> The right to health is recognised under Article 12 of the International Covenant on Economic, Social and Cultural Rights (1966) and is indivisible from all other rights. Articles relating to the right to health can be found in CEDAW, CERD, CRPD and the UNCRC. Under international human rights law, Scotland has agreed to legal standards which ensure that individuals can realise their human rights.<sup>8</sup> These legal standards hold the Scottish and UK Government responsible for the prevention, control, and treatment of disease, for ensuring access to healthcare,<sup>9 10</sup> and for correcting those conditions that limit access to the realisation of the right to health.<sup>11</sup>

High levels of health inequality exist in Scotland compared with the rest of the UK and Europe.<sup>12</sup> There is strong evidence that disadvantage and barriers to positively influencing the social determinants in Scotland result in inequality of access to health services and good health in general.<sup>13</sup>

## Key aspects of the right to health

The right to health goes beyond access to health services, to include the social determinants of health such as housing, employment, environment, equality, and community. It is made up of freedoms (freedom from negative experiences), and entitlements (access to timeous, equal, and appropriate healthcare, alongside participation in informed decision making). The right to health can be analysed using the AAAQ framework (Availability, Accessibility, Acceptability, and Quality).<sup>14</sup> The UN Special Rapporteur stipulates that the right to health must be progressively realised by the State, through positive actions which ensure the fulfilment of rights, and without pursuit of actions which regress the fulfilment of rights. They must adhere to minimum standards, be equal and non-discriminative, must be accessible and accountable. Importantly, the right for all to be able to seek health-related information is protected by the stipulation of full participation in health-related decision making.<sup>15</sup>



## Participation in the right to health

Everyone should know and understand their rights and have the right to participate in decisions which affect their human rights. They should be able to claim their right to health when they need to. Participation must be active, free, and meaningful. Information should be accessible and, in a format, and language which can be understood by all.<sup>16</sup>

The Scottish Government has made a series of commitments to participation relating to the right to health across a range of strategy and policy frameworks. These include, but are not limited to, the Primary care: national monitoring and evaluation strategy,<sup>17</sup> Scotland's Open Government Action Plan 2021-2025<sup>18</sup> and the Charter of patient rights and responsibilities.<sup>19</sup>

People in the most deprived areas are significantly more likely to report that they find it difficult to find information on their health, and their right to health for themselves than people in more affluent areas.<sup>20</sup> People with fewer formal qualifications, and people with limiting long term conditions found it more difficult to access health information than other groups.<sup>21</sup> People living in more affluent areas felt more informed and empowered regarding their healthcare, were more likely to report finding it easy to find out information about healthcare and were more likely to feel able to ask questions and to understand their healthcare. Those people with long term conditions were least likely to report the same.

## Right to health in Scotland

The Human Rights Act 1998 requires all public authorities to adhere to, and promote, the rights contained in the European Convention on Human Rights (ECHR). Those rights protected under the act can be enforced by the UK courts. Under the Act, public bodies have positive obligation (a legal duty) to protect a person's life when they are at risk of serious harm or loss of life. This obligation permits public bodies to take steps to eliminate barriers to human rights.<sup>22</sup>

Most of the rights in the ECHR are included in the Human Rights Act, but not all, in particular article 1 (the obligation to respect human rights), and article 13 (the right to an effective remedy). Recent proposals to change the Human Rights Act have caused concerns in Scotland over the impact they would have on the Scottish Parliament and Scotland's Devolution Settlement. This, in turn, will impact on people's ability to claim and enforce their right to health, amongst other human rights.<sup>23</sup>

The Scotland Act 1998 prevents the Scottish Parliament from creating laws that are incompatible with the ECHR, and it cannot take any action, or inaction that may breach those rights. The Scottish Parliament is also bound by other treaties to which the UK is signatory: Universal Declaration on Human Rights, International Covenant on Civil and Political Rights, International Covenant on Economic, Social and Cultural Rights, UN Convention against Torture.

Scotland's first National Action Plan for Human Rights (SNAP 1) was launched in 2013, with the objective of implementing a human rights-based approach to policy making. One of its' key commitments was the right to health. At the time, there were a number of groups created to support implementation of the plan, including the Health and Social Care Action Group, which was co-convened by NHS Scotland and the ALLIANCE. SNAP 1 ran to 2017.

SNAP 2, Scotland's second National Action Plan (2023-2030) was introduced in 2023, and it states medium term outcomes including; "More rights holders have a greater understanding of how human rights affect their lives" and "More rights holders know about, understand and support international human rights", with a long term objective of "each of us is empowered to understand and embrace the value of human rights, asserting them in all parts of our lives". The action plan outlines evidence of a lack of understanding and acceptance of human rights by the public, specific groups of rights holders and duty bearers.

SNAP 2 highlights the importance of awareness and understanding of human rights, stating that "everyone needs to be aware of, accept and understand human rights, so that people are empowered to own and claim their rights, and public bodies can meet their obligations".

Primary care is recognised as a central part of a country's health system and contributing both to the social and economic development. Primary care acts as the initial point of contact where individuals and communities engage with the health system and marks the first stage in an ongoing healthcare journey.<sup>24</sup>

The Scottish Government notes that "different groups have different levels of agency and empowerment when accessing primary care. These differences are complex and likely reflective of power structures and inequalities in Scottish society more broadly. This makes them difficult for primary care to tackle... (and) suggests that a different, more targeted, and nuanced approach may be needed to empower patients with equity". The incorporation of human rights into Scots law offers an opportunity to challenge the systematic failures that lead to inequality in agency and empowerment, thereby offering more equitable access to primary care.



# Findings

## Findings section 1: Barriers to accessing information on the right to health

### Do people understand how to access information on the right to health?

Findings from the research suggest that there is a prevalent lack of understanding within the public of both the right to health and of how to access information on the right to health. Very few people have a legal or formal understanding of the right to health.



**There is a lack of information on health and wellbeing in general, never mind the right to health**

Respondents detailed how information provision on claiming rights in general for the public is very poor. Resources can be found at academic and research level but require considerable amounts of advocacy and support to guide individuals through the process of claiming their rights. Respondents observed that people do not know how to access information on their rights, and as a result do not know how to claim their rights.

### Which groups face the greatest barriers in accessing information on the right to health?

Respondents underlined how the lack of understanding in accessing information on the right to health is likely to be particularly prevalent in underrepresented groups. These 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, people who have experienced mental ill health, and people who live in areas of social and economic deprivation. Stigma and/or discrimination can act as a barrier for these groups when accessing information about their rights. Respondents noted that the implications of structural inequalities apply to the provision of information on the right to health. Societal perceptions and conditioning, individual's self-perception, and limitations in access to public spaces negatively impact on an individual's ability to access on information on the right to health. One respondent observed that this is likely to be reflected in institutional failings, for

example where health information campaigns are directed towards specific demographic groups. The respondent reflected on the need for effective evaluation to ensure that those campaigns are reaching more marginalised groups, especially those who are less likely to access services.

Respondents predicted that the groups who are most likely to access information about their rights tend to be those who are already easily reached, who have family support systems in place, or who have strong information and digital literacy skills. Information provision from the third sector can vary depending on the level of representation a group may have, the size of the third sector organisation offering support or advocacy and the funding those organisations receive.

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## **How does the design and content of information on the right to health impact on accessibility?**

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The format and language used in existing health information has an impact on accessibility, and respondents agreed that there is a risk that this may be reflected in information resources produced on the right to health. Information may not be disseminated effectively to marginalised groups or produced in multiple languages or use accessible language or formats. Respondents described how sometimes services do not understand the cultural values of the different groups that they work with, and the barriers that limit those groups' ability to access information or healthcare, for example by failing to understand that family dynamics can impact on the appropriateness of relatives translating for family members, or by expecting people to undertake an extra step to access information in a language other than English, or in an accessible format. Furthermore, respondents warned that the language of healthcare can be a barrier to accessing information by excluding people who do not have medical literacy or access to advocacy and information support.

Respondents described how people could be overwhelmed by the amount of information that is required to ensure that people understand all the rights that they have claim to, including the right to health. To avoid overburdening people with information, provision would need to be accessible, avoid using legal terms, and translate rights into practical terms. The complexity of rights as a topic might require that information simply directs people to support organisations that can help them to understand the rights that they are entitled to.

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## **Do healthcare providers understand the right to health?**

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Some respondents argued that there is a shortfall in understanding by NHS staff and services of people's entitlement to the right to health. It was suggested that NHS staff do not understand their role in upholding the rights of individuals. Further to this, respondents described how the people they work with feel that power imbalances between rights holders and duty bearers allow duty bearers to be unaccountable. Respondents suggested that one reason for failures in the realisation of people's right to health is a lack of resources within the NHS.

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## Do people understand human rights in general?

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Human rights are difficult to understand as a concept, and respondents cited this as one reason for the lack of availability of information. For activists, human rights are a tangible, empowering, and a useful framework for challenging failures to fulfil the right to health, but it is much harder to have those conversations and debates at an individual level. Framing health information from a human rights perspective can make it less accessible for individuals.



**Human rights in general are seen as something 'other', as something that is not owned at an individual level**

Specifically, the right to health was described by respondents as being “too complex”, and not yet “alive” as a policy issue. One respondent recognised the awareness of Scotland’s developing human rights framework at policy level whilst debating the prevalence of engagement with the right to health as a tool in general discourse and at individual level. There was a general agreement by the respondents that until the right to health is better understood and defined in practical terms both at policy level and at street level, any information provision would be at risk of being inaccessible and redundant.

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## Will people seek fulfilment of their right to health?

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Respondents observed that claiming human rights is a challenge too far for some people, thereby rendering information provision on human rights as a futile exercise. They voiced frustration and confusion over how an individual would claim their right to health in practical terms, arguing that it is unrealistic to expect individuals to pursue their rights through a legal process. Furthermore, they observed that there is no accessible recourse for people whose human rights are not being met, despite the Scottish Government’s promise to incorporate human rights into legislation in Scotland. This was cited as a barrier for people at an individual level, and respondents observed that human rights are not a useful tool to address inequality for individual people.



**If you have the right to something, but can't actually claim it, in what context can you claim it?**

Respondents described how people tend to seek support with the specific barriers or health issues that they are experiencing, rather than their health and wellbeing, and human rights overall. Support and third sector organisations are likely to use a human rights approach in their work, but when working with individuals will concentrate on specific barriers, such as

exclusion, discrimination, or lack of access to specific healthcare rather than a right to health specifically. This is reflected in the existing lack of information provision; respondents described using human rights-based practices in their work but in the main their organisations do not produce information specific to the right to health (see findings section 3: What are organisations doing in relation to information on the right to health).

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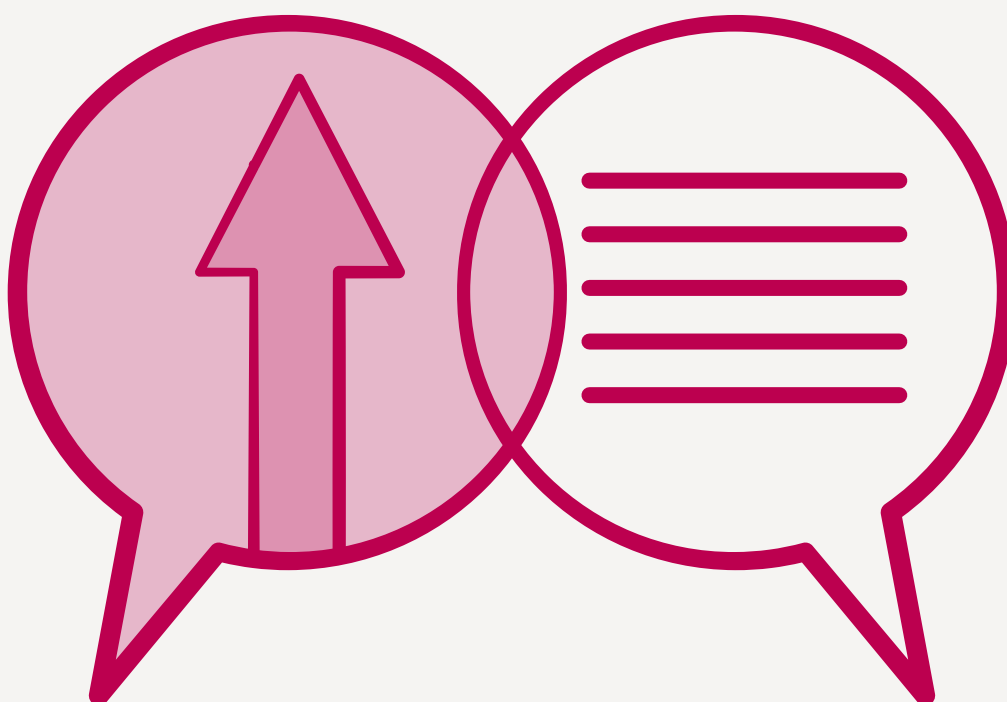
## What is needed for people to claim their right to health?

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Respondents questioned the integrity of governmental assertions of fulfilment of the right to health in Scotland, given the challenges faced by healthcare services after a decade of austerity and service cuts. One respondent argued that as the UN definition of the right to health is the highest attainable standard of health; those people who are most affluent are demonstrating what is an attainable standard of health in Scotland, and those who are not attaining that standard are being deprived of their right to health. The respondent observed that failures in policy decisions which have not addressed those social and economic determinants of health and wellbeing that have negative impact render the concept of universal right to health as abstract and redundant.



**(Under present conditions, incorporation of the right to health will allow) individuals who are almost certainly going to be the most empowered and most enabled in society to exert their rights, whereas those who are least able to exert their rights will be disadvantaged as the most empowered are given yet another tool with which to jump the queue**





## Findings section 2: What happens when the right to health is not fulfilled?

### Do people know how to complain?

Respondents agreed that people often do not understand how to make a complaint about their right to health not being fulfilled, and that complaints processes are too complicated. Respondents described the complaints process as long and difficult to navigate, observing that people “are re-traumatised by the complaints process.”

Respondents outlined that people do not feel confident to make a complaint when their rights are not being met, and they do not understand the language of complaints. Complaints or feedback processes are perceived to be pointless; respondents reported that they rarely found evidence that the complaints process had a positive outcome. Furthermore, respondents described people’s experiences of early gatekeeping in the complaints process, where their concerns were dismissed by duty bearers. In addition, behaviour blaming had been used as a tool to move responsibility for the failure to claim a human right onto the claimant, for example, personal lifestyle and/or personal health choices.

People, or carers of people with multiple health challenges who are supported by a range of services, would have to make several complaints about failures to fulfil duties that cut across different agencies. That complexity further discourages complaints by presenting a logistical challenge which is increased by a lack of clarity as to which agency is responsible for which duty of the individual’s right to health.

Observing that only a small proportion of people may have the resources, education, and experience to be able to make complaints, respondents agreed that many people may not be able to access the tools they need for a positive outcome to a complaint process. Some will not know that they are entitled to a standard of healthcare provision, so do not realise that there is a complaint to be made. Respondents pointed out that some groups will not make complaints because societal conditioning and the challenges of public spaces will impact on perceptions of satisfaction, leading to acceptance of lower standards of healthcare provision rather than complain or enter a conflict situation.



People didn’t have the language, the literacy, the ability, the power to lever that change for themselves. And those who did, were doing so in a context that wasn’t ready to change; duty bearers weren’t ready to step into their space...

One respondent's organisation had undertaken research that suggested that data on NHS complaints are not broken down by certain demographics, and therefore do not consider factors such as gender dynamics or intersectionality. Furthermore, factors such as these are not considered as part of the design of the NHS complaints process. This impacts on certain demographic groups' likelihood of complaining if their right to health is not fulfilled, especially if they have had negative experiences with other services.

One respondent noted that in their experience healthcare cases leading to complaints tended to be as a result of a failure in communication, rather than a failure in fulfilment of the right to health.

Negative experiences of health services can be very impactful because people who are accessing healthcare are often doing so whilst feeling at their most vulnerable or when unwell. This can impact on the power balance in the situation, the individual can feel powerless, even after they have become well. This can limit people's ability and willingness to come forward to make a complaint when their right to health is not being met. These experiences can be more significant if their rights are breached. Respondents observed that although there are advocacy and support service to make a complaint about health services, and complaints tribunals offer a chance to have their voice heard, the process of making a complaint is very difficult.



**People have to put themselves through (the process of making a complaint) in order to claim their rights, which itself is a huge deterrent for people. They have to go through this horrendous journey, often with pretty unsatisfactory outcomes... nobody ever wins these things, so why would they put themselves through that re-traumatisation?**

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## What are the outcomes of complaints?

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Complaints about failures in the fulfilment of the right to health are perceived by respondents and the groups they represent to have little value, to have no positive outcome and can even make things worse. They suggested that people would be concerned about how a complaint would impact their interactions with other services or bring the risk of losing the care that they may already have. Respondents agreed that underrepresented and minority groups would tend to be reluctant about making a complaint as there is a fear of repercussion and victimisation. Power dynamics impact on the complaints process, leading to people either choosing to not complain, or to become frustrated or angry about their experiences.

Respondents noted that individuals are less likely to complain about their right to health not being fulfilled if they have had negative experiences with other services, such as social services, or immigration services. One respondent's organisation had gathered data that indicated that people who experience stigma and discrimination through any official process anticipate that the same thing will happen in future processes.

Respondents observed that for those groups who have historically been treated poorly in accessing healthcare, such as Gypsy/Traveller and Roma groups, the assumption that their right to health will not be met is normalised, so they are unlikely to complain. Further to this, respondents noted that the official nature of the complaints process might require a sharing of information that might have negative consequences for them.

Respondents shared case studies describing that when people do complain, their complaint may be dismissed by the duty bearer, or be told that they misunderstood a situation. Respondents noted that those breaches do not appear to have any recourse for the duty bearer, and that there seems to be a reticence by services against making an apology for an error, even though it would often offer a resolution for the complainant. One respondent observed that people would often prefer for solutions to be found via dialogues with healthcare providers, thereby supporting accountability mechanisms and building a human rights culture, rather than making complaints.

## Findings section 3: What are organisations doing in relation to information on the right to health?

In the main, respondents stated that although they underpin their work with a human rights-based approach, they do not offer explicit support or outreach or produce resources in regard to accessing information on the right to health. Respondents observed that the right to health is tangential, and that they do not choose to prioritise the right to health over other rights in the work that they do. One respondent who represented a public body stated that collaborative work that their organisation had undertaken with the third sector through information partnerships and support, specific to the general public, did not seem to have been effective in raising awareness of the right to health.

### **Resources and activities undertaken by respondents' organisations specifically on the right to health included:**

- Production of 'social stories' books for both individuals and healthcare staff; accessible representations of case studies of good practice in fulfilling the right to health, particularly for individuals from an intersectional perspective.
- Provision of face to face and online programmes for individuals accessing services based on health rights and self management skills.
- School visits designed to increase awareness of healthcare provision and expectations in healthcare settings.

## Resources and activities undertaken by their organisation on human rights in general that respondents described included:

- Production of 'social stories' books for both individuals and healthcare staff; accessible representations of case studies of good practice in fulfilling the right to health, particularly for individuals from an intersectional perspective.
- Provision of face to face and online programmes for individuals accessing services based on health rights and self management skills.
- School visits designed to increase awareness of healthcare provision and expectations in healthcare settings.
- Resources and activities undertaken by their organisation on human rights in general that respondents described included:
  - Promotion of public health messaging of specific medical issues.
  - Application of the findings from service user engagement to policy analysis and advocacy.
  - Work with medical professionals on increasing understanding of the barriers to health that some groups face.
  - Issuing guidance on the PANEL principles (Participation, Accountability, Non-Discrimination and Equality, Empowerment and Legality) to healthcare professionals.
  - Training and e-learning resources for nursing, medical, allied health, and dental students and professionals to raise awareness of human rights and on upcoming human rights legislation.
  - Research examining to what level there is understanding of human rights in healthcare provision.
  - Learning and development sessions with support organisations to increase understanding of the human rights of the people they work with.
  - Website, online chat, and helpline services for individuals which detail rights, support, and information resources on human rights.
  - Drop ins, outreach, and training and development sessions with individuals who access services to reinforce their understanding of their rights entitlement and human rights awareness.
  - Provision of regular human rights group sessions for individuals, where a human rights lens is used in relation to the challenges that individuals have experienced with the offer of practical advice.
  - Information leaflets and online resources on a range of human rights, produced in different languages and formats so that they are accessible to all communities.
  - Collaborative working with other organisations on capacity building, training and information sharing on human rights.

All respondents to this research agreed that they and their organisation would be open to collaborative work with the ALLIANCE on improving access to information on the right to health.

## Findings section 4: Other factors

### Trust in service providers and institutions

Respondents commented on how the level of trust that some groups have in public institutions and service providers has an impact on their understanding of their right to health, and in them accessing information on the right to health. Respondents suggested that there needs to be acknowledgement by public bodies of the trust gap that some groups have in systems and legal frameworks. They noted that even if information on the right to health is accessible and widely disseminated, its efficacy is dependent on the trust given to the person and institution/organisation dispensing the information. Having had negative experiences with other services may make people less likely to trust the information and care given by healthcare providers. Furthermore, respondents described a lack of trust in healthcare providers' willingness to believe them when they report ill-health.



They won't believe me; they will say that I'm over exaggerating

Respondents noted that some groups use, and trust **NHS inform** as a source of information, particularly for those groups where access to healthcare can be complicated. Minority communities and other underrepresented groups may be likely to use and trust third sector organisations for information provision on the right to health. Respondents observed that individuals who have accessed day to day support from third sector organisations for matters outside of healthcare may choose to avoid healthcare settings when seeking information on their health. Rather they might choose to return to the same bodies for healthcare support, because they have built a trusting relationship with them, or they communicate effectively with them.

One respondent noted that the people they support want less contact with healthcare providers on health; they look for more support on their social side, so that they can be active citizens and engage with society. For them "health is more problematized than seen as a positive right in the most empowering sense."

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## Individual self-identity

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Respondents underlined how consideration of power dynamics in the relationship between the individual and healthcare providers is important and underlined that the right to health is not perceived as a universal right.

Respondents pointed to how marginalised groups in particular can feel that they don't 'deserve' healthcare or support provision, resulting in their likelihood to not attend preventative healthcare appointments, rather waiting until they are in crisis. They argued that people's ability and willingness to engage with their right to health can be tied to their self-identity, their self-perception of worth, and social status. Some groups such as migrant and ethnic minority communities feel that they are treated as outsiders, resulting in them being unaware of what healthcare they have the right to access. Communities have been told for generations that they are a burden on the state, they don't belong here, they should 'go home'. They feel guilty for placing additional requirements on systems that are already under high levels of pressure.



**(They feel that) we are not worthy; we do not have the same value**

Respondents observed that for information provision to be effective people must know that the information is there, is available, and be confident in their right to access it. Some groups experience additional barriers as they need information in their own spoken language, or in a format that is accessible to them. Having to ask for information in another format adds another level of need to some groups and makes them feel that they are a greater drain on resources.



**If you can't read in English, you're not as important**

Sources of information on the right to health should be universally accessible, and easily accessible in ways that do not limit a different group's ability to access them; there should be no additional workload involved in accessing the information. Self-perception is that of being a burden, and that information on the right to health should articulate clearly that it is a universal right that can be claimed by all, irrespective of status.

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## Data collection

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Respondents underlined the importance of effective data collection in addressing health inequalities and ensuring that everyone can access the right to health.

One respondent noted that the Scottish healthcare system's emphasis on acute healthcare targets, such as delayed discharge statistics, diverts attention from preventative healthcare. This diversion has a more substantial impact on limiting access to the right to health compared to the failure to promote health agendas. Another respondent called for effective use of data, intelligence, and evidence to identify those people who are least likely to claim their rights and most likely to be marginalised, and most impacted by a failure by society and systems to recognise their rights. Respondents agreed that data on healthcare collection practices could be improved and should include demographic information that would allow for effective analysis of health inequality.

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## The bigger picture

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Respondents commented on how the present understanding and framing of rights as a concept can be problematic. Respondents found it hard to imagine a world where human rights are not being breached, and they argued that if attention is concentrated on what options are available when rights are breached, then there is a tendency to forget to think about the structural changes required for rights to be realised in the first place. Respondents expressed concerns about the implementation of rights in practice, and observed the need for a shift to a culture where human rights and practices are embedded, noting the considerable demands of the training, capacity building, and resourcing that this shift would require.

Respondents observed that there is a challenge in disseminating information about the right to health in that it should be applicable to individuals who are facing complex challenges and framing it as a tool to improve their experiences, rather than as another task to add to their to do list. They stated that the realisation of rights needs to be meaningful, and person centred, alongside being realistic.



**Rights are often held on paper, but that doesn't mean much in reality**

One respondent noted that there might be a lack of understanding of the right to health in terms of impacts that exist out with a healthcare setting; for example, people who experience domestic abuse may not frame structural failures to address the determinants of domestic abuse as impeding on their right to health, despite the recognised impact of domestic abuse on health. Similarly for the social determinants of health, and for specific challenges that certain groups face in society.

Another respondent voiced surprise that the right to health is being singled out specifically for this research. They noted the importance of recognising that poor health is impacted by failure to meet all rights, resulting in the social determinants of health, and argued that people should be enabled and empowered to claim all their rights, not just the right to health. This highlights the need to raise awareness that the right to health is an inclusive right which extends to the underlying determinants of health.

Citing that systemic issues are the biggest barrier to the right to health, rather than simply empowerment, another respondent pointed out how the social determinants of health have overarching impact on health. Furthermore, stigma and discrimination further restrict people's ability to claim their right to health.



**How can someone have a right to health if they are living in poverty, or they are living in a vulnerable housing situation? Our data compounds that we are a good way off realising the right to health**

One respondent was particularly critical of moves to promote the right to health by the Scottish Government, arguing that institutional failures within healthcare make it impossible for the right to health to be claimed by all, or to be even considered a human right. They argued that to use the term right to health in the context of the present healthcare system would seem disingenuous; declaring it more important to people to see healthcare services fixed than an abstract concept being applied to a fragmented NHS.

The respondent stated that the right to health is a duty on government to deliver; it is not a concept that can be promised at an individual level if the system is not able to meet the needs of the whole population, arguing that the reality of the highest attainable level of healthcare in Scotland would require a fundamental shift in how the NHS works where we can only afford to offer a service if everyone can access it.



**If *everyone* doesn't have a right to health, then it is not a right**

Furthermore, the respondent observed that if only a minority of people who have been empowered to gain differential access healthcare by using the terminology of rights, then the right to health is not being met for all and becomes a redundant concept.





Using a right to health without a fundamental policy commitment that is narrowing inequalities will simply provide the already empowered with another tool to shout louder and assert their ability to access services

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## Responsibilities of duty bearers

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Respondents discussed who should be held accountable for the fulfilment of people's rights. They questioned the status quo of individuals holding the responsibility of claiming their rights, rather than duty bearers taking responsibility for delivering rights. Responsibility is placed on the rights holders to act, to hold understanding of their rights or to research their rights. Respondents criticised the blaming of people for failing to claim their rights, stating that it should be the responsibility of structures and organisations to advance and promote human rights, and to create those conditions required for them to be achieved.

Respondents observed that by placing the emphasis for rights claiming on the individual, they are required to have the capability and capacity to negotiate what can be a complex system. When these demands are made on people when they are unwell, and/or feel disempowered by their healthcare experience, it is even less likely that they will be willing to attempt to claim their rights. Furthermore, respondents observed that when an individual makes a complaint about the failure to fulfil their right to health, the responsibility of comprehensively evidencing the failure is on the individual, whereas the duty bearer only has to deny the failure with no supporting evidence. Respondents pointed out that healthcare complaints processes can suffer from a lack of transparency around the process, in terms of the expectations on each side of the complaint.

Respondents argued that to offset routine or systemic failures in fulfilment of people's rights, duty bearers should have a better understanding of right to health and should be accountable for doing so and thereby be incentivised to have that knowledge.



Duty bearers should lead rather than be chased

Respondents observed that there is an imbalance in the realisation of rights – for duty holders, failure to realise an individual's rights can be inconsequential, even beneficial to the duty holder. However, to the rights holder, failure to have their rights realised can be hugely meaningful, even catastrophic. Rights are considered as a system, rather than from individual perspective.

# Recommendations

Respondents listed a range of suggestions and recommendations, offering insight at governmental, organisational, and local levels.



For me, it is about advocacy, empowerment, community capacity building, encouraging literacy and health literacy, citizenship, where people understand that services are available and that they have a right to access them, and that when those services are not enabling them to achieve their rights or their potential, that they have recourse to complain

The recommendations for the Scottish Government, other healthcare duty bearers, and the third sector set out below are drawn from respondents' proposals and research analysis. They reflect four of the eight United Nations criteria for best practice in national human rights plans of action.

## These include:

- 1 Be evidence based: Recommendations are based on the collection and analysis of robust qualitative research, although limited by time and financial restraints.
- 2 Be inclusive: Efforts have been made to interview a range of support services representatives for a diverse range of groups.
- 3 Be action orientated.
- 4 Be realistic: The report offers several future action recommendations. These recommendations are designed to form specific, practical, and achievable aims.

# Scottish Government and Healthcare Public Bodies

- **Promote rights fulfilment at leadership level**, and direct cultural changes and implementation of human rights delivery from leadership positions.
- **Undertake research and community engagement to examine trust in healthcare and legal systems, and their information provision in Scotland**, particularly among marginalised or underrepresented communities. Gain insight into actions that could help address any trust gap.
- **Engage with SNAP 2's action plan recommendation** that Scotland develop a national human rights tracker tool (Scotland's National Action Plan for Human Rights, 2023, p.42).
- **Develop accessible, practical, and inclusive information on human rights**, ensuring the use of multiple inclusive formats and languages. As per the language of Scotland's upcoming Human Rights Bill, embed co-production and engagement when producing information resources on human rights by collaborating with rights holders, and at community and group level. Collaborate with rights holders, community, and group-level knowledge to ensure targeted engagement, thereby reaching those who are most likely to have their rights breached and who often face challenges accessing information. Resource development should be underpinned by robust monitoring and evaluation frameworks, to ensure effective impact and reach.
- **Develop and promote accessible, practical, and inclusive language for human rights.** Translate complex legal human rights language into layman's terms, and promote shared, simple language on human rights. There is a need for resources which help people to get to grips with the 'legal speak' to increase confidence in the human rights framework and its incorporation into Scots law.
- **Scottish Government should develop a human rights resource library** to share best practices in designing and disseminating accessible information on the right to health across third sector networks and between policy makers, duty bearers and third sector organisations. Include resources from smaller third sector organisations, and community-led and grassroots organisations. Facilitate access to the resource library for community members in positions of trust to access, sense check, and disseminate information. This could be implemented in conjunction with SNAP 2's action to "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".
- **Scottish Government should seek to promote human rights policy coherence and information provision across government silos** to prevent duplication and enhance synergy between separate legislative frameworks based on human rights, thereby avoiding repetition of demands on an already overburdened public and third sector.

- **Scottish Government should develop and facilitate a Community Leader Assembly**, where community and group leaders act as expert reference groups to support accessible design and effective dissemination of information on the right to health within their own community and support the recruitment and development of future leader assembly members.<sup>25</sup>
- **Scottish Government should undertake a mapping exercise of Scotland's third sector organisations**, examining whether support provision for different communities and groups is effectively spread and offers equal representation across Scotland. Investigation of opportunities to develop a more coordinated, cohesive, and collaborative approach to third sector representation across Scotland.
- **Healthcare Public Bodies should develop a central library of NHS information resources on human rights alongside good practice examples**, to avoid duplication of existing resources and to ensure style and content conformity across NHS and IJB Boards, departments, and services.
- **Healthcare Public Bodies should develop a one-stop-shop process for complaints across the NHS** to simplify and unify the complaints process and to allow for effective intersectional data collection on the fulfilment of healthcare needs. Complaints should be addressed at the nearest point to the service provision as possible.
- **Healthcare Public Bodies should engage in research and innovation to influence policy**. Participate in the policy setting process to support the Scottish Government's commitment to shift the balance of care to proactive and preventative healthcare.
- **Build reflexive practice requirements into healthcare systems and processes for duty bearers**. Develop systems and processes within healthcare provision around reflection, assessment, and improvement.
- **Provide training in human rights legislation, policy, principles, and practice to students in healthcare and social care sectors**. Training should be delivered on practical terms, so that professionals can effectively use the learning in their working lives. In accordance with the Scottish Government's commitment, training should reframe healthcare thinking to proactive and preventative health.
- **Ensure that information on human rights is disseminated throughout duty bearer organisations to support implementation**. Information on topics such as the right to health is often addressed at management level, but that information does not always disseminate to front line staff.
- **Recognise the constant change to healthcare demands in response to societal and economic changes**, requiring adaptable and flexible policy and service design.

## Third Sector

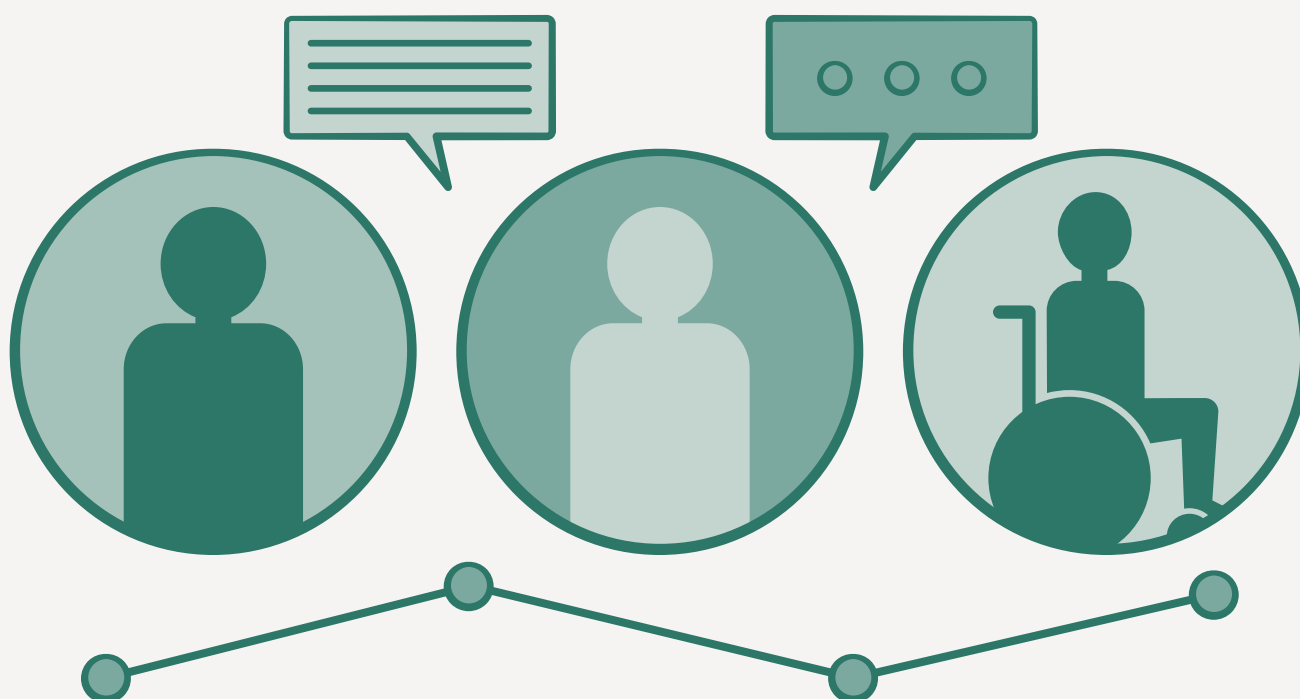
- **Maintain pressure on the Scottish Government and on duty bearers to address rights fulfilment**, in particular from the perspective of marginalised groups.
- **Engage in research and innovation to influence policy.** Participate in the policy setting process to support the Scottish Government's commitment to shift the balance of care from proactive to preventative healthcare. Further to this, undertake research and community engagement to examine trust in healthcare and legal systems, and their information provision in Scotland. Engage with a range of communities and groups, in particular those who are marginalised or underrepresented, to examine their relationship with public bodies and to gain insight into actions that could help address any trust gap.
- **Call on the Scottish Government to undertake a review of how evidence, monitoring and evaluation of health data is undertaken.** The review should examine whether the existing system of data collection identifies and effectively analyses the experiences of all demographics, communities, and groups, but should consider in particular those sections of the population who are furthest from realising their right to health.
- **Develop and facilitate a 'community leader network'** where community and group leaders act as expert reference groups to support accessible design and effective dissemination of information on the right to health within their own community and support the recruitment and development of future leader assembly members.

## The ALLIANCE

Respondents unanimously voiced agreement that they would welcome the opportunity to work collaboratively with the ALLIANCE and other organisations on effective delivery of information on the right to health.

- **Support and inform policy makers in designing health policy that is inclusive and intersectional** by calling on the considerable knowledge, lived experience and insight held within the ALLIANCE network.
- **Maintain pressure on the Scottish Government and on duty bearers to address rights fulfilment**, especially for marginalised groups.
- **Foster engagement on the right to health between policy makers, duty bearers, and third sector organisations, and members of the ALLIANCE network** to allow organisations to reach as wide a range of communities with lived and living experience as possible, alongside informing meaningful, group specific design of, and impactful dissemination of information and resources on the right to health.

- **Facilitate engagement across stakeholders in Scotland in defining a shared understanding of the right to health, its language, and practical applications.**
- **Conduct research on the accessibility of information on the right to health, with a focus on the experiences of marginalised and intersectional groups.** By selectively engaging those individuals from the most disadvantaged backgrounds with the least access to the right to health might allow the ALLIANCE to help influence culture where rights duty bearers uphold their responsibilities.
- **Support and advocate for selected individuals from the most disadvantaged backgrounds with the least access to the right to health, helping them understand and access their rights, and to hold duty bearers accountable.** This process may allow the ALLIANCE to prompt culture change, including through legal actions addressing systemic failures within the healthcare provision in Scotland.
- **Develop and facilitate a ‘community leader network’ on behalf of the Scottish Government** where community and group leaders act as expert reference groups to support accessible design and effective dissemination of information on the right to health within their own community and support the recruitment and development of future leader assembly members.
- **Collaborative opportunities include;**
  - Co-creation and dissemination of information and resources on the right to health through the ALLIANCE network.
  - Co-design and co-provision of human rights training and outreach events with tailored resources for different groups.
  - Co-production of media resources, such as blog posts and podcasts on human rights, for staff in duty-bearing organisations and third sector organisations.



# Appendix 1: Research methods

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## Aims

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### The aims and objective of this research were;

- To briefly quantify the level of understanding of the concept of the right to health across different groups in Scotland.
- To seek an understanding of the barriers of access to information on the right to health in Scotland.
- To form a picture of the work being undertaken and being planned by representatives of different groups to inform and support the individuals they work with in claiming their right to health.
- To investigate opportunities for the Health and Social Care Alliance Scotland to develop information and education resources on the right to health for representatives of different groups and the people they support.

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## Selection of survey participants and participant representativeness

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A total number of thirteen participants were interviewed for the research. Participants were selected to recognise and acknowledge the value of the individuals they work with lived experience and input. Interviews were conducted using a range of participants who were identified as offering representative of a proportion of those bodies who engage with different groups in relation to rights, and to the right to health. A cross-section of organisations was used to gather diverse and representative responses, especially in relation to those people whose rights are most often at risk. It should be noted that, whilst every effort was made to present findings that are representative of the experiences of a wide range of different groups and bodies, time and funding restraints limited the scope of the interview process. Care should be taken when making generalisations from the findings in this report. Findings reflect the views of the interview respondents.



## Respondent profile

Quota	Role	Additional information
3x public bodies.	Senior manager within healthcare setting; Senior Officer within healthcare setting; Senior practitioner within care setting.	Professional experience within healthcare management, within a healthcare education setting, and within a regulatory body.
1x Older Person's organisation.	Project Manager within the third sector.	Professional experience in older people's rights campaigning and policy.
1x third sector mental health organisation.	Senior manager within the third sector.	Professional experience in mental health rights campaigning and policy.
1 x third sector organisation in the children's sector.	Senior manager within the third sector.	Professional experience in children's rights campaigning and policy.
1 x National Carer organisation.	Senior manager within the third sector.	Professional experience in carer's rights campaigning and policy.
1 x third sector organisation in the housing sector.	Senior manager within the third sector.	Professional experience in housing rights campaigning and policy.
1 x representative from a primary care setting.	Principle GP and Academic in Medicine.	Professional experience in health rights campaigning and policy.
1 x representative from a primary care setting.	Principle GP and Academic in Medicine.	Professional experience in health rights campaigning and policy.



1 x organisation in the women's sector.	Senior manager within the third sector.	Professional experience in women's rights campaigning and policy.
1 x race equality organisation.	Rights and Equalities Officer within the third sector.	Professional experience in race equality rights campaigning and policy.

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## Interview Methods

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One-to-one semi-structured interviews were selected as the method choice for this research. Interviews were conducted online. The intention of semi-structured interviews is to gain knowledge on a specific area, whilst giving respondents the opportunity to offer insights previously unconsidered in the research process. The seniority of several of the respondents allows for findings which consider both institutional knowledge and processes, and community and culture understanding, alongside knowledge sets gained over years of experience.

All except two interviews were conducted one on one. Two interviews were conducted with two respondents, at the request of the respondents. All respondent data has been anonymised. Fieldwork took place between 13th June and 25th August 2023.

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## Ethics

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Ethical considerations for this research included the vulnerability of those groups represented by the participants, alongside appropriate representation of their voices. Participants were informed of the content, structure, and survey questions in advance of the interviews, and the option to opt-out at any time in the process was made clear at several points in the process. Participants were given a verbal explanation of the content of the interviews in advance and were given the opportunity to ask questions in advance, during and after the interview, either by email or by phone. Consent forms were verbally discussed and completed before any data collection started in the interview sessions, and confidentiality and anonymity were discussed as part of this process. Permission was asked at the start of the sessions for audio recording. Confidentiality of both the groups represented and the participants was maintained, and all data was anonymised. All data was securely stored in password protected folders in a password protected cloud storage system.

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## Analytical Methods

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Recurring themes, key words, and recommendations were identified from audio recordings of the interviews, and illustrative quotes for those themes were transcribed. Gathered themes were identified to centre around what would be of most use and interest to duty bearers and third sector and support organisations. The completed report was sent to the interview respondents for review.

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## Limitations

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Time and financial limitations meant that the research could only include a limited number of interviews of a small proportion of representatives of the different groups in Scottish society. The research recognises that there are many more groups, including marginalised groups, who have insight and experience that is valuable and offers different perspectives.

## Appendix 2: Interview documentation

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### What is the purpose of this research?

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The purpose of this research is to examine to what extent understanding of, and access to information about the right to health is prevalent, in particular across those groups who might experience health inequalities. The rationale of the research is to gain an understanding of the availability and accessibility of information on the right to health, to what extent information provision is consistent for different groups, and how the Health and Social Care Alliance Scotland may contribute to improving information provision and dissemination.

The research aims to support the Health and Social Care Alliance Scotland's response to the Scottish National Action Plan for Human Rights' 2023-2030 action plan call for a strategic programme to "develop and deliver a strategic programme across Scotland to significantly increase understanding of human rights, human rights law and a human rights-based approach amongst rights holders – particularly those whose rights are most at risk – and those who work in public services".

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### Interview structure

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The interview format is intended to be informal and semi-structured. I will use 'prompt' questions to keep the conversation within the research aims, but the intention is for me to give you the freedom to explain your, and your service users' experiences of accessing information on the right to health. A list of the prompt questions is below, these may be adapted slightly if certain themes emerge from the interviews I conduct. The questions are as a guide only and are shown below to give you an idea of the area of research.

Interviews will be online, held using Zoom. I will send you an invite in advance of the interview with a link to the meeting and a passcode to join. I will also email you this information sheet and an interview consent form for you to sign and return to me before the interview.

With your permission I will record the interview using Zoom's record function. I will also record the audio of the interview on a handheld Dictaphone, as a back-up of the data. I will hold the interview from my home office. My office is a closed space, and I do not share it with anyone during the working day.

At the start of the interview, I will briefly introduce the topic of the research, and will then discuss the ethical considerations of the interview and will read through the interview consent form with you. **You are free to stop the interview at any time, you are also free to cancel our appointment in advance, or to request that the interview data is not used after the interview** (although I would ask that you do so in a reasonably short time after we meet before I start the data analysis). I am available to answer questions about the interview and research at any time. Along with the Health and Social Care Alliance Scotland, I am very grateful to you for your participation, but there is no requirement for you to do so.

The interview will last approximately 30 minutes, with additional time at the end for any questions that you may have. Given the short timescale of the interview, I will use the 'prompt' questions to keep us on track, and I may ask us to move on from any topic that we discuss that is not directly related to the area of research. It is not expected that the interview will cover sensitive issues.

The data gathered from the Interview (Zoom recording, audio recording, transcripts, type-written notes, and data analysis) will be held in password protected cloud-based storage, only accessible by me. Once the final draft of the report is submitted and accepted, all data held on the cloud will be securely disposed of. All data will be anonymised prior to analysis, and research findings will be reported in such a way that participants cannot be identified. Data from a number of interviews will be aggregated as part of the data analysis process, however anonymised quotes may be used.

The final report will be used by Health and Social Care Scotland to inform future research. Findings from the final report may be used in future literature and research produced by the Health and Social Care Scotland, however respondents' anonymity will be maintained.

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## Interview Questions

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**Topic:** Your service users' understanding and experiences of accessing information about the right to health.

- How much do your service users know about their right to health? How easy is it for them to access information on the right to health? What are the experiences of your service users in relation to understanding and accessing information on the right to health? Do your service users connect with the idea of a right to health, and do they understand how to claim or engage with it as a concept?

**Topic:** Your service users understanding and experiences of complaining about lack of access to information about their right to health.

- Do your service users understand how to complain if they are restricted in their right to health? How do you help them do so? Do they know how to make claim to their right to health? Are complaints procedures accessible and user friendly for the people and groups that you represent? Are they appropriate? Are they effective?

**Topic:** What your organisation is doing to support service users to access information on their right to health.

- What is your organisation doing in relation to information dissemination on the right to health? What information and resources do you use to support your service users' understanding of the right to health, what tools do you use? Have those resources been evaluated, and what were the findings? What insights into solutions or recommendations in relation to information provision on the right to health can your organisation offer?

**Topic:** What your organisation is planning to do to support service users to access information on their right to health.

- What is your organisation planning to do in relation to information dissemination on the right to health? Are you planning to design resources/ offer training on the right to health to your service users? Are you planning on doing so in partnership with your service users?

**Topic:** What your organisation is planning to do to support service users to access information on their right to health.

- What is your organisation planning to do in relation to information dissemination on the right to health? Are you planning to design resources/ offer training on the right to health to your service users? Are you planning on doing so in partnership with your service users?

**Topic:** Identifying the gaps in information provision on the right to health.

- What are the gaps in information provision on the right to health that service providers can identify? How could your service users' understanding of the right to health be built and supported? What are the information gaps that the Health and Social Care Alliance Scotland could fill? What would be the best format for that information?

**Topic:** Identifying collaborative opportunities.

- Would your organisation consider collaborative working in designing and providing information on the right to health? Could you suggest a format that might take?



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## Interview consent form

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**Research project title:** Investigating knowledge and understanding of the right to health.

**Research investigator:** Helen Oxley

**Research participant name:**

Thank you for agreeing to be interviewed as part of Health and Social Care Alliance Scotland's ongoing research into the knowledge and understanding of the right to health. This consent form ensures that you explicitly agree to being interviewed, and that you understand how the information gathered from the interview will be used.

The interview is based on informed consent. Every attempt has been made to provide information about the context and content of the interview. However, should you have any questions please contact me by email and I will respond as soon as possible.

The interview will take approximately 30 minutes. We do not anticipate that there are any risks associated with your participation, but **you are free to stop the interview at any time, you are also free to cancel our appointment in advance, or to request that the interview data is not used after the interview.**

**Please read the accompanying information sheet and then sign this form to certify that you approve the following:**

- The interview will be recorded (audio and video), and a full transcript of the interview may be produced.
- The information gathered from the interview will be analysed by Helen Oxley as the research investigator.
- Access to the interview recordings and any transcript will be limited to Helen Oxley as the research investigator, and Lucy Mulvagh and Jane Miller at the Health and Social Care Alliance Scotland, as research supervisors.
- Any summary interview content and analysis, or direct quotations from the interview will be anonymised so that you cannot be identified, and care will be taken to ensure that you cannot be identified from other information from the interview.
- The actual recordings and transcripts will be kept for the duration of the research analysis of the interview and production of the final report. Once this is completed those documents will be destroyed securely.
- Any variations in the above conditions will only occur with your further explicit approval.

**All or part of the anonymised content of your interview may be used;**

- As part of ongoing research by the Health and Social Care Alliance Scotland.
- On the Health and Social Care Alliance Scotland website and in other media.
- As part of reports or recommendations made by the Health and Social Care Alliance Scotland.
- In the Health and Social Care Alliance Scotland’s archive of projects.

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**Consent agreement**

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**Please initial next to the statements below:**

	I understand that my words may be quoted directly. I agree to be quoted directly if my name is not published and a made-up name (pseudonym) is used.
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	I agree that the Health and Social Care Alliance Scotland may publish documents that contain anonymised quotations by me.
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### **By signing this form, I agree that;**

- 1** I am voluntarily taking part in this project. I understand that there is no requirement to take part, that I can choose to exit the research and I can stop the interview at any time;
- 2** The recordings, transcription or extracts from the interview may be used as detailed above;
- 3** I have read the information sheet;
- 4** I do not expect to receive any benefit or payment for my participation;
- 5** I have been able to ask any questions that I might have, and I understand that I am free to contact the researcher with any questions I may have in the future.

### **Contact information**

This research has been commissioned by the Health and Social Care Alliance Scotland. If you have any further questions or concerns about this research, please contact the research investigator, Helen Oxley, via the ALLIANCE:

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## Appendix 3: Examples of good practice

Respondents highlighted examples of good practice on human rights information from different public bodies and third sector organisations.

### They included:

- The Gypsy/ Traveller Action Plans 2019-2023<sup>26</sup> offers an example of effective communication of the right to health to a hard-to-reach community using accessible language, alongside staff training and engagement with community leaders.
- The Care Inspectorate produce a three weekly provider update which is sent out to services, which signposts good practice to rights-based practice within services. The Care Inspectorate uses a quality indicator framework which includes a toolbox of resources which supports good practice in service user rights.
- See Me, Voices of Experience, and the Scottish Recovery Network ran a “Rights for Life” Programme in 2016,<sup>27</sup> which was designed to engage people living in Scotland who identified with having poor mental health, increase understanding of rights in general, to encourage people to claim those rights, and to take action if their rights were not met. A national co-production initiative resulted in the ‘Rights for Life’ Declaration.
- ENGENDER ran a **CEDAW roadshow** in 2018/19, which sought to educate women as to what their rights are and used a superhero persona for CEDAW to make it more accessible as a concept. The roadshow lifted the CEDAW concept off the page to make it easier for people to engage with. Data from feedback gathered as part of the roadshow was also fed into the shadow report submitted to the CEDAW committee.
- One respondent observed that paediatric healthcare providers in Scotland offer good practice in fulfilment of children’s health rights; they offer effective support and will delay the transition of a patient’s status from child to adult if it is in the best medical interest of the child.
- Children’s Health Scotland produce ‘social stories’ books which are accessible representations of case studies of good practice in fulfilling the right to health of children using an intersectional approach. These books are divided into a story for the child which explains in an accessible way a particular medical experience and how their right to health should be fulfilled, and an information section which is directed towards parents and professionals to support them in ensuring that the child’s right to health is being met.



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# About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for health and social care, bringing together a diverse range of people and organisations who share our vision, which is a Scotland where everyone has a strong voice and enjoys their right to live well with dignity and respect.

We are a strategic partner of the Scottish Government and have close working relationships with many NHS Boards, academic institutions and key organisations spanning health, social care, housing and digital technology.

Our purpose is to improve the wellbeing of people and communities across Scotland. We bring together the expertise of people with lived experience, the third sector, and organisations across health and social care to inform policy, practice and service delivery. Together our voice is stronger and we use it to make meaningful change at the local and national level. Our vision is a Scotland where everyone has a strong voice and enjoys their right to live well with dignity and respect.

The ALLIANCE has a strong and diverse membership of over 3,500 organisations and individuals. Our broad range of programmes and activities deliver support, research and policy development, digital innovation and knowledge sharing. We manage funding and spotlight innovative projects; working with our members and partners to ensure lived experience and third sector expertise is listened to and acted upon by informing national policy and campaigns, and putting people at the centre of designing support and services.

## We aim to:

- Ensure disabled people, people with long term conditions and unpaid carers voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change that works with individual and community assets, helping people to live well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner, and foster cross-sector understanding and partnership.



**ALLIANCE**  
HEALTH AND SOCIAL CARE  
ALLIANCE SCOTLAND  
people at the centre

# About the Academy

The Health and Social Care Academy (the Academy) is an ALLIANCE programme which helps to drive long term, meaningful and sustainable change in Scotland's health and social care. The Academy offers a cross sectoral safe space to support, collaborative thinking, the dissemination of evidence and learning, and to promote the voice of lived experience with a focus on health and care integration. The Academy's 'Five Ambitions for the Future of Health and Care' help to shine a light on successful approaches in Scotland, and beyond. They are intended to inspire, encourage action, and help identify the steps we need to take for a future where people and wellbeing are at the centre.

## Health and Social Care **ACADEMY**





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